

Rheumatologists' knowledge, attitude and current management of fatigue in patients with rheumatoid arthritis (RA)

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Received: 20 March 2008 / Revised: 18 June 2008 / Accepted: 26 June 2008 / Published online: 12 July 2008
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Abstract To describe rheumatologists' knowledge, attitude and current management of fatigue in patients with rheumatoid arthritis (RA), a postal questionnaire was sent to all rheumatologists ($N=204$) and trainees ($N=49$), members of the Dutch Society of Rheumatology. The overall response rate was 44% ($N=110$). In general, rheumatologists' knowledge about RA-related fatigue was in accordance with the literature but they perceive a lack of their own knowledge about aetiology and evidence-based interventions to prevent and treat fatigue. The majority of the rheumatologists believe that fatigue is a multi-disciplinary diagnosis and is preferably managed by the nurse specialist (34%). Assuming that the patient will raise the issue, most of the rheumatologists pay attention to fatigue during the first consultation and less often during follow-up consultations. There is a need for knowledge about causes and treatments for RA-related fatigue to ensure that patient outcomes are improved.

Keywords Attitude · Fatigue · Knowledge · Management · Rheumatoid arthritis · Rheumatologist

Introduction

Patients with rheumatoid arthritis (RA), one of the musculoskeletal conditions, experience many different symptoms and, after pain, fatigue is by now widely recognised as the most bothersome symptom [1–5]. To deliver professional care, rheumatologists need knowledge about and a positive attitude toward RA-related fatigue, but little is known about current knowledge and practice.

Because of differences in definition and measures, varying prevalence rates have been found. Wolfe et al. 1996 described clinically important levels of fatigue in 42% of patients with RA, whereas other studies found prevalence rates of 80% and more [2, 6, 7]. An agreed definition for fatigue in RA has not been developed; however, it has been described as a subjective feeling that incorporates total body feelings from tiredness to exhaustion, creating an unrelenting overall condition that interferes with the individual's ability to function normally [8]. The aetiology of RA-related fatigue is multi-dimensional, involving physical, psychological, social, cognitive and behavioural aspects. In several cross-sectional studies on predictors and correlates of fatigue in RA, higher levels of fatigue were related to higher levels of pain, disease activity and disability, but results are contradictory [1, 2, 7, 9–17]. In the few longitudinal studies carried out, it has been found that fatigue is relatively stable over days to months [2, 18, 19] and Mancuso et al. found that over a period of 1 year, fatigue in RA is associated with psychosocial factors and disability, but not with pain [20]. Recently, it has been

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found that persistent severe fatigue in RA is predicted by disability and general health [21]. Only a few studies focused on the treatment of fatigue. Cognitive behavioural therapy (CBT), regular exercise and the use of biological therapies seem to be effective; however, more research is needed to prove these findings [22–25]. Qualitative studies on fatigue, as experienced by patients, show that RA fatigue varies in duration and frequency and is different from normal tiredness because it is extreme, often unexpected and most of the time an every day experience [3, 26, 27]. The consequences of fatigue for RA patients are physical, emotional, social and cognitive [28]; therefore, they use self-management strategies but with limited success [3].

Most patients do not explicitly discuss fatigue with their healthcare professionals because they feel it is dismissed and they think that nothing can be done, as it is part of the disease and they manage fatigue by “trial and error” [3, 26]. Moreover, patients mentioned that the advice they received was not always suitable to carry out [26].

Musculoskeletal conditions are the most common cause of severe long-term pain and physical disability and have a large impact on health-related quality of life. There are a lot of studies about the relationship between doctor–patient communication and patients satisfaction or quality of care. However, only a few studies have been conducted in patients with rheumatic diseases. Hewlett conducted a review of the available evidence in relation to patient and physician views about outcomes in arthritis. She found considerable variation between the two perspectives (physician’s and patient’s) and suggested that the personal meaning and individual impact of outcomes are important for patients and should be incorporated in assessments [29].

However, for attitude and knowledge related to quality of care, there is a lack of literature. Moreover, undergraduate education in rheumatology is underdeveloped in most of the universities worldwide and does not get the attention it deserves [30]. The International League of Associations for Rheumatology launched the Undergraduate Medical Education in Rheumatology 2000 (UMER 2000) project with fundamental concepts. The first is to convince medical faculties and schools educating health professionals worldwide that skills in examination, a knowledge of management of musculoskeletal diseases and a positive attitude to disability are the basis of good medical practice [31].

