Four different patterns of fatigue in rheumatoid arthritis patients: results of a Q-sort study

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Abstract

Objectives. Many patients with RA complain about fatigue. Whereas qualitative studies have covered the meaning of fatigue for RA patients, it was still unknown whether subgroups of patients could be distinguished. This study aimed to describe different perspectives on the experience of fatigue.

Methods. Participants were 30 outpatients with established controlled RA of the Medical Spectrum Twente, with a mean fatigue severity score of 4.67 (visual analogue scale 0–10). They evaluated 57 statements about fatigue according to Q-methodology. Data were analysed with PCQ for Windows (Portland, OR, USA), using centroid factor analysis with varimax rotation (i.e. the participants but not the items of a scale are the variables). Factor scores of statements on the different dimensions were calculated to investigate which items are relevant when describing and distinguishing fatigue experiences. Demographic and clinical patient characteristics were collected to describe each of the dimensions that resulted from centroid factor analysis.

Results. After statistical and theoretical considerations, a four-factor structure of the data was obtained. Each factor represented a perspective on the experience of fatigue, shared by a certain group of patients. Physical, psychological and social patient characteristics seemed to be associated with those experiences. The factors were labelled as: ‘Little impact of fatigue’; ‘Good coping and bad sleep’; ‘Search for balance’; and ‘High distress’.

Conclusions. Results indicated that fatigue experience is a complex phenomenon. Existing questionnaires to measure fatigue do not meet this complexity. Extensive research is warranted and new efforts to develop instruments that take into account all aspects of fatigue are indicated.

Key words: Fatigue, Rheumatoid arthritis, Patient perspective, Q-methodology, Q-sort.

Introduction

Fatigue is a common problem for patients with RA [1, 2]. Patients mention fatigue as one of their most annoying problems [3, 4]. Primarily, fatigue is a subjective experience that can be described as ‘extreme and persistent tiredness, weakness or exhaustion—mental, physical or both’ [5]. However, an internationally accepted definition of fatigue in RA does not exist [6], and little is known about its aetiology [7]. Nevertheless, the number of studies including fatigue as outcome measure has rapidly increased over the last 2 years. This is problematic as so little is still known about fatigue. A theoretical model explaining the experience of fatigue in RA is still lacking [8] and consensus about an adequate way to measure it has hence not yet been reached. First, more insight into the complexity of the phenomenon fatigue should be obtained.

In analogy with pain we should assume that fatigue is what a patient says it is, and it is as bad as the patient says it is. Consequently, the most appropriate starting point is the perspective of the patients [4]. To date, four qualitative studies examining patients’ experience of fatigue in RA have been conducted in the USA, the UK and The Netherlands [9–12]. They all showed that RA patients experience fatigue as a multidimensional, annoying symptom with far-reaching consequences. Our previous study [12] revealed inter- and intra-individual differences in the
patients’ experience of fatigue in RA: emotions, consequences and management of fatigue differed with age and gender. Some of these differences were related to the number of daily roles that patients had to fulfil. Many patients reported that the severity, frequency and duration of their fatigue varied, with some even reporting they experienced different forms of fatigue. It is not yet fully understood which factors cause such inter- and intra-individual differences in fatigue in RA patients. Although we know about the experience of fatigue in general, it is still not known whether there are certain groups of RA patients who experience fatigue in a similar way, and which patient characteristics are related to differences in fatigue experiences between such groups.

Studies on predicting factors of fatigue in RA show that not only physical but also psychological and social aspects can be related to fatigue. Several studies found that pain [1, 2, 13–15], physical disabilities [1, 2, 16, 17], impaired general health [16], longer symptom duration [13], less physical activities, comorbid conditions [2], lower sleep quality [1, 2] and female gender [2, 13] were predictive of fatigue in RA. Moreover, psychosocial factors emerged, which are: depressive symptoms [1, 13, 14]; anxiety [17]; social stress and problematic social support [13]; lower self-efficacy [15, 18]; a lower perceived sense of control [19]; and in female RA patients, negative interpersonal events predicted higher levels of fatigue [20]. Regarding the relationship between disease activity and fatigue, the literature shows inconsistent results [1, 7, 13–16, 18, 21, 22].

