FATIGUE

in patients with Rheumatoid Arthritis

Han Repping-Wuts

Fatigue in patients with Rheumatoid Arthritis

Han Repping-Wuts

Colofon:

ISBN: 978-90-713-8286-4

Design Cover: Theo Repping en Han Repping-Wuts
General Design: Theo Repping en Han Repping-Wuts
Lay-out: Gildeprint Drukkerijen - Enschede
Printing: Gildeprint Drukkerijen - Enschede

Publication of this thesis was financially supported by: the “Dutch Arthritis Association”, Schering-Plough B.V., Amgen B.V., Roche Nederland B.V., ABBOTT B.V.

Het probleem van het antwoord is de vraag
(Gerrit Komrij)

Fatigue in patients with Rheumatoid Arthritis

Een wetenschappelijke proeve
op het gebied van de Medische Wetenschappen

Proefschrift

ter verkrijging van de graad van doctor
aan de Radboud Universiteit Nijmegen
op gezag van de rector magnificus prof. mr. S.C.J.J. Kortmann,
volgens besluit van het College van Decanen
in het openbaar te verdedigen op donderdag 5 maart 2009
om 15.30 uur precies

door

Johanna Wilhelmina Joseph Repping-Wuts

geboren op 13 januari 1952
te Horst

Promotores

Prof.dr. T. van Achterberg
Prof.dr. P.L.C.M. van Riel

Manuscriptcommissie

Prof.dr. A.R.M.M. Hermus
Prof.dr. M.J.F.J. Vernooij-Dassen
Prof.dr. C.M.A. Frederiks

Contents

FATIGUE

GENERAL INTRODUCTION

1

Introduction

This thesis

The research presented in this thesis started with an invitation from the head nurse and the senior nurse of the clinical department of Rheumatology to discuss how to initiate nursing research in rheumatic diseases. The aim of nursing research in general is to develop knowledge to support and facilitate decision making in nursing practice.

After discussing nursing research with professionals in rheumatology care we decided to explore relevant items for patients with rheumatic diseases and for nurses taking care of this specific patient group. This exploration resulted in fatigue (chapter 2) as the main problem for patients with Rheumatoid Arthritis (RA), leading to the studies performed in this thesis.

Rheumatoid Arthritis

Rheumatoid Arthritis (RA) is a chronic inflammatory and systemic disease, which predominantly affects the joints. It is characterised by an unpredictable course with periods of exacerbation, spontaneous remission of disease activity seldom occurs, and the precise aetiology is still unclear[1]. Patients with RA show a reduction in physical functioning compared to healthy persons[2]. In many patients symptoms such as pain, stiffness, fatigue and decreased muscle strength cause difficulties with daily activities[3]. Moreover, RA has been linked to depression, helplessness, anxiety, and in general has a considerable impact on quality of life[4-6]. RA occurs in 0.5-1.0% of the adult population worldwide and two to four times more in women than in men[7]. In the Netherlands the prevalence of RA is approximately 150.000, making it the most common inflammatory joint disease[8]. Treatment of RA is mainly focussed on controlling disease activity, preventing functional disability and training in self-management.

Fatigue

Many studies have repeatedly shown that fatigue is a common complaint in the general population[9,10], among employees[11,12] and in clinical populations[13-16]. In 1989 The North American Nursing Diagnosis Association defined fatigue as '*an overwhelming, sustained sense of exhaustion and decreased capacity for physical and mental work*'[17,18]. This definition was followed by the definition of Piper, by now a widely used definition in international studies: '*chronic fatigue is perceived as unpleasant, unusual, abnormal or excessive whole-body tiredness,* *disproportionate to or unrelated to activity or exertion and present for more than one month. Chronic fatigue is constant or recurrent, it is not dispelled easily by sleep or rest and it can have a profound negative impact on the person's quality of life'* [19].

However, the actual mechanisms that cause fatigue are unknown[20] and fatigue is mostly described as a multicausal, multidimensional and complex concept in which psychological, biochemical and physiological mechanisms play a role[21-23].

To distinguish between fatigue and Chronic Fatigue Syndrome (CFS) specific criteria for CFS have been formulated by the Centres for Disease Control and Prevention (CDC), including 1) clinically evaluated, unexplained, persistent or relapsing chronic fatigue that is of new or definite onset (has not been lifelong); is not the result of ongoing exertion; is not substantially alleviated by rest; and results in substantial reduction in previous levels of occupational, educational, social, or personal activities; and 2) the concurrent occurrence of four or more of the following symptoms, all of which must have persisted or recurred during 6 or more consecutive months of illness and must not have predated the fatigue: self-reported impairment in short-term memory or concentration severe enough to cause substantial reduction in previous levels of occupational, educational, social or personal activities; sore throat; tender cervical or axillary lymph nodes; muscle pain, multi-joint pain without joint swelling or redness; headaches of a new type, pattern, or severity; unrefreshing sleep; and postexertional malaise lasting more than 24 hours[24]. The studies in this thesis focus on (chronic) fatigue in patients with RA and not on CFS.

Fatigue in Rheumatoid Arthritis

In the twentieth century RA-related fatigue was not such a specific subject of research as it is nowadays. In the Netherlands only a few studies concerning RA-related fatigue have been published. One of them is the study of Riemsma et al. (1998). They performed a cross-sectional study and concluded that RA-related fatigue could be explained by pain, self-efficacy towards coping with RA, and towards asking for help and problematic support[25]. Other Dutch studies are of Suurmeijer et al. and Rupp et al. Both studies concluded that RA-related fatigue has a large impact on quality of life and another study of De Croon et al. found that RA-related fatigue predicts low work ability[26-28].

In the US, RA-related fatigue has had a more prominent place in research and several studies were performed before and after 2000. However, because of differences in definition and measures of fatigue, varying prevalence rates have been found. Wolfe et al described clinically important levels of fatigue in 42% of patients with RA, whereas other studies found prevalence rates of 80% and more[29-32].

In published studies on predictors and correlates of fatigue contradictory results were found. Tack found that among an RA population higher levels of fatigue were most strongly associated with increased depressive symptoms and pain, and with poorer overall mood[33]. Belza et al. found that RA-related fatigue was best explained by sex- and disease-related variables and Crosby reported that increased disease activity, disturbed sleep, and increased physical effort were mostly related to fatigue[31,34]. Huyser et al. concluded that RA-related fatigue was strongly associated with psychosocial factors[35].

In the UK, Hewlett et al. performed several studies on RA-related fatigue. In 2003, they concluded that RA patients identified fatigue and a general feeling of unwellness as important outcomes of their disease[36] and in 2005, data showed that fatigue is important, intrusive, and overwhelming, and that patients struggle to manage fatigue alone[37].

Nevertheless, in published studies before 2000 it remained unclear whether fatigue was more common in RA patients than in healthy subjects and whether RA patients suffered from higher levels of fatigue.

Finally, although fatigue has become a common symptom in RA, it is not, just like pain, a recommended core outcome for clinical trials[38,39]. The "core set" of outcome measures for Rheumatoid Arthritis clinical trials were developed at OMERACT 1 (Outcome Measures for Arthritis Clinical Trials)[40] and at the workshop of OMERACT 8 it was concluded that fatigue in RA patients is a symptom that is important to patients, is commonly reported by patients, is often severe, can be measured by several current instruments that pass the OMERACT filter, is responsive to some interventions, and provides information additional to that commonly obtained from currently used outcomes[41].

Rheumatology Care

As RA cannot be cured the principal aim of the management of RA is to control disease activity.

For nursing care the most widely known definition is that of Henderson who states that '*the unique function of the nurse is to assist the individual sick or well in the performance of those activities contributing to health or its recovery (or to a peaceful death) that he would perform unaided if he had the necessary strength, will or knowledge, and to do this in such a way as to help him gain independence* *as rapidly as possible'* [42]. Although this definition is not new, it contains the elements relevant to today's health care with its emphasis on empowerment, rehabilitation, education and wherever possible, enabling the patient to actively participate in self-management activities. Greater consideration is given to factors which contribute to health, and to the impact of illness and disease on functioning and lifestyle of the individual[43]. The nursing care of patients with rheumatic diseases must not focus only on managing the exacerbations of the condition, but must also provide a framework for promoting health and empowering patients to manage their everyday lives. The very special situation posed by rheumatoid arthritis and perhaps one of the most difficult aspects for the patient to adjust to, is the unpredictability of the disease. Empowerment and facilitating ability to self-manage are prime nursing functions and are known to be associated with improved outcome in RA[44,45]. Rheumatology nurses have a therapeutic relationship with the patient and provide both an action and emotional component to care. The nursing skills required to deal with this aspect include being empathetic, genuine and facilitative. As RA is a chronic disease, RA patients require different types of nursing care at different times and a patient-centred communication. Moreover, to improve the quality of care we should be aware of current knowledge and attitude of health professionals in rheumatology and the way RA-related fatigue is communicated.

Much is unknown about RA-related fatigue. In published studies it remains unclear what the level of fatigue is in RA patients and moreover there is a lack of knowledge about determinants of fatigue, effective strategies to prevent or treat fatigue and the current management of fatigue by health professionals and by patients themselves. Finally, there are no published studies on the way fatigue is communicated between RA patients and their health professionals.

Aims of the thesis

To meet patients' needs we started a priority research, to find out which symptoms of RA were the most difficult to handle for patients and which symptoms could be of interest for rheumatology nurses (chapter 2). Fatigue was most frequently proposed by patients and in presenting the results of this study, rheumatologists and rheumatology nurses, agreed on the need for more knowledge on RA-related fatigue to help patients to handle this problem. Therefore RA-related fatigue is the subject of the studies in this thesis with the following aims:

1) To determine the severity and course of fatigue in RA patients;
2) To explore fatigue from the perspective of both the RA patient (experience and self-management strategies), and the healthcare professional (knowledge, attitude and current management of fatigue);
3) To evaluate the communication on fatigue between RA patients and health care professionals in real practice.

Outline of the thesis

This thesis starts with a general introduction of the definitions of Rheumatoid Arthritis, fatigue and nursing care and the interaction between these (**chapter 1).**

In **chapter 2,** the results of a quantitative study among nurses and patients regarding items for nursing research and the most difficult complaints for RA patients to handle are presented. Patients and nurses from the clinical department of Rheumatology and from the outpatient clinic are included, using a written questionnaire.

Based on the results of the study in chapter 2, in which RA patients reported fatigue as the most bothersome symptom to handle, **chapter 3** focuses on the severity and course of fatigue and the predictors of persistent severe fatigue. In this one-year longitudinal study we used the Checklist Individual Strength (CIS), an assessment instrument often used in the Netherlands to measure fatigue in many different patient groups as well as in healthy controls. We included 123 RA patients and measured fatigue at baseline and at follow up. Disease activity, disability, haemoglobin (Hb) and rheumatoid factor were assessed to identify predictors of persistent severe fatigue. Multiple logistic regression with backward selection was used to identify predictors of persistent severe fatigue.

Chapter 4, 5 and 6, reporting partly on quantitative and partly on qualitative studies, focus on RA- related fatigue from the perspective of the patient and fatigue knowledge, attitude and management in current care by rheumatology nurses and rheumatologists. RA patients (N=29) participated in an audio-taped, semi structured individual interview and filled out written questionnaires to explore fatigue from the perspective of the patient (chapter 4).

British and Dutch nurses (N=232) filled out a written questionnaire on knowledge,

attitude and management of RA-related fatigue (chapter 5).
An almost identical questionnaire was sent out to all Dutch rheumatologists (N= 253) to explore their knowledge, attitude and current practice in RA-related fatigue (chapter 6).

Chapter 7 focuses on the discrepancy between health professionals' perceptions of their attention to fatigue and the qualitative data from patients suggesting that they handle fatigue by "trial and error" as found in study 4-6. In this qualitative study we evaluate the communication of fatigue between RA patients and their direct health care professionals at the outpatient clinic of the department of Rheumatology by using the Medical Interview Aural Rating Scale (MIARS) to analyse video-tapes of 20 RA patients. The use of cues or concerns in relation to fatigue and the interaction between patients and health professionals in this communication are explored.

In **chapter 8,** an editorial**,** results of published studies are systematically presented to show what is known and what is needed about the concept, assessment instruments, causes and treatment of RA-related fatigue.

This dissertation concludes with a general discussion, with principal findings of the studies of this thesis, implications for nursing care and directions for future research in **chapter 9.**

References

1. Bresnihan B. Pathogenesis of joint damage in rheumatoid arthritis. J Rheumatol 1999;26(3):717-9.
2. Heiberg T, Finset A, Uhlig T, Kvien TK. Seven year changes in health status and priorities for improvement of health in patients with rheumatoid arthritis. Ann Rheum Dis 2005;64(2):191-5.
3. Krishnan E, Fries JF. Reduction in long-term functional disability in rheumatoid arthritis from 1977 to 1998:a longitudinal study of 3035 patients. Am J Med 2003;115(5): 371-6.
4. Boers M, Dijkmans B, Gabriel S, Maradit-Kremers H, O'Dell J, Pincus T. Making an impact on mortality in rheumatoid arthritis: targeting cardiovascular comorbidity. Arthritis Rheum 2004;50(6):1734-9.
5. Rupp I, Boshuizen HC, Dinant HJ, Jacobi CE, van den Bos GA. Disability and health-related quality of life among patients with rheumatoid arthritis: association with radiographic joint damage, disease activity, pain, and depressive symptoms. Scand J Rheumatol 2006;35(3):175-81.
6. Pollard L, Choy EH, Scott DL. The consequences of rheumatoid arthritis: quality of life measures in the individual patient. Clin Exp Rheumatol 2005;23(5 Suppl 39):S43-S52.
7. Hannan MT. Epidemiologic perspectives on women and arthritis: an overview. Arthritis Care Res 1996;9(6):424-34.
8. Volksgezondheid Toekomst Verkenning (VTV) 2006 2007.
9. Loge JH, Ekeberg O, Kaasa S. Fatigue in the general Norwegian population: normative data and associations. J Psychosom Res 1998;45(1 Spec No):53-65.
10. Pawlikowska T, Chalder T, Hirsch SR, Wallace P, Wright DJ, Wessely SC. Population based study of fatigue and psychological distress. BMJ 1994;308(6931):763-6.
11. Bultmann U, Kant I, Kasl SV, Beurskens AJ, van den Brandt PA. Fatigue and psychological distress in the working population: psychometrics, prevalence, and correlates. J Psychosom Res 2002;52(6):445-52.
12. Janssen N, Kant IJ, Swaen GM, Janssen PP, Schroer CA. Fatigue as a predictor of sickness absence: results from the Maastricht cohort study on fatigue at work. Occup Environ Med 2003;60 (Suppl 1):i71-i76.
13. Vercoulen JH, Swanink CM, Fennis JF, Galama JM, van der Meer JW, Bleijenberg G. Prognosis in chronic fatigue syndrome: a prospective study on the natural course. J Neurol Neurosurg Psychiatry 1996;60(5):489-94.
14. van der Werf SP, de Vree B, Alberts M, van der Meer JW, Bleijenberg G. Natural course and predicting self-reported improvement in patients with chronic fatigue syndrome with a relatively short illness duration. J Psychosom Res 2002;53(3):749-53.

15. Franssen PM, Bultmann U, Kant I, van Amelsvoort LG. The association between chronic diseases and fatigue in the working population. J Psychosom Res 2003;54(4):339-44.
16. de Jong N, Candel MJ, Schouten HC, Abu-Saad HH, Courtens AM. Prevalence and course of fatigue in breast cancer patients receiving adjuvant chemotherapy. Ann Oncol 2004;15(6):896-905.
17. Voith AM, Frank AM, Smith Pigg J. Nursing Diagnosis: Fatigue. In: R.M. Carroll Johnson (eds) *Classification of Nursing Diagnoses,* Proceedings of 8th Conference NANDA: Mosby, St Louis. 1989.
18. NANDA. Nursing Diagnoses: definitions and classification 1999-2000. Philadelphia,PA: North American Nursing Diagnosis Association, 1999; 2007.
19. Piper BF. Fatigue. Pathofysiological phenomena in nursing. 2th ed. 1993. p. 279-302.
20. Piper BF, Lindsey AM, Dodd MJ. Fatigue mechanisms in cancer patients: developing nursing theory. Oncol Nurs Forum 1987;14(6):17-23.
21. Ream E, Richardson A. Fatigue: a concept analysis. Int J Nurs Stud 1996;33(5): 519-29.
22. Smets EM, Garssen B, Bonke B, de Haes JC. The Multidimensional Fatigue Inventory (MFI) psychometric qualities of an instrument to assess fatigue. J Psychosom Res 1995;39(3):315-25.
23. Vercoulen JH, Alberts M, Bleijenberg G. De checklist Individual Strenght. Gedragstherapie 1999;32:131-6.
24. Fukuda K, Straus SE, Hickie I, Sharpe MC, Dobbins JG, Komaroff A. The chronic fatigue syndrome: a comprehensive approach to its definition and study. International Chronic Fatigue Syndrome Study Group. Ann Intern Med 1994;121(12):953-9.
25. Riemsma RP, Rasker JJ, Taal E, Griep EN, Wouters JM, Wiegman O. Fatigue in rheumatoid arthritis: the role of self-efficacy and problematic social support. Rheumatology (Oxford) 1998;37(10):1042.
26. Suurmeijer TP, Waltz M, Moum T, Guillemin F, van Sonderen FL, Briancon S, et al. Quality of life profiles in the first years of rheumatoid arthritis: results from the EURIDISS longitudinal study. Arthritis Rheum 2001;45(2):111-21.
27. de Croon EM, Sluiter JK, Nijssen TF, Kammeijer M, Dijkmans BA, Lankhorst GJ, et al. Work ability of Dutch employees with rheumatoid arthritis. Scand J Rheumatol 2005;34(4):277-83.
28. Rupp I, Boshuizen HC, Jacobi CE, Dinant HJ, van den Bos GA. Impact of fatigue on health-related quality of life in rheumatoid arthritis. Arthritis Rheum 2004;51(4): 578-85.
29. Belza BL. Comparison of self-reported fatigue in rheumatoid arthritis and controls. J Rheumatol 1995;22(4):639-43.

30. Wolfe F, Hawley DJ, Wilson K. The prevalence and meaning of fatigue in rheumatic disease. J Rheumatol 1996;23(8):1407-17.
31. Belza BL, Henke CJ, Yelin EH, Epstein WV, Gilliss CL. Correlates of fatigue in older adults with rheumatoid arthritis. Nurs Res 1993;42(2):93-9.
32. Pinals RS, Masi AT, Larsen RA. Preliminary criteria for clinical remission in rheumatoid arthritis. Arthritis Rheum 1981;24(10):1308-15.
33. Tack BB. Fatigue in rheumatoid arthritis. Conditions, strategies, and consequences. Arthritis Care Res 1990;3(2):65-70.
34. Crosby LJ. Factors which contribute to fatigue associated with rheumatoid arthritis. J Adv Nurs 1991;16(8):974-81.
35. Huyser BA, Parker JC, Thoreson R, Smarr KL, Johnson JC, Hoffman R. Predictors of subjective fatigue among individuals with rheumatoid arthritis. Arthritis Rheum 1998;41(12):2230-7.
36. Carr A, Hewlett S, Hughes R, Mitchell H, Ryan S, Carr M, et al. Rheumatology outcomes: the patient’s perspective. J Rheumatol 2003;30(4):880-3.
37. Hewlett S, Cockshott Z, Byron M, Kitchen K, Tipler S, Pope D, et al. Patients’ perceptions of fatigue in rheumatoid arthritis: overwhelming, uncontrollable, ignored. Arthritis Rheum 2005;53(5):697-702.
38. Felson DT, Anderson JJ, Boers M, Bombardier C, Chernoff M, Fried B, et al. The American College of Rheumatology preliminary core set of disease activity measures for rheumatoid arthritis clinical trials. The Committee on Outcome Measures in Rheumatoid Arthritis Clinical Trials. Arthritis Rheum 1993;36(6):729-40.
39. Boers M, Tugwell P, Felson DT, van Riel PL, Kirwan JR, Edmonds JP, et al. World Health Organization and International League of Associations for Rheumatology core endpoints for symptom modifying antirheumatic drugs in rheumatoid arthritis clinical trials. J Rheumatol Suppl 1994;41:86-9.
40. Tugwell P, Boers M. Developing consensus on preliminary core efficacy endpoints for rheumatoid arthritis clinical trials. OMERACT Committee. J Rheumatol 1993;20(3):555-6.
41. Kirwan JR, Minnock P, Adebajo A, Bresnihan B, Choy E, de Wit M, et al. Patient perspective: fatigue as a recommended patient centered outcome measure in rheumatoid arthritis. J Rheumatol 2007;34(5):1174-7.
42. Henderson V. The nature of nursing. 1966. Collier-MacMillan, London.
43. Madigan A, FitzGerald O. Multidisciplinary patient care in rheumatoid arthritis: evolving concepts in nursing practice. Baillieres Best Pract Res Clin Rheumatol 1999 Dec;13(4):661-74.

44. Lorig KR, Mazonson PD, Holman HR. Evidence suggesting that health education for self-management in patients with chronic arthritis has sustained health benefits while reducing health care costs. Arthritis Rheum 1993;36(4):439-46.
45. Ryan S. Living with rheumatoid arthritis: a phenomenological exploration. Nurs Stand 1996;10(41):45-8.

PRIORITIES FOR A RHEUMATOLOGY NURSING RESEARCH PROGRAMME

Han Repping-Wuts
Marijke de Hullu
Pilar Barrera
Anita van Rossum
René Bakker
Annemieke Koopman
Jacqueline Deenen
Joke Alberts-Pijnenborg

2

This chapter is an extended version of:
Prioriteiten verpleegkundige onderzoekslijn Reumatologie.
Nederlands Tijdschrift voor Reumatologie 2003; 4: 56-62

Abstract

Background

Scientific nursing research is necessary to facilitate evidence based practice and to improve the quality of care for patients.

Objective

The aim of this study was to establish which topics are relevant and important for a Rheumatology nursing research programme.

Methods

A cross-sectional priority study with written questionnaires was used. In this priority study both nurses (N=28) and patients (N=57) from the day care unit and the outpatient clinic of the department of Rheumatology of the Radboud University Nijmegen Medical Centre were involved.

Results

It was shown that there is a distinct difference between the topics nurses choose and the symptoms which patients experience as most difficult to handle. The differences can be explained by the fact that the psychosocial aspects which are often chosen by nurses as topic for nursing research are not the symptoms which patients experience as most difficult to handle. Besides that, patients are particularly burdened by the restricted freedom of movement which nurses did not choose as a main topic. Both nurses and patients mentioned fatigue and pain as a research theme. Furthermore, it was shown that more than 50% of the nurses are interested in participating in setting up research and collecting data.

Conclusion

As patients and nurses mentioned fatigue and (chronic) pain as highest priority, these topics should be part of the future Rheumatology nursing research programme.

The performance of a priority study is a meaningful method to shape scientific nursing research in a department. Involving patients in a priority study fits in with the aspiration for demand driven care, care which closely fits the needs and wishes of the patient.

Introduction

Just like within the medical discipline it is important within the nursing discipline to found the nursing care on the available evidence. Arguments which have been derived from available scientific knowledge are considered objective, strong and decisive. It is known from literature that there is a distinct difference between theory and practice. Although theoretically there is an evident interest in using available scientific knowledge for the benefit of patient care, in practice however, it is applied by nurses to a limited extent. A study by Hunt has shown that problems which have been researched, are not considered by nurses to be their problems and that nurses are not familiar with or do not understand research reports[1]. In 2001 a number of reasons have been added which not only focus on nurses but also on managers. This was done because the research climate in any organisation is an important factor in the application of research results in practice. The lack of necessary skills to perform and evaluate literature studies, lack of time to perform literature studies, no access to the proper sources and working in an environment where immediate answers are expected are given as additional reasons[2]. These findings are a result of studies both from England and the United States[3]. Despite the fact that these findings are the result of research outside the Netherlands, it is very likely that the situation in the Netherlands is comparable. As nurses consider problems that have been researched not to be their problems, it is necessary to investigate which topics nurses consider important for scientific nursing research. This can be done by means of a priority study.

A literature research identified a number of nursing priority studies in oncology, psychiatry, gerontology, nephrology and critical care nursing[4-7]. In all these studies, respondents are nurses working within the specific patient population. The results of these studies showed that quality of life had the highest priority for nursing research. No priority studies were found among rheumatology nurses, so it is unknown which specific topics nurses believe to be of interest for nursing research in rheumatology care. Furthermore, literature research revealed no published priority studies in which, besides nurses, patients were included. However, involving patients in a priority study fits in with the aspiration for demand driven care, care which closely fits the needs and wishes of the patient. Therefore the aims of this study were:

- To determine which topics nurses at the department of rheumatology consider important for scientific nursing research for the improvement of quality of care?

- To determine which aspects/symptoms of their disease rheumatology patients consider most difficult to handle?