A search of the literature (Medline and Cinahl, 1985–2007) revealed two studies on nurses’ knowledge and attitude towards fatigue in cancer patients, a study of Miller and Kearny and a study of Vogelzang et al. [32, 33]. They confirmed the high prevalence of cancer-related fatigue, the underestimation of fatigue incidence by nurses, poor knowledge and practice regarding fatigue assessment and management and poor fatigue communication. To date, no

studies were found about the knowledge, attitude and current care for fatigue in RA patients.

Identifying ways to reduce fatigue and improve quality of life for RA patients are important. To improve self-management strategies for fatigue in RA patients, a thorough understanding of healthcare professionals’ perception of fatigue is necessary. However, no research has been carried out into rheumatologists’ knowledge about and attitude towards RA-related fatigue and the way rheumatologists help patient to manage fatigue.

Study aims

To describe knowledge, attitude and current management of fatigue in RA patients by Dutch rheumatologists.

Materials and methods

Setting and sample

The study was performed in the Netherlands. All rheumatologists ($N=204$) and trainees ($N=49$), members of the Dutch Society for Rheumatology, were invited to fill out a written questionnaire.

Research design

A search of the literature (Medline and Cinahl, 1985–2006) revealed only one nurses’ knowledge and attitude questionnaire, which was in cancer-related fatigue [32]. In the study of Miller, the questionnaire was tested by a number of health professional groups, such as medical staff, nursing staff, rehabilitation and social workers. Based on the differences between causes and treatment of fatigue in cancer patients and RA patients, this published 25-item US questionnaire was adapted for RA-related fatigue by HR. Pre-testing was conducted with doctors and nurses in Rheumatology in the Netherlands in order to determine relevance and appropriate style of question wording, as well as general appearance and acceptability of the overall questionnaire. Only small changes were made. For questions about current RA fatigue management practices, we used the topic list of the qualitative studies by Hewlett et al. and Repping-Wuts et al. [3, 26]. For knowledge of the causes of RA fatigue, the questions were based on results from published studies [3, 7, 11, 21]. Because of a lack of literature for attitude in RA, the researcher (HR) proposed the questions on attitude, based on qualitative patient reports [3, 26]. This resulted in a slightly longer questionnaire of 38 questions: 16 items for knowledge, 10 items for

attitude and 12 items for current care. Eleven questions on demographic data were requested separately.

Following the cancer questionnaire, the majority of questions were closed and a few were open-ended (questionnaire available from the authors on request). As patients were not involved in the study, ethics approval from a certified medical ethics committee was not necessary.

Data collection

An invitation to participate was sent to all rheumatologists and trainees, with an information sheet, anonymous questionnaire and reply-paid envelope. Respondents were given 2 weeks in which to return the questionnaire. Return of the questionnaire was considered as consent to participate. A second mailing was sent after 3 weeks. For those who returned the questionnaire, this was a ‘thank you’ and for non-responders, a repeated request to fill out the questionnaire.

Data analysis

All data were entered into the software program SPSS 14.0 and analysed descriptively. All open-ended questions were coded afterwards and entered in SPSS for analysis. For the analysis, six-point scales’ questions were converted to a two-point scale with on the one hand ‘always’ and ‘most of the time’ and on the other hand ‘sometimes’, ‘occasionally’, ‘rarely’ and ‘never’. Where more than 5% of data were missing, this was separately reported.

Results

Demographics

For the total group, the response was 44%, 93 rheumatologists (46%) and 17 trainees (35%). Half of the responding rheumatologists were males and half were females. The mean age was 47 (standard deviation (SD) 9.4; range 25–67 years). Most of the rheumatologists worked in a general hospital (57%). Others worked in an academic hospital (35%) or in a home care institute (8%). On average, rheumatologists took care of 108 RA patients each month (range 10–400). The practical experience in caring for RA patients ranged from 3 months to 32 years with a mean of 15 years. Responding rheumatologists did not differ from the total group of rheumatologists working in the Netherlands as the main age of the total group was 45 (SD 9.4; range 28–67 years), 47% was female and 53% was male and 34% of the total group was working in an academic hospital.

