

Patients' Perceptions of Fatigue in Rheumatoid Arthritis: Overwhelming, Uncontrollable, Ignored

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Objective. Fatigue is commonly reported by patients with rheumatoid arthritis (RA) but is rarely a treatment target. The aim of this study was to explore the concept of fatigue as experienced by patients with RA.

Methods. Fifteen patients with RA and fatigue (≥ 7 on a 10-cm visual analog scale) were individually interviewed and asked about the description, cause, consequence, and management of fatigue. Transcripts were systematically analyzed by 2 researchers independently, relevant phrases were coded, and earlier transcripts were checked for the emerging codes. A random sample of analyses were independently reviewed. A total of 191 codes arising from the data were grouped into 46 categories and overarching themes.

Results. Vivid descriptions reflect 2 types of fatigue: severe weariness and dramatic overwhelming fatigue. RA fatigue is different from normal tiredness because it is extreme, often not earned, and unresolving. Participants described physical, cognitive, and emotional components and attributed fatigue to inflammation, working the joints harder, and unrefreshing sleep. Participants described far-reaching effects on physical activities, emotions, relationships, and social and family roles. Participants used self-management strategies but with limited success. Most did not discuss fatigue with clinicians but when they did, they felt it was dismissed. Participants held negative views on the management of fatigue.

Conclusion. The data show that RA fatigue is important, intrusive, and overwhelming, and patients struggle to manage it alone. These data on the complexity of fatigue experiences will help clinicians design measures, interventions, and self-management guidance.

KEY WORDS. Fatigue; Rheumatoid arthritis; Qualitative; Tiredness; Outcome; Importance; Perception.

INTRODUCTION

Fatigue in rheumatoid arthritis (RA) is often considered by professionals to be a general symptom of disease activity. However, unlike pain and disability, fatigue is rarely addressed as a treatment target in its own right, is infrequently reported separately in trials, and is not a recommended core outcome for clinical trials (1). Fatigue is a

significant symptom experienced almost universally by patients with RA (88–98%), often on a daily basis, and patients rate the impact and importance of fatigue as similar to pain (2–7).

The causality of RA fatigue is likely to be multidimensional, involving inflammation, pain, anemia, poor sleep, and psychosocial factors (3,8–10). Specific pharmacologic interventions for RA fatigue have not yet been developed; therefore, ways of enabling patients to self manage this major, common, and important symptom are required. To develop self-management strategies, it is first necessary to understand the concept of fatigue as experienced by the patient. Patients' experiences of the nature of RA fatigue, their beliefs about its causes and consequences, and their strategies for coping with it may all influence fatigue self management.

Although quantitative research can examine the intensity of symptoms, qualitative methods are the most appropriate way of ascertaining the experience of subjective symptoms, ensuring that the data are grounded in the patient's language and experience (11). A search of the literature (Medline, Embase, AMED, Cinahl, and PsychoInfo, 1985–2004) revealed only one qualitative explo-

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Table 1. Interview schedule

- 1 How would you describe this fatigue or tiredness?
- 2 What do you think causes the fatigue?
- 3 What are the consequences of fatigue?
- 4 How do you deal with your fatigue?
- 5 How do you sleep?
- 6 Is fatigue discussed in clinic?

ration of patients' experiences of fatigue in RA (12). Twenty patients with RA in the United States participated in individual interviews and were asked 15 detailed questions about fatigue. A recognized coding framework of conditions, strategies, and consequences was applied to the data. The study found that fatigue is experienced during conditions of inflammatory activity and poor sleep, participants manage fatigue using strategies to enhance energy (social support, distraction, re-prioritizing, pacing), and the consequences of fatigue are physical, emotional, social, and cognitive.

Our understanding of the patient's experience of fatigue in RA is therefore based on a single qualitative study and should be verified or enhanced in a second population, where different methods of analysis and interpretation by different researchers may confirm, elucidate, or challenge the findings. There may be subtle differences in the experience, perception, or self management of fatigue in a non-US culture, and the current trend toward involvement of patients in research study design, analysis, and interpretation may also influence findings (13). Therefore, the aim of this study was to explore the experience of fatigue in patients with RA in the United Kingdom.