The purpose of this study was to identify different perspectives on the experience of fatigue in RA. Furthermore, in order to investigate whether several patient characteristics are associated with the fatigue experiences, we collected a broad range of characteristics that covered not only disease-specific information but also topics relating to the patient’s daily life. So besides disease-specific variables (e.g. disease activity, disability, pain), we included social (e.g. age, marital status, daily roles) and psychological variables (e.g. anxiety, depression).

**Patients and method**

**Q-methodology**

We used Q-methodology, which is a valuable tool in research on highly subjective topics, such as fatigue. Especially in situations when a topic is not yet well understood, this method is recommended [23]. In comparison with the Likert attitude questionnaires, Q-methodology provides highly detailed information and identifies groups of people sharing similar views on a certain topic [24]. It has already been used to examine the acceptance of chronic pain [25] and to identify characteristics of adolescent cancer patients sharing a common experience of fatigue [26].

In Q-methodology, a by-person factor analysis is applied, whereby the participants but not the items of a scale are the variables [27]. First, the researchers had to prepare 40–60 statements that cover all aspects of the topic under study [28]. We developed a comprehensive pool of statements by collecting items from multi-item fatigue scales and by selecting relevant statements from our interview material [12]. For this, we used the items of the Multidimensional Assessment of Fatigue (MAF) scale [29, 30], Functional Assessment of Chronic Illness Therapy Fatigue (FACIT-F) scale [31, 32], Profile of Mood States (POMS) [33] and Short Form 36 (SF-36) vitality subscale [34]. In a systematic review on measurement of fatigue in RA [6], evidence of reasonable validation could be identified for these scales, although even they did not meet all the criteria for validation. Moreover, we used the items of the Checklist Individual Strength (CIS) [35, 36] and the Bristol RA Fatigue Multi-Dimensional Questionnaire (BRAF-MDQ) [37], two scales which are undergoing validation in RA at the moment. This resulted in 200 items, which were systematically reduced. In cases of overlapping content of items, we chose the formulation from the interviews or the clearest formulation (when two questionnaire items overlapped). We discussed the remaining items, whereby those were identified that represented the most relevant categories, based on the interview results and relevant scientific literature. Ultimately, 57 items were selected that covered 14 categories: negative emotions, consequences, impact/meaning, benefit finding, different forms of fatigue, severity, duration, frequency, cognition/concentration, energy, sleep, description, social support and coping/management.

The items were then printed on cards, which had to be sorted by each participant on a worksheet with a Q-sort figure, to reflect his/her agreement with the statements [28] during the previous 7 days. We used a Q-sort figure (Fig. 1) with 11 piles, ranging from strongly disagree (–6) to strongly agree (+6). The piles consisted of different numbers of squares, whereby most of the cards could be sorted in the neutral regions and the fewest in the extremes. To check the feasibility of the selected items, we piloted the Q-sort with two patients. Both the patients judged the method as clear and the items as comprehensive and relevant.

**Patients**

This study was performed in collaboration with the patient research partners of our Arthritis Centre Twente. In March 2009, 30 RA outpatients of the rheumatology clinic of Medical Spectrum Twente participated in the study. When using Q-methodology, the adequate number of participants depends on the number of statements that have to be sorted [38]. Ideally, the number of statements is at least twice the number of participants [39]. Since we used 57 statements in this study, 30 participants is the absolute maximum number to be able to conduct a methodologically correct analysis. Our aim was to include a diverse sample of patients, giving an adequate reflection of the usual RA outpatient population with all levels of fatigue. Selection criterion was a diagnosis of RA at least 2 years previously to make sure that the patients had sufficient experience with RA to be able to sort the statements on
fatigue. According to local regulations in The Netherlands (WMO), the study did not need approval of the ethical review board; only (non-intervention) studies with a high burden for patients have to be reviewed. Patients underwent no intervention or treatment and the burden of participation was relatively low. Before starting the Q-sort, patients signed an informed consent, to make sure that they decided consciously to participate in this study, and completed a questionnaire.