Knowledge

In general, for knowledge, attitude and current management, no significant differences were found between rheumatologists and trainees. The mean percentage of RA patients with fatigue, as rated by all respondents was 54% (SD 21.6, range 10–100%). Two thirds of the total group reported a lack of their own knowledge about RA related fatigue, and received fatigue training is limited (Table 1). Rheumatologists had a need for knowledge about prevention, the aetiology of fatigue and evidence-based interventions and agreed that more information was welcome.

Almost all rheumatologists believed that patients discuss their fatigue with the nurse specialist (96%) or the rheumatologist (70%). Most of the rheumatologists (94%) think that RA patients have a need for information, especially written information as in a leaflet with advice on how to deal with fatigue and more knowledge about the causes of fatigue and the relationship between fatigue and RA.

According to the rheumatologists, the most frequently mentioned causes of fatigue by patients would be (1) the disease, (2) medication and pain and (3) sleep problems. Most rheumatologists agreed that a low haemoglobin, depression and inflammatory activity would not always be related to fatigue and that getting a good night sleep or a controlled disease activity are not effective interventions for RA fatigue. Almost all rheumatologists reported that patients’ complaints of fatigue are often not believed or understood by family members (84%) and by healthcare professionals (62%; Table 1). Trainees tend to rate their knowledge about RA fatigue lower than rheumatologists did.

Attitude

Only seven respondents reported the use of an assessment instrument for fatigue although 56% would like to use one, some with the restriction that therapeutic consequences should be added (Table 2). According to rheumatologists, fatigue is a multi-disciplinary diagnosis (57%) and not a specific nursing or medical diagnosis and they prefer treatment of fatigue by the nurse specialist (34%) compared to a rheumatologist (11%) or a psychologist (3%). Lack of effective treatment options for RA-related fatigue did not prevent rheumatologists from asking a patient about fatigue. Trainees tend to believe more than rheumatologists did that fatigue should be treated by nurses.

Current care

Questions addressing current care were divided according to the specific themes they addressed, namely management and communication.

Table 1 Knowledge of RA-related fatigue (*N*=110)

Questions	Yes			<i>P</i>	References
	Total group (<i>N</i> =110)	Rheumatologists (<i>N</i> =93)	Trainees (<i>N</i> =17)		
Do you have enough knowledge about RA related fatigue?	38	43	19	NS	
Fatigue as experienced by RA patients is stable during the day ^a	26	29	18	NS	[2, 18, 19]
Do RA patients discuss their fatigue with the nurse specialist?	96	98	100	NS	[3, 21]
Do RA patients discuss their fatigue with the rheumatologist?	70	70	82	NS	[3, 21]
Do RA patients have a need for information about fatigue?	94	96	100	NS	[21]
Fatigue is always an insoluble problem	6	7	6	NS	[22]
Fatigue is always a problem for RA patients	27	30	12	NS	[23, 27]
After pain, fatigue is the most bothersome symptom in RA	64	68	65	NS	[3]
An abnormal low Hb level always goes together with fatigue	2	2	0	NS	[21]
Simply getting a good night's sleep will always resolve fatigue	2	2	0	NS	[3, 21]
RA patients complaining of fatigue must be depressed	5	4	6	NS	[17]
Fatigue is always the result of inflammatory activity in RA	12	12	12	NS	[21]
If you control disease activity, patient will not become fatigued	12	12	12	NS	[1, 2, 6, 7]
Patient's fatigue often not believed or understood by family	84	86	88	NS	[3]
Patient's fatigue often not believed/understood by professionals	62	63	65	NS	[3]
RA patients have the same type of fatigue as healthy individuals	4	7	19	NS	[3, 21]

Values are percentages

NS Not significant

^aSeven percent is missing

Management

The results demonstrate that the majority of rheumatologists appreciate the importance of managing a patient's fatigue, with 93% of respondents indicating that fatigue should still be considered a problem for patients even if pain is successfully resolved (Table 2). According to

rheumatologists, nurse specialists help patients with their fatigue followed by physiotherapists and occupational therapists, and five rheumatologists think that nobody helps the patients with fatigue. Forty-five percent of the rheumatologists do not refer patients on to other disciplines for the treatment of fatigue (Tables 3 and 4), but when they do, this is mostly to the nurse specialist (38%), the physiotherapist

Table 2 Attitude to RA-related fatigue (*N*=110)