Design and performance of the study

Methodology

A cross-sectional, descriptive study was performed. For this study questionnaires were drawn up which were based on the questionnaire, used in the study of Mooney et al. (1991). In this study 113 research topics divided into eight categories for nurses taking care for oncology patients were included[4]. This questionnaire was adjusted for the rheumatology patient group on the basis of literature research. The Medline and Cinahl databases were searched for the terms "research priorities", "nursing diagnoses", "nursing problems", "nursing interventions" and "rheumatology". On the basis of the results from the literature research the questionnaire was adjusted for rheumatology. This means that specific topics for this patient group were added and topics specific for oncological patients were removed. To investigate the content validity of the questionnaire, it was presented to a panel of experts (nurses with ample experience within the specialism, members of the multidisciplinary consultation and rheumatology clinical nurse specialists, who were asked to assess the relevance of the topics). It was decided beforehand that if 75% of the experts were to indicate a topic as not relevant, the topic would be removed from the questionnaire. On the basis of this criterion no topics were removed. For nurses and patients two different versions of the questionnaire were used.

Description of the questionnaire for nurses

The questionnaire consisted of two parts. Part 1 contained questions about personal data, the current involvement in nursing research and the wish to be involved in nursing research. Part 2 contained 113 topics divided into six groups. These groups were: dealing with symptoms, psychosocial aspects of care, special populations or groups, the continuum of care, health stimulating behaviour and decisions with regard to treatment. Each topic was assessed by the respondents for its degree of importance for research. The answers were given on a 5-point Likert scale, ranging from 1 (not important) to 5 (very important). Finally a top 10 of all topics from the questionnaire was determined.

Description of the questionnaire for patients

The questionnaire for the nurses was used as concept for the questionnaire for the patients. Two ‘expert’ patients assessed the questionnaire. They showed that a number of topics were not relevant for patients. These topics especially related to nursing care and special populations or groups. These topics (n=21) were removed from the patient questionnaire. It was also clear that patients do not reason from the need for nursing research topics, but from the difficulties they experience from the symptoms of their disease. The questionnaire was adjusted and the 5-point Likert scale for patients runs from 1 (no difficulties at all) to 5 (many difficulties).

The sample survey

All RN nurses at the department of Rheumatology of the Radboud University Nijmegen Medical Centre and the rheumatology outpatient clinic were included in this study (N=36). The inclusion criteria for the patients were: suffering from a rheumatological disorder, being treated at the department of Rheumatology of the Radboud University Nijmegen Medical Centre, and a command of the Dutch language in speech and in writing. Both clinical patients and outpatients were involved in the study in the period between October and November 2001 (N=67).

Analysis of the data

The answers were coded and entered into a database of the statistical program SPSS 9.0. Both the coding of the questionnaires and the entry into SPSS were checked and corrected for possible errors.

All the questions in the questionnaire were turned into frequency tables. For every item of all the research topics, in part 2 of the questionnaire, the sum was calculated separately. This means that the respondents’ answers for every topic were added separately. The topic with the highest score received the highest priority. For obtaining the top 10 a sum was used of the number of times a topic was mentioned in different places of the top 10. A topic ranked at number 1 was the most important one and a topic ranked at number 10 was the least important.

Nurses' results

The response rate of the nurses was almost 78% (N=28), two thirds were women with a mean age of 39 years. Half of the group had an hospital-based nursing education and a mean experience of 6,4 years in taking care for rheumatology patients. Of the total group of nurses 68% wanted to be involved in future research. Collecting data and participating in setting up research were the most important items for nurses (Table 1).

Table 1. Nursing characteristics (N=36)

Response	77.8 %
Age (mean)	39 year
Inservice training	50 %
Higher Vocational Education-Nursing	18 %
MDGO-Nursing	18 %
Nursing assistant training	14 %
Number of years of experience within the specialism (mean)	6.4 year
Current involvement in research	17.9 %
Wish to be involved in research	67.9 %

Table 2. Top 10 of most important topics for scientific nursing research for nurses (N=28)

	Number of times as first priority	Number of times as a topic of the top 10
1. Chronic pain (1*)	8	16
2. Acceptance of the disease (2*)	2	13
3. Patient information (5*)	1	10
4. Fatigue (1*)	2	7
5. Changing pattern of the disease (1*)	0	7
6. Coping/adjusting (2*)	0	6
7. Changes in social roles (2*)	1	5
Compliance to therapy (5*)	1	5
8. Pain during the night (1*)	1	4
9. Dependence (2*)	0	4

* The numbers behind the items refer to the group the item originates from. 1. Coping with symptoms, 2. Psychosocial aspects of care, 3. Special populations or groups, 4. The continuum of care, 5. Health stimulating behaviour and 6. Decisions relating to treatment.

Chronic pain, acceptance of the disease, pain information, fatigue and the changing pattern of the disease were the top five in this top 10 (Table 2).
The topics appearing in the top 10 originated from the groups ‘dealing with symptoms’, ‘psychosocial aspects of care’ and ‘health stimulating behaviour’. No topics appear from the groups ‘decisions relating to treatment’, ‘the continuum of care’ and ‘special populations or groups’.

Patients’ results

The response rate for the patients was 79% (N=57). The mean age of patients was 54 years (range 20-86) and almost 70% were women. The largest group of respondents (55%) had rheumatoid arthritis. This group of respondents was a good cross section of the total population of rheumatological patients who visit the RUNMC every year for treatment of their disease.
The most difficult symptoms for patients to handle in the top five were fatigue, limited freedom of movement, chronic pain, joint pain and limitations in daily life activities (Table 3). The topics listed in the top 10 of the patients mainly originated from the group ‘dealing with symptoms’.
Summarising, the following differences appear to exist between patients and nurses. Nurses consider topics from the group ‘psychosocial aspects of the disease’ and the topic ‘acceptance of the disease’ of particular importance. Few patients have chosen these topics. Patients consider the long term effects of treatment and limited freedom of movement as more important matters which should receive attention, while nurses do not list these topics as the most important one for future nursing research.
In the patients’ top 10 several topics relating to pain are mentioned (see table 3), while nurses only mention “chronic pain” (at number 1).
The similarities between patients and nurses occur particularly in the topics fatigue and (chronic) pain.

Table 3. Top 10 of most difficult symptoms for patients to handle (N=31)

	Number of times as first priority	Number of times as a topic of the top 10
1. Fatigue (1*)	4	16
2. Limited freedom of movement (1*)	1	16
3. Chronic pain (1*)	2	13
4. Joint pain (1*)	2	12
5. Limitations in activities daily life (2*)	0	12
6. Acute pain (1*)	7	11
7. Muscle pain (1*)	2	10
8. Pain during the night (1*)	0	10
9. Morning stiffness (1*)	0	9
Muscular weakness (1*)	0	9

* The numbers behind the items refer to the group the item originates from. 1. Coping with symptoms, 2. psychosocial aspects of care and 3. general aspects which require attention.

Discussion

The aim of this study was to determine priorities for the rheumatology nursing research programme. The results from this priority study show that the performance of a priority study is a meaningful method to start scientific nursing research at a department. As Hunt concluded in her study, one of the reasons why nurses do not use results from scientific nursing research in daily practice is that they do not recognise the problems studied as their problem[1]. By choosing a priorised theme for research there is a better connection with the problems people experience in practice.

The questionnaire which was used in this priority study consists of many topics that nurses have to assess for the extent to which they are of interest for scientific nursing research. The length of the questionnaire may have influenced how it was filled out. It is possible that the last items on the list are assessed differently from the topics at the beginning of the list. For this reason the respondents where asked in both questionnaires to compile a top 10 from all the topics mentioned in the questionnaire. In the current study there are not many differences between this top 10 and the scores which were filled in for the 113 topics on the Likert scale. Perhaps filling in the top 10 only, instead of assessing each topic separately for the extent in which it is considered important, would suffice.

Apart from a semi-quantitative approach, a priority study could also be performed according to a qualitative approach, where nurses and patients could be asked questions by means of interviews. It is interesting to investigate if the performance of a priority study by means of a qualitative study would lead to different results. Involving patients in a priority study is meaningful, because it fits in with demand driven care. As patients have indicated in this study at the department of Rheumatology, it is difficult for them to assess topics for the extent to which they are important as research topics, but they can assess the topics to the subjective extent in which they experience symptoms as difficult to handle.

As the group of patients included in this study is a good cross section of the total population, results can be generalised to the total group of rheumatological patients who visit the RUNMC every year for treatment.

The results of the current study are important for nurses who work at the department of Rheumatology because they give direction to the consolidation (embedding) of nursing research in practice. The generalisability of the results to other hospitals will have to be investigated.

Conclusion

As patients and nurses mentioned fatigue and (chronic) pain as highest priority, these topics should be part of the future Rheumatology nursing research programme.

Moreover, examining research priorities affords different perspectives to guide practice, education, research and management. To develop evidence-based care, and deliver patient-centred care, healthcare professionals need to know which symptoms patients find the most difficult to handle.

References

1. Hunt J. Indicators for nursing practice: the use of research findings. J Adv Nurs 1981;6(3): 189-194.
2. Hunt J. Research into practice: the foundation for evidence-based care. Cancer Nurs 2001;24(2): 78-87.
3. Walczak JR, McGuire DB, Haisfield ME, Beezley A. A survey of research-related activities and perceived barriers to research utilization among professional oncology nurses. Oncol Nurs Forum 1994;21(4): 710-715.
4. Mooney KH, Ferrell BR, Nail LM, Benedict SC, Haberman MR. 1991 Oncology Nursing Society Research Priorities Survey. Oncol Nurs Forum 1991;18(8): 1381-1388.
5. Adams T. Informal family caregiving to older people with dementia: research priorities for community psychiatric nursing. J Adv Nurs 1996;24(4): 703-710.
6. Brower HT, Crist MA. Research priorities in gerontologic nursing for long-term care. Image J Nurs Sch 1985;17(1): 22-27.
7. Hoffart N. Characteristics of nephrology nurse researchers and their research. ANNA J 1995;22(1): 33-39.

FATIGUE

PERSISTENT SEVERE FATIGUE IN PATIENTS WITH RHEUMATOID ARTHRITIS

Han Repping-Wuts
Jaap Fransen
Theo van Achterberg
Gijs Bleijenberg
Piet van Riel

3

Journal of Nursing and Healthcare of Chronic Illness in association with
Journal of Clinical Nursing 2007; 16(11c): 377-383

Abstract

Aim

To determine whether persistent severe fatigue in patients with rheumatoid arthritis can be predicted by inflammation and disability.

Methods

A follow-up study with a one-year duration was performed. From an existing rheumatoid arthritis cohort, 150 consecutive patients, with established rheumatoid arthritis, were asked to assess fatigue, using the subscale Checklist Individual Strength-fatigue of the Checklist Individual Strength at baseline and 12 months later. The Checklist Individual Strength-fatigue scores were classified into 'normal' (score between 8–27), 'moderate' (score between 27–34) or 'severe' (score 35 or above) fatigue. Disease-related variables were: tender joints, swollen joints, general health, disability and laboratory measures (erythrocyte sedimentation rate, rheumatoid factor and haemoglobin). Predictors of persistent severe fatigue were identified by multiple logistic regression analyses with backward selection (selection criteria: $p<0.05$).

Results

At baseline, 137 patients agreed to participate and 123 patients completed the study. Severe fatigue was experienced by as many as 50% of the patients, both at baseline and at the end of the study (n=123). Moreover, 49 patients (40%) experienced severe fatigue at baseline as well as at follow-up, which we called 'persistent severe fatigue'. Persistent severe fatigue was predicted by mean general health and disability at baseline [odds ratio (OR) = 2.03 and 2.83, respectively] in this group of rheumatoid arthritis patients with a low-to-moderate level of disease activity and disability.

Conclusion

The data show that severe fatigue is not resolved spontaneously in rheumatoid arthritis patients, and persistent severe fatigue is mainly predicted by general health and disability. The relation with inflammation or a low level of haemoglobin, which is often assumed in clinical practice, was not found.

Relevance to clinical practice. Fatigue in patients with rheumatoid arthritis has to be considered as a symptom that needs to be addressed by professionals in the same way as pain and disability. In current care, fatigue is insufficiently addressed.

Introduction

Rheumatoid arthritis (RA) is a chronic, inflammatory, systemic disease causing synovitis predominantly in the joints of the hands and feet[1]. Major symptoms of RA are pain, stiffness, loss of function and fatigue. Fatigue may have a marked impact on quality of life in RA patients[2] and, besides pain, is mentioned by RA patients as their most prominent problem[3-5]. Fatigue in RA has not generally received much attention in clinical care, and one of the reasons may very well be that it is unclear whether and how fatigue should be treated. To begin with, it is unclear how many RA patients suffer from fatigue. Because of differences in definition and measures, varying prevalence rates have been found. Wolfe et al.[5] described clinically important levels of fatigue in 42% of patients with RA, whereas other studies found prevalence rates of 80% and more[4-7]. 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[4,5,7-16]. In the few longitudinal studies carried out, it has been found that fatigue is relatively stable over days to months[4,17,18]. Recently, it has been suggested that over a period of one year, fatigue in RA is associated with psychosocial factors and disability, but not with pain[19]. From these studies, it remains unclear whether fatigue is more common in RA patients than in healthy subjects, whether RA patients suffer from higher levels of fatigue, and whether excessive fatigue is related to the disease. In addition, the role of inflammation in relation to fatigue has not been incorporated in these longitudinal studies.

We therefore identified a need to carry out a follow-up study in RA patients, assessing degree of inflammation by means of erythrocyte sedimentation rate (ESR) and swollen joint counts (SW28). We used a validated fatigue questionnaire [Checklist Individual Strength (CIS)], with the aim of determining whether persistent severe fatigue in RA patients can be predicted by disease-related variables, especially inflammation and disability.

Approval from a certified Medical Ethics Committee was obtained for a series of studies in a cohort of RA patients. Our study was one in this series of studies. Nurse specialists informed patients about the study and written information was attached to the fatigue questionnaire (CIS), which was delivered by the nurse specialist at the outpatient clinic. In returning the questionnaire, patients declared to take part in the study.

Patients and method

Patients

We used a follow-up design, with one-year duration. During a period of three months, 150 consecutive patients visiting the outpatient clinic for a regular check-up were asked to participate in this study by the rheumatology nurse specialists. Most patients were part of a large inception cohort (n=500) of RA patients of the Department of Rheumatology of the Radboud University Nijmegen Medical Centre[20]. Patients who were not proficient in the Dutch language were not included.

Data collection

Fatigue and disability were assessed at baseline and 12 months by patient questionnaire. RA disease activity was assessed at these time points and also at three, six and nine months, using 28 joint counts for tenderness and swelling, ESR and through completion of a patient-assessed general health (GH) questionnaire. Rheumatoid factor and socio-economic variables were provided by patient records at baseline. Haemoglobin was measured at baseline and at follow-up.

Measurement instruments

Fatigue

Fatigue was assessed by using the fatigue subscale (CIS-fatigue, eight items, range: 8–56) of the CIS measuring patients' level of fatigue for the previous two weeks[21-27]. Each item was scored on a seven-point Likert scale. Based on scores in healthy controls, a score below 27 (mean score for healthy adults plus 1 SD) was equated with a 'normal' experience of fatigue, a score between 27–34 indicated 'moderate' fatigue, and a score of 35 or higher indicated 'severe' fatigue[28]. A level of 'severe' fatigue in the CIS was comparable with fatigue as experienced by patients with Chronic Fatigue Syndrome (CFS). A score of 35 or above at baseline as well as at 12 months was called 'persistent severe fatigue' in this study.

The psychometric properties of the CIS-fatigue subscale have been tested in various patient populations (e.g. CFS, multiple sclerosis, neuromuscular disorders, stroke, after treatment for cancer and in Cambodia veterans), and results have confirmed its validity[26,28-32]. In this study, the subscale's reliability coefficient for the CIS was 0.94 at baseline and 0.92 at follow-up.

Disease-related variables

Disease activity was assessed by 28 tender (TE28) and swollen (SW28) joint counts, ESR (1–140 mm first hour) and patient-rated GH measured on a 100-mm visual analogue scale (VAS: 0 = best possible overall health, 100 = worst possible overall health)[33,34]. The Disease Activity Score (DAS28) was calculated by using the following formula: $DAS28 = 0.56\sqrt{}\,(TE28) + 0.28\sqrt{}\,(SW28) + 0.70\ln(ESR) + 0.014\,(GH)$.

The DAS28 has a range from zero to 10 indicating the current activity of RA. A DAS28 above 5.1 indicates high disease activity; a DAS28 score between 3.2 and 5.1 represents moderate activity, whereas a score below 3.2 represents low-disease activity[35]. ESR<20 mm/h for male and <30 mm/h for female were utilized as normal levels in this study[6].

Disability was assessed by the Health Assessment Questionnaire-Disability Index (HAQ-DI)[36,37]. The HAQ-DI ranges from zero to three, higher values indicating more difficulties when performing activities of daily living.

Laboratory measures were rheumatoid factor positivity (RF) and haemoglobin level (Hb).

Socio-economic variables

The socio-economic variables included were gender, age, relationship and education. Relationship was classified as living with or without a partner. Educational level was classified as primary, secondary and tertiary educational level, representing seven, 12, and 17 years of education, respectively.

Statistical methods

For the description of the differences between patients with and without persistent severe fatigue on socio-economic and disease-related variables, Student's t-test and the chi-squared test were used, as appropriate. For determining which disease-related variables predicted persistent severe fatigue, average and baseline variables associated with persistent severe fatigue in the univariate analysis (selection criterion: $p<0.10$) were entered into a logistic regression model as independent variables, applying a backward procedure (selection criterion: $p<0.05$). Average values were entered into the logistic regression model because it can be assumed that, for example, persistent pain may increase fatigue. The analyses were carried out by using SPSS 12 0.1 for Windows (Statistical Package for Social Sciences, Gorinchem, the Netherlands).

Results

Study population

From the 150 patients that agreed to participate in the study, 137 patients could be enrolled and 123 completed the oneyear follow-up. Non-responders at follow-up (n=14) showed no relevant differences on socio-economic or disease-related variables (disease activity, disability, level of Hb and RF positivity) and baseline scores on CIS-fatigue with patients that completed the study (not shown). These non-responders were not part of the analyses.

At baseline, patients in the study had a mean age of 57.6 years (range: 24–82 years). The majority were women, lived with a partner and had an elementary or secondary education (Table 1). Disease duration at baseline of this study ranged from two years to 32 years.

Table 1. Socio-economic characteristics at baseline (N=123)

Age (years)	57.6 12.7)
Gender (female)	68%
Relationship (living with partner)	76%
Educational level (elementary or secondary)	83%

Values are percentages and mean (SD)

Between baseline and follow-up, no large differences were found for any of the disease activity or disability variables (Table 2).

Table 2. Patient’s clinical variables at baseline and at follow-up (N=123)

	At baseline	At follow-up	p-value
CIS-fatigue	34.2 (10.2)	32.6 (12.1)	0.04
Hb mmol/l	7.8 (0.8)	7.8 (0.8)	0.12
ESR mm/h	10 (5-20)	9 (5-18)	0.06
SW28	5 (3-8)	4 (2-7)	0.01
TE28	2 (0-5)	1 (0-5)	0.78
VAS-GH	27 (16-45)	35 (17-49)	0.02
DAS28	3.4 (1.1)	3.3 (1.2)	0.21
HAQ-DI	1.0 (0.5-1.5)	0.9 (0.4-1.4)	0.01

Hb = haemoglobin; ESR = erythrocyte sedimentation; TE28 = 28 joint count for tenderness; SW28= 28 joint count for swelling; DAS28 = Disease Activity Score 28; VAS GH = Visual Analogue Scale for General Health; HAQ = Health Assessment Questionnaire-Disability Index; CIS = Checklist Individual Strength.
Values are mean (SD) or median (interquartile range) for variables that are skewed

The scores for DAS28 and HAQ-DI at baseline and at follow-up indicated that most patients had low-to-moderate levels of disease activity. The levels of Hb and ESR were within the normal range for most patients at both assessment points (Table 2).

Fatigue severity

In Table 2, it can be seen that the scores on fatigue did not show a great change at group level. Sixty-four patients (52%) met the 'cut-off' criteria for severe fatigue (i.e. CIS-fatigue ≥ 35) at baseline and 61 patients (50%) met these criteria at follow-up (Fig. 1).

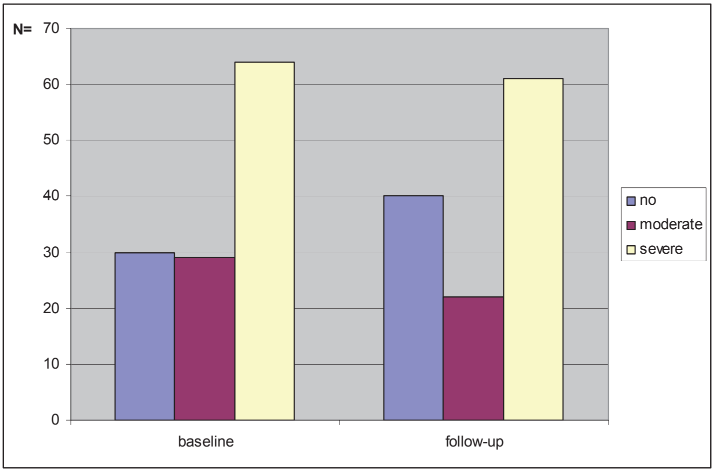

Figure 1. The scores on the Fatigue subscale of the Checklist Individual Strength in N=123 RA patients at baseline and 12 months later.

The level of baseline fatigue was highly related to the level of fatigue at follow-up (p=0.0001), and remained constant for most patients. Overall, 15/123 (12%) worsened by one class or more, whilst 29/123 (23%) improved by one class or more. Fortynine patients (40%) had severe fatigue at baseline as well as at follow-up: this was identified as 'persistent severe fatigue'.

Predictors of persistent severe fatigue

For the univariate analyses, we divided patients into two groups: those with stable severe fatigue and those without stable severe fatigue. Table 3 shows the results of these univariate analyses for the differences of socio-economic and disease-related variables between patients with and without persistent severe fatigue.

Disease-related variables are presented as baseline values and averaged over the time of follow-up.

No differences between the two groups were found for the socio-economic variables of gender, age, education, relationship or disease duration. There was also no difference in Hb, which was normal for most patients in both groups. ESR was also normal in most patients from both groups, neither was there any important difference in swollen joint counts. The most striking differences were found in the number of tender joints, global assessment of health, and assessment of disability, at baseline and at follow-up.

Table 3. Differences between patients with and without persistent severe fatigue on socio-economic and disease-related variables (N=123)

	Persistent severe fatigue		
	No (N= 74)	Yes (N= 49)	p-value
Age (years)	58 (13)	57 (12)	0.45
Gender (female)	69%	67%	0.85
Educational level (elementary or secondary)	80%	83%	0.87
Relationship (living with partner)	77%	77%	0.78
RF (positive)	78%	81%	0.69
Hb mmol/l baseline	7.8 (0.8)	7.7 (0,9)	0.50
ESR mm/h	10 (5-20)	9 (5-22)	0.45
Average ESR	9 (4-20)	12 (6-23)	0.57
SW28	5 (3-7)	5 (4-11)	0.05
Average SW28	5 (3-7)	6 (4-9)	0.02
TE28	1 (0-3)	3 (1-6)	0.01
Average TE28	1 (0-3)	3 (2-6)	<0.001
VAS-GH	21 (12-37)	38 (21-51)	0.001
Average VAS-GH	24 (17-41)	48 (39-55)	<0.001
HAQ-DI baseline	0.8 (0.1-1.3)	1.4 (1.1-1.8)	<0.001
HAQ-DI follow-up	0.6 (0.0-1.1)	1.3 (0.9-1.8)	<0.001

Values are percentages, mean (SD) or median (interquartile range) for variables that are skewed

Hb = haemoglobin; RF = rheumatoid factor; ESR = erythrocyte sedimentation; TE28 = 28 joint count for tenderness; SW28= 28 joint count for swelling; VAS GH = Visual Analogue Scale for General Health; HAQ = Health Assessment Questionnaire-Disability Index.

In backward logistic regression, with persistent severe fatigue as dependent variable, ESR, SW28, TE28, VAS-GH and HAQ-DI were used as independent variables. Socioeconomic variables and disease duration were not incorporated into the logistic regression model, as these were not related to persistent severe fatigue in the univariate analysis. However, ESR and SW28 were included in the starting model, because of their importance for the assessment of inflammation (Table 4). After stepwise removal of non-significant variables from the equation, the final model only included the mean VAS-GH and HAQ-DI at baseline. The variables most directly reflecting inflammation, ESR and SW28, were removed from the model, as could be expected from the univariate analyses.

Variables predictive of persistent severe fatigue in the logistic regression analysis were HAQ-DI at baseline (OR =2.8) and average VAS-GH (OR = 2.0) (Table 4).