PATIENTS AND METHODS

To identify patients who experience fatigue, patients with confirmed RA (14) were asked to answer the question "How tired have you felt in the last 24 hours?" using a 10-cm visual analog scale (VAS). End points were "Wide awake/full of energy" and "No energy/very tired/exhausted." Patients who scored ≥ 7 were invited to take part in a one-to-one semistructured qualitative interview (SH or MH) lasting ~45 minutes. Patients may experience fatigue in either the presence or absence of inflammation; therefore outpatients who were prescribed a single intramuscular glucocorticoid injection for an inflammatory episode were approached, as well as outpatients who did not require medication change. Participants were purposively selected to reflect a mix of sex, age, disease duration, and work status. Recruitment continued until no new data emerged ($n = 15$). Independent ethics approval and written consent were obtained.

The project steering group, which included a patient research partner (KK), defined 4 neutral, nondirective interview questions on the description, cause, consequence, and management of fatigue (Table 1). Two questions that emerged from the data were incorporated into later interviews (sleep and discussing fatigue in the clinic). Interviewers followed up the participants' responses with further probing questions as appropriate.

Analysis. Interviews were audio taped, transcribed verbatim, anonymized, and systematically analyzed to establish themes grounded in the data (11,15,16). Transcripts were read and reread, and all phrases were systematically coded independently by 2 researchers (SH and MH), who compared codes after every 3 transcripts to resolve any differences. Earlier transcripts were checked for the emerging new codes (constant comparison). The final transcript yielded no new codes, indicating data saturation. The transcripts and analyses of 5 randomly selected interviews were then independently reviewed by 2 other researchers (ZC and KK) who suggested some additional interpretation and confirmed the codes. Codes were grouped into categories (by SH), discussed and revised by the steering group, and then the categories were grouped into overarching themes (by SH and MH) that were again reviewed by the steering group. The final report was returned to the participants, who did not suggest any changes.

To remain unbiased for data collection and analysis, the previous qualitative study was not reviewed in depth until after analysis. Some participants found it difficult to restrict their conversation to fatigue as opposed to other RA symptoms such as pain; therefore only data that participants clearly related to fatigue are presented.

RESULTS

Participants had a median fatigue score of 8.1 (interquartile range 7.55–8.55), including one participant with fatigue >7 of 10 at screening who recorded a score of 4.1 at the interview some weeks later but still considered fatigue his major problem. The cohort reflected a mix of disease duration, sex, work status, and age (Table 2).

Initially, 191 codes were identified, which were then grouped into 46 categories, and finally into 3 overarching themes. The data showed that participants experienced RA fatigue as A) overwhelming and different from normal tiredness and B) permeating every sphere of life, and that C) self management is variable and professional support is rare. These 3 themes, with the most common categories and codes raised by at least one-third of participants, are shown in Figure 1.

Overwhelming and different from normal tiredness ("wipeout"). Two different types of fatigue were described. Some participants experienced fatigue as heaviness or weight: "It's a bit like someone giving you a big rucksack to do everything with, so, yeah, okay I could go shopping, but if you give me a big rucksack full of stones on my back . . . and then I go shopping!" (patient D). Other participants experienced an extreme, absolute, and exhausting fatigue, which left them unable to carry on. This sometimes had a sudden and dramatic onset: "Well, my phrase is 'wipeout,' I call it my wipeout days . . . Or my wipeout moments . . . Because I really don't want to do anything else but sleep and feel totally drained of energy. It was a very sudden definite whoosh, you know, as if the energy drained from me" (patient F). Some participants appeared to differentiate between ordinary tiredness that they experienced before RA, and the more intense RA