**Method**

For conducting the Q-sort, the researcher (S.N.) made individual appointments with the patients. Most of them chose to complete the Q-sort at home, and two at the university. They were asked to read the statements about fatigue and to make three initial global piles (agreed with; did not agree with; and neutral/doubtful). Then patients sorted the cards on the worksheet, starting with the statement they agreed with least, until all statements they disagreed with were on the worksheet. Then they did the same with statements they did agree with. Next, patients sorted the remaining statements in the middle of the worksheet. After finishing the task, they read the items again, so they could rearrange the cards if necessary. Finally, the researcher (S.N.) noted the numbers of the statements (which were written on the back of the cards) on a record sheet with the Q-sort figure.

For analysis the Q-sorts were correlated, whereby a high correlation indicated that participants sorted the cards in a similar way. By-person factor analysis was used to analyse the Q-sort correlation matrix, obtaining factors that represented groups of participants with a similar opinion [28]. Factor scores were calculated for each statement, which resulted in one representative Q-sort per group. The diversity of participants was more important than the sample size, which was large enough when factor stability and a clear understanding of the factors’ meaning were ensured [38]. For an appropriate analysis, considerably more statements were needed than participants (ideally, the number of items should be at least twice the number of participants) [39].

**Measurements**

**Patient characteristics**

Patients answered questions about marital status, children living at home, work situation, important life events, exercise, medication and recent medication change, comorbidity, health status, hours of sleep during the night and napping during daytime.

**Daily roles**

With eight items, patients were asked to indicate how many hours per week they normally spent on the following eight areas: work; study; housekeeping (cooking, shopping, washing, cleaning); caring for people at home (e.g. children, ill spouse, parents); caring for people outside home; voluntary work; gardening and pets. They could choose one of the following six answers: not applicable to me (scored as 0); on average >0 and <3 h/week; >3 and <10 h; >10 and <20 h; >20 and <30 h; and >30 h (scored as 5). By adding up all the scores, we calculated a personal role score (range: 0–40).

**Visual analogue scales**

Patients completed a visual analogue scale (VAS) for pain and impact of the disease, and three VAS fatigue scales [40] for severity (‘Please place a mark on the line to show your level of fatigue over the past 7 days’ (anchors: no
fatigue—totally exhausted; impact (‘Please place a mark on the line to show the effect that fatigue has had on your life over the past 7 days’ (anchors: no effect—a great deal of effect); and coping (‘Please place a mark on the line to show how well you have coped with fatigue over the past 7 days’ (anchors: not at all well—very well). As these three VASs were developed in the UK, they were translated into Dutch according to the recommended translation procedure for cross-cultural adaptation [41].

Anxiety, depression and disability
The Dutch versions of the anxiety subscale of the Hospital Anxiety and Depression Scale (HADS) [42], the 15-item Geriatric Depression Scale (GDS) [43] and the 10-item version of the HAQ-II [44] were completed.

Laboratory values
The 28-joint DAS, CRP, ESR and haemoglobin (Hb) values were collected.

Analysis
The Q-sort data were analysed with PCQ for Windows [45], using centroid factor analysis with varimax rotation. The decision for four factors with a significance level of 0.40 was based on the following considerations: a maximum number of Q-sorts loading significantly on one factor; all factors having an eigenvalue >1; a maximal explained variance; no factors with only one significantly loading Q-sort; and as few as possible consensus items and no bipolar factors. For the theoretical interpretation of the factors, we used those statements with extreme factor loadings (+4, +5, +6 and −4, −5, −6). First, we looked at the four patterns of fatigue experience based on the content of these statements. Then, we also looked at which patient variables (supplementary table S1, available as supplementary data at Rheumatology Online) characterized the four groups. To this end, we used percentages and median values with inter-quartile ranges. We described the most prominent patient characteristics in each group, without testing for statistically significant differences. Owing to the small sample size in the groups, the power would be too small in such an analysis.