Questions	Yes			<i>P</i>
	Total group (<i>N</i> =110)	Rheumatologists (<i>N</i> =93)	Trainees (<i>N</i> =17)	
Would you like to use an assessment instrument for fatigue?	56	58	60	NS
Fatigue is always a nursing diagnosis	1	1	0	NS
Fatigue is always a medical diagnosis	5	7	0	NS
Fatigue is always a multi-disciplinary diagnosis	57	54	77	NS
Preferably, fatigue should be treated by the rheumatologist	11	12	6	NS
Preferably, fatigue should be treated by the nurse	34	31	63	0.01
Patient with fatigue should always be referred to a psychologist	3	2	6	NS
After successfully treating a patient's pain, the patient should be grateful that he/she only has fatigue	4	6	0	NS
As fatigue is a subjective symptom it cannot be measured	17	18	18	NS
Because there is no effective treatment for fatigue in RA patients, it is better not to ask the patient about it	4	5	0	NS

Values are percentages

NS Not significant

Table 3 Current management of RA-related fatigue (N=110)

Questions	Always, most of the time			P
	Total group (N=110)	Rheumatologists (N=93)	Trainees (N=17)	
Do you pay attention to fatigue in your current care for RA patients?	47	48	41	NS
Is fatigue a topic of conversation in your first consultation with an RA patient?	72	75	53	NS
Is fatigue a topic of conversation in the following consultations with RA patients?	33	34	24	NS
If you ask patients about fatigue, how often do they say it's not a problem?	16	13	29	NS
Do other members of the team refer patients to you specifically to help with fatigue?	1	1	0	0.01

Values are percentages
NS Not significant

(31%), the psychologist (19%), the social worker (13%) and the occupational therapist (9%). Improvement of condition (46%) and balance between activity and rest (45%) were the types of advice most frequently given by rheumatologists. Only half of the rheumatologists think that patients follow their advice depending on the individual patient's willingness and possibility to change his attitude or lifestyle. Surprisingly, 35% of the rheumatologists did not respond to the question about patient adherence to advice, believing that patients follow advice sometimes or that they just do not know. Only 64% of the rheumatologists document fatigue and the specific given advices in the patient's record. Rheumatologists believed other advice might help but they did not offer this to the patients. Their advice was variable: from CBT to RA-related advice such as optimise medication and coping or acceptance. Rheumatologists tend to document fatigue more often and refer

patients more often to other disciplines to treat fatigue than trainees did.

Communication

On average, 95% of all rheumatologists attach importance to communicating about fatigue with the patient, despite the ambiguity on effective treatments. However, in current care, only 47% of the rheumatologists pay regular attention to fatigue, with 72% during the first consultation and 33% during the following consultations (Tables 3 and 4). Moreover, 74% of the rheumatologists assume that the patient is the person who usually raises the issue of fatigue and 84% of the rheumatologists recognise that if you ask patients about fatigue, they seldom say it is not a problem.

Almost 70% of the rheumatologists thought that communication about fatigue is poor and only 5% believed that

Table 4 Current management of RA-related fatigue (N=110)

Questions	Yes			P
	Total group	Rheumatologists (N=93)	Trainees (N=17)	
Do you measure/assess fatigue?	6	8	0	NS
Do you think patients follow your advice? ^a	52	63	41	NS
Do you document fatigue and the specific advice you gave the RA patient in the patient's record?	60	69	35	<0.001
Do you ever refer your patients on for treatment of their fatigue? ^b	30	34	12	NS
As fatigue is a subjective symptom it cannot be measured	17	18	18	NS
Communication about fatigue between the healthcare provider and the RA patient is generally excellent/good	31	36	6	< 0.05
Healthcare providers place as much emphasis on the treatment of fatigue as they do on other symptoms such as pain or stiffness? (strongly agree/agree)	5	6	6	NS

Values are percentages
NS Not significant

^a Thirty-five percent was missing

^b Twenty-six percent was missing

healthcare professionals placed as much emphasis on the treatment of fatigue as they do on pain or stiffness. Trainees think that the communication about fatigue is worse than rheumatologists think it is (Tables 3 and 4).