Table 2. Demographic data of 15 patients with rheumatoid arthritis experiencing fatigue*

| Patient | Sex | Age† | Disease duration, years‡ | Fatigue, (range 0–10)§ | Work status | Inflammation |
|---------|-----|------|--------------------------|------------------------|-------------|--------------|
| A | F | 62 | 7 | 9.4 | Housewife | Yes |
| B | M | 63 | 18 | 9.6 | DLA | Yes |
| C | F | 45 | 12 | 8.8 | Housewife | Yes |
| D | F | 40 | 5 | 7.9 | Working | Yes |
| E | F | 63 | 15 | 7.6 | DLA | Yes |
| F | F | 65 | 5 | 7.5 | Retired | Yes |
| G | M | 53 | 14 | 8.1 | Working | Yes |
| H | F | 80 | 30 | 7.9 | Retired | Yes |
| I | F | 67 | 10 | 8.6 | Retired | Yes |
| J | F | 28 | 7 | 8.5 | Working | No |
| K | F | 64 | 18 | 7.2 | Retired | No |
| L | F | 50 | 29 | 8.4 | Housewife | No |
| M | F | 31 | 3 | 7.5 | Working | Yes |
| N | M | 57 | 15 | 4.1 | DLA | No |
| O | F | 66 | 1.5 | 8.5 | Retired | Yes |

* DLA = disabled living allowance.
 † Mean ± SD 55.6 ± 14.4 years.
 ‡ Mean ± SD 12.6 ± 8.6 years.
 § Mean (interquartile range) 8.1 (7.55–8.55).

experience of fatigue: “When you’re tired, you feel tired because you’ve been doing things because you’ve been busy, because perhaps you haven’t slept very well and you actually feel tired, just tired. But with this kind of fatigue it’s, it’s total wipeout for me” (patient F).

Fatigue varies in duration (minutes, days) and frequency (daily, several times a week, constant), and has physical elements of weariness, feeling drained, and loss of physical energy: “Just weary, sort of exhausted, fatigued, I dunno, just as though everything’s drained away from me” (patient E) and may feel like having the flu: “Well, I generally describe as like having flu . . . and a kind of all over, I don’t know whether you call it aching or weariness or whether you can call it both” (patient D). Participants also described a loss of mental energy, motivation, and cognition: “Well, you feel as though you don’t wanna do nothing.

You just feels as though, you know, you’re just quite satisfied to sit down an’ do nothing. The enthusiasm’s gone, you know, you just lose interest” (patient H) and emotional components to fatigue: “And now the other, fatigue, would just come over me, when my eyes were suddenly feeling all watery, you know? More like tearfulness kind of thing, which really is I suppose, I guess, stressful fatigue” (patient O).

Participants considered the fatigue of RA to be different from normal tiredness, which occurred before the diagnosis of RA, or which is experienced by individuals without RA: “Because I mean I’ve got friends that’s similar to my age and they’re nowhere near as tired as what I get and they’re just, I call them normal” (patient A). RA fatigue is not normal because episodes are often not preceded by activity (i.e., not earned): “I just really feel very tired, like

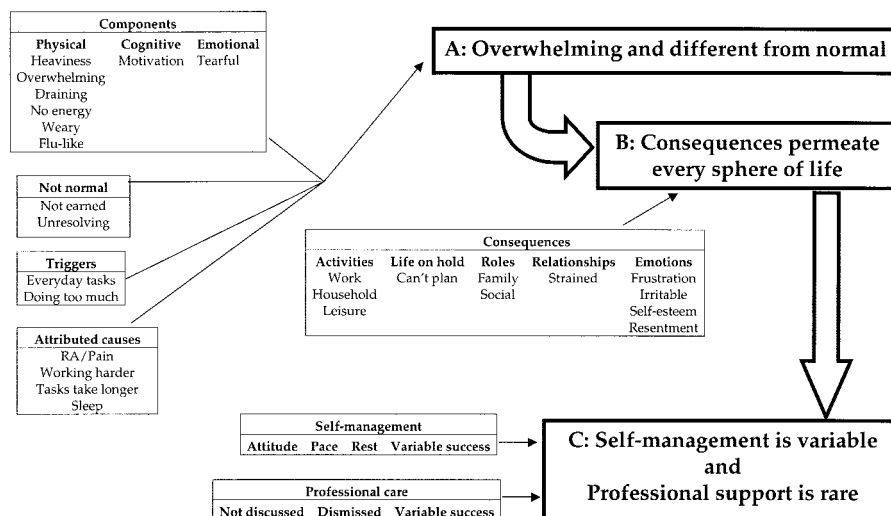


Figure 1. The 3 themes of fatigue and major categories and codes. RA = rheumatoid arthritis.

abnormally tired, like not normal, not 'I have done something to make me tired' " (patient M), which makes RA fatigue unpredictable: "I can't put a time on them [wipe-outs] . . . There's no, there's no knowing when it comes" (patient F).