Results
Sample
The sample consisted of 13 men and 17 women with a mean age of 60 years (±12.15 years), ranging from 38 to 82. The mean score of daily roles was 6.8 (±3), ranging from 1 to 12. Further sample characteristics and health-related outcomes are shown in supplementary table S1, available as supplementary data at Rheumatology Online. The mean disease duration was 9.9 years (±6 years; range: 2–26 years). The range of VAS fatigue scores for severity (range 1–9), impact (range 1–9) and coping (range 2–10) showed that patients with all levels of fatigue were included. The Cronbach’s α values of the scales to measure anxiety, depression and disability were 0.76 (HADS), 0.60 (GDS) and 0.85 (HAQ-II).

Patterns of fatigue experience
Factor analysis showed that the optimal solution for this Q-sort data was a four-factor structure. Thereby, two-thirds of the Q-sorts loaded significantly on one factor. Of the remaining 10 Q-sorts, 8 did not load significantly on any factor and 2 were confounders (significant factor loadings on 2 factors). The explained variance was 40%. The four-factor solution was also the best alternative for theoretical interpretation.

The factor groups are described as follows: those items with extreme factor loadings (+4, +5, +6 and −4, −5, −6) were used for the description of the fatigue experience. Furthermore, per group, the most distinctive patient characteristics are described briefly. These results are summarized in Table 1. Extensive tables are provided as supplementary data, available as supplementary data at Rheumatology Online: supplementary table S1 quantitatively summarizes the patient characteristics per factor; supplementary table S2 shows the factor scores per statement and eigenvalues, percentage explained variance and median factor scores per factor; and supplementary table S3 shows the most characterizing statements per group (statements with the strongest agreement and also the strongest disagreement).

Group A: little impact of fatigue (n = 7)
Group A consisted of seven patients having Q-sorts with negative factor loadings, so the Q-sorts had to be interpreted in the reverse way [46]. It means that, for example, the patients strongly agreed with the statement in column 6. For better readability, the interpretable correct algebraic signs were used in supplementary tables S2 and S3, available as supplementary data at Rheumatology Online. Group A patients reported days without any fatigue, only being tired after doing too much and that the fatigue would pass if they rested. Furthermore, they agreed with having a lot of energy and having good coping competencies. However, the ability to cope well with fatigue varied. These patients belonged to the oldest group, with the fewest daily roles (see supplementary table S1, available as supplementary data at Rheumatology Online). Group A had moderate disease activity in absolute terms, which reflects the highest disease activity of all four groups. They scored low on pain, fatigue severity and fatigue effect, and had high fatigue coping scores. More than half of the Group A patients reported to seldom rest during the day. Compared with Groups B and C, Group A had average disease duration and reported less exercising. They had higher disability scores than Group C, but the same as Group B. In this group, no biologicals were used.
Group B: Good coping and bad sleep (n = 5)
Group B patients reported disrupted and non-refreshing sleep. They also had days without any fatigue and could cope with it well. They did not let on to anyone when they were tired and felt physically impeded by their fatigue. Group B consisted of more women than men (see supplementary table S1, available as supplementary data at Rheumatology Online). Compared with the other groups, Group B patients had an average number of daily roles and reported the least number of hours they usually slept during the night. Four of the five patients reported not resting during the day on a regular basis. None of

The fatigue experiences in this table are based on the statements with extreme factor loadings (+4, +5, +6 and −4, −5, −6).
them had fatigue-related comorbidities. They had the longest disease duration, the lowest fatigue severity and impact scores of all four groups, and also their pain score was low. Four of the five patients in Group B reported exercising on a weekly basis. Moreover, Group B patients rated their general health as better and the impact of their disease on their life as lower than patients in the other groups. Three of the five patients used a biological.