Table 4. Results of logistic regression analyses predicting persistent severe fatigue (N=123)

Variables	Beta	OR	p-value
Starting model			
ESR	0.06	1.06	0.28
Average ESR	-0.05	0.95	0.38
SW28	0.20	1.22	0.15
Average SW28	-0.13	0.88	0.46
TE28	0.02	1.02	0.88
Average TE28	-0.09	0.92	0.59
VAS-GH (per 10 mm)	-0.25	0.78	0.27
Average VAS-GH (per 10 mm)	1.32	3.74	<0.001
HAQ-DI at baseline	1.18	3.25	0.03
HAQ-DI at follow-up	-0.06	0.94	0.81
Constant	-6.05	--	0.002
Final model			
Average VAS-GH (per 10 mm)	0.71	2.03	<0.001
HAQ-DI at baseline	1.04	2.83	0.009
Constant	-4.29	--	<0.001

HAQ = Health Assessment Questionnaire-Disability Index; TE28 = 28 joint count for tenderness; SW28= 28 joint count for swelling; ESR = erythrocyte sedimentation; VAS GH = Visual Analogue Scale for General Health; OR = odds ratio.

Discussion

In this one-year follow-up study, we have shown that (1) even in a well-controlled RA population, 40% of the patients have persistent severe fatigue, and (2) persistence of high levels of fatigue is related to GH and disability. A low Hb level and inflammation per se did not explain fatigue, in contrast to the ideas that seem to prevail in clinical practice.

Many studies have used VAS scales for the assessment of fatigue, which are useful to study relationships between variables or changes in fatigue. However, it is difficult to attach a meaning to such VAS scores: how important is a fatigue of over 40 mm? Therefore, in this study, a validated fatigue questionnaire (CIS) was used, with the advantage that the scale scores can be classified into normal, moderate-or severe levels of fatigue. Normal fatigue can be regarded as a level of complaint common to most healthy people, whilst severe fatigue is similar to the level of complaint common to most patients with CFS. As many as 50% of the patients in this study showed severe fatigue at baseline as well as at the end of the study, which is remarkable when it is considered that the patients had low-to-moderate disease activity and disability, were relatively young and generally had normal Hb values. In addition, gender and age were not related to fatigue, so differences in distribution of age and gender may not explain differences in fatigue experienced between patient populations.

The main problem with fatigue is not necessarily that its level can increase but that, if not resolved, it becomes persistent. Thus, even an elevated level of fatigue may be regarded as acceptable as long as it is transient. Therefore, in this study, the primary outcome was persistence of severe fatigue. The importance of finding modifiable factors that predict persistent severe fatigue is that these may be used for its prevention and treatment. Therefore, it is important to consider that in this study it was found that GH and disability were associated with persistence of fatigue, and that there was no direct relationship with inflammation. In a recent study by Mancuso et al.[19], it was also found that high fatigue levels are mainly linked to psychosocial factors and disability, whilst an association with pain was not found.

Tack[38] found that higher levels of fatigue were most strongly associated with increased depressive symptoms and pain, and with poorer overall mood. Other variables that may influence fatigue levels were not explicitly examined[38]. Crosby[9] found that increased disease activity, disturbed sleep and increased physical effort were identified by individuals with RA as being most responsible for increases in fatigue. Belza et al.[7] found that fatigue in an RA sample was best explained by sex- and disease-related variables, without assessment of disease activity. Wolfe et al.[5] found that the strongest independent predictors of fatigue were pain, sleep disturbance, depression, tender joint count and disability. An association between the inflammatory process and fatigue was not found[5]. Huyser et al.[10] found that the ‘best’ predictors of increased fatigue were higher levels of pain, more depressive symptoms and female sex, together with symptom duration, perceived adequacy of social support and disease activity.

Our study has several limitations. Firstly, the assessment of fatigue only at baseline and 12 months means that the level of fatigue in the intervening period is unknown.

Therefore, it may be worthwhile to measure fatigue more frequently in future research. Secondly, the patients in this study had relatively low-to-moderate levels of disease activity, and it is therefore not possible to know whether high levels of disease activity would have contributed differently to fatigue. Thirdly, other fatigue-related variables, e.g. mood and coping, were not included in this study. Pain was also not included as a specific disease-related variable. It was assessed from patients’ records at the end of the study resulting in an availability of only 57 patients for this variable. The correlation between VAS-GH and VAS-pain, however, was high ($r=0.82$; $p<0.001$), and in the acquired final logistic regression model VAS-GH could be replaced by VAS-pain.

In conclusion, this study showed the persistence of severe fatigue in a group of RA patients and its relation with disability and GH. An additional longitudinal study is recommended, including other physical, psychological, social, cognitive and behavioural aspects related to RA fatigue. Hopefully, this will result in future in prevention or treatment of fatigue in RA patients.

References

1. Conaghan PG, Green MJ, Emery P. Established rheumatoid arthritis. Baillieres Best Pract Res Clin Rheumatol 1999;13(4): 561-575.
2. Rupp I, Boshuizen HC, Jacobi CE, Dinant HJ, van den Bos GA. Impact of fatigue on health-related quality of life in rheumatoid arthritis. Arthritis Rheum 2004;51(4): 578-585.
3. Repping JWJ, de Hullu MCM, Barrera P, et al. Priorities nursing research in Rheumatology. 4 ed. 2003, 19-23.
4. Belza BL. Comparison of self-reported fatigue in rheumatoid arthritis and controls. J Rheumatol 1995;22(4): 639-643.
5. Wolfe F, Hawley DJ, Wilson K. The prevalence and meaning of fatigue in rheumatic disease. J Rheumatol 1996;23(8): 1407-1417.
6. Pinals RS, Masi AT, Larsen RA. Preliminary criteria for clinical remission in rheumatoid arthritis. Arthritis Rheum 1981;24(10): 1308-1315.
7. Belza BL, Henke CJ, Yelin EH, Epstein WV, Gilliss CL. Correlates of fatigue in older adults with rheumatoid arthritis. Nurs Res 1993;42(2): 93-99.
8. Suurmeijer TP, Waltz M, Moum T, et al. Quality of life profiles in the first years of rheumatoid arthritis: results from the EURIDISS longitudinal study. Arthritis Rheum 2001;45(2): 111-121.
9. Crosby LJ. Factors which contribute to fatigue associated with rheumatoid arthritis. J Adv Nurs 1991;16(8): 974-981.
10. Huyser BA, Parker JC, Thoreson R, Smarr KL, Johnson JC, Hoffman R. Predictors of subjective fatigue among individuals with rheumatoid arthritis. Arthritis Rheum 1998;41(12): 2230-2237.
11. Riemsma RP, Rasker JJ, Taal E, Griep EN, Wouters JM, Wiegman O. Fatigue in rheumatoid arthritis: the role of self-efficacy and problematic social support. Rheumatology (Oxford) 1998;37(10): 1042.
12. Wolfe F. Determinants of WOMAC function, pain and stiffness scores: evidence for the role of low back pain, symptom counts, fatigue and depression in osteoarthritis, rheumatoid arthritis and fibromyalgia. Rheumatology (Oxford) 1999;38(4): 355.
13. Heiberg T, Finset A, Uhlig T, Kvien TK. Seven year changes in health status and priorities for improvement of health in patients with rheumatoid arthritis. Ann Rheum Dis 2005;64(2): 191-195.
14. Breedveld FC, Han C, Bala M, et al. Association between baseline radiographic damage and improvement in physical function after treatment of patients with rheumatoid arthritis. Ann Rheum Dis 2005;64(1): 52-55.

15. Moss-Morris R, Chalder T. Illness perceptions and levels of disability in patients with chronic fatigue syndrome and rheumatoid arthritis. J Psychosom Res 2003;55(4): 305-308.
16. Pollard LC, Choy EH, Gonzalez J, Khoshaba B, Scott DL. Fatigue in rheumatoid arthritis reflects pain, not disease activity. Rheumatology (Oxford) 2006.
17. Stone AA, Broderick JE, Porter LS, Kaell AT. The experience of rheumatoid arthritis pain and fatigue: examining momentary reports and correlates over one week. Arthritis Care Res 1997;10(3): 185-193.
18. Wolfe F, Michaud K. Fatigue, rheumatoid arthritis, and anti-tumor necrosis factor therapy: an investigation in 24,831 patients. J Rheumatol 2004;31(11): 2115-2120.
19. Mancuso CA, Rincon M, Sayles W, Paget SA. Psychosocial variables and fatigue: a longitudinal study comparing individuals with rheumatoid arthritis and healthy controls. J Rheumatol 2006;33(8): 1496-1502.
20. Welsing PM, van Riel PL. The Nijmegen inception cohort of early rheumatoid arthritis. J Rheumatol Suppl 2004;69: 14-21.
21. Vercoulen JH, Alberts M, Bleijenberg G. De checklist Individual Strenght. Gedragstherapie 1999;32: 131-136.
22. Vercoulen JHMM, Hommes OR, Swanink MA, et al. The measurement of fatigue in patients with multiple sclerosis - A multidimensional comparison with patients with chronic fatigue syndrome and healthy subjects. Arch Neurol 1996;53(7): 642-649.
23. Beurskens AJ, Bultmann U, Kant I, Vercoulen JH, Bleijenberg G, Swaen GM. Fatigue among working people: validity of a questionnaire measure. Occup Environ Med 2000;57(5): 353-357.
24. Bultmann U, de Vries M, Beurskens AJ, Bleijenberg G, Vercoulen JH, Kant I. Measurement of prolonged fatigue in the working population: determination of a cutoff point for the checklist individual strength. J Occup Health Psychol 2000;5(4): 411-416.
25. Servaes P, Verhagen S, Bleijenberg G. Determinants of chronic fatigue in disease-free breast cancer patients: a cross-sectional study. Ann Oncol 2002;13(4): 589-598.
26. van der Werf SP, Prins JB, Vercoulen JH, van der Meer JW, Bleijenberg G. Identifying physical activity patterns in chronic fatigue syndrome using actigraphic assessment. J Psychosom Res 2000;49(5): 373-379.
27. Vercoulen JHMM, Swanink CMA, Galama JMD, et al. The persistence of fatigue in chronic fatigue syndrome and multiple sclerosis: Development of a model. J Psychosom Res 1998;45(6): 507-517.
28. Vercoulen JH, Swanink CM, Fennis JF, Galama JM, van der Meer JW, Bleijenberg G. Dimensional assessment of chronic fatigue syndrome. J Psychosom Res 1994;38(5): 383-392.

29. Vercoulen JH, Swanink CM, Fennis JF, Galama JM, van der Meer JW, Bleijenberg G. Prognosis in chronic fatigue syndrome: a prospective study on the natural course. J Neurol Neurosurg Psychiatry 1996;60(5): 489-494.
30. Vercoulen JHMM, Bazelmans E, Swanink CMA, et al. Physical activity in chronic fatigue syndrome: Assessment and its role in fatigue. J Psychiatr Res 1997;31(6): 661-673.
31. Kalkman JS, Schillings ML, van der Werf SP, et al. Experienced fatigue in facioscapulohumeral dystrophy, myotonic dystrophy, and HMSN-I. J Neurol Neurosurg Psychiatry 2005;76(10): 1406-1409.
32. Servaes P, van der Werf S, Prins J, Verhagen S, Bleijenberg G. Fatigue in disease-free cancer patients compared with fatigue in patients with Chronic Fatigue Syndrome. Support Care Cancer 2001;9(1):11-17.
33. Prevoo ML, 't Hof MA, Kuper HH, van Leeuwen MA, van de Putte LB, van Riel PL. Modified disease activity scores that include twenty-eight-joint counts. Development and validation in a prospective longitudinal study of patients with rheumatoid arthritis. Arthritis Rheum 1995;38(1): 44-48.
34. Fuchs HA, Pincus T. Reduced joint counts in controlled clinical trials in rheumatoid arthritis. Arthritis Rheum 1994;37(4): 470-475.
35. Prevoo ML, van Gestel AM, van THM, van Rijswijk MH, van de Putte LB, van Riel PL. Remission in a prospective study of patients with rheumatoid arthritis. American Rheumatism Association preliminary remission criteria in relation to the disease activity score. Br J Rheumatol 1996;35(11): 1101-1105.
36. Zandbelt MM, Welsing PM, van Gestel AM, van Riel PL. Health Assessment Questionnaire modifications: is standardisation needed? Ann Rheum Dis 2001;60(9): 841-845.
37. Fries JF, Spitz PW, Young DY. The dimensions of health outcomes: the health assessment questionnaire, disability and pain scales. J Rheumatol 1982;9(5): 789-793.
38. Tack BB. Fatigue in rheumatoid arthritis. Conditions, strategies, and consequences. Arthritis Care Res 1990;3(2): 65-70.

FATIGUE

FATIGUE AS EXPERIENCED BY PATIENTS WITH RHEUMATOID ARTHRITIS (RA): A QUALITATIVE STUDY

Han Repping-Wuts
Ruud Uitterhoeve
Piet van Riel
Theo van Achterberg

4

International Journal of Nursing Studies 2008; 45(7): 995-1002

Abstract

Objective

Interest in fatigue research has grown since the finding that fatigue is, besides pain, the symptom most frequently reported by patients with rheumatoid arthritis (RA). The aim of this study was to explore the experience of fatigue from the patients’ perspective.

Methods

Twenty-nine patients with RA filled-out written questionnaires on fatigue severity, disability, quality of life and sleep disturbance, and disease activity was calculated using the Disease Activity Score (DAS28). All patients were individually interviewed and asked about fatigue. Qualitative analyses were completed using software program ‘‘The Observer’’. Basic codes, a code plan and coding rules were developed by two researchers through a consensus-based review process. Frequencies of the central codes were calculated by the program SPSS.

Results

RA fatigue is verbalised as a physical everyday experience with a variety in duration and intensity. Its sudden onset and exhausting nature is experienced as frustrating and causing anger. Patients mentioned having RA as the main cause of their fatigue. The consequences of fatigue are overwhelming and influence patients’ everyday tasks, attitudes and leisure time. Patients described how they have to find their own management strategies by trial and error and described pacing and rest, relaxation and planning activities as the most appropriate interventions. Downward comparison and acceptance as part of the disease are also reported as successful coping strategies for fatigue. Most patients did not discuss fatigue with clinicians explicitly, accepting that they were told that fatigue is part of the disease and believing that they have to manage it alone.

Conclusion

The results show that RA fatigue is experienced as being different from “normal” fatigue. Patients do not expect much support from health care professionals, assuming that they have to manage fatigue alone as it is part of the disease. These results will help professionals caring for RA patients to communicate about fatigue, to explore the nature of fatigue individually and to develop tailored interventions.

Introduction

Rheumatoid arthritis (RA) is a systemic, chronic inflammatory disease with a prevalence of about 1% in western countries. Two thirds of the patients are female. RA affects joints, which leads to pain, joint destruction and disability, but also to fatigue. Fatigue is a complex, disruptive, stressful and subjective personal experience with no well-accepted definition. According to Piper, it can be considered an abnormal experience that has negative effects on bodily function and daily life[1]. Fatigue as a chronic symptom is a well-known manifestation of a number of chronic and somatic disorders, like cancer, multiple sclerosis, Parkinson's disease and cerebrovascular disorders. In RA fatigue is, besides pain, the most disturbing symptom, mentioned by RA patients[2,3]. The aetiology of RA fatigue is not known but is thought to be multidimensional: involving pain, disability, inflammation, sleep disturbance and psychosocial factors[2,4-9]. Specific pharmacologic interventions for fatigue in RA patients are not yet available; therefore, health professionals need skills and knowledge, enabling patients to self-manage this major, common and distressing symptom. To support patients in self-management strategies, it is necessary to understand fatigue from the patients point of view; their experiences of the nature of fatigue in RA, their beliefs about causes and consequences and, their interventions to cope with it may all influence self-management.

Quantitative research can examine the frequency and severity of symptoms; however, qualitative research is the most appropriate method to assess the experience of subjective symptoms such as fatigue, by simply asking patients for their experience. Literature research (Medline, Cinahl and PsychoInfo, 1990–2007) revealed only two qualitative studies on the patients' perception of fatigue in RA, one in the United States (US, N=20) and one in the United Kingdom (UK, N=15). The results of both studies were partly in accordance with each other and partly contradictory[2,10]. Multidimensional causes and major, wide-ranging consequences for RA fatigue are similar across the continents. However, differences were found in perceptions of fatigue management. UK patients 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. In contrast, US patients 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. To confirm the results of the UK and US studies, and to add new results for conflicting parts, a specific study in a Dutch RA population was performed.

The aim of this study was to explore the experience of fatigue in Dutch RA patients, including the concept, causes and consequences of fatigue, patients' self-management strategies and bottlenecks in professional care.

Patients and methods

Patients and methods

Thirty-one consecutive patients, attending the rheumatology outpatient clinic, were invited to participate in this study by telephone. Selection criteria were: diagnosis of RA, ability to speak and read the Dutch language, no previous history of a psychiatric illness, and willingness to participate in the study. Experiencing fatigue was not a criterion for inclusion. Patients completed written questionnaires at home prior to their visit to the outpatient clinic. Interviews, lasting 30–60 min, were conducted prior to, or immediately following the patient's appointment with a rheumatologist and/or a nurse specialist. Patients were recruited over a period of 4 months, in the period January–April 2006. All interviews were conducted by the same researcher (HR), in separate rooms at the outpatient clinic.
The study proposal was presented to the local ethics committee (CMO-Nijmegen/Arnhem). The committee concluded that formal approval was not needed as medical treatment was not modified for this study and filling-out questionnaires and being interviewed on fatigue were not seen as burdensome.

Written questionnaires

Several, well validated, quantitative assessment instruments were used to describe the study population. Fatigue was measured by the fatigue subscale (CIS-fatigue, range 8–56) of the Checklist Individual Strength (CIS)[11-13] and disease activity (inflammatory activity) by the Disease Activity Score (DAS28, range 0–10)[14,15]. The DAS28 was calculated using the following formula: 0.56 √ (TE28, 28 joint count for tenderness) +0.28 √ (SW28, 28 joint count for swelling) +0.70 In(ESR, Westergren's Erythrocyte Sedimentation Rate) +0.014(VAS-GH, patient's global assessment of disease activity on visual analogue scale of 100 mm). Disability was assessed by the Health Assessment Questionnaire-Disability Index (HAQ-DI, range 0–3)[16,17] and quality of life was assessed using the Short Form 36 questionnaire (SF-36, range 0–100)[18]. Sleep disturbance was measured by the Groninger sleep quality scale (GSQS, range 0–14)[19].

Interviews

Patients participated in an audio-taped, semi-structured individual interview, lasting 30–60 min. A topic list was used to structure the interview (Table 1). In order to standardise the interviews, each patient was asked the same questions in the same order. The standard was piloted in three interviews by the researcher and a nurse specialist, and only minor amendments were made. The three, piloted interviews were therefore included in the analysis. Opportunity for additional comments was available at the end of each interview and field notes were made to record special events.

Patients were informed that all interviews would be anonymous and that the tapes would be destroyed after analysis. Subjects showed no sign of "stage fright" once the interview was started. The positive reactions of the patients seemed to contribute to the validity of the data obtained. During the interview, patients were able to talk spontaneously about fatigue, and some patients mentioned the added value of self-analysing fatigue during the interview.

In order to avoid influencing patients in advance, all patients were first exclusively invited to answers on the five topics in their own words. After extensively verbalising their experience, written lists for concept, causes and consequences, based on literature research, were handed over, to help patients broaden their thoughts.

Analysis

Each of the audio-taped interviews was subjected to analysis using the software program The Observer[20]. The Observer is a professional manual event recorder for the collection, management, analysis and presentation of data. The program allows marking for later editing and notes can be written during the coding session. All data are stored on the computer hard disk. A theoretical framework, based on literature research, was developed and used for setting basic codes (called configuration) by which to judge a given text, e.g. for the topic "what causes your fatigue", the basic codes were having RA, pain, stress, age, etc. With regard to the topic list in this study, the basic codes were clustered into the following four topics (Table 1): "physical", "emotional", "mental" and "psycho-social". For topic five, the clusters were: "communication", "information", "satisfaction" and "support". The configuration of The Observer allows for the development of subcodes, called modifiers, under each basic code. For example, under the code "physical" for causes of fatigue sub-codes were identified as "having RA", "age", "disability", "treatment" and "having co-morbidities".

Two researchers (RU and HR) discussed the predefined code plan and through a

consensus-based review process the description of the code plan was refined and coding rules were developed. Coding rules were described in a coding manual.
To assess interrater-reliability, two researchers (HR and RU) independently coded three interviews. These three interviews were (randomly) selected from the total group of patients, to avoid interdependency. The interrater-reliability test of the Observer permits one to see how both coders have coded and a good agreement was found between the two coders. Subsequently, one coder coded the remainder of the tapes. Furthermore, frequencies of the central topics were calculated by the program SPSS.

Table 1. The topics for the semi-structured interviews

1. How would you describe your fatigue (concept)?
2. What causes your fatigue?
3. What are the consequences of your fatigue on daily life?
4. How do you manage your fatigue?
5. Which bottlenecks do you experience in today's professional care for fatigue

Results

Study population

Out of 31 patients who were contacted by phone, 30 patients agreed to participate. One patient was excluded from the study because of a psychiatric disorder, so finally 29 patients were enrolled.

Table 2. Population characteristics (N=29)

	N
Gender (female)	17
Relationship (living with partner)	23
Educational level (elementary or secondary)	23
Treatment by a physiotherapist*	9
Using home care	4
Using family care	11
Retired	8
Co-morbidities (one or more)	18
Medication use:	
DMARDs	24
NSAIDs	23

* Occupational therapist, psychotherapist, psychologist and psychiatrist were not in consult

Participating patients had a mean age of 59 years (range 36–80 years, S.D. 11.9); the majority were women, lived together with a partner and had an elementary or secondary education. A quarter of the respondents were retired and almost half of the group used family care. The majority of the patients had one or more co-morbidities and used disease modifying antirheumatoid drugs and/or non-steroidal anti-inflammatory drugs (DMARDs/NSAIDs). A minority was seeing a physiotherapist (Table 2).

Disease duration ranged from 2 to 34 years with a mean of 12.5 years (S.D. 8.3). The scores for DAS28 and HAQ-DI indicated that most patients had low-to-moderate levels of disease activity and disability (Table 3).

Table 3. Disease related characteristics (N=29)

		Range
Disease duration (years)	12.6 (8.3)	2 - 34
TE28	1.0 (0.5-3.5)	0 - 16
SW28	5.0 (2.0-8.5)	0 – 12
VAS-GH	25 (15-49)	7 - 63
ESR	12 (6.3-21.5)	2 - 60
DAS28	3.4 (1.0)	1.1 –5.5
HAQ-DI	1.1 (0.2-1.6)	0 – 2.3

Values are mean (SD) or median (interquartile range) for variables that are skewed.
TE28, 28 joint count for tenderness; SW28, 28 joint count for swelling; VAS-GH , Visual Analogue Scale for General Health; ESR, erythrocyte sedimentation rate; DAS28, Disease Activity Score 28; HAQ-DI, Health Assessment Questionnaire-Disability Index.

Twenty-eight percent (N=8) of the study group had normal levels of fatigue, 17% (N=5) had a moderate fatigue and 55% (N=16) had severe fatigue. The mean score for the CIS-fatigue was 33.6 (S.D. 11.4). A normal level of fatigue is defined as fatigue as experienced by most people in daily life, generally related to some identifiable form of exertion, rapid in onset, short in duration and relieved by rest or a good night's sleep.

Scores on the Groningen sleep quality scale indicated undisturbed sleep. Mean scores for the SF-36 were relatively low to moderate on all dimensions, confirming the profound impact of RA on quality of life. The same results on quality of life in RA patients were found in a study by Rupp et al.[4] (Table 4).

Table 4. Quality of life scores and sleep quality

	Study group		Healthy reference group
	Mean (SD)	Range	Mean (SD)
SF-36-Physical functioning	53.8 (28.5)	5-100	90.0 (15.8)
SF-36-Social functioning	45.7 (9.0)	25-75	92.7 (21.4)
SF-36-Role limitations (physical)	22.4 (39.7)	0-100	91.7 (23.9)
SF-36-Role limitations (emotional)	72.4 (37.7)	0-100	94.4 (18.7)
SF-36-Mental Health	60.6 (5.5)	48-100	86.7 (22.5)
SF-36-Vitality	46.7 (8.0)	30-95	74.2 (20.9)
SF-36-Pain	39.9 (17.6)	33-69	82. 0 (24.7)
SF-36-General health perception	52.9 (10.0)	20-85	78.2 (19.3)
SF-36-Changes in health	50.0 (22.2)	25-100	---
The Groningen Sleep Quality Scale	4.9 (4.0)	0-14	---

SF-36, 36-item short form health survey; reference group from the study of West et al. (West and Jonsson, 2005)

The fatigue experience

Mostly unpredictable

Respondents described a variable fatigue, mostly unpredictable, sudden of onset and not occurring at regular times or same days of the week, with a variety in duration and intensity. More recently, diagnosed respondents differentiated between fatigue as experienced prior to the diagnosis of RA and fatigue they experienced at the time of the study: "Before I had RA, I never felt tired, my energy was Unlimited". "Prior to having RA my fatigue was explainable and this "RA fatigue" is more y complex, I call it my "RA fatigue" (R29, 71 years male). Almost half of the respondents explained having a daily experience of fatigue with a greater impact on daily life than pain. On a list with 32 adjectives for fatigue, the words most often used (N≥10) were: physical, temporary, frustrating, causing anger, exhausting, aggravating and acceptable. Some respondents recalled knowing the cause of fatigue before they had RA (working hard or a lack of sleep), but RA fatigue occurs without a specific reason, often unexpected and without a pattern, which makes it frustrating and difficult to handle: "Frustrating, my mind is full of energy but my body doesn't have that energy, is unwilling to react … it is just tired and nothing else, totally worn out" (R18, 55 years female). Although fatigue is a mostly unpredictable experience, most of the respondents explained that they recognised some signs and symptoms of becoming fatigued, e.g. by more pain and stiffness, yawning, and experiencing heavy legs or tired eyes:

"My legs become very heavy and I have to sit down, just doing nothing" (R28, 65 years male). Fatigue in RA patients is recognised by most people in the close circle of family and friends by patients becoming pale, a change in their eyes "not as bright", being less concentrated, getting irritated and having more mobility problems: "My wife tells I have to lay down because I don't react as expected and I cannot find the appropriate words, I lose my concentration" (R11, 71 years male). All respondents mentioned having RA as the main cause of fatigue. Almost half of the respondents mentioned age, co-morbidity and disability as a possible cause of their fatigue. Some respondents recognised the use of medication as a minor possible cause of fatigue. On a list of 20 possible causes of fatigue, respondents marked having RA, stiffness in the joints, decreased grip strength, disabilities, decreased physical activity, unrest full wakening and age as the most important causes of their fatigue (N≥10).