Participants did think that some specific episodes of fatigue had triggers, but this could be just performing everyday tasks: "Doing anything, even standing up peeling potatoes, things like that, and I think 'Oh, gosh!' Yeah, simple things like that" (patient K) or doing too much: "Yes, things like trying to do too much in one day . . . Um, physical exertion . . . I mean exercise is good, but too much would . . . I would be completely exhausted for about 2 or 3 days afterwards" (patient J). Most participants believed the underlying mechanism of their fatigue is RA: "I think it's accepted . . . it's part of the disease for a start" (patient N) and see the main cause as RA flares: "I find that after I've been swollen, if I've got a really nasty flare, for a week or 2 after that flare if the swellings all gone and the pain . . . I'm really tired, so it takes me quite a bit more to recover" (patient M). Having to work harder and longer because of disability, and having to expend more energy to make disrupted joints perform normal actions were also thought to be causes of fatigue: "Everything seems to take twice or 3 times as long to do as it once did and this all contributes to making one fatigued" (patient K); "So there's . . . the weakness of joints which is annoying and would contribute to probably making you weary throughout the day 'cos you're struggling against it . . ." (patient D). Many participants perceive disturbed sleep as an important cause of fatigue: "I get quite restless because the pains seem to intensify and I seem to have more and more difficulty finding somewhere to lay where I can sort of cope with the pain, and go back to sleep again, and as I say, by the time I get up I feels sort of exhausted" (patient O), while others report sleeping well, but that the sleep is still unrefreshing: "I wake up once in a night's sleep . . . One of those questions [in questionnaires] is 'Do you wake up refreshed in the morning?' and I laugh every time I read that because that's just, like, the thing that doesn't happen" (patient D); "So I can have a good night's sleep . . . Um, and still wake up feeling very, very tired and exhausted, and heavy" (patient J).

Given these vivid accounts, fatigue is understandably considered a very important symptom that is present from the onset of RA: "But what I do remember about the beginning of the rheumatoid arthritis was the massive weariness being almost, almost the biggest symptom" (patient D). Some participants suggested that their most important symptom is the one that they have difficulty controlling, therefore some rate fatigue as more important, whereas others rate pain as more important: "I feel that fatigue is my worst symptom. I can tolerate the pain to a certain extent because I know that with a flare it will go . . . I've learned ways to help a flare, but the fatigue, you asked me earlier what sort of things I did to help it and . . . Some things do help it lessen but it's never gone away from me" (patient J); "Yes the pain is the worst. The fatigue you can hopefully rest and you'll get over the fatigue, but the pain . . ." (patient I).

Consequences permeate every sphere of life. The consequences of fatigue permeate every part of life such that activities are reduced to a minimum or "dumbed down": "It affects everything. It sort of dumbs down everything that I want to do really" (patient L). Participants struggled to carry on with work, leisure, and household activities: "Well, I've always liked to go out to dancing, and liked night clubs, and now I find I just don't have the energy to do that any more" (patient M); "When I get home I feel as though I've done a week's, what I should have done in a week, and we've just gone and got some groceries. I mean my husband brings it in and unpacks it and puts it all away, which I would normally do and I just collapse on a chair. It just, I don't know, it just don't seem right" (patient C).

The nature of fatigue restricted the participants' ability to fulfill their normal roles in the family, including physically playing with the children (haring around): "It restricts what I do, if my nine year old son is running around I tend to sit and watch . . . So, his Dad needs to do all that stuff that I used to, like haring around" (patient D); "So I am, in a way, restricted in the time I spend with my family. . . . My family are relatively understanding about it but I'm the only one in the family that's got rheumatoid arthritis, and the only one who seems to have a problem with fatigue, so it is quite difficult sometimes to try and get them to understand how it is" (patient J), and their social lives: "I have fell asleep when I've had company round like, you know? They've been chatting and all of a sudden I started to nod, it's not very sociable really, you know?" (patient B).