**Group C: search for balance (n = 6)**

Group C consisted of six patients. They were not refreshed in the morning, took a nap during the day, lived in a constant struggle to find a balance between activity and rest and just carried on when they were fatigued. Moreover, they reported only being tired after doing too much and could cope well with their fatigue. Group C was the youngest group (see supplementary table S1, available as supplementary data at Rheumatology Online). All patients were living with a partner, most of them had paid work and half of them had children living at home. The role score was the highest of all groups. In addition, most of the patients exercised on a weekly basis. This group scored higher on pain, fatigue severity and impact, lower on the ability to cope with fatigue and had shorter disease duration than Groups A and B. Disability scores were lower than those in the other groups. In this group, as many biologicals are used as in Group B and also DMARDs were frequently reported.

**Group D: high distress (n = 2)**

Group D was the smallest group with two patients. They found it difficult to accept the fatigue, were frustrated when they were too fatigued to do things they wanted to do, had difficulty concentrating when they were fatigued, were often awake during the night and had to plan everything they did because of their fatigue. Group D patients reported the highest levels of pain and fatigue (severity and effect), most comorbidities, high levels of anxiety and depression and the shortest disease duration (see supplementary table S1, available as supplementary data at Rheumatology Online). Group D patients had the highest disability scores, did no regular exercise and their general health was worse. Of all the groups, they reported the most hours’ sleep during the night, and regularly taking a nap during the day. They had slightly lower coping fatigue scores on the VAS than patients in the other groups.

**Discussion**

In this study, we identified four different perspectives on the experience of fatigue in RA. Although parts of the fatigue experiences overlapped in the groups, there were remarkable differences, also regarding the patients’ living situation and other characteristics.

For Group A patients, fatigue had almost no impact on their lives. Their fatigue was comparable to normal fatigue. The higher age in Group A did not seem to be associated with longer disease duration. So the low impact of fatigue cannot be explained by a longer time of experience of coping with RA. It is more likely that the higher age in this group was related to the few daily roles that patients had to fulfil. After retirement, people have fewer roles [47], and expectations from others are less demanding. In addition, older people’s psychological resources to adapt to fatigue might be higher because they have learned to adjust to changing life circumstances and accommodate their goals and standards with greater flexibility than younger people [48]. Group B patients reported disrupted and non-refreshing sleep, and being physically impeded by their fatigue. However, four of the five patients said they exercised on a weekly basis and, in general, fatigue had little impact on their lives. Some explanations for their good coping ability could be the fact that the patients had the longest disease duration and the least fatigue severity of all groups, and that they had an average but not high number of daily roles. Group C patients experienced more impact of fatigue than Group A and B patients. They knew how to deal with their fatigue, but in line with the high amount of activity in Group C, they lived in a constant struggle to find a balance between activity and rest. That struggle was not always successful as its impact was worse in Group B. This struggle might be related to the fact that Group C was the youngest group with the most daily roles. Those patients with multiple roles (e.g. housekeeping, working, being a spouse, parent), seemed to live in a constant tension between adequate fulfillment of their roles and the need for rest or relaxing activities. This finding is in line with the results of our interview study that the impact of fatigue was worst in young women with multiple roles [12]. Patients in Group D were very distressed and fatigue had a great impact on their lives. Compared with the other groups, they had the most physical and mental health problems. The high levels of physical and psychological distress in this group probably made it difficult for patients to accept their fatigue and cope with it in a constructive way.