Discussion

Rheumatologists underestimate RA-related fatigue as 26% of the respondents rate, the percentage of fatigued RA patients below 40% in contrast to rates between 40–80% as found in published studies, and only 65% of all respondents identified fatigue as the most bothersome symptom for RA patients. The majority of rheumatologists are willing to assess and manage fatigue. In contrast to RA patients who explained that they receive support for fatigue by persons in the close circle of family and friends [26, 28], most rheumatologists think that fatigue is ignored by family members. Despite the acknowledgement of poor communication about fatigue and the awareness that if you ask patients about fatigue they seldom deny the symptom, rheumatologists reported that it is the patient rather than the rheumatologist who raises the issue of fatigue during the consultation. However, in qualitative studies [3, 26], patients indicated that they seldom discuss fatigue with healthcare professionals, assuming that they have to manage fatigue alone because it is part of the disease. To address this discrepancy in beliefs, further studies have to be performed, to establish whether or not patients or rheumatologists (or neither) raise the issue of fatigue during consultations. In daily practice, rheumatologists should be aware that patients feel supported by family and friends in the close circle, despite their own assumption that these family members do not believe patients' complaints about fatigue [26, 28].

In comparison with the results of qualitative studies, rheumatologists' advices concerning fatigue are mainly active lifestyle to improve physical condition and finding a balance between rest and activities, whilst patients mainly use pacing and rest as effective interventions [3, 26]. Only half of the rheumatologists think that the advice given will be followed by patients and this is in accordance with the results of the study of Repping-Wuts et al. in which half of the patients explained that they handle fatigue by 'trial and error'.

Despite the increasing studies on RA-related fatigue, there are no similar studies to compare the strengths and weaknesses of this study. One strength of this study is the access to the majority of rheumatologists in the Netherlands through a professional society. Moreover, this study provides insight in current practice and can be used to develop and implement educational programs on fatigue for rheumatol-

ogists and other healthcare professionals once intervention data are available. A second strength is the use of all aspects related to fatigue practices: knowledge, attitude and management. It seems obvious that attitude and practice are closely related, as attitude will affect practice, e.g. rheumatologists, believing that fatigue should preferably be treated by the nurse, will not refer patients on to an other discipline to help the patient cope with fatigue. Besides, knowledge and attitude are also related, e.g. do rheumatologists really know that patients discuss fatigue with their nurse specialist or is it an assumption.

The limitations of our study are the relatively low response rate, although this is normal for postal questionnaires [34]. The knowledge, attitude and practice of the non-responders could be of interest. It could be suggested that non-responders had poor knowledge and attitude and did not include fatigue in current practice, which was reflected in their choice not to fill out the questionnaire. However, no differences were found between non-responders and responders which may suggest that results were reliable for the total group of rheumatologists in the Netherlands. A few significant differences were found between responding rheumatologists and trainees, which might be the result of the small sample size and the amount of variables. As training status is not of influence on current management of RA fatigue, it might be of interest to study other aspects that might be related to attitude, e.g. gender of the doctor or specific patient characteristics.

A second limitation of our study might be the adaptation of a previous questionnaire; the opportunity could have been taken to improve some of the phrasing making it less dogmatic (e.g. fatigue is always the result of inflammatory activity) given that the cause and management of fatigue vary widely between and within patients. Three so very closely related aspects as knowledge, attitude and current care for fatigue need to be communicated between healthcare professionals and also between patients and healthcare professionals, in order to provide the most tailored care for RA patients with fatigue. According to Welsing et al. [35], the course of disease activity has become milder in recent years, but it has been shown that even in a well-controlled RA population, 40% of the patients have severe fatigue [21]. Therefore, fatigue is likely to remain a prominent symptom of RA in the future and should be measured in future studies whenever possible [36].

As knowledge of management of musculoskeletal diseases and a positive attitude to disability are the basis of good medical practice, fatigue should be part of education programmes of healthcare professionals. Moreover, as communication seems to be related to patient satisfaction and quality of care, further studies should be conducted on the communication of fatigue between RA patients and healthcare professionals in daily practice.

Acknowledgements The authors would especially like to thank all rheumatologists who made this study possible and Anita van Rossum (head nurse of the clinical Department of Rheumatology) for the use of her facilities for this study. For the development of the questionnaire, we thank Prof. Sarah Hewlett, Judy Ammerlaan and Hanneke Voorneveld. We thank the Dutch Society for Rheumatology for delivering the addresses of all rheumatologists on address labels, which saved us a lot of time.

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