Fatigue takes an emotional toll on relationships, leading to frustration, irritability, and loss of control: "So hence the kids and the partner and stuff so everything becomes quite curt and short and brief and it does . . . You know, if you ask a child to do something and they don't do it, on a good day if you're refreshed, ok, eventually they'll do or they won't do it. On a bad day it's like 'Why won't you just do this!'" (patient D); "I feel very limited and restricted in what I can do, so get limited and restricting . . . Um, frustrating . . . Yeah, it's a very negative feeling and it's like I've lost the control over certain things I can do" (patient J). The consequences of fatigue reduce self-esteem, leading to resentment: "I feel useless, because I've got 2 grandchildren, I feel I can't do things that I want to do with them because I get too tired" (patient C); "I think, well, I've not done anything to be tired . . . It just don't seem fair. . . . because I think 'Well should I get like this?' 'Why can't I do that?'" (patient C).

Self management is variable, professional support is rare ("You don't know what to do"). Participants reported trying a variety of self-management strategies, particularly acceptance: "But you got to accept that sometimes, and try and work around it, and work with it rather than just think 'Oh, I'll battle through' because I can make myself more fatigued and more tired" (patient J), adopting positive attitudes: "And I think it's because I've got a positive attitude that I get through it, and I don't go round complaining. I never say to my son, 'Oh, you know I feel dreadful' or 'I'm tired.' I just get on with it" (patient K), and persistence: "I'm aware at the moment that I'm fighting it

in that I'm working through it" (patient D). Participants reported using specific actions to deal with fatigue, particularly pacing and rest: "I just do a little bit in the morning, then I'll take a bit of a rest . . . and then when I come back I'll do whatever else needs to do" (patient M). Occasionally they made a choice to carry on regardless and take the consequences: "Or you go out and do it all in one day. Go mad and suffer for about 3 days after" (patient B).

The strategies have variable success and some participants were uncertain about how best to manage fatigue: "It's just, you just feel as though you don't know what to do to make things right" (patient C). Participants believed professional support is rare, because the emphasis is on physical problems and disease activity. Most said they did not discuss fatigue with their health professional, but those who did thought it was dismissed: "It's funny that you don't get much response from doctors or consultants when you try and explain that, there's a big chunk of what's wrong isn't something they can touch or feel or xray or blood tests" (patient D); "I suggested it [fatigue] to him then, and he just sort of pooh-pooed it really . . . He just said 'Oh, well, you know, we're interested in your physical symptoms, whether you've got pain in this joint or that joint, has it improved, has it got worse, have you got any swelling, what's the mobility like?' Those sort of questions that I regularly get asked, which are fine, but the fatigue is a physical symptom to me, and I kind of felt well maybe I'm the only one with rheumatoid arthritis that felt like that, and that's how he made me feel" (patient J).

All participants had experiences of receiving intramuscular injections of glucocorticoids during their disease lifetime and variously reported some effect on fatigue, no effect, and reduced effect of repeated injections. Some participants felt that controlling disease activity may reduce fatigue, but generally they believed that professional treatment would have limited success: "I don't, I don't honestly know, because if we can't prevent flare-ups, you can't prevent things getting, being a drain on you" (patient C). There were no differences between the views of men and women, except that 2 of the 3 men attributed their fatigue to laziness, which no women mentioned.

DISCUSSION

These qualitative data show that for these patients with RA, fatigue is a frequent, extreme, and multidimensional experience. The consequences of fatigue intrude on every sphere of life and cause major disruption and distress. Participants reported that they struggle to manage their fatigue with little professional support, perceive it to be dismissed, and assume it cannot be treated and that they must manage alone.

The US and UK studies complement each other. The UK participants seemed to place more emphasis on dramatic, overwhelming fatigue than the US participants, a difference that might be explained by language, interview questions, analysis, or patient selection. The cohorts both described multidimensional causes and major, wide-ranging consequences for RA fatigue that are similar across the continents. However, differences arose in perceptions of

the management of fatigue. UK participants perceived that they must manage fatigue alone, and expressed negative attitudes that nothing can be done to manage fatigue either by themselves or their clinicians. These beliefs may reflect a reluctance to engage support from health professionals or others, reinforced by a perception that such requests have been dismissed in the past. They may also reflect an isolation that might be based in a more reserved "stiff upper lip" British culture where acceptance, struggling on, and perseverance, rather than asking for help, are expected. In contrast, US participants reported using friends and family to help manage and share the problem, and positive coping strategies such as downward comparison and altering life values to place greater importance on relationships. This may be related to an American culture where speaking out, sharing problems, and expressing emotions are more accepted.