This study is descriptive and cannot examine causal relationships. Our aim was not to find such relationships or statistically significant differences between groups. Rather, we made a first attempt to describe dominant perspectives on fatigue experience in RA and to describe the patient groups which share a certain perspective. However, it is an outstanding finding that Group A patients had the highest but still moderate disease activity, although they experienced the least impact of fatigue. We assume that this points to the importance of psychological and social aspects, beside physical ones, in the experience of fatigue in RA. It seems likely that the fatigue experience in patients with established controlled RA is not so much influenced by disease-specific characteristics as by personal and situational characteristics. The differences in fatigue experience appeared to be related to tasks, external demands and coping resources. The complexity of the fatigue experience in RA is further underlined by the fact that one-third of the patients could not be allocated to one of the groups. Furthermore, there was no item with which all patients strongly agreed
(sorted between +4 and +6 in all groups) or disagreed (sorted between −4 and −6 in all groups). This shows that measurement instruments should include items that reflect a broad spectrum of fatigue experiences in order to be able to adequately describe fatigue experiences in RA patients and to distinguish between patients with different patterns of fatigue experience.

When looking at the existing multi-item fatigue scales, MAF, FACIT-F, POMS, SF-36 vitality subscale, CIS and the BRAF-MDQ, it becomes obvious that none of them covers all categories. A comparable conclusion has already been drawn by Nicklin et al. [49], who showed that neither the MAF, SF-36 vitality subscale, POMS or FACIT-F covers all of the following patient-reported categories of fatigue: frequency/severity, duration, energy, impact, emotion, coping, social life, planning, relationships, cognition, quality of life and sleep. All of these categories also turned out to be relevant in our study; the categories social life, planning, relationships and quality of life were included in the ‘consequences’ category in our study. The CIS consisting of the dimensions ‘subjective feeling of fatigue’, ‘concentration’, ‘motivation’ and ‘physical activity’ does not cover all dimensions either. The BRAF-MDQ was recently developed and validated in a British population and is based on interviews with patients scoring seven or higher on a fatigue severity VAS. So we assume that there is still no measurement instrument available which embraces the full diversity of the subjective experience of fatigue with its several dimensions and possible ranges of fatigue severity. To be able to measure fatigue in RA with all its facets, new ways of measurement are needed in the future. Not only should more aspects of fatigue then be included but also new developments in measurement applications should be used. Computer-adaptive testing seems to be a promising method to comprehensively measure fatigue with relatively few items per patient [50].

New measurement instruments should also be used for screening purposes. In clinical practice, a patient’s perspective on fatigue experience should be identified. Consequently, it would be possible to provide tailored support. Patients with a fatigue experience such as patients in Group D might benefit from a psycho-social intervention that is focused on the high level of distress, whereas patients with an experience similar to patients in Group C might be aided by an approach emphasizing the balancing of roles and demands. Patients with a fatigue experience such as patients in Group B could probably benefit from support focused on sleep. However, for patients with an experience similar to patients in Group A, support seems unnecessary.

Our sample of 30 RA outpatients was sufficient for using Q-methodology [28, 38, 39]. Since this research raises new hypotheses, generalizations to the entire population of RA patients should be made with caution and need more research. However, evidence for the test–retest reliability and also the reliability across subjects in Q-sort results could be identified in research concerning different topics [24]. All patients in our study had a disease duration of at least 2 years. We acknowledge that we missed patients with recently developed RA and patients in flare. As those patients mostly have anaemia, high disease activity with fever and very high levels of fatigue, it is important to include them in future research on fatigue experiences. Moreover, DASs were relatively low in this sample, which raises the question of to what extent our results can be generalized to patients with high disease activity. However, nowadays, high disease activity is not very common among RA outpatients. In a recent study about the patients’ perspective on fatigue in RA, relatively low disease activity was reported in a comparable sample also [11].

This study revealed different types of fatigue experience, reflecting the patients’ perspective and showing the match with patient characteristics. Results indicated that fatigue experience is a complex phenomenon related to physical, psychological and social resources and competencies.

**Rheumatology key messages**

- Dominant perspectives on fatigue experience can be distinguished among patients with established controlled RA.
- Fatigue experience seems to be influenced not only by disease-specific characteristics but also by psychological and social aspects.

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**Supplementary data**

Supplementary data are available at *Rheumatology* Online.

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