Stress, doing too much and physical or mental busyness as perpetuating factors are mentioned by a quarter of the respondents.

Affecting everyday life

Half of the respondents described the major influence of fatigue on daily life, particularly on relationships, leisure time and emotional aspects: "To see my family I have to invite them to my home because visiting them at their home is too exhausting" (R4, 71 years female) "My partner has to do the cooking because after my working hours I am totally worn out" (R1, 55 years female). "I had to give up my weekly bridge evening because I had to phone my bridge partners too often that I could not be present that evening and I hate being the disturbing factor in the group" (R9, 59 years female). "Sometimes I cry when I discover something else that is no longer possible for me to carry out" (R30, 61 years female). The majority of the respondents mentioned cancelling family appointments, barriers in playing with (grand) children and asking for help: "I would like to take care of my grandchildren but it is not possible for me to do it alone, I cannot lift them and I need my husband to play with them" (R27, 61 years female). A quarter of the respondents described other consequences of fatigue such as: restricting work or changing work hours, unable to participate in weekly leisure activities, and asking for help with household activities, especially vacuum cleaning and window cleaning. Half of the respondents mentioned that they had to give up their favourite sport. Irritability, crying and a decrease of motivation and concentration are mentioned by almost half of the respondents. A minority described the influence on sleep as being more and more often awake and having impaired sleep quality. On a list of 11 possible consequences of fatigue, respondents marked consequences for hobbies, sleep habits and household activities as the most important consequences of their fatigue (NX10).

Professional care and self-management are variable

The majority of the respondents mentioned pacing and rest as the first intervention, followed by relaxation and acceptance. Pacing and rest imply taking one's time, limiting the number of activities to be completed in a day, going to bed for a good afternoon sleep, just sitting in an easy chair or going to bed early in the evening. Interventions were not always effective: "When I have to clean the house, well I have to choose the highest priority for that day and even then …. I have to carry on in stages". "I cannot iron all the laundry in one go. I have to take breaks". "I have to lay down for a while y and plan to finish the job afterwards y but afterwards it still is not possible because I am too tired to carry on y it is frustrating" (R6, 46 years female). Respondents mentioned different kinds of relaxation with reading and listening to music as the most important ones. However, taking a bath or looking for entertainment, e.g. watching TV, were also mentioned: "I get into my car and go to a restaurant, park my car as close as possible and enjoy a cup of coffee and watching people" (R13, 63 years female). Respondents reported having to plan activities, making choices and changing their attitude. Some respondents mentioned that they occasionally made the choice to carry on, regardless, and accept the consequences. Acceptance, fatigue as part of the disease and using a downward comparison strategy, discussing fatigue with a partner and staying active to prevent stiffness and pain were also mentioned by almost half of the respondents: "There is no reason for me to complain. There are others with diseases that are much more difficult; compared to other patients with my illness ….. I feel privileged that I can take care of myself" (R3, 61 years female). Almost all respondents reported to manage fatigue alone, not discussing it as a specific symptom with their rheumatologist or nurse specialist. Downward comparison, fatigue as an insoluble part of the disease and not willing to be a complainer were the main reasons for this self-management strategy. Half of the respondents mentioned that learning by trial and error is the best way to manage fatigue.

Most respondents did not remember or were unable to formulate the received professional advice for fatigue. Professional support was not always patient-specific and therefore not suitable to carry out for some of the respondents: "I was told to take a rest during the day with two young children I don't know how to do that!" (R15, 36 years female) "I got the advice to listen to my body, but how?” (R11, 71 years male) “My doctor told me to slow down, but I didn’t listen because it is difficult for me to give no for an answer when someone asks me for help” (R23, 49 years male).

The majority of the respondents would have appreciated more information on fatigue at the start of the disease, not knowing what that information should consist of. Some respondents mentioned that in contrast to pain, nothing could be done for fatigue, as it is part of the disease and the lack of medication for fatigue. Almost two-thirds of the respondents gained support by persons in their close circle of family and friends. Overall, respondents mentioned being satisfied with the professional care they received.

Discussion

The results of this study show that fatigue is an unpredictable, almost daily experience for RA patients with a great impact on quality of life, while patients struggle alone to manage it. Furthermore, half of the respondents described fatigue as even more bothersome than pain. The concept of fatigue is described as physical, exhausting and frustrating, having consequences for roles, relationships, leisure time, with emotional aspects, requiring everyday adaptation. Respondents mentioned having RA as the main cause for their fatigue but “normal” causes of fatigue such as stress and working hard were also reported. Respondents verbalised that they seldom mentioned fatigue explicitly to their professional healthcare providers, assuming that it cannot be treated, and that they must manage it alone.

The samples of the UK, US and the present study were comparable for gender, age and disease duration and in general representative for RA patients. For the level of fatigue the three studies differ, partly due to the different measurement instruments. In the UK study, only patients with a score of X7 on a visual analogue scale (VAS) were included and for the US study an equal VAS was used, but the levels of fatigue were not presented in the article. A VAS scale is useful to study relationships between variables or changes in fatigue. However, it is difficult to attach a meaning to such VAS scores: how important is 47 out of 10? In our study, the CIS-fatigue was used, a measurement instrument with the possibility to define patients in normal, moderate or severe fatigue and we found an equal percentage of severe fatigue as we found in previous research[22]; however, the samples are too small for statistical analysis and conclusions for each level of fatigue on the selected topics.

Compared to the UK and US studies, the results for Dutch RA patients share many commonalities but differ in some aspects. Multidimensional causes, and farreaching consequences are similar in the results of the three studies. However, Dutch RA patients explained that they, just like the UK participants, have to manage fatigue alone, not knowing which interventions could be successful, so learning by trial and error and believing that there is no effective treatment. The Dutch RA population differed from the UK respondents in not expressing negative attitudes concerning the experienced self-management strategy. Compared to US participants the Dutch RA group mentioned similar positive coping strategies such as downward comparison and acceptance to handle fatigue. Downward comparison allowed the respondents to view their illness as less severe than disease in other patients.

Is RA fatigue different to fatigue as experienced in other chronic illnesses? Literature research on the fatigue experience in other chronic diseases revealed the same results on consequences on daily life and self-management strategies, but different results for causes. In a study of adults living with HIV, the consequences for relationships were expressed and participants developed selfmanagement strategies over many years of trial and error[23]. In a study of patients with chronic obstructive pulmonary diseases and with asthma, fatigue influences daily activities and two types of coping strategies to manage fatigue are identified: problem focused, including energy conservation and emotional focused, including being positive and acceptance[24]. In studies on fatigue in patients with cancer, fatigue is related to treatment with chemotherapy or radiation and therefore predictable[25,26]. In previous chronic diseases and in RA, fatigue is a present rather than a temporary phenomenon, has an insidious onset, is cumulative and persists over time[27]. This in contrast to the fatigue which most people encounter in their daily lives, which is generally related to some identifiable form of exertion, rapid in onset, short in duration and relieved by a good night’s sleep.

The present study has limitations. The size of the sample (N=29), while relatively large for qualitative research, is small for statistical analysis, and generalising results to a larger RA population may not be possible.

The strengths of this study include the validity, as a second independent nurse specialist conducted three of the interviews; two researchers developed the code plan and coded three interviews (RU and HR). To increase both validity and reliability, we aimed to adhere as closely as possible to the patients’ words in this article, for example, by quoting their exact words. The use of a validated fatigue questionnaire made it possible to give a clear description of the level of fatigue in the research population.

Whereas fatigue is the most prominent symptom besides pain, respondents manage fatigue alone and accept that fatigue is part of the disease, not discussing fatigue explicitly at the outpatient clinic or asking for advice from specialised healthcare professionals. In general, it is assumed that communication between patients and professionals is not always sufficient and patients often find it difficult to directly express their concerns and instead offer cues that indicate worry or concern[28]. However, to develop patient self-management strategies, professionals should be aware of the fatigue experience in RA patients, advocating that fatigue is a legitimate complaint to the person living with it and offer patients opportunities to communicate fatigue in an open way and to give information and advice. Further research is needed to explore the communication between RA patients and healthcare professionals.

References

1. Piper BF. Fatigue. Pathofysiological phenomena in nursing. 2th ed. 1993, 279-302.
2. Tack BB. Fatigue in rheumatoid arthritis. Conditions, strategies, and consequences. Arthritis Care Res 1990;3(2): 65-70.
3. Wolfe F, Hawley DJ, Wilson K. The prevalence and meaning of fatigue in rheumatic disease. J Rheumatol 1996;23(8): 1407-1417.
4. Rupp I, Boshuizen HC, Jacobi CE, Dinant HJ, van den Bos GA. Impact of fatigue on health-related quality of life in rheumatoid arthritis. Arthritis Rheum 2004;51(4): 578-585.
5. Pollard LC, Choy EH, Gonzalez J, Khoshaba B, Scott DL. Fatigue in rheumatoid arthritis reflects pain, not disease activity. Rheumatology (Oxford) 2006.
6. Huyser BA, Parker JC, Thoreson R, Smarr KL, Johnson JC, Hoffman R. Predictors of subjective fatigue among individuals with rheumatoid arthritis. Arthritis Rheum 1998;41(12): 2230-2237.
7. Riemsma RP, Rasker JJ, Taal E, Griep EN, Wouters JM, Wiegman O. Fatigue in rheumatoid arthritis: the role of self-efficacy and problematic social support. Rheumatology (Oxford) 1998;37(10): 1042.
8. Crosby LJ. Factors which contribute to fatigue associated with rheumatoid arthritis. J Adv Nurs 1991;16(8): 974-981.
9. Mancuso CA, Rincon M, Sayles W, Paget SA. Psychosocial variables and fatigue: a longitudinal study comparing individuals with rheumatoid arthritis and healthy controls. J Rheumatol 2006;33(8): 1496-1502.
10. Hewlett S, Cockshott Z, Byron M, et al. Patients' perceptions of fatigue in rheumatoid arthritis: overwhelming, uncontrollable, ignored. Arthritis Rheum 2005;53(5): 697-702.
11. Vercoulen JH, Alberts M, Bleijenberg G. De checklist Individual Strenght. Gedragstherapie 1999;32: 131-136.
12. Bultmann U, de Vries M, Beurskens AJ, Bleijenberg G, Vercoulen JH, Kant I. Measurement of prolonged fatigue in the working population: determination of a cutoff point for the checklist individual strength. J Occup Health Psychol 2000;5(4): 411-416.
13. Beurskens AJ, Bultmann U, Kant I, Vercoulen JH, Bleijenberg G, Swaen GM. Fatigue among working people: validity of a questionnaire measure. Occup Environ Med 2000;57(5): 353-357.
14. Prevoo ML, 't Hof MA, Kuper HH, van Leeuwen MA, van de Putte LB, van Riel PL. Modified disease activity scores that include twenty-eight-joint counts. Development and validation in a prospective longitudinal study of patients with rheumatoid arthritis. Arthritis Rheum 1995;38(1): 44-48.

15. Fuchs HA, Pincus T. Reduced joint counts in controlled clinical trials in rheumatoid arthritis. Arthritis Rheum 1994;37(4): 470-475.
16. Fries JF, Spitz P, Kraines RG, Holman HR. Measurement of patient outcome in arthritis. Arthritis Rheum 1980; 23(2): 137–145.
17. Zandbelt MM, Welsing PM, van Gestel AM, van Riel PL. Health Assessment Questionnaire modifications: is standardisation needed? Ann Rheum Dis 2001;60(9): 841-845.
18. van der Zee K, Sanderman R. Het meten van de algemene gezondheidstoestand met de RAND-36: Een handleiding [SF-36, Manual Dutch version]. Noorderlijk Centrum voor Gezondheids-vraagstukken: Groningen, 1993.
19. Meijman T, de Vries-Griever AH, de Vries G. The evaluation of the Groningen Sleep Quality Scale. Groningen: Heymans Bulletin (HB 88-13-EX), 1988, 2006.
20. Noldus LP, Trienes RJ, Hendriksen AH, Jansen H, Jansen RG. The Observer Video-Pro: new software for the collection, management, and presentation of time-structured data from videotapes and digital media files. Behav Res Methods Instrum Comput 2000;32(1): 197-206.
21. West E, Jonsson SW. Health-related quality of life in rheumatoid arthritis in Northern Sweden: a comparison between patients with early RA, patients with medium-term disease and controls, using SF-36. Clin Rheumatol 2005;24(2): 117-122.
22. Repping-Wuts JWJ, Fransen J, van Achterberg T, Bleijenberg G, van Riel P. Persistent severe fatigue in patients with Rheumatoid Arthritis. J Clin Nurs 2007; 16(11c): 377-383.
23. Jenkin P, Koch T, Kralik D. The experience of fatigue for adults living with HIV. J Clin Nurs 2006;15(9): 1123-1131.
24. Small S, Lamb M. Fatigue in chronic illness: the experience of individuals with chronic obstructive pulmonary disease and with asthma. J Adv Nurs 1999;30(2): 469-478.
25. Magnusson K, Moller A, Ekman T, Wallgren A. A qualitative study to explore the experience of fatigue in cancer patients. Eur J Cancer Care (Engl) 1999;8(4): 224-232.
26. Mock V, Atkinson A, Barsevick A, et al. NCCN Practice Guidelines for Cancer-Related Fatigue. Oncology (Williston Park) 2000;14(11A): 151-161.
27. Ream E, Richardson A. Fatigue: a concept analysis. Int J Nurs Stud 1996;33(5): 519-529.
28. de Rijk AE, Schreurs KM, Bensing JM. Patient factors related to the presentation of fatigue complaints: results from a women’s general health care practice. Women Health 2000;30(4): 121-136.

FATIGUE

RHEUMATOLOGISTS' KNOWLEDGE, ATTITUDE AND CURRENT MANAGEMENT OF FATIGUE IN PATIENTS WITH RHEUMATOID ARTHRITIS (RA)

Han Repping-Wuts
Piet van Riel
Theo van Achterberg

5

Clinical Rheumatology, 2008; 27(12): 1549-1555

Abstract

To describe rheumatologists’ knowledge, attitude and current management of fatigue in patients with Rheumatoid Arthritis, 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 multidisciplinary 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.

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 multidimensional, 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 contradictive[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. [2006] found that over a period of one year, fatigue in RA is associated with psychosocial factors and disability, but not with pain[20]. Recently it has been 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 world wide and does not get the attention it deserves[30]. The International League of Associations for Rheumatology (ILAR) 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 world wide 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 items 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 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 three 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 (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's 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 there 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 multidisciplinary 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	Yes		*P*	References
	Total group (N=110)	Rheumatologists (N=93)	Trainees (N=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*	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, * Seven percent is missing

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

Questions	Yes Total group (N=110)	Yes Rheumatologists (N=93)	Trainees (N=17)	*P*
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 multidisciplinary 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

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 (Table 3), but when they do, this is mostly to the nurse specialist (38%), the physiotherapist (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 cognitive-behavioural therapy (CBT) to RA-related advice such as optimize medication, and coping or acceptation.

Rheumatologists tend to document fatigue more often and refer patients more often to other disciplines to treat fatigue than trainees did.

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

Questions	Always, most of the time			*P*
	Total group (N=110)	Rheumatologist (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

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 (Table 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 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 (table 3 and 4).

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

	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?[1]	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?[2]	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; [1]Thirty-five percent was missing ; [2] Twenty-six percent was missing; *NS* Not significant

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' advice concerning fatigue are mainly active lifestyle to improve physical condition and finding a balance between rest and activities, while 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 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 rheumatologists 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 Netherland. 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.

References

1. Wolfe F, Hawley DJ, Wilson K. The prevalence and meaning of fatigue in rheumatic disease. J Rheumatol 1996;23(8): 1407-1417.
2. Belza BL. Comparison of self-reported fatigue in rheumatoid arthritis and controls. J Rheumatol 1995;22(4): 639-643.
3. Hewlett S, Cockshott Z, Byron M, et al. Patients' perceptions of fatigue in rheumatoid arthritis: overwhelming, uncontrollable, ignored. Arthritis Rheum 2005;53(5): 697-702.
4. Minnock P, Bresnihan B. Pain outcome and fatigue levels reported by women with established rheumatoid arthritis. Suppl:S471 ed. 2004.
5. Hewlett S, Carr M, Ryan S, et al. Outcomes generated by patients with rheumatoid arthritis: how important are they? Musculoskeletal Care 2005;3(3): 131-142.
6. Pinals RS, Masi AT, Larsen RA. Preliminary criteria for clinical remission in rheumatoid arthritis. Arthritis Rheum 1981;24(10): 1308-1315.
7. Belza BL, Henke CJ, Yelin EH, Epstein WV, Gilliss CL. Correlates of fatigue in older adults with rheumatoid arthritis. Nurs Res 1993;42(2): 93-99.
8. Ream E, Richardson A. Fatigue: a concept analysis. Int J Nurs Stud 1996;33(5): 519-529.
9. Suurmeijer TP, Waltz M, Moum T, et al. Quality of life profiles in the first years of rheumatoid arthritis: results from the EURIDISS longitudinal study. Arthritis Rheum 2001;45(2): 111-121.
10. Crosby LJ. Factors which contribute to fatigue associated with rheumatoid arthritis. J Adv Nurs 1991;16(8): 974-981.
11. Huyser BA, Parker JC, Thoreson R, Smarr KL, Johnson JC, Hoffman R. Predictors of subjective fatigue among individuals with rheumatoid arthritis. Arthritis Rheum 1998;41(12): 2230-2237.
12. Riemsma RP, Rasker JJ, Taal E, Griep EN, Wouters JM, Wiegman O. Fatigue in rheumatoid arthritis: the role of self-efficacy and problematic social support. Rheumatology (Oxford) 1998;37(10): 1042-1046.
13. Wolfe F. Psychological distress and rheumatic disease. Scand J Rheumatol 1999;28(3): 131-136.
14. Heiberg T, Finset A, Uhlig T, Kvien TK. Seven year changes in health status and priorities for improvement of health in patients with rheumatoid arthritis. Ann Rheum Dis 2005;64(2): 191-195.
15. Breedveld FC, Han C, Bala M, van der Heide D, Baker D. Association between baseline radiographic damage and improvement in physical function after treatment of patients with rheumatoid arthritis. Ann Rheum Dis 2005;64(1): 52-55.

16. Moss-Morris R, Chalder T. Illness perceptions and levels of disability in patients with chronic fatigue syndrome and rheumatoid arthritis. J Psychosom Res 2003;55(4): 305-308.
17. Pollard LC, Choy EH, Gonzalez J, Khoshaba B, Scott DL. Fatigue in rheumatoid arthritis reflects pain, not disease activity. Rheumatology (Oxford) 2006.
18. Stone AA, Broderick JE, Porter LS, Kaell AT. The experience of rheumatoid arthritis pain and fatigue: examining momentary reports and correlates over one week. Arthritis Care Res 1997;10(3): 185-193.
19. Wolfe F, Michaud K. Fatigue, rheumatoid arthritis, and anti-tumor necrosis factor therapy: an investigation in 24,831 patients. J Rheumatol 2004;31(11): 2115-2120.
20. Mancuso CA, Rincon M, Sayles W, Paget SA. Psychosocial variables and fatigue: a longitudinal study comparing individuals with rheumatoid arthritis and healthy controls. J Rheumatol 2006;33(8): 1496-1502.
21. Repping-Wuts H, Fransen J, van Achterberg T, Bleijenberg G, van Riel P. Persistent severe fatigue in patients with rheumatoid arthritis. J Clin Nurs 2007;16(11C): 377-383.
22. Evers AW, Kraaimaat FW, van Riel PL, de Jong AJ. Tailored cognitive-behavioral therapy in early rheumatoid arthritis for patients at risk: a randomized controlled trial. Pain 2002;100(1-2): 141-153.
23. Lee EO, Kim JI, Davis AH, Kim I. Effects of regular exercise on pain, fatigue, and disability in patients with rheumatoid arthritis. Fam Community Health 2006;29(4): 320-327.
24. Moreland LW, Genovese MC, Sato R, Singh A. Effect of etanercept on fatigue in patients with recent or established rheumatoid arthritis. Arthritis Rheum 2006;55(2): 287-293.
25. Neill J, Belan I, Ried K. Effectiveness of non-pharmacological interventions for fatigue in adults with multiple sclerosis, rheumatoid arthritis, or systemic lupus erythematosus: a systematic review. J Adv Nurs 2006;56(6): 617-635.
26. Repping-Wuts H, Uitterhoeve R, van Riel P, van Achterberg T. Fatigue as experienced by patients with rheumatoid arthritis (RA): A qualitative study. Int J Nurs Stud 2008;45(7): 995-1002.
27. Carr A, Hewlett S, Hughes R, et al. Rheumatology outcomes: the patient's perspective. J Rheumatol 2003;30(4): 880-883.
28. Tack BB. Fatigue in rheumatoid arthritis. Conditions, strategies, and consequences. Arthritis Care Res 1990;3(2): 65-70.
29. Hewlett SA. Patients and clinicians have different perspectives on outcomes in arthritis. J Rheumatol 2003;30(4): 877-879.

30. Dequeker J, Rasker H. High prevalence and impact of rheumatic diseases is not reflected in the medical curriculum: the ILAR Undergraduate Medical Education in Rheumatology (UMER) 2000 project. Together everybody achieves more. International League of Associations for Rheumatology. J Rheumatol 1998;25(6): 1037-1040.
31. Dequeker J, Rasker JJ, Woolf AD. Educational issues in rheumatology. Baillieres Best Pract Res Clin Rheumatol 2000;14(4): 715-729.
32. Miller M, Kearney N. Nurses' knowledge and attitudes towards cancer-related fatigue. Eur J Oncol Nurs 2001;5(4): 208-217.
33. Vogelzang NJ, Breitbart W, Cella D, et al. Patient, caregiver, and oncologist perceptions of cancer-related fatigue: results of a tripart assessment survey. The Fatigue Coalition. Semin Hematol 1997;34(3 Suppl 2): 4-12.
34. Swanborn PG. Methoden van sociaal-wetenschappelijk onderzoek. 1994.
35. Welsing PM, Fransen J, van Riel PL. Is the disease course of rheumatoid arthritis becoming milder? Time trends since 1985 in an inception cohort of early rheumatoid arthritis. Arthritis Rheum 2005;52(9): 2616-2624.
36. Kirwan JR, Minnock P, Adebajo A, Bresnihan B, Choy E, de Wit M et al. Patient perspective: fatigue as a recommended patient centered outcome measure in rheumatoid arthritis. J Rheumatol 2007;34(5): 1174-1177.

FATIGUE

FATIGUE IN PATIENTS WITH RHEUMATOID ARTHRITIS: BRITISH AND DUTCH NURSES’ KNOWLEDGE, ATTITUDES AND MANAGEMENT

Han Repping-Wuts
Sarah Hewlett
Piet van Riel
Theo van Achterberg

6

Journal of Advanced Nursing, accepted for publication.

ABSTRACT

Aim

This paper is a report of a study conducted to compare the knowledge, attitudes and current management of rheumatoid arthritis-related fatigue in British and Dutch rheumatology nurses.

Background

After pain, fatigue is the most important symptom for patients with rheumatoid arthritis, but little is known about current management of this fatigue by healthcare professionals.

Methods

A questionnaire was mailed to rheumatology nurses who were members of British Health Professionals in Rheumatology (N=267) and the Dutch Society of Rheumatology Nurses (N=227). Descriptive statistics, independent samples t-test and Pearson χ^2 tests were used for statistical analysis.

Results

A total of 494 nurses returned questionnaires (response rate 48%). In general, their knowledge about rheumatoid arthritis fatigue was in accordance with the literature and all indicated a positive attitude towards assessing and managing rheumatoid arthritis-related fatigue. However, respondents reported contradictory views about managing fatigue. Although they believed that other team members could help patients, they seldom referred patients on to other professionals. Although nurses believed that other advice besides pacing and balance between activity and rest, might help, they did not offer this to patients. Despite acknowledging that there is poor communication about fatigue between patients and nurses, respondents reported that it is patients rather than nurses who raise the issue of fatigue in consultations.

Conclusion

British and Dutch rheumatology nurses are sympathetic but do not know how to manage rheumatoid arthritis-related fatigue. Strategies to support self-management for this fatigue, and to increase communication between healthcare professionals and patients should be initiated to help improve patient outcomes for rheumatoid arthritis-related fatigue.

INTRODUCTION

Rheumatoid arthritis (RA) is an autoimmune disease that causes unpredictable and repeated lifelong episodes of synovitis in multiple joints, often leading to joint destruction, disability, pain, loss of work and psychological distress. Fatigue is the most important symptom in patients with RA after pain, with a prevalence rate of 42-80%[1-5]. No agreed definition for fatigue has been developed in RA. However, chronic fatigue 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[6,7].

BACKGROUND

The aetiology of RA-related fatigue is multidimensional, involving physical, psychological, social, cognitive and behavioural aspects. Contradictory results have been found in several cross-sectional studies on predictors and correlates of fatigue in RA. In some studies, higher levels of fatigue were related to higher levels of pain, disease activity and disability[1,5,8-17]. In contrast, other studies showed that RA-related fatigue was not related to disease activity per se, but was best predicted by disability and general health, but not related to gender[18]. In the few longitudinal studies carried out, it has been found that fatigue is relatively stable over days and months[1,19,20]. Mancuso et al.[21] found that over a period of 1 year, fatigue in RA is associated with psychosocial factors and disability, but not with pain.

Only a few researchers have focused on the treatment of fatigue. Cognitive-behavioural therapy (CBT), regular exercise and the use of biological therapies may be effective, although more research is needed[22-25].

Qualitative studies on fatigue experienced by people with RA show that RA fatigue varies in duration and frequency and is different from normal tiredness because it is extreme, often unexpected and occurs almost every day[3,26,27]. The consequences of fatigue for people with RA are physical, emotional, social and cognitive[28]. 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"[3,27].

To deliver professional nursing care in daily practice, rheumatology nurses need knowledge about RA fatigue and a positive attitude toward managing it, but little is known about their knowledge of, attitudes towards or current management of RA-related fatigue. A search of the literature (Medline and Cinahl, 1985-2007) using the terms rheumatoid arthritis and nurses' knowledge or nurses' attitude in the title revealed one abstract from Poland, but this focussed on patients' level of knowledge. No papers on RA and nurses' management were found, suggesting a clear lack of literature regarding these issues.

However, two studies on nurses' knowledge and attitude towards fatigue in patients with cancer were found[29,30]. These confirmed the high prevalence of cancer-related fatigue, the underestimation of fatigue incidence by cancer nurses, their poor knowledge and practice regarding fatigue assessment and management, and poor fatigue communication. No papers were found about research into the knowledge, attitudes and current care of fatigue in people with RA.

To improve self-management strategies for fatigue in people with RA, a thorough understanding of healthcare professionals' perception of fatigue is necessary. Based on the current lack of information relating to knowledge of and attitudes towards RA-related fatigue, we conducted a study to evaluate the current knowledge of and attitude towards RA-related fatigue by rheumatology nurses in two countries: the United Kingdom (UK) and the Netherlands.

In the Netherlands nurses may undertake a specific 9-month diploma course in rheumatology nursing, while a Master's degree level course and numerous short courses are available in the UK. However, both UK and Dutch nurses are allowed to care for patients with rheumatological conditions without such specialist training.

To gain insight in current practice for RA-related fatigue, we also asked rheumatology nurses how they help people with RA to handle this important symptom, and to identify areas where deficiencies exist in order to target future educational efforts appropriately.

THE STUDY

Aim

The aim of the study was to compare the knowledge, attitudes and current management of RA-related fatigue in British and Dutch rheumatology nurses.

Design

A postal survey was used, with a structured questionnaire. The study proposal was developed by HR and peer-reviewed (including a patient research partner in the UK).

Participants

All Rheumatology nurses who were members of the British Health Professionals in Rheumatology (N=267) and the Dutch Society for Rheumatology (N=227) were invited to complete a questionnaire in the period March-May 2007. Rheumatology nurses are Registered Nurses (RN), with or without a special training in rheumatology, who care for patients with all kind of rheumatic diseases.

Data collection

Instrument development

A search of the literature (Medline and Cinahl, 1985-2006) revealed only one fatigue knowledge and attitudes questionnaire, which was in cancer-related fatigue.[29] This covered nurses' knowledge, attitudes or beliefs and their current fatigue management practice. Given the differences in causes and treatment of fatigue between cancer patients and people with RA, this 25-item United States (US) questionnaire had to be adapted for RA-related fatigue (by HR, reviewed by experts in the field of rheumatology and nursing, including a UK patient research partner).

To develop questions about current RA fatigue management practices, the findings from two qualitative studies were used[3,27]. Questions about knowledge of the causes of RA fatigue were based on results of published studies[3,8,12,18]. Because of a lack of literature on nurses' attitudes towards RA, questions were based on the qualitative patient reports[3,27]. This resulted in a slightly longer questionnaire of 41 questions: 18 knowledge items, 9 attitude items and 14 current care items. Demographic data were requested separately.

In line with the cancer scale, the majority of questions were closed/quantitative, and a few were open-ended /qualitative (questionnaire available from the authors on request).

Questionnaire distribution
Prior to posting the questionnaire, a flyer was attached to the quarterly newsletter of the Dutch Society for Rheumatology, briefly informed rheumatology nurses about the study and inviting them to set aside 20 minutes of their time to complete a questionnaire. Subsequently, in both countries an invitation to participate was sent, with an information sheet, anonymous questionnaire and reply-paid envelope. Rheumatology nurses were given 2 weeks in which to return the questionnaires. A second mailing was sent after 3 weeks (the Netherlands only, ethics approval for further contact was denied in the UK).

Ethical consideration

As patients were not involved in the study, ethics approval in the Netherlands was not necessary. Approval for the UK was gained from the appropriate ethics committee. Return of a completed questionnaire was taken as consent to participate.

Data Analysis

All data were entered into the software program SPSS 14.0. Descriptive statistics, independent samples t-test for normally distributed data and Pearson chi-square for nominal data were used for the statistical analysis of the quantitative data.
$P < 0.05$ was considered to be statistically significant. Analyses of the free text data were largely based on specific themes for each question, drawn from the results of previous qualitative research.

RESULTS

Respondents

For the total group, the response was 48%: UK 39% (N=103), Netherlands 57% (N=129) (Table 1). Comparison of geographical and job-related aspects revealed only minor differences. Overall, the sample contained more women than men, with a mean age of 45.5 years (range 24-64). The mean years of experience in caring for people with RA was 9.9 years (range 0-30). All respondents were RN. UK rheumatology nurses were more often employed in a non-academic hospital, while Dutch rheumatology nurses were more often working in an academic hospital. UK rheumatology nurses cared for three times as many people with RA each month compared with their Dutch colleagues (104 vs 39, p=<0.001), had more experience in taking care of people with RA (mean 12 [sd 6] vs mean 8 [sd 6] years, p=<0.001) and tended to have more years of experience in nursing (mean 25 [sd 9] vs mean 21 [sd 10] years p=0.003)

Table 1. Demographics of United Kingdom (UK) and Dutch rheumatology nurses

	Overall (N=232)	UK nurses (N=103)	Dutch nurses (N=129)	P
Mean age (years)	46	46	45	0.12
Sex (n females, %)	221(95)	101(98)	120 (93)	0.15
Area of work, n (%):				
Hospital	152 (66)	91(88)	61 (47)	
Academic Hospital	37 (16)	8 (8)	29 (22)	
Home care institute	16 (7)	-	16 (12)	
Other	27 (12)	4 (4)	23 (18)	
Job title, n (%):				
Nurse	25 (11)	6 (6)	19 (15)	
District nurse	3 (1)	-	3 (2)	
Clinical nurse specialist	154 (66)	82 (80)	72 (56)	
Senior staff nurse	11 (5)	1 (1)	10 (8)	
Nurse practitioner	14 (6)	7 (7)	7 (5)	
Other	25 (11)	7 (7)	18 (14)	
Patients each month [mean (SD)]	67 (63)	104 (75)	39 (32)	<0.001
Working as a nurse [mean years, (SD)]	23 (9)	25 (9)	21 (10)	0.003
Experience in RA care [mean years, (SD)]	10 (6)	12 (6)	8 (6)	<0.001
Education about RA-related fatigue (% yes)	65	52	68	0.04
Percentage fatigued people with RA [mean (SD)]	76 (17)	75 (18)	76 (16)	0.55

P values are based on *t*-test except for gender (Pearson chi-square)
RA=rheumatoid arthritis

Knowledge

Quantitative findings

All respondents were aware of the prevalence of fatigue in people with RA, with a mean 76.4% of Dutch rheumatology nurses (SD 15.7, range 15-100), and 74.9% of UK rheumatology nurses (SD 18.1, range 25-100) (Table 1). In general, participants responded correctly to questions about their knowledge of RA-related fatigue, although the majority reported a lack of knowledge in how they should manage fatigue (table 2). Although the qualitative literature shows that patients believe that families understand their fatigue, almost all rheumatology nurses wrongly assumed that family members do not (91%). Overall, participants agreed with qualitative data from patients that healthcare professionals do not understand their fatigue, although more UK than Dutch nurses reported this (78% vs 47% $p < 0.001$). Qualitative data suggest that people with RA do not discuss their fatigue with healthcare professionals (although no quantitative data have been published), yet 92% of Dutch and 84% of UK rheumatology nurses believed that people with RA do discuss their fatigue with their nurse specialist. In contrast, 54% and 32% respectively assumed patients do not discuss fatigue with their rheumatologist.

Qualitative findings

Dutch rheumatology nurses gained their knowledge about RA-related fatigue from courses (93%) while UK participants gained knowledge from courses (29%), conferences (24%) and reading published articles (20%). Almost half of the UK nurses wanted more information about interventions to manage fatigue. Whilst Dutch nurses were more unsure about the knowledge they need, the majority overall agreed that more knowledge would be welcome.

United Kingdom and Dutch respondents agreed that RA or an inflammatory flare of RA were the most frequently mentioned causes of fatigue by patients (Table 3). Dutch rheumatology nurses believed that patients thought the causes of fatigue were often sleep problems (22%) or over workload (24%). UK rheumatology nurses thought that most patients were unsure about the cause of their fatigue (27%) (Table 3).

Table 2. Knowledge of rheumatoid arthritis (RA)-related fatigue

Questions	Correct answer (Refs)	Overall % correct N=232	UK nurses % correct N=103	Dutch nurses % correct N=129	P
22. Do you have enough knowledge about RA related fatigue?	Yes	35	27	42	0.008
26. Fatigue as experienced by RA patients, is stable during the day	No [1,19,20]	84	86	81	0.33
28. Do RA patients discuss their fatigue with the nurse specialist?	No [3,27]	12	16	8	0.19
29. Do you think RA patients discuss fatigue with the rheumatologist?	No[3,27]	44	32	54	<0.001
30. Do RA patients have a need for information about fatigue?	Yes [23]	97	96	98	0.47
31. Fatigue is always an insoluble problem	No [22]	94	94	96	0.48
38. Fatigue is always a problem for RA patients	No [26,34]	61	68	60	0.20
39. After pain, fatigue is the most bothersome symptom in RA	Yes [35]	93	96	91	0.15
40. An abnormal low Hb level always goes together with fatigue	No [18]	96	93	100	0.002
41. Simply getting a good night's sleep will always resolve fatigue	No [3,27]	99	100	99	0.37
42. RA patients complaining of fatigue must be depressed	No [14]	98	100	98	0.20
43. Fatigue is always the result of inflammatory activity in RA	No [18]	87	87	90	0.55
44. If you control disease activity, patient will not become fatigued	No [1,5,8,36]	86	86	91	0.28
45. Patient's fatigue often not believed or understood by family	No [3]	9	6	10	0.32
46. Patient's fatigue often not believed / understood by professionals	Yes[3]	61	78	47	<0.001
47. RA patients have the same type of fatigue as healthy individuals	No [3,27]	96	94	98	0.08

P values are based on Pearson chi-square
Hb, haemoglobin.

Table 3. Knowledge of rheumatoid arthritis (RA) -related fatigue (personal knowledge and based on literature)

	UK nurses % (N=103)	Dutch nurses % (N=129)	P
22. Do you have enough knowledge about RA related fatigue? If no, what would you like to know more?			
Do you have enough knowledge about RA related fatigue? (Yes)	27	42	0.008
	12	10	0.70
Causes of fatigue			
Interventions	44	13	<0.001
Other knowledge such as:			
Measurement instruments	14	19	
Results from studies	5	5	
I don't know, but more is always welcome	12	19	
27. What do you think RA patients believe is a cause of their fatigue?			
Medication	16	15	0.87
Having RA or an RA flare	61	76	0.02
Sleep problems	8	22	0.004
Doing to much	18	24	0.22
Patients are unsure	27	16	0.04
Other causes such as anaemia, doing to little, stress, depression, age and deconditioning	32	35	-
30. Do you think RA patients have a need for information about fatigue? If yes, which kind of information do you think they need?			
Self management strategies	42	55	0.06
Meet other patients	13	7	0.15
Written information	50	16	<0.001
Information about causes of fatigue	20	35	0.02
Other information such as coping strategies, verbal information, recognition and awareness	45	47	-

P values are based on Pearson chi-square.

Participants from both countries thought that people with RA need more information about fatigue: UK nurses were more likely to believe that this should be written information (50% vs 16%), while Dutch nurses tended to think that the information should address the causes of fatigue (35% vs 20%), and both wanted self-management information.

Attitudes

Overall, respondents believed fatigue is a multidisciplinary diagnosis (69%) rather than a specific nursing or medical diagnosis (27%, 11%). However, Dutch rheumatology nurses more often thought that fatigue was either a nursing diagnosis (44% Dutch vs 6% UK p<0.001) or medical diagnosis (19% vs 1% p<0.001) (Table 4). Lack of evidence-based, effective nursing interventions for RA- related fatigue did not stop nurses from asking their patients it. Respondents believed that occupational therapists (UK 89%, Netherlands 73%), physiotherapists (UK 68%, Netherlands 83%) and rheumatologists (UK 41%, Netherlands 67%) could all help patients with their fatigue.

Table 4. Attitude to rheumatoid arthritis (RA) -related fatigue

Questions	Overall* % (N=232)	UK nurses* % (N=103)	Dutch nurses* % (N=129)	P
19. Would you like to use an assessment instrument for measuring fatigue?	87	87	86	0.49
32. Fatigue is always a nursing diagnosis	27	6	44	<0.001
33. Fatigue is always a medical diagnosis	11	1	19	<0.001
34. Fatigue is always a multidisciplinary diagnosis	69	68	69	0.88
35. Preferably, fatigue should be treated by the Rheumatologist	15	19	11	0.07
36. Preferably, fatigue should be treated by the nurse	56	48	62	0.04
37. Patient who experience fatigue should always be referred to a psychologist	3	5	2	0.14
48. After successfully treating a patient's pain, the patient should be grateful that he/she only has fatigue	2	3	1	0.21
49. As fatigue is a subjective symptom it cannot be measured	16	18	15	0.51
50. Because there are no effective treatments for fatigue in RA patients, it is better not to ask the patient about it	0	0	0	-

*Values are percentages of "yes" answers, P values are based on Pearson chi-square.

A minority of all participants (3%) believed that fatigued people with RA should always be referred to the psychologist. Dutch participants believed more often than UK participants that nurse specialists should treat fatigue (62 % vs 48%, p=0.04).

Current management

In daily practice almost all rheumatology nurses reported that they addressed fatigue, mostly during the first consultation but also during follow-up consultations (Table 5). Forty percent reported that it is the nurse who usually raises the issue of fatigue, 46% believed that it is the patient and 14% thought that it could be both. The majority (87%) reported that if patients are asked about fatigue, they seldom say that it is not a problem.

In current practice, people with RA were hardly ever referred to rheumatology nurses specifically to help them with their fatigue. Despite the high levels of belief about the ability of team members to help manage fatigue (41-89%), few participants (30%) referred patients on to other professionals for the treatment of fatigue. Only 12 UK and 19 Dutch rheumatology nurses (respectively 11% and 15%) used an assessment instrument to measure fatigue (usually a visual analogue scale), although almost all were willing to use an assessment instrument.

Qualitative findings

Pacing and balance between activity and rest were the types of advice most frequently given by rheumatology nurses to people with RA (table 6). UK respondents were more likely than Dutch respondents to give advice about disease-related issues, such as control of disease activity or adjustment of medication (28% vs 7%, p<0.001), while Dutch respondents tended to give more advice on physical exercise and planned rests (41% vs 28%, p=0.04). Participants believed that other advice might help, but they did not offer this to patients. UK rheumatology nurses tended to believe more than Dutch rheumatology nurses that relaxation might help (13% vs 5%, p=0.03), along with education (17% vs 6%, p=0.01) and psychosocial support (21% vs 9%, p=0.01) (Table 6).

Table 5. Current management for rheumatoid arthritis (RA) -related fatigue

Questions	Overall* % (N=232)	UK nurses* % (N=103)	Dutch nurses* % (N=129)	P
13. Do you pay attention to fatigue in your current care for RA patients?	85	83	88	0.52
14. Is fatigue a topic of conversation in your first consultation with an RA patient?	80	76	84	0.77
15. Is fatigue a topic of conversation in the following consultations with RA patients?	72	65	78	0.03
17. If you ask a patient about fatigue, how often do they say it's not a problem?	13	14	12	0.32
18. Do other members of the team refer patients to you specifically to help with fatigue?	4	1	7	<0.001
19. Do you measure/assess fatigue?	13	12	15	0.50
21. Do you think patients follow your advices?	62	64	61	0.01
23. Do you document fatigue and the specific advice you gave the RA patient in the patient's record?	82	70	91	<0.001
25. Do you ever refer your patients on for treatment of their fatigue?	31	30	31	0.86
51. Communication about fatigue between the health care provider and the RA patient is generally excellent/good	36	37	35	0.22
52. 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)	24	25	22	0.58

*Values are percentages for question 13-18 for answers of "always" and "most of the time", for question
19 – 25 for answers of "yes". P values are based on Pearson chi-square.

Table 6. Current practice to rheumatoid arthritis (RA) -related fatigue, open-ended questions

	UK nurses % (N=103)	Dutch nurses % (N=129)	P
20 a. What advices do you give your patients about fatigue?			
Pacing/balance between activities and rest	86	84	0.57
Disease-related advices	28	7	<0.001
Pain management	8	5	0.32
Explanation about fatigue	11	8	0.44
To be more active	25	45	0.002
To take moments of rest	28	41	0.04
Other advices such as:			
Diet	15	12	
Delegate jobs to others	7	9	
Listen to their body	7	9	
Sleep advices	23	8	
Goal setting (not to overload and set priorities)	13	12	
Lifestyle advices	3	13	
Refer to occupational therapist/ physiotherapist/social work	6	4	
20 b. What else do you think might help, even if you don't offer it?			
Meet others	7	5	0.48
Relaxation	13	5	0.03
Education about fatigue and RA	17	6	0.01
Psych/counselling	21	9	0.01
Other advices such as exercise, diet, sleep advices, aromatherapy, recognition, to refer to other disciplines, acceptation and good treatment of RA	39	43	-

P values are based on Pearson chi-square.

Communication

A quarter of all respondents did not answer the question about whether patients follow the advice they are given, and added in the explanation box: "sometimes", "I do not know" or "depending on the personal experience of patients". UK nurses tended to think that it was more often the patient who started talking about fatigue.

Fatigue and the specific advice given by rheumatology nurses were documented in the patient's record by most of the nurses, although statistically significantly more by Dutch rheumatology nurses.

Seventy percent of all respondents thought that communication about fatigue was poor and only 25% believed that healthcare providers placed as much emphasis on the treatment of fatigue as they did on pain or stiffness (table 5).

DISCUSSION

Study limitations

The limitations of our study are the relatively low response rate, although this is normal for postal questionnaires.[31] The relatively small response from the UK makes it necessary to take the positive results of this group with a little more caution, and results may not be able to be generalized to the larger UK rheumatology nurse population. It is possible that non-responders may have poorer knowledge about and attitudes towards RA fatigue, and do not include fatigue in their current practice, which may have biased the positive results of this study. Without objective information on the non-responders these remain speculations.

A second limitation of our study was the adaptation and translation of a previous US questionnaire on cancer. 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 causes and management of fatigue vary widely between and within patients. The reliability and validity of the questionnaire should be tested in future research.

A third limitation of our study was that it was not possible to explore the differences in knowledge and management of RA-related fatigue by comparing rheumatology specialist and non-specialist nurses. Finally, all results were based on self-reported data and therefore do not necessarily represent participants' actual practice.

Discussion of results

Rheumatology nurses in both countries are aware of the high incidence of RA-related fatigue. Their views on causes reflect published studies and they report positive attitudes toward assessing and managing fatigue, although they would like more information on how to help patients handle their fatigue. Despite awareness of their own lack of knowledge and the belief that other team members can help, respondents did not refer patients on to other professionals to help them with fatigue. Despite acknowledgement of poor communication about fatigue, and the awareness that if a patient is asked about fatigue they seldom deny the symptom, participants reported that it is the patient rather than the nurse who raises the issue of fatigue during the consultation. However, in qualitative studies[3,27], patients indicated that they seldom discuss fatigue with healthcare professionals, assuming that they have to manage it alone because it is part of the disease. In daily practice rheumatology nurses should be aware that, despite their own assumption that family members do not believe patients' complaints about fatigue, patients feel supported by family and friends[27,28].

Rheumatology nurses' reported advice was in line with patient self-management strategies as reported in qualitative studies, and mainly concerned pacing and finding a balance between rest and activities[3,27]. More than half of the rheumatology nurses thought that this advice would be followed by patients, which somewhat contradicts the published evidence that patients manage fatigue by 'trial and error'[27]. However, many UK and Dutch respondents also admitted that they lacked knowledge about adherence to advice.

No great differences were found between the two countries. However, in the UK, rheumatology nurses cared for a much larger group of patients each month compared to Dutch rheumatology nurses, which may influence the time available to spend in consultation. The desire for more written information about fatigue for people with RA in the UK may be related to this time constraint. Moreover, UK respondents did not consider that fatigue was a nursing diagnosis, while almost half of their Dutch colleagues assumed the opposite. It remains unclear what causes this difference: one suggestion is that it might be related to UK nurses having less time to spend with their patients or not being familiar with the term nursing diagnosis.

Another difference was that UK nurses less frequently documented fatigue in the patient records. Without data comparing actual documentation rates, we can only speculate whether time constraints might be a reason. Compared to Dutch rheumatology nurses, those in the UK reported that they focussed more on disease -related advice for managing fatigue. This difference might be related to education on fatigue, but further research is needed to explore this issue.

Despite the increasing number of studies of RA-related fatigue, there are no similar studies with which to compare the strengths and weaknesses of this study. One strength is the access to the majority of rheumatology nurses in the UK and in the Netherlands through professional societies. Moreover, this study gives insight into current practice and can be used to develop educational programs on fatigue for rheumatology nurses, once data on effective interventions are available. A second strength is the exploration of all aspects related to fatigue practice: knowledge, attitudes and management. It seems obvious that attitudes and practice will be related, as attitudes will affect practice, e.g. if nurses believe that fatigue is a nursing diagnosis and should be treated by nurses, then they will not refer patients to other professionals for fatigue management. In addition, knowledge and attitudes are also related, e.g. do rheumatology nurses really know whether patients discuss fatigue with their rheumatologist or do they just assume that patients do not talk to their rheumatologists about it?

We found a similar commitment to assessing fatigue and a desire for information on management strategies in rheumatology nurses caring for patients with RA fatigue as has been shown with cancer fatigue[29]. A similar discrepancy about communication was also found, whereby professionals believe that patients usually mention fatigue, but the literature reports that patients do not talk about fatigue with their healthcare professionals[30]. The reasons for poor communication on fatigue by rheumatology nurses are unknown. However, it could be that nurses do not have the skills to do this or that they feel uncomfortable discussing fatigue when there is a lack of evidence-based interventions.

These so very closely related aspects of knowledge, attitudes and current care for fatigue need to be communicated between healthcare professionals, and also between patients and healthcare professionals, in order to provide tailored care for people with RA with fatigue. According to Welsing et al.[32] the course of disease activity has become milder in recent years, but it has been shown that even in an RA population where disease is well-controlled, 40% of the patients have severe fatigue[18]. Therefore, fatigue is likely to remain a prominent symptom of RA in the future and should be measured in future studies whenever possible[33].

To improve patient outcome in RA-related fatigue, strategies to increase communication and to develop management strategies should be initiated. Options for symptom management could focus on supporting patients in talking about fatigue with their healthcare professionals. Moreover, energy conservation techniques, CBT and low-impact aerobic exercise[25] may benefit some patients.

CONCLUSION

Our data show that rheumatology nurses’ need for further communication and management skills are the first step to enable us to develop interventions to prevent and treat RA-related fatigue.

Our study raises some questions that could be examined in future studies. First, can education rheumatology nurses influence knowledge and management of RA-related fatigue? Second, what are the knowledge, attitudes and current management of fatigue by rheumatologists, and how do they compare with these data from rheumatology nurses?. Third, research is needed to address the discrepancy in beliefs about communication on fatigue to establish whether or not patients, rheumatology nurses, rheumatologists or neither raise the issue of fatigue during consultations. Fourth, the reliability of the questionnaire developed in this study should be tested.

References

1. Belza BL. Comparison of self-reported fatigue in rheumatoid arthritis and controls. J Rheumatol 1995;22(4): 639-643.
2. Hewlett S, Carr M, Ryan S, Kirwan J, Richards P, Carr A, Hughes R. Outcomes generated by patients with rheumatoid arthritis: how important are they? Musculoskeletal Care 2005;3(3): 131-142.
3. Hewlett S, Cockshott Z, Byron M, Kitchen K, Tipler S, Pope D, Hehir M. Patients' perceptions of fatigue in rheumatoid arthritis: overwhelming, uncontrollable, ignored. Arthritis Rheum 2005;53(5): 697-702.
4. Minnock P, Bresnihan B. Pain outcome and fatigue levels reported by women with established rheumatoid arthritis. Arthritis Rheum 2004;Suppl:S471. [Abstract]
5. Wolfe F, Hawley DJ, Wilson K. The prevalence and meaning of fatigue in rheumatic disease. J Rheumatol 1996;23(8): 1407-1417.
6. Ream E, Richardson A. Fatigue: a concept analysis. Int J Nurs Studies 1996;33(5): 519-529.
7. Trendall, J. Concept analysis: chronic fatigue. J Adv Nurs 2000;32(5): 1126-1131.
8. Belza BL, Henke CJ, Yelin EH, Epstein WV, Gilliss CL. Correlates of fatigue in older adults with rheumatoid arthritis. Nursing Research 1993;42(2): 93-99.
9. Breedveld FC, Han C, Bala M, van der Heijde D, Baker D, Kavanaugh AF, Maini RN, Lipsky PE. Association between baseline radiographic damage and improvement in physical function after treatment of patients with rheumatoid arthritis. Ann Rheum Dis 2005;64(1): 52-55.
10. Crosby LJ. Factors which contribute to fatigue associated with rheumatoid arthritis. J Adv Nurs 1991; 16(8): 974-981.
11. Heiberg T, Finset A, Uhlig T, Kvien TK. Seven year changes in health status and priorities for improvement of health in patients with rheumatoid arthritis. Ann Rheum Dis 2005;64(2): 191-195.
12. Huyser BA, Parker JC, Thoreson R, Smarr KL, Johnson JC, Hoffman R. Predictors of subjective fatigue among individuals with rheumatoid arthritis. Arthritis Rheum 1998;41(12): 2230-2237.
13. Moss-Morris R, Chalder T. Illness perceptions and levels of disability in patients with chronic fatigue syndrome and rheumatoid arthritis. Journal of Psychosomatic Research 2003;55(4): 305-308.
14. Pollard LC, Choy EH, Gonzalez J, Khoshaba B, Scott DL. Fatigue in rheumatoid arthritis reflects pain, not disease activity. Rheumatology (Oxford) 2006; 45(7), 885-889.

15. Riemsma RP, Rasker JJ, Taal E, Griep EN, Wouters JM, Wiegman O. Fatigue in rheumatoid arthritis: the role of self-efficacy and problematic social support. Rheumatology 1998;37(10): 1042.
16. Suurmeijer TP, Waltz M, Moum T, Guillemin F, van Sonderen FL, Briancon S, Sanderman R, van den Heuvel WJ. Quality of life profiles in the first years of rheumatoid arthritis: results from the EURIDISS longitudinal study. Arthritis Rheum 2001;45(2): 111-121.
17. Wolfe F. Psychological distress and rheumatic disease. Scand J Rheumatol 1999;28(3): 131-136.
18. Repping-Wuts JWJ, Fransen J, van Achterberg T, Bleijenberg G, van Riel PL. Persistent severe fatigue in patients with Rheumatoid Arthritis. Journal of Nursing and Healthcare of Chronic Illness in association with Journal of Clinical Nursing 2007;16(11c): 377-383.
19. Stone AA, Broderick JE, Porter LS, Kaell AT. The experience of rheumatoid arthritis pain and fatigue: examining momentary reports and correlates over one week. Arthritis Care Res 1997;10(3):185-193.
20. Wolfe F, Michaud K. Fatigue, rheumatoid arthritis, and anti-tumor necrosis factor therapy: an investigation in 24,831 patients. J Rheumatol 2004;31(11): 2115-2120.
21. Mancuso CA, Rincon M, Sayles W, Paget SA. Psychosocial variables and fatigue: a longitudinal study comparing individuals with rheumatoid arthritis and healthy controls. J Rheumatol 2006;33(8): 1496-1502.
22. Evers AW, Kraaimaat FW, van Riel PL, de Jong AJ. Tailored cognitive-behavioral therapy in early rheumatoid arthritis for patients at risk: a randomized controlled trial. Pain 2002;100(1-2):141-153.
23. Lee EO, Kim JI, Davis AH, Kim I. Effects of regular exercise on pain, fatigue, and disability in patients with rheumatoid arthritis. Family Community Health 2006;29(4): 320-327.
24. Moreland LW, Genovese MC, Sato R, Singh A. Effect of etanercept on fatigue in patients with recent or established rheumatoid arthritis. Arthritis Rheum 2006;55(2): 287-293.
25. Neil J, Belan I, Ried K. Effectiveness of non-pharmalogical interventions for fatigue in adults with multiple sclerosis, rheumatoid arthritis, or systemic lupus erythematosus: a systematic review. J Adv Nurs 2006;56(6): 617-635.
26. Carr A, Hewlett S, Hughes R, Mitchell H, Ryan S, Carr M, Kirwan J. Rheumatology outcomes: the patient's perspective. J Rheumatol 2003;30(4): 880-883.
27. Repping-Wuts JWJ, Uitterhoeve R, van Riel P, van Achterberg T. Fatigue as experienced by patients with Rheumatoid Arthritis. Int J Nurs Studies 2008;45(7): 995-1002.
28. Tack BB. Fatigue in rheumatoid arthritis. Conditions, strategies, and consequences. Arthritis Care Res 1990;3(2): 65-70.

29. Miller M, Kearney N. Nurses' knowledge and attitudes towards cancer-related fatigue. Eur J Oncology Nursing 2001;5(4): 208-217.
30. Vogelzang NJ, Breitbart W, Cella D, Curt GA, Groopman JE, Horning SJ, Itri LM, Johnson DH, Scherr SL, Portenoy RK. Patient, caregiver, and oncologist perceptions of cancer-related fatigue: results of a tripart assessment survey. The Fatigue Coalition. Semininars in Hematology 1997; 34(3) Suppl 2: 4-12.
31. Swanborn PG. Methoden van sociaal-wetenschappelijk onderzoek. Meppel: Boom, 1994: 268.
32. Welsing PM, Fransen J, van Riel PL. Is the disease course of rheumatoid arthritis becoming milder? Time trends since 1985 in an inception cohort of early rheumatoid arthritis. Arthritis Rheum 2005;52(9): 2616-2624.
33. Kirwan JR, Minnock P, Adebajo A, Bresnihan B, Choy E, de Wit M, Hazes M, Richards P, Saag K, Suarez-Almazor, M, Wells G, Hewlett S. Patient perspective: fatigue as a recommended patient centered outcome measure in rheumatoid arthritis. J Rheumatol 2007;34(5), 1174-1177.
34. Neville C, Fortin PR, Fitzcharles MA, et al. The needs of patients with arthritis: the patient's perspective. Arthritis Care Res 1999;12(2): 85-95.
35. Repping JWJ, de Hullu MCM, Barrera P, et al. Priorities for a Rheumatology nursing research programme. Dutch Journal of Rheumatology 2003; 4, 19-23.
36. Pinals RS, Masi AT, Larsen RA. Preliminary criteria for clinical remission in rheumatoid arthritis. Arthritis Rheum 1981;24(10): 1308-1315.

F
A
T
I
G
U
E

FATIGUE COMMUNICATION AT THE OUT-PATIENT CLINIC OF RHEUMATOLOGY

Han Repping-Wuts
Theo Repping
Piet van Riel
Theo van Achterberg

7

Patient Education and Counseling, 2008; doi:10.1016/j.pec.2008.11.011

Abstract

Objective

To describe nurse-patient and rheumatologist-patient interaction in fatigue communication at the Rheumatology out-patient clinic.

Methods

Consultations of 20 rheumatoid arthritis (RA) patients with the nurse specialist and the rheumatologist were videotaped and analysed using the Medical Interview Aural Rating Scale (MIARS). Subsequently, patients were asked to fill out a concern questionnaire asking how worried they felt and how satisfied they were with attention given by both healthcare professionals. Finally, patients were interviewed on reasons for being not or not completely satisfied with the care received.

Results

Fatigue was discussed in 42% of the rheumatologists' consultations and 83% of the nurse specialists' consultations. RA patients more often used implicit cues instead of explicit concerns related to fatigue. Almost 72% of the patients felt worried about fatigue and in general they were more satisfied with the nurse specialist's attention to fatigue than with the attention from the rheumatologist.

Conclusion

Fatigue is not structurally communicated at the rheumatology out-patient clinic and exploring and acknowledging communication techniques can help patients to express their concerns about fatigue.

Practice implications

Healthcare professionals must recognise fatigue as a severe problem for RA patients and start the conversation on fatigue instead of waiting for the patient to mention fatigue spontaneously.

Introduction

This study focusses on fatigue as a common problem in patients with rheumatoid arthritis (RA) and the way fatigue is communicated during patients' regular follow-up contacts with the rheumatologist and the nurse specialist at the rheumatology out-patient clinic. Depending on the definition and measurement instruments, 40-85% of RA patients experience fatigue[1-4]. Rheumatoid arthritis is a systemic, inflammatory disease which predominantly affects the joints, leading to irreversible damage. Pain, morning stiffness, but also fatigue, are the most bothersome symptoms of the disease for the patients[5]. These symptoms affect well-being and functioning in daily life. Qualitative studies showed that patients seldom discuss fatigue with their health professionals, believing that it is part of the disease, that it is dismissed and that they have to handle it alone by "trial and error"[6,7]. Contradictory, results from a quantitative study on nurses' knowledge, attitude and current management of RA-related fatigue in the UK and the Netherlands showed that nurses reported that it is usually the patient who raises the issue of fatigue during a consultation. Furthermore, 85% of all nurses reported (yet unpublished study of Repping-Wuts et al.), that they themselves pay attention to fatigue, especially in the first consultation (80%) but also in the follow-up consultations (72%). A similar study was carried out among Dutch rheumatologists and they reported that they paid attention to fatigue in the first consultation (72%) and for a minor part (33%) in the follow-up[8].

Because fatigue is a subjective symptom, the only way to understand the patient's fatigue is by listening to the patient and by paying attention to his/her concerns. Although there has been an increase of awareness over the past years regarding fatigue in RA patients and the patients' experience of fatigue, the way RA patients and healthcare professionals communicate about fatigue remains unknown.

In searching the literature on patient communication, several articles were found on patient-centred communication or patient-centred consultations. The results of these studies show that patient-centred communication helps patients to express their concerns[9-11]. Furthermore, a study of Meeuwesen et al. showed that in general practice fatigue communication is related to gender, in a way that female general practitioners (GP) were more affective than their male colleagues, and they used gender-specific communication strategies to explore the patient's agenda[12].

For rheumatoid arthritis and communication, three studies were found: two recent studies of Sleath et al. (2008) on the communication about depression and about complementary and alternative medicine (CAM) between RA patients and rheumatologists and one study of Iversen et al. on communication about exercise and physical therapy[13-15]. Sleath et al. concluded that only 19% of the patients with moderate to severe symptoms of depression discussed depression during the consultation with the rheumatologist and patients started the discussion each time. In the study on communication about CAM it was concluded that if rheumatologists used more participatory styles of decision making with patients and involve them when making treatment decisions, patients were more likely to tell them about their CAM use. Although in 53% of the encounters rheumatologists and patients discussed exercise, Iversen et al. concluded that when rheumatologists initiated exercise discussion, there was nearly twice as much discussion.

No studies were found about the communication between healthcare professionals and RA patients with a special focus on fatigue. In several studies on concern communication between patients and healthcare professionals it is concluded that patients seldom express their concerns directly and explicitly to their healthcare professionals but instead communicate concerns implicitly as 'cues' that something is worrying them[16-18].

Although fatigue communication has been studied in primary care and in patients with cancer, to our knowledge no prior study has examined the extent to which healthcare professionals and RA patients discuss fatigue during out-patient encounters. Therefore, the purpose of this exploratory study was to examine whether RA patients and healthcare professionals communicate about fatigue, who initiates the discussion, whether patients use concerns or cues in their communication on fatigue, whether healthcare professionals use adequate or inadequate cue or concern responding behaviour and how satisfied RA patients were with attention received from both healthcare professionals.

Study aim

To describe nurse-patient and rheumatologist-patient interaction in fatigue communication during contacts at the rheumatology out-patient clinic.

Methods

Setting and sample

All nurse specialists (N=4) working at the out-patient Department of Rheumatology of a University Medical Centre in the Netherlands were invited to participate between December 2006 and March 2007. Their patients were asked to participate by phone by the researcher (HR). Subsequently, consulting rheumatologists were asked to participate. Patients were eligible if they were able to speak and read the

Dutch language and if they had no problems with videotaping of the consultations with both professionals.

This resulted in 6 male and 14 female RA patients (N=20) with a mean age of 61 years (range 24-82). The mean disease duration of the patients was 7 years (range 0-19: < 3 years (N=9), >3 and <10 years (N=3) and > 10 years (N=8)).

All nurse specialists (N=4) were female Registered Nurses (RN) with a mean age of 43 years and a mean experience in taking care for RA patients of, 8.5 years (range 3-15). All nurses had followed a special course in rheumatology.

Three male and three female rheumatologists (N=6) were involved in the consultations and three of them were trainees (two females and one male). The mean age of the rheumatologists was 49 years and the mean age of the trainees was 33 years.

Videotapes were made of all patients during their consultation with the rheumatologist and the nurse specialist. Videotaping started before the patient entered the room and stopped after the patient left the room.

Patients, nurse specialists and rheumatologists involved, were told that the study concerned communication at the out-patient clinic, without stressing the focus on fatigue. The aim was to recruit 5 patients per nurse specialist, resulting in 20 patients and 40 consultations (one nurse and one rheumatologist consultation with each patient on the same day).

Research design

An explorative, observational study was performed, using qualitative and quantitative data sampling by videotaping both the consultation of the patient with the rheumatologist and with the nurse specialist. Additional to the consultations of rheumatologist and nurse specialist, patients were asked to fill out a questionnaire with 21 RA-related concerns. Finally they were interviewed on the reasons for being not or not completely satisfied with the healthcare provider's attention to a specific concern.

Data collection

Instruments

A review of the literature revealed two advanced oncological observation instruments for research into patient-nurse communication suitable to the aim of this study. First, the Cancer Research Campaign Interview Rating Manual (CRCIRM)[19]. This instrument has been applied, reviewed and adapted in several oncology settings[20-22]. Second, the Medical Interview Aural Rating Scale (MIARS) was built on the

CRCIRM, and especially directed at providers' communication related to patient's disclosure of cues or concerns[23].

Patients fatigue communication

The aim of this study was to describe the communication on fatigue without special attention to emotions. In the MIARS, the basic unit of observation is each turn of speech, for both healthcare professional and patient. Patients' turns of speech can be coded as cues or concerns. As the definition for cues and concerns in the MIARS were emotionally focused, in this study the definition of a cue as formulated by Butow et al. was used[16].

A cue is a statement in a non-question asking form that is given by the patient to signal a need for information or emotional support.

And, for concern the definition of del Piccolo et al. was used[24].

A concerns is a verbal expression, which explicitly, indicates an issue of importance for the patient.

The MIARS was employed for this study while viewing concerns as clear explicit sentences on fatigue, such as 'I am tired' or 'I don't have energy' and cues as vague implicit descriptions, such as 'I was not motivated to do anything' or 'in the morning I cannot get out of my bed'.

The MIARS distinguishes three levels of patients' cues, depending on the extent to which feelings are disclosed. For this study these three levels of disclosure were not used, as the focus was not on the level of emotion but on the frequency of sending a cue on fatigue by the RA patient.

Healthcare professional responses

Each response by the health professional to a patient's cue or concern can be coded according to its function. Function includes whether a cue or concern is explored (by asking questions, summarising, clarifying or repeating), acknowledged (by an empathetic statement) or distanced from (switching the focus or inappropriate reassurance). Exploring and acknowledging are rated as adequate behaviour (disclosure of cues and concerns) and distancing is rated as inadequate behaviour.

Videotapes were made of all patients during their consultation with the rheumatologist and the nurse specialist.

The 21 RA-related concerns questionnaire was based on the questionnaire developed by Neville et al. and further validated by experts in the field of rheumatology and nursing[25]. Each concern was scored on a five-point Likert scale on how worried they felt in the week before visiting the out-patient clinic (range not worried to almost always worried) and how satisfied they were with attention received from both healthcare professionals separately (range dissatisfied to very satisfied).

The ethics committee approved the study.

Analysis

Each of the videotapes was subjected to analysis using the software program The Observer XT 7.0[26]. The Observer is a professional manual event recorder for the collection, management, analysis and presentation of data. This program allows marking for later editing and notes can be written during the coding session. For the videotapes the MIARS classes were incorporated into The Observer to facilitate the coding without transcribing the total consultations. The validity of this program in combination with the MIARS has been demonstrated[27].

Two researchers (HR and TR) independently coded six of the videotapes, three consultations with the rheumatologists and three with the nurse specialists. These videotapes were randomly selected to avoid interdependency. Each coder reviewed the videotapes more than once; patient and healthcare behaviours were coded in separate 'runs'. The codes were compared and differences between the coders were discussed and consensus was achieved for the verbal communication. For the non-verbal communication both researchers differed in their codes, probably due to a different background and education of both researchers. Based on the uncertainty to confirm the true relationship between the non-verbal communication and fatigue, it was decided to exclude the non-verbal communication on fatigue in the coding system. Subsequently, one researcher coded the remainder of the videotapes (HR). SPSS, version 14.0 was used to analyse the questionnaires.

Results

Study sample

Twenty-four patients were asked to participate while 4 patients refused for different reasons (depending on others for transport to the hospital, time of the day and not willing to be videotaped). 95% of the consultations were follow-up consultations. Three videotaped consultations were inaudible because of equipment failure and therefore excluded from the analysis, resulting in 37 consultations (19 consultations with the rheumatologist and 18 consultations with the nurse specialist respectively) with a total duration of 879 min.

Finally, 5 patients were not able to complete the interview, two due to being too tired and three because additional medical examinations were required. Two patients filled out the questionnaire at home and sent it back by post, resulting in 17 questionnaires and 15 interviews.

Patients' fatigue communication

For all patients together, fatigue was part of the communication between RA patients and healthcare professionals for 52 out of 879 consultation minutes (6%).

In 62% of the consultations (N=23) fatigue was discussed (8 consultations with the rheumatologists (42%) and 15 (83%) with the nurse specialist), meaning that either patients or healthcare professionals did express concerns or cues on fatigue.

Table 1. Patient and healthcare professional elements of the Medical Interview Aural Rating Scale (MIARS) in consultation with RA patients in which fatigue was discussed

	Nurse specialists	N=15	Rheumatologists	N=8
	N	N (%)	N	N (%)
Fatigue mentioned by the healthcare professional	13		1	
Concerns mentioned by the patient	17		6	
Responding on concern by healthcare professional*				
Exploring		9 (53)		1 (17)
Acknowledging		7 (41)		0 (--)
Distancing		3 (18)		5 (83)
Cues mentioned by the patient	29		8	
Responding on cues by healthcare professional*				
Exploring		11 (38)		4 (50)
Acknowledging		9 (31)		2 (25)
Distancing		9 (31)		2 (25)

* Healthcare professionals could use more than one type of responding behaviour to an expressed concern or cue by the patient.

In the 15 consultations with the nurse specialist fatigue was a subject in the communication 59 times: 17 times as a concern and 29 times as a cue as expressed by the patient. The nurse specialists started the conversation on fatigue 13 times. In the 8 consultations with the rheumatologists fatigue was a subject in the conversation 15 times, of which the patients expressed a concern 6 times and a cue 8 times. One rheumatologist started the conversation on fatigue in the communication (Table 1). So, on average fatigue was a subject in the consultation with the nurse specialist three times and in the consultations with the rheumatologists it was zero to one time.

Health professionals' interaction

Adequate responding to concerns was found in 16/19 of the occasions in the communication with the nurse specialists in using exploring and acknowledging behaviour by asking questions or being empathetic. Rheumatologists used adequate responding to 1/6 of the concerns (Table 1). Distancing functions, in switching the focus to pain or the disease, were used in most of the rheumatologists' communication in reaction to concerns expressed by patients. When using exploring and acknowledging behaviour, the communication on fatigue was twice as long.

The extracts shown in Fig. 1 illustrate adequate and inadequate responses of healthcare professionals to patients' cues or concerns.

Inadequate responses to cues or concerns of patients		**MIARS coding**
Patient	I am so tired, I am really worn out	Concern
Doctor	But does it also hurt in your legs?	Distancing
Patient	I am tired and cold	Concern
Doctor	… and is your pain less?	Distancing
Patient	… some days I cannot get off the couch	Cue
Nurse	But you have to move	Distancing

Adequate responses to cues or concerns of patients:		**MIARS coding**
Patient	I am also so tired	Concern
Nurse	Yes, I understand, but are you tired the whole day?	Acknowledging and exploring
Patient	I have to sit down	Cue
Nurse	You cannot finish the things you have to do?	Exploring
Patient	The battery is empty	Cue
Doctor	So, the battery is empty	Exploring
Patient	It didn't feel good at that time	Cue
Doctor	When did it start feeling less good? Is the battery empty?	Exploring

Figure 1. Healthcare professionals responses to patients' cues or concerns, coded with the Medical Interview Aural Rating Scale (MIARS)

Concern questionnaire and communication

In analysing the concern questionnaires (N=17), 71% of the patients (N=12) reported being worried about fatigue, ranging from a bit worried to almost always worried. The question was formulated as follows: "How worried did you feel in relation to fatigue during the last two weeks?" Patients were invited to rate this on a scale from 'not worried' to 'almost always worried'. Fatigue, as one of the 21 concerns on the questionnaire, thereby scored third place, after limited freedom of movement (83%) and pain (78%). In the consultations with the patients who were almost always worried about fatigue (N=2), fatigue was communicated with the nurse specialist as well as with the rheumatologist. In the consultation with patients who filled out on the questionnaire that they often worried about fatigue (N=3), fatigue was only communicated in the consultation with the nurse specialist. In the other consultations in which patients felt worried or a bit worried about fatigue (N=7), fatigue was communicated in 6 of the nurses' consultations and in 5 consultations with the rheumatologist.

Satisfaction with received attention

All patients who worried about fatigue (N=12) were satisfied with attention received for fatigue from the rheumatologist and the nurse specialist, ranging from somewhat satisfied to very strongly satisfied. In general they were more satisfied with the attention received from the nurse specialist (87%) than the attention from the rheumatologist (73%) and used terms like having more time, being a better listener and giving more suitable advice as most important reasons for this difference. In addition they declared in the interview that talking about fatigue with the nurse specialist was more 'normal' for them than talking about fatigue with the rheumatologist and most stated this as a normal reaction because of the expected differences between the 2 consultations.

Discussion and conclusion

Discussion

The aim of this study was to describe nurse-patient and rheumatologist-patient interaction in the fatigue communication at the rheumatology out-patient clinic. In 62% of the consultations with the healthcare professionals fatigue was discussed, although most of the time initiated by the patient. This is somewhat contradictory to the results of studies by Hewlett et al. and Repping-Wuts et al.[6,7] in which patients reported that they seldom discuss their fatigue with the healthcare professionals, assuming that it is dismissed and that they have to handle fatigue by trial and error. However, patients used implicit cues more than explicit concerns in their communication on fatigue.

Furthermore, the results of this study confirm the results of another study of Repping-Wuts et al. in which rheumatologists reported that they pay attention to fatigue most of the time in the first consultation with the patient and less often in the follow-up contacts with the patient[8]. As all videotapes were made of follow-up consultations, it is unknown if fatigue was or will be discussed in previous or future consultations with the patient. This makes it impossible to draw a conclusion about the total care process but only about a single contact between patient and healthcare professional.

The present study confirms the results of a study on the knowledge, attitude and management of fatigue by rheumatology nurses in which nurses reported that most of the time they do pay attention to fatigue during their consultations with the patient. The beliefs of patients that nurses have more time during their consultation and patients' expectations that nurses' consultations differ from rheumatologists' consultations are in line with these findings.

In responding to patients' concerns about fatigue, compared to the nurse specialist, rheumatologists more often use a distancing function and switch the conversation to pain. However, it remains unclear whether rheumatologists believe that pain and fatigue in RA patients are closely related or whether rheumatologists switch the focus onto pain because they do not know how to respond to an expressed concern about fatigue. Moreover, more than half of the patients had a disease duration of more than 3 years, so fatigue may have been discussed in previous consultations.

In our study it was concluded that fatigue was only communicated in 6% of the total consultation time and that patients initiated the communication on fatigue in the consultations most of the time. For patients who were almost always worried about fatigue, fatigue was discussed in the consultation with both healthcare professionals. This is somewhat contradictory to the results of the study of Sleath et al. in which it was found that only 19% of the patients with moderate to severe symptoms of depression discussed depression during the consultation with the rheumatologist. And, when depression was discussed, the patient initiated the discussion every time.

In a study of Iversen et al. it was found that when rheumatologists initiated exercise discussion, there was nearly twice as much discussion. We have no data to compare these results in this study because fatigue communication was only initiated by the rheumatologists once. This is worrisome, as initiating the communication on fatigue by healthcare professionals may lead to more discussion on fatigue.

According to the literature, patients more often use cues to express their worries instead of communicating their concerns[18]. Our study shows the same results. RA patients more often send an implicit cue instead of mentioning fatigue as a real concern.

The study has some limitations. First, the study was performed in one centre, which may limit the external validity of the study findings. Second, fatigue is a subjective symptom and coding fatigue as a cue may be subjective too. So, on the one hand it is possible that we have missed some cues and on the other hand it is possible that we interpreted some cues incorrectly as related to fatigue. Third, the cross-sectional design gives no information on the contents of previous consultations. Fourth, the small sample of healthcare professionals does not make it possible to analyse data on the relation between communication and gender and results cannot be compared to the study of Meeuwesen et al.[12].

This is the first videotaped study of healthcare professional-patient communication about fatigue in RA. It examines the contribution of both patient and healthcare professional in the communication about fatigue, a symptom of concerns, ranked by patients on the third place. Clarifying the need for further research on patient and healthcare professionals' barriers to communicate about fatigue in rheumatology practices.

Conclusion

Although fatigue is a common and severe symptom for RA patients, only 6% of the encounter time is spent on communication on fatigue between RA patients and healthcare professionals. Moreover, communication on fatigue is more often initiated by the patient than by the healthcare professional and more often as an implicit cue instead of an explicit concern. And, information about fatigue is more presented to rheumatology nurses than to rheumatologists. In general, rheumatology nurses use adequate responding behaviour to expressed cues or concerns of RA patients. Fatigue was communicated in 8 out of 19 consultations with the rheumatologists only, which makes it impossible to draw conclusions about adequate responding behaviour by rheumatologists.

Practice implications

Healthcare professionals must recognise fatigue as a severe problem for RA patients and start the conversation on fatigue in the consultations instead of waiting for the patient to mention fatigue spontaneously. The use of a clinical assessment instrument could help to start the conversation on fatigue.

References

1. Wolfe F, Hawley DJ, Wilson K. The prevalence and meaning of fatigue in rheumatic disease. J Rheumatol 1996; 23: 1407-1417.
2. Belza BL, Henke CJ, Yelin EH, Epstein WV, Gilliss CL. Correlates of fatigue in older adults with rheumatoid arthritis. Nurs Res 1993; 42: 93-99.
3. Belza BL. Comparison of self-reported fatigue in rheumatoid arthritis and controls. J Rheumatol 1995; 22: 639-43.
4. Repping JWJ, de Hullu MCM, Barrera P, van Rossum A, Bakker R, Koopman A, Deenen J, Alberts-Pijnenbrog J. Priorities nursing research in Rheumatology. Dutch Journal of Rheumatology 2003; 4: 19-23.
5. Kirwan JR, Minnock P, Adebajo A, Bresnihan B, Choy E, de Wit M, Hazes M, Richards P, Saag K, Suarez-Almazor M, Wells G, Hewlett S. Patient perspective: fatigue as a recommended patient centered outcome measure in rheumatoid arthritis. J Rheumatol 2007; 34: 1174-77.
6. Hewlett S, Cockshott Z, Byron M, Kitchen K, Tipler S, Pope D, Hehir M. Patients' perceptions of fatigue in rheumatoid arthritis: overwhelming, uncontrollable, ignored. Arthritis Rheum 2005; 53: 697-702.
7. Repping-Wuts JWJ, Uitterhoeve R, van Riel P, van Achterberg T. Fatigue as experienced by patients with Rheumatoid Arthritis (RA): A qualitative study. Int J Nurs Studies 2008; 45: 995-1002.
8. Repping-Wuts H, van Riel P, van Achterberg T. Rheumatologists' knowledge, attitude and current management of fatigue in patients with Rheumatoid Arthritis (RA). Clinical Rheumatology 2008; 27:1549-1555.
9. Zandbelt LC, Smets EM, Oort FJ, Godfried MH, de Haes HC: Patient participation in the medical specialist encounter: does physicians' patient-centred communication matter? Patient Educ Couns 2007; 65: 396-406.
10. Mead N, Bower P. Patient-centred consultations and outcomes in primary care: a review of the literature. Patient Educ Couns 2002; 48: 51-61.
11. Mead N, Bower P. Patient-centredness: a conceptual framework and review of the empirical literature. Soc Sci Med 2000; 51: 1087-1110.
12. Meeuwesen l, Bensing J, van den Brink-Muinen. Communicating fatigue in general practice and the role of gender. Patient Educ Couns 2002;48:233-242
13. Iversen MD, Fossel AH, Daltroy LH. Rheumatologist-patient communication about exercise and physical therapy in the management of rheumatoid arthritis. Arthritis Care Res 1999; 12: 180-92.

14. Sleath B, Chewning B, de Vellis BM, Weinberger M, de Vellis RF, Tudor G, Beard A. Communication about depression during rheumatoid arthritis patient visits. Arthritis Rheum 2008; 59: 186-91.
15. Sleath B, Callahan LF, de Vellis RF, Beard A. Arthritis patients' perceptions of rheumatologists' participatory decision-making style and communication about complementary and alternative medicine. Arthritis Rheum 2008; 59: 416-21.
16. Butow PN, Brown RF, Cogar S, Tattersall MH, Dunn SM. Oncologists' reactions to cancer patients' verbal cues. Psychooncology 2002, 11: 47-58.
17. Heaven C, Clegg J, Maguire P: Transfer of communication skills training from workshop to workplace: the impact of clinical supervision. Patient Educ Couns 2006; 60: 313-25.
18. Maguire P, Faulkner A, Booth K, Elliott C, Hillier V. Helping cancer patients disclose their concerns. Eur J Cancer 1996; 32A: 78-81.
19. Cancer Research Campaign Psychological Medicine Group CRC Interview Rating Manual. 1994. Stanley House, Christie Hospital, Manchester: CRC Psychological Medicine group.
20. Booth K, Maguire PM, Butterworth T, Hillier VF. Perceived professional support and the use of blocking behaviours by hospice nurses. J Adv Nurs 1996; 24: 522-27.
21. Maguire P, Faulkner A, Booth K, Elliott C, Hillier V. Helping cancer patients disclose their concerns. Eur J Cancer 1996; 32A: 78-81.
22. Heaven CM, Maguire P. Training hospice nurses to elicit patient concerns. J Adv Nurs 1996; 23: 280-86.
23. Heaven CM, Green C. Medical Interview Aural Rating Scale. Psychological Medicine Group, Christie Hospital, Stanley House, Manchester 2001.
24. Piccolo LD, Goss C, Zimmermann C. The Third Meeting of the Verona Network on Sequence Analysis. Finding common grounds in defining patient cues and concerns and the appropriateness of provider responses. Patient Educ Couns 2005; 57: 241-44.
25. Neville C, Fortin PR, Fitzcharles MA, Baron M, Abrahamowitz M, Du Berger R, Esdaile JM. The needs of patients with arthritis : the patient's perspective. Arthritis Care Res 1999;12:85-95.
26. Noldus LP, Trienes RJ, Hendriksen AH, Jansen H, Jansen RG. The Observer Video-Pro: new software for the collection, management, and presentation of time-structured data from videotapes and digital media files. Behav Res Methods Instrum Comput 2000; 32: 197-206.
27. Fletcher I, Heaven C, Maguire P & Dunn G: A comparison of traditional vs. computerised methods of rating communication skills. Elsevier, International Conference on Communication in Healthcare 14-17 September 2004, Bruges, Belgium.

FATIGUE

8

FATIGUE IN PATIENTS WITH RHEUMATOID ARTHRITIS: WHAT IS KNOWN AND WHAT IS NEEDED

Han Repping-Wuts
Piet van Riel
Theo van Achterberg

Rheumatology (Oxford) 2008; doi:10.1093/rheumatology/ken 399

Concept and definition

Fatigue is, just like pain, a subjective symptom which may occur in patients with many different diseases and thereby also in patients with Rheumatoid Arthritis. In the literature a consensus definition for fatigue is not presented. However, most authors define fatigue as: *"an overwhelming, sustained sense of exhaustion and decreased capacity for physical and mental work"*[1]. For chronic fatigue, Piper's definition is widely used in international studies and is as follows: *'chronic fatigue is perceived as unpleasant, unusual, abnormal or excessive whole-body tiredness, disproportionate to or unrelated to activity or exertion and present for more than one month. Chronic fatigue is constant or recurrent, it is not dispelled easily by sleep or rest and it can have a profound negative impact on the person's quality of life'*[2]. To distinguish between chronic fatigue and the chronic fatigue syndrome (CFS), the Centre for Disease Control and Prevention (CDC) has formulated special criteria for CFS[3].

In published studies, fatigue is mostly described as a multicausal, multidimensional and complex concept in which psychological, biochemical and physiological mechanisms play a role. As with pain, the definition is not the most important issue in clinical practice but the way fatigue can and should be assessed is, because quantifying fatigue enables us to study fatigue.

Assessment instruments

Researchers have made great efforts to develop assessment instruments to diagnose or evaluate fatigue severity, however, at this moment no gold standard is available. A systematic review of scales which are being used to assess RA fatigue revealed only six scales with evidence of reasonable validation: the Multidimensional Assessment of Fatigue scale (MAF), the Short Form 36 vitality subscale (SF36-vitality), the Functional Assessment of Chronic Illness Therapy fatigue scale (FACIT-F), the Profile of Mood States (POMS), the Visual Analogue Scales (VAS) and ordinal scales ("no" to "very severe" fatigue)[4]. However, the researchers concluded that further validation of scales for RA fatigue is needed.

As fatigue is a multidimensional concept, the use of a multidimensional scale offers the possibility to measure the full spectrum of the fatigue complaint and will help to identify different outcomes for fatigue interventions. Such a multidimensional instrument, which is already being used to measure RA fatigue, is the Checklist

Individual Strength (CIS), with four dimensions of fatigue, namely: fatigue severity, motivation, concentration and activity. Furthermore, based on research of patients with Chronic Fatigue Syndrome (CFS), cancer survivors and healthy controls, cut-off scores for the CIS-fatigue are available, offering the possibility to distinguish between normal, moderate and severe fatigue (severe fatigue is CIS-fatigue >=35)[5,6]. The CIS has been used in a single study on RA fatigue (5), but was previously used in patients with many different diseases and showed good reliability, discriminative validity, and sensitivity to change[7-11].

To compare results from different studies on RA fatigue the use of a valid scale to measure fatigue is necessary. Researchers in the Netherlands are currently validating the CIS for RA and hopefully validation in other countries will follow. Besides, researchers in the UK are developing and validating a VAS scale for RA fatigue which , after further validation, could help to assess fatigue in daily practice.

Finally, although fatigue is a common symptom in RA, it is not yet, just like pain, a recommended core outcome for clinical trials[12,13]. The "core set" of outcome measures for Rheumatoid Arthritis clinical trials has been developed at OMERACT 1 in 1992 (Outcome Measures for Arthritis Clinical Trials)[14]. And, only at the workshop of OMERACT 8 in 2006 it was concluded that fatigue is a symptom that is important to RA patients and should be measured in all RA clinical trials whenever possible. The research agenda for fatigue that emerged from OMERACT 8 focuses on the validity of the assessment instrument for RA fatigue, the relationship between fatigue and other outcomes and the consequences of fatigue[15]. This will help to develop and test interventions.

Prevalence, course, severity and predictors of fatigue

Due to differences in definition and instruments to measure RA fatigue, prevalence rates between 42-80% have been found[16-19]. Measured with the Checklist Individual Strength (CIS), 40% of RA patients experience persistent severe fatigue, a level of fatigue that is comparable with fatigue as experienced by patients with Chronic Fatigue Syndrome (CFS)[5].

In studies on correlates and predictors of fatigue contradictory results were found. The first question is, is fatigue related to disease activity. In some studies, the evidence for the relation between disease related variables and fatigue is found. In other studies, higher levels of fatigue were associated with increased depressive symptoms, pain, disturbed sleep, increased physical effort, gender or psychosocial factors[5,20]. Although, these variables are not directly disease related, the question remains unanswered about the indirect relation between these items, e.g. disturbed sleep may be related to disease activity and as a consequence also related to fatigue. A combination of variables might be the underlying mechanism for RA fatigue. However, no prospective study has included all these variables. In spite of the sometimes inconsistent findings, consensus on the large impact fatigue has on quality of life in RA patients exists[21,22].

The patient's experience

For patients with Rheumatoid Arthritis (RA) fatigue is, besides pain, the most bothersome symptom to handle[23,24]. RA patients described fatigue as unpredictable, overwhelming and different from normal tiredness because it is extreme, often not earned, unresolved and has a greater impact on daily life than pain[6,23]. For most patients fatigue is caused by RA, the inability to perform daily activities or an unrefreshing sleep[6,23]. RA patients struggle and manage fatigue by trial and error and –with limited success- use self-management strategies. Most patients do not discuss fatigue with their healthcare professionals because they feel it is dismissed or they simply accept fatigue as being part of the disease.

Current care for fatigue

There are no published studies on current care for RA fatigue. In a yet unpublished, postal survey about knowledge, attitude and current management of RA fatigue among 232 British and Dutch Rheumatology nurses and 110 Dutch Rheumatologists, it was shown that healthcare professionals have accurate knowledge of and a positive attitude towards RA fatigue. With regard to the management of fatigue in daily practice the results revealed two main findings. First, rheumatology nurses seldom refer patients to other disciplines although they believe that other team members could help the patient with fatigue. Second, rheumatologists pay attention to fatigue in the first consultation and less often during follow-up consultations.

A combined qualitative and quantitative study, in which 20 patients were videotaped during their out-patient consultation at the department of Rheumatology revealed four major results. First, patients more often use implicit cues instead of explicit concerns related to fatigue. Second, fatigue is communicated in almost all consultations with nurse specialists and in less than half of the medical consultations. Third, it is rather the patient than the healthcare professional who raises the issue of fatigue during the consultation. Fourth, in general, nurse specialists use more adequate responses to patients' cues or concerns about fatigue than rheumatologists do.

Treatment of fatigue

Disappointingly, given the fact that fatigue is by now recognised as a common symptom of RA, only few studies have focused on the treatment of RA fatigue. Studies on the effectiveness of biologic agents showed evidence of significant improvements in RA fatigue[25,26]. Moreover, the results of a randomised controlled study of cognitive-behavioural therapy (CBT) showed significant improvement in fatigue[27]. Also, a randomised controlled study on non-pharmacological interventions on home aerobic training demonstrated a trend towards improvement of fatigue[28].

Other interventions need to be tested. For example, we do not know the effects of nursing interventions on fatigue, such as advice regarding sleeping patterns, the balance between activity and rest, or social support, as components of self-management strategies. Otherwise, as CBT seems to be effective, is it possible for other members of the rheumatology team to deliver special interventions of that therapy.

Although, until now, causes of fatigue are unknown and RA patients with even a low to moderate disease activity are severe fatigued, healthcare professionals should pay attention and assess and manage fatigue routinely and effectively, in the same way as they manage pain.

Conclusions

What is known?

1. Fatigue is a common, severe and chronic complaint of patients with RA.
2. RA fatigue is overwhelming and has a large impact on quality of life.
3. Patients and healthcare professionals do not know enough about how to manage fatigue.
4. Fatigue is, just like pain, not structurally discussed with patients.

What is needed?

1. A validated assessment instrument for RA fatigue is needed to facilitate comparison of results across studies. For research purposes, the multidimensional aspect of fatigue must be represented in the measurement instrument. For daily clinical assessment, a brief and simple assessment instrument would be most appropriate.
2. Information about causes and treatment of RA fatigue is needed to support and help patients in using self-management strategies. Also, more research is needed to accomplish evidence informed practice for RA patients.
3. As with pain, fatigue should be addressed and explored systematically in clinical practice, instead of waiting for the patients to mention the symptom spontaneously.

References

1. Voith AM, Frank AM, Smith Pigg J. Nursing Diagnosis: Fatigue. In: R.M. Carroll Johnson (eds) Classification of Nursing Diagnoses, Proceedings of 8th Conference NANDA: Mosby, St Louis. 1989.
2. Piper BF. Fatigue. Pathofysiological phenomena in nursing. 2th ed. 1993, 279-302.
3. Fukuda K, Straus SE, Hickie I, Sharpe MC, Dobbins JG, Komaroff A. The chronic fatigue syndrome: a comprehensive approach to its definition and study. International Chronic Fatigue Syndrome Study Group. Ann Intern Med 1994;121(12): 953-959.
4. Hewlett S, Hehir M, Kirwan JR. Measuring fatigue in rheumatoid arthritis: A systematic review of scales in use. Arthritis Rheum 2007;57(3): 429-439.
5. Repping-Wuts H, Fransen J, van AT, Bleijenberg G, van Riel PL. Persistent severe fatigue in patients with rheumatoid arthritis. J Clin Nurs 2007;16(11C): 377-383.
6. Repping-Wuts H, Uitterhoeve R, van Riel PL, van Achterberg T. Fatigue as experienced by patients with rheumatoid arthritis (RA): A qualitative study. Int J Nurs Stud 2008;45(7): 995-1002.
7. Beurskens AJ, Bultmann U, Kant I, Vercoulen JH, Bleijenberg G, Swaen GM. Fatigue among working people: validity of a questionnaire measure. Occup Environ Med 2000;57(5): 353-357.
8. Stulemeijer M, de Jong LW, Fiselier TJ, Hoogveld SW, Bleijenberg G. Cognitive behaviour therapy for adolescents with chronic fatigue syndrome: randomised controlled trial. BMJ 2005;330(7481): 14.
9. Prins JB, Bleijenberg G, Bazelmans E, et al. Cognitive behaviour therapy for chronic fatigue syndrome: a multicentre randomised controlled trial. Lancet 2001;357(9259): 841-847.
10. Vercoulen JH, Alberts M, Bleijenberg G. De checklist Individual Strenght. Gedragstherapie 1999;32: 131-136.
11. Vercoulen JHMM, Hommes OR, Swanink MA, et al. The measurement of fatigue in patients with multiple sclerosis - A multidimensional comparison with patients with chronic fatigue syndrome and healthy subjects. Arch Neurol 1996;53(7): 642-649.
12. Felson DT, Anderson JJ, Boers M, et al. The American College of Rheumatology preliminary core set of disease activity measures for rheumatoid arthritis clinical trials. The Committee on Outcome Measures in Rheumatoid Arthritis Clinical Trials. Arthritis Rheum 1993;36(6): 729-740.
13. Boers M, Tugwell P, Felson DT, et al. World Health Organization and International League of Associations for Rheumatology core endpoints for symptom modifying antirheumatic drugs in rheumatoid arthritis clinical trials. J Rheumatol Suppl 1994;41(: 86-89.

14. Tugwell P, Boers M. Developing consensus on preliminary core efficacy endpoints for rheumatoid arthritis clinical trials. OMERACT Committee. J Rheumatol 1993;20(3): 555-556.
15. Kirwan JR, Hewlett S. Patient perspective: reasons and methods for measuring fatigue in rheumatoid arthritis. J Rheumatol 2007;34(5): 1171-1173.
16. Belza BL. Comparison of self-reported fatigue in rheumatoid arthritis and controls. J Rheumatol 1995;22(4): 639-643.
17. Belza BL, Henke CJ, Yelin EH, Epstein WV, Gilliss CL. Correlates of fatigue in older adults with rheumatoid arthritis. Nurs Res 1993;42(2): 93-99.
18. Wolfe F, Hawley DJ, Wilson K. The prevalence and meaning of fatigue in rheumatic disease. J Rheumatol 1996;23(8): 1407-1417.
19. Pinals RS, Masi AT, Larsen RA. Preliminary criteria for clinical remission in rheumatoid arthritis. Arthritis Rheum 1981;24(10): 1308-1315.
20. Huyser BA, Parker JC, Thoreson R, Smarr KL, Johnson JC, Hoffman R. Predictors of subjective fatigue among individuals with rheumatoid arthritis. Arthritis Rheum 1998;41(12): 2230-2237.
21. Rupp I, Boshuizen HC, Jacobi CE, Dinant HJ, van den Bos GA. Impact of fatigue on health-related quality of life in rheumatoid arthritis. Arthritis Rheum 2004;51(4): 578-585.
22. Suurmeijer TP, Waltz M, Moum T, et al. Quality of life profiles in the first years of rheumatoid arthritis: results from the EURIDISS longitudinal study. Arthritis Rheum 2001;45(2): 111-121.
23. Hewlett S, Cockshott Z, Byron M, et al. Patients' perceptions of fatigue in rheumatoid arthritis: overwhelming, uncontrollable, ignored. Arthritis Rheum 2005;53(5): 697-702.
24. Repping JWJ, de Hullu MCM, Barrera P, et al. Priorities nursing research in Rheumatology 2003; 4: 19-23.
25. Moreland LW, Genovese MC, Sato R, Singh A. Effect of etanercept on fatigue in patients with recent or established rheumatoid arthritis. Arthritis Rheum 2006;55(2): 287-293.
26. Weinblatt ME, Keystone EC, Furst DE, et al. Adalimumab, a fully human anti-tumor necrosis factor alpha monoclonal antibody, for the treatment of rheumatoid arthritis in patients taking concomitant methotrexate: the ARMADA trial. Arthritis Rheum 2003;48(1): 35-45.
27. Evers AW, Kraaimaat FW, van Riel PL, de Jong AJ. Tailored cognitive-behavioral therapy in early rheumatoid arthritis for patients at risk: a randomized controlled trial. Pain 2002;100(1-2): 141-153.

28. Neill J, Belan I, Ried K. Effectiveness of non-pharmacological interventions for fatigue in adults with multiple sclerosis, rheumatoid arthritis, or systemic lupus erythematosus: a systematic review. J Adv Nurs 2006;56(6): 617-635.

FATIGUE

GENERAL DISCUSSION

9

As fatigue has been rated as more important than joint swelling or pain[1] by patients with Rheumatoid Arthritis, the aims of this thesis were to determine 1) the severity and course of fatigue in patients with Rheumatoid Arthritis, 2) to explore fatigue from the perspectives of both the patient (experience and self-management strategies) and the healthcare professionals (knowledge, attitude and current management of fatigue) and 3) to evaluate the communication on fatigue between RA patients and healthcare professionals.

Main findings

Severity and course of RA-related fatigue

One of the principal findings of our priority research (chapter 2) is, that for RA patients fatigue is the most difficult complaint of the disease to handle. For nurses other topics for research are of interest but fatigue was also part of the top 10 of most important issues for future nursing research. In presenting the results of the priority study to healthcare professionals, fatigue was chosen as topic for further research. First, because it was rated by patients as the most difficult symptom to handle. Second, based on the need for knowledge on RA-related fatigue as mentioned by the healthcare professionals.

The use of a validated fatigue questionnaire that can distinguish between normal, moderate and severe fatigue offered the possibility to compare the severity of RA-related fatigue with fatigue in healthy controls and patients with Chronic Fatigue Syndrome (CFS) (chapter 3)[2]. By using cut-off criteria for severe fatigue of ≥35 on the Checklist Individual Strength-fatigue (CIS-fatigue) we showed that more than 50% of RA patients had a level of fatigue comparable to fatigue in patients with CFS, and at one-year follow-up 40% of the patients had persistent severe fatigue, results that were not previously reported in the literature on RA-related fatigue. Predictors of persistent severe fatigue were disability and general health. Inflammation and a low level of haemoglobin, as often assumed in clinical practice, were not related to persistent severe fatigue, neither were demographic variables such as age, gender and education.

RA-related fatigue: the patient's and healthcare professionals' perspective

The results of the studies on fatigue from the view of the RA patient and the management of fatigue by healthcare professionals (chapter 4-6) showed that there are differences in “beliefs” about RA-related fatigue. Where RA patients reported that they seldom discuss their fatigue with the rheumatologist or the nurse specialist, both healthcare professionals reported the opposite, in their view patients usually raise the issue of fatigue in the consultation. In the qualitative study on fatigue from the view of the RA patient, most patients mentioned the acknowledgement of fatigue by their families and others in the close circle, while both healthcare professionals reported that family members do not believe or understand patients’ fatigue.

In general, rheumatologists and rheumatology nurses have a good knowledge about RA-related fatigue and are willing to assess fatigue. Despite the ambiguity on effective treatment options they attach importance to communication about fatigue. However, both healthcare professionals believe that fatigue is poorly communicated and does not have an important place in the treatment of RA as pain does. In current management patients and healthcare professionals use strategies to handle or treat fatigue, both without being completely satisfied with the achieved results.

RA-related fatigue communication

Although fatigue is the most bothersome symptom for RA patients, it is not structurally communicated between healthcare professionals and RA patients (chapter 7). In most of the consultations with healthcare professionals, RA patients used implicit cues instead of explicit concerns in the communication on fatigue. Fatigue was twice as often a subject in the consultation with the nurse specialist compared to the consultation with the rheumatologist. Nurse specialists used more adequate responding behaviour than rheumatologists did.

Strengths and limitations

As fatigue is a common complaint of RA patients, the aim of this thesis was to explore RA-related fatigue. We therefore used a combination of research methods in which quantitative and qualitative studies on fatigue were performed. Advantages of this combination of methods are: 1) the two methods are complementary; 2) the integrated approach leads to an extensive insight into the multidimensional nature of fatigue; and 3) supplementary findings lead to further research.

We explored fatigue extensively, including its severity, the experience of the RA patient and the knowledge, attitude, management and communication of rheumatologists and rheumatology nurses.

Possible limitations of our studies will be discussed in the following paragraphs: patient and healthcare professional selection, instruments and qualitative analysis.

Patient selection

In general, RA patients were very willing to participate in the patient studies on fatigue (chapter 2-4 and 7), and although our data refer to the setting of an academic medical centre, we have no specific indications for selection bias in these studies.

However, it is difficult to state whether our results represent fatigue as experienced by all Dutch patients. Still, demographic variables, such as age, gender, education and disease duration, are equal to those found in other studies in RA patients. In all studies RA patients had a low-to-moderate disease activity, a trend that was also found in studies by Welsing et al. and Uhlig et al. (2005 and 2008)[3,4].

In the longitudinal study (chapter 3) on the severity of fatigue, 150 consecutive RA patients were asked to participate and 123 completed the study. In this study the non-responders showed no relevant differences on socio-economic or disease-related variables.

In the qualitative study on fatigue (as experienced by RA patients) (chapter 4), one patient refused and one patient was excluded because of a psychiatric disorder, all other 29 consecutive patients were included based on having RA and being able to speak and read the Dutch language. This was a high response rate with a large sample size for a qualitative study. The inclusion criteria made the inclusion of minority groups not possible and therefore results may not be applicable to these specific patient populations.

In the study on communication (chapter 7) patients were recruited by the nurse specialists. The inclusion criteria were: having RA, being able to read and communicate in Dutch and being able to spend one hour on the interview, in addition to the time needed for consultation of the nurse specialist and the rheumatologist. Although the inclusion criteria were clear, selection might have been biased by personal preferences of the nurse specialist by selecting those patients with whom they had good communication experience in previous consultations.

Healthcare professional selection

All participating UK and Dutch nurses were members of the British Health Professionals in Rheumatology and the Dutch Society of Rheumatology Nurses respectively (chapter 5). The knowledge, attitude and current management of the non-members and non-responders were not studied and we can only speculate on their knowledge and attitude and do not know if they include fatigue in their daily practice. The response rates were low, but average for postal questionnaires and we did not find large differences between nurses from the UK and from the Netherlands.

For the rheumatologists the response rate was also low but average (chapter 6) and respondents were recruited from all over the Netherlands and from various institutes, so results might be generalisable to all Dutch rheumatologists. Assuming a correlation between responding and a positive attitude towards RA fatigue, the non-responders may cause selection bias.

Instruments

In this thesis the subscale fatigue of the multidimensional Checklist Individual Strength (CIS) was used to measure fatigue. A systematic review of Hewlett et al. (2007) shows that there are many scales used for the assessment of RA-related fatigue[5]. The results of the review showed evidence of reasonable validation for 6 of 23 scales which are being used to measure RA fatigue. In the review, the CIS was evaluated in a single study of Evers et al in patients with Rheumatoid Arthritis (2002) and demonstrated sensitivity to change. Although, the CIS-fatigue has not been tested for reliability or validity in RA, it was previously used in patients with many different diseases and showed good reliability, discriminative validity and sensitivity to change[6-8].

To assess knowledge, attitude and management of RA-related fatigue by healthcare professionals, a self-report questionnaire for knowledge and attitude in cancer fatigue has been adapted due to the lack of a questionnaire for RA. To assess management of fatigue, topics from previous qualitative studies were included[1,9]. For future research this questionnaire has to be further evaluated and adapted.

Qualitative analysis

In two studies we applied qualitative analysis namely in the studies on the patient's experience of fatigue (chapter 3) and the communication on fatigue between patients and healthcare professionals (chapter 5). Qualitative research is about subjectivity and complexity; it seeks not to count or reduce, put provide a way of entering into the patient's world[10]. Analysing qualitative data is an intensive activity, guided by few standardised rules. Three prototypical analytical styles have been identified: 1) a template analysis style that involves the development of an analysis guide to sort the data; 2) an editing analysis style that involves an interpretation of the data on which a categorisation scheme is based; and 3) an immersion/crystallisation style that is characterised by the analyst 's total immersion in and reflection of text materials[11]. In the qualitative studies of this thesis The Observer has been used to code and analyse data. The Observer is a software program that enables direct coding while observing videotapes or listening to audiotapes. The analysis with The Observer is based on literature and a theoretical framework. Two researchers discussed the coding scheme and to improve validity they analysed a randomly selected number of the video- and audiotapes.

Main conclusions

- For RA patients fatigue is a very difficult symptom to handle in daily life, with more than half of the patients having severe fatigue.
- Because of the use of different instruments to measure fatigue, predictors for RA fatigue are still largely unknown. Moreover, published results are contradictory.
- RA patients do not often discuss their fatigue with the healthcare professionals and handle it by 'trial and error', assuming that nothing can be done. They are in need of information on causes and management strategies;
- Rheumatologists and nurse specialists are sympathetic about fatigue but feel it is not well addressed or managed. In general they are willing to assess fatigue but they need more knowledge on management strategies;
- Fatigue is not structurally communicated in the consultations between healthcare professionals and RA patients and patients use indirect cues more than explicit concerns in their communication on fatigue. Healthcare professionals have to use more exploring and acknowledging behaviour in their communication with RA patients to help patients express and explore fatigue.

Implications for Interdisciplinary Care

Our studies showed that healthcare professionals do not assess fatigue although they are willing to use a short instrument to measure fatigue in clinical practice. From the point of view of the patient, fatigue is a severe problem, is difficult to handle and is often not discussed by the patient. Patients use self-management strategies but with limited success[9].

For fatigue in other chronic patients groups, such as Multiple Sclerosis[12], patients with neuromuscular disorders[13] and patients with breast cancer (unpublished N. de Jong) models of variables that influence fatigue are being developed, offering the possibility to implement and test tailored interventions to treat fatigue. However, a specific model for RA-related fatigue has to be developed in the future.

By now, only a few studies have focused on the treatment of RA-related fatigue. Cognitive-behavioural therapy (CBT), regular exercise and the use of biological agents may be effective, however, more research is needed[14-16]. CBT seems to be effective for severely fatigued disease-free cancer patients[17,18]. CBT focuses on six perpetuating factors of post-cancer fatigue, which were based on existing literature and experience in clinical practice and involve: (1) insufficient coping with the experience of cancer, (2) fear of disease recurrence[19,20], (3) dysfunctional cognitions concerning fatigue[21,22], (4) dysregulation of sleep[23,24], (5) dysregulation of activity[20,24,25] and (6) low social support and negative social interactions[22]. For RA patients factor 2 is not relevant as RA is a chronic disease although RA patients might experience fear for exacerbation of the disease and for factor 6 the results of our qualitative study (chapter 3) showed that patients feel supported by family and friends in the close circle but negative social interaction was not an outcome measure. These perpetuating factors could be of interest in the communication on fatigue between nurses, rheumatologists and RA patients, but possibly also others.

The effectiveness of other non-pharmacological interventions, such as exercise and energy conservation on fatigue are subjects of a few studies on RA-related fatigue[26-31]. All studies showed reductions in fatigue. However, more research is needed.

As nurses can be seen as the healthcare providers concentrated on managing all kinds of distressing, unrelenting symptoms of diseases, specific interventions by nurses like education, counselling and interventions based on the principles of behaviour therapy are brought into perspective[32]. The management of symptoms of diseases is the domain of nursing science and Rheumatology nurses are aware of physical restrictions that RA patients might experience and understand which barriers could arise. They are in the unique position to help patients manage their fatigue in daily life.

However, to know how severely fatigued patients are, healthcare professionals need to assess fatigue and to use that information to start the communication on fatigue.

Besides, in the consultation, rheumatology nurses and rheumatologists must be aware of patients' cues to RA-related fatigue and to use this knowledge in their exploring and acknowledging behaviour in the communication with RA patients. Knowing that if you ask patients about fatigue they seldom deny the symptom, must stimulate rheumatology nurses and rheumatologists to give patients the opportunity to report their fatigue complaints which might give some relief and recognition, and this (patient-centred) communication might be the first step in the management of fatigue and help patients to explore personal causes of fatigue and to develop patient-centred care.

Directions for future research

With this thesis, the first step in the recognition of fatigue as a very serious problem for RA patients has been made. Studies for validating the CIS are ongoing and in daily practice a simple assessment instrument would be helpful. For the clinical assessment of fatigue the Abbreviated Fatigue Questionnaire (AFQ) would be suitable but validation of this instrument in RA patients is needed[33,34]. The AFQ is a shortened version of the CIS, which measures fatigue with four items. Scores range from 4 to 28; higher scores indicate higher levels of fatigue.

Furthermore, the need for more information about causes and interventions for fatigue is expressed by RA patients and healthcare professionals. To develop tailored multidisciplinary interventions to prevent and treat fatigue, future research has to be performed on perpetuating factors for RA fatigue.

Furthermore, interventions for RA fatigue need to be tested in pilot studies to develop self-management strategies for prevention and treatment of RA fatigue.

To meet RA patients' need for information about fatigue a leaflet and supportive program could be developed based on the results of this thesis and using an Intervention-Mapping (IM) framework. IM was previously used to develop health promotion programs for smoking cessation[35], asthma management[36] and for the development of a “Lively Legs” program on therapy compliance and physical exercise in venous leg ulcer patients[37]. IM guides the identification of health promoting behaviour and their determinants, development of intervention objectives, selection of methods and strategies for inducing change, and planning of program implementation, and evaluation of its impact.

References

1. Repping-Wuts H, Uitterhoeve R, van Riel P, van Achterberg T. Fatigue as experienced by patients with rheumatoid arthritis (RA): A qualitative study. Int J Nurs Stud 2007.
2. Vercoulen JH, Swanink CM, Fennis JF, Galama JM, van der Meer JW, Bleijenberg G. Dimensional assessment of chronic fatigue syndrome. J Psychosom Res 1994;38(5): 383-392.
3. Uhlig T, Heiberg T, Mowinckel P, Kvien TK. Rheumatoid arthritis is milder in the new millennium: Health status in RA patients 1994-2004. Ann Rheum Dis 2008.
4. Welsing PM, Fransen J, van Riel PL. Is the disease course of rheumatoid arthritis becoming milder? Time trends since 1985 in an inception cohort of early rheumatoid arthritis. Arthritis Rheum 2005;52(9): 2616-2624.
5. Hewlett S, Hehir M, Kirwan JR. Measuring fatigue in rheumatoid arthritis: A systematic review of scales in use. Arthritis Rheum 2007;57(3): 429-439.
6. Kalkman JS, Schillings ML, van der Werf SP, et al. Experienced fatigue in facioscapulohumeral dystrophy, myotonic dystrophy, and HMSN-I. J Neurol Neurosurg Psychiatry 2005;76(10): 1406-1409.
7. Dittner AJ, Wessely SC, Brown RG. The assessment of fatigue: a practical guide for clinicians and researchers. J Psychosom Res 2004;56(2): 157-170.
8. Servaes P, van der Werf S, Prins J, Verhagen S, Bleijenberg G. Fatigue in disease-free cancer patients compared with fatigue in patients with Chronic Fatigue Syndrome. Support Care Cancer 2001;9(1): 11-17.
9. Hewlett S, Cockshott Z, Byron M, et al. Patients' perceptions of fatigue in rheumatoid arthritis: overwhelming, uncontrollable, ignored. Arthritis Rheum 2005;53(5): 697-702.
10. Broom A. Using qualitative interviews in CAM research: a guide to study design, data collection and data analysis. Complement Ther Med 2005;13(1): 65-73.
11. Polit DF, Beck CT. Nursing Research, principles and methods. 7th ed. Lippincott Williams & Wilkens, 2007.
12. Vercoulen JH, Swanink CM, Galama JM, et al. The persistence of fatigue in chronic fatigue syndrome and multiple sclerosis: development of a model. J Psychosom Res 1998;45(6): 507-517.
13. Kalkman JS, Schillings ML, Zwarts MJ, van Engelen BG, Bleijenberg G. The development of a model of fatigue in neuromuscular disorders: a longitudinal study. J Psychosom Res 2007;62(5): 571-579.
14. Evers AW, Kraaimaat FW, van Riel PL, de Jong AJ. Tailored cognitive-behavioral therapy in early rheumatoid arthritis for patients at risk: a randomized controlled trial. Pain 2002;100(1-2): 141-153.

15. Lee EO, Kim JI, Davis AH, Kim I. Effects of regular exercise on pain, fatigue, and disability in patients with rheumatoid arthritis. Fam Community Health 2006;29(4): 320-327.
16. Moreland LW, Genovese MC, Sato R, Singh A. Effect of etanercept on fatigue in patients with recent or established rheumatoid arthritis. Arthritis Rheum 2006;55(2): 287-293.
17. Gielissen MF, Verhagen S, Witjes F, Bleijenberg G. Effects of cognitive behavior therapy in severely fatigued disease-free cancer patients compared with patients waiting for cognitive behavior therapy: a randomized controlled trial. J Clin Oncol 2006;24(30): 4882-4887.
18. Gielissen MF, Verhagen CA, Bleijenberg G. Cognitive behaviour therapy for fatigued cancer survivors: long-term follow-up. Br J Cancer 2007;97(5): 612-618.
19. Servaes P, Verhagen S, Schreuder HW, Veth RP, Bleijenberg G. Fatigue after treatment for malignant and benign bone and soft tissue tumors. J Pain Symptom Manage 2003;26(6): 1113-1122.
20. Young KE, White CA. The prevalence and moderators of fatigue in people who have been successfully treated for cancer. J Psychosom Res 2006;60(1): 29-38.
21. Broeckel JA, Jacobsen PB, Horton J, Balducci L, Lyman GH. Characteristics and correlates of fatigue after adjuvant chemotherapy for breast cancer. J Clin Oncol 1998;16(5): 1689-1696.
22. Servaes P, Verhagen S, Bleijenberg G. Determinants of chronic fatigue in disease-free breast cancer patients: a cross-sectional study. Ann Oncol 2002;13(4): 589-598.
23. Servaes P, Prins J, Verhagen S, Bleijenberg G. Fatigue after breast cancer and in chronic fatigue syndrome: similarities and differences. J Psychosom Res 2002;52(6): 453-459.
24. Prue G, Rankin J, Allen J, Gracey J, Cramp F. Cancer-related fatigue: A critical appraisal. Eur J Cancer 2006;42(7): 846-863.
25. Servaes P, Verhagen C, Bleijenberg G. Fatigue in cancer patients during and after treatment: prevalence, correlates and interventions. Eur J Cancer 2002;38(1): 27-43.
26. Neuberger GB, Press AN, Lindsley HB, et al. Effects of exercise on fatigue, aerobic fitness, and disease activity measures in persons with rheumatoid arthritis. Res Nurs Health 1997;20(3): 195-204.
27. Daltroy LH, Robb-Nicholson C, Iversen MD, Wright EA, Liang MH. Effectiveness of minimally supervised home aerobic training in patients with systemic rheumatic disease. Br J Rheumatol 1995;34(11): 1064-1069.
28. Rall LC, Meydani SN, Kehayias JJ, Dawson-Hughes B, Roubenoff R. The effect of progressive resistance training in rheumatoid arthritis. Increased strength without changes in energy balance or body composition. Arthritis Rheum 1996;39(3): 415-426.

29. Noreau L, Martineau H, Roy L, Belzile M. Effects of a modified dance-based exercise on cardiorespiratory fitness, psychological state and health status of persons with rheumatoid arthritis. Am J Phys Med Rehabil 1995;74(1): 19-27.
30. Furst GP, Gerber LH, Smith CC, Fisher S, Shulman B. A program for improving energy conservation behaviors in adults with rheumatoid arthritis. Am J Occup Ther 1987;41(2): 102-111.
31. Gerber L, Furst G, Shulman B, et al. Patient education program to teach energy conservation behaviors to patients with rheumatoid arthritis: a pilot study. Arch Phys Med Rehabil 1987;68(7): 442-445.
32. Uitterhoeve RJ, Vernooy M, Litjens M, et al. Psychosocial interventions for patients with advanced cancer - a systematic review of the literature. Br J Cancer 2004;91(6): 1050-1062.
33. Alberts M, Smets FMA, Vercoulen JHMM, Garssen B, Bleijenberg G. Verkorte vermoeidheids-vragenlijst: een practisch hulpmiddel bij het scoren van vermoeidheid. 141 ed. 1997, 1526-1530.
34. Alberts M, Vercoulen JH, Bleijenberg G. The practical utility of the subjective feeling of fatigue in research and clinical practice. In Vingerhoets A, ed. Assessment in behavioural medicine. Brunner Routledge, 2001, 301-327.
35. Mullen PD, DiClemente CC, Bartholomew LK. Theory and context in project PANDA: a program to help postpartum women stay off cigarettes. In Bartholomew LK, Parcel GS, Kok G, Gottlieb NH, eds. Intervention mapping: designing theory and evidence-based health program development. Mayfield Publishing Co., 2007.
36. Bartholomew LK, Gold RS, Parcel GS, et al. Watch, Discover, Think, and Act: evaluation of computer-assisted instruction to improve asthma self-management in inner-city children. Patient Educ Couns 2000;39(2-3): 269-280.
37. Heinen MM, Bartholomew LK, Wensing M, van de Kerkhof P, van Achterberg T. Supporting adherence and healthy lifestyles in leg ulcer patients: systematic development of the Lively Legs program for dermatology outpatient clinics. Patient Educ Couns 2006;61(2): 279-291.

F A T I G U E

SUMMARY

Fatigue is a common symptom in patients with Rheumatoid Arthritis (RA) with a great impact on patients' quality of life. This thesis studies the severity and course of fatigue, fatigue from the point of view of RA patients, the attitude, knowledge and management of fatigue in healthcare professionals and fatigue-communication between patients and healthcare professionals.

Chapter 1

In Chapter 1, an introduction is presented regarding Rheumatoid Arthritis, fatigue and nursing care. Moreover, results from previous studies on RA-related fatigue are described. This chapter ends with the outline and aims for this thesis namely: 1) To determine the severity and course of fatigue in RA patients; 2) to explore fatigue from the perspective of both the RA patient (experience and self-management strategies) and the healthcare professional (knowledge, attitude and current management) and 3) to evaluate the communication on fatigue between RA patients and healthcare professionals in real practice.

Chapter 2

In Chapter 2, a priority research for nursing research at the department of Rheumatology was described. A quantitative design with written questionnaires was used, asking nurses about items which could be of interest for nursing studies and asking patients about the symptoms of their disease that were the most difficult to handle. The results show that there is a distinct difference between the subjects nurses choose and the symptoms which patients experience as most difficult to handle. The differences can be explained by the fact that psychosocial aspects, which are often chosen by nurses as a subject for scientific nursing research, are not the symptoms which patients experience as most difficult to handle. Fatigue and pain were the first two items on a final top ten composed by patients.

Chapter 3

In chapter 3 the severity, course and predictors of fatigue in RA patients were studied. A longitudinal study with a one-year duration was performed and data were collected with written questionnaires. Next to disease related variables (presence of tender and swollen joints, general health and disability), 150 consecutive patients from an existing RA cohort, were asked to assess fatigue, using the Checklist Individual Strength at baseline and 12 months later. The Checklist Individual Strength-fatigue scores were classified into 'normal' (score between 8–27), 'moderate' (score between 27-34) or 'severe' (score 35 or above). Finally 123 patients completed the study and 50% of the patients were moderately to severely fatigued at baseline and at the end of the study. Moreover, 40% experienced severe fatigue at baseline as well as at follow-up, which we called 'persistent severe fatigue'. General health and disability were predictors of persistent severe fatigue.

Chapter 4

Clarifying fatigue as experienced by RA patients was the objective of chapter 4. A combined quantitative and qualitative design was used with written questionnaires and a semi-structured interview. Twenty-nine patients with RA filled out questionnaires on fatigue severity, disability, quality of life and sleep disturbance at home, prior to a scheduled visit at the outpatient clinic. They were interviewed at the time of the visit where the disease activity was calculated using the Disease Activity Score (DAS28). All interviews were audio-taped and analysed using the software program 'The Observer'. The results show that RA-related fatigue is different from normal fatigue because it is extreme and often unexpected. Patients manage fatigue by trial and error, and without (professional) help, assuming that fatigue is part of the disease and cannot really be resolved.

Chapter 5

In Chapter 5 Dutch Rheumatologists were asked about their knowledge, attitude and their current practice regarding RA-related fatigue.

A cross-sectional quantitative design and a written questionnaire were used. All rheumatologists (N=204) and rheumatology trainees (N=49), members of the Dutch Society of Rheumatology were sent a postal questionnaire with 52 questions. Descriptive statistics were used for the analysis. The response was 44% and in general rheumatologists' knowledge regarding RA-related fatigue was in accordance with published literature. However, almost all rheumatologists perceived a lack of knowledge about aetiology and evidence-based interventions to prevent and treat fatigue. In general they had a positive attitude towards RA-related fatigue, although they discussed fatigue less often in follow-up consultations, assuming that the patient would raise the issue. Most rheumatologists agree that healthcare professionals do not place as much emphasis on the treatment of fatigue as they do on pain or stiffness.

Chapter 6

In Chapter 6, the knowledge, attitude and current management of RA-related fatigue of British and Dutch rheumatology nurses was explored. A survey, using a structured written questionnaire was performed. The postal questionnaire was sent to all rheumatology nurses, members of the British Health Professionals in Rheumatology (N=267) and the Dutch Society of Rheumatology Nurses (N=227). The total response was 48% (39% UK and 57% Dutch nurses). In general, UK and Dutch nurses' knowledge about RA-related fatigue was in accordance with the literature and all nurses indicated a positive attitude to RA-related fatigue. However, in managing fatigue nurses reported contradictory views. Although nurses believed that other team members could help the patient, they seldom referred patients on to other disciplines. Although nurses believed that, besides pacing and balance between activity and rest, other advice might help, they did not offer this to patients. Despite the acknowledgement of poor communication about fatigue, nurses reported that it is rather the patient than the nurse who raises the issue of fatigue in the consultation.

Chapter 7

Chapter 7 focussed on the communication on fatigue between RA patients and healthcare professionals using a qualitative and quantitative design.

Twenty patients with Rheumatoid Arthritis, visiting the outpatient clinic for a regular combined check-up by the nurse specialist and the rheumatologist participated in the study. All consultations (N=40) were videotaped and analysed using the Medical Interview Aural Rating Scale (MIARS) on expressed cues or concerns by the patient, and the response of the healthcare professionals by using adequate (exploring or acknowledging) or inadequate behaviour (distancing). In addition to both consultations, patients were asked to fill out a questionnaire with 21 RA-related concerns, asking patients how worried they felt about each concern in the week before visiting the outpatient clinic (range not worried to almost always worried) and how satisfied they were with attention to each concern from both health professionals separately (range dissatisfied to very satisfied). Fatigue was one of the concerns on the questionnaire. Finally, they were interviewed on the experienced concerns, asking for reasons for being not or not completely satisfied.

Finally 20 patients were included of which 37 videotaped consultations, 17 questionnaires and 15 interviews were analysed. Fatigue was not discussed in 58% of the consultations with the rheumatologist and in 17% of the consultations with the nurse specialist. RA patients more often used implicit cues instead of explicit concerns related to fatigue. Rheumatology nurses more often used adequate responses to patients' expressed cues or concerns compared to rheumatologists. Almost 72% of the patients felt worried about fatigue (ranging from a bit worried to almost always worried) and in general they were more satisfied with