Qualitative explorations of fatigue in other chronic illnesses demonstrated similar multidimensional components and consequences, but different perceived causes and implications. In a study of cancer, fatigue was attributed to chemotherapy and therefore could be predicted and prepared for (17). In multiple sclerosis, fatigue was perceived as exacerbating existing symptoms, whereas in RA existing symptoms are perceived to exacerbate fatigue (18). Fatigue in healthy workers has similar symptoms and consequences to the fatigue of chronic illness, but is attributed to over-exertion and is therefore viewed as preventable, predictable, manageable, and short lived (19). A review of the classifications of fatigue found that unlike normal tiredness, fatigue in chronic illness is pervasive, serves no useful purpose, and is not relieved by sleep, findings that were reflected in this study (20).

Study participants thought their unsupported self-management strategies for fatigue have limited success, reflecting the evidence that perceived self efficacy for coping with fatigue is lower than for other RA symptoms (4). To obtain guidance on self-management strategies, patients need to discuss fatigue with the multidisciplinary team, but patients do not often raise the issue of fatigue in the clinic. This reluctance was also reported in a study of the general population that showed 74% of women attending their family practice had fatigue, but only 22% discussed it (21). Participants perceived that fatigue is dismissed by professionals. Anecdotally, clinicians respond to questions about fatigue by saying it is part of RA, and although this may reassure patients that fatigue is normal, it does little to help them manage the problem. Before the multidisciplinary team can develop patient self-management strategies, they must first address the patients' perceptions of poor response to fatigue from professionals, which may deter patients from discussing fatigue. Second, professionals need to address patients' negative perceptions that nothing can be done. Discussion of potential self-management strategies would validate the patient's feelings of fatigue, and might enhance feelings of control. Fatigue may exacerbate pain and disability, therefore addressing the management of fatigue may also improve a larger cluster of symptoms. Clinical experience indicates that energy conservation techniques such as pacing or reprioritizing activities may benefit some patients, and research is

needed to develop effective fatigue self-management training.

Some participants used the word "fatigue" to describe the overwhelming RA experience and considered "tiredness" as referring to the feelings experienced by others or before the onset of RA; therefore wording of fatigue VAS scales is crucial. A review of scales used to measure RA fatigue has revealed numerous variations of wording, making comparison of studies very difficult (22). A proposal for standardizing VAS fatigue wording could be explored with these qualitative data and clarified with a patient panel, and should then be subjected to validation studies.

One limitation of this study is that it comprised participants with fatigue levels ≥ 7 of 10, a cutoff point selected to ensure that they had extensive experiences to relate. However, lower fatigue levels may be equally important and intrusive, and may be different in nature, consequence, and self management. The VAS wording in this study was not ideal because it combined tiredness, fatigue, and energy, which may have different meanings. It is possible to not be full of energy but still not feel fatigued, thus energy and fatigue may not be opposite ends of a single continuum. The components of fatigue described as lack of motivation, energy, or unrestorative sleep may relate to depression, which was not measured. RA fatigue is associated with pain and depression, although studies vary in their conclusions and causality cannot always be implied (3,7). Up to 90% of patients with RA report fatigue (7) and the prevalence of depression is 17–53.5% (23); therefore, some overlap between fatigue and depression is possible in these participants, but systematic bias in selecting those with depression was unlikely.

The strengths of the study are the use of multiple checks for validity by independent researchers and the contribution of the Patient Research Partner (KK) who suggested including patients not currently experiencing disease flare, reviewed transcripts, and highlighted fatigue as an early symptom, and also contributed to discussions on coding and themes. We have reported common issues raised by a substantial number of participants, and although this means omitting some rich individual patient data, it provides a robust reflection of fatigue in RA.

This study shows the multidimensional facets of fatigue and its wide-ranging consequences. These data raise new issues of uncertainty on how to self manage, and indicate a perceived lack of support from the health professional team. Professionals have expended a lot of effort in managing pain and disability and now need to address fatigue with some urgency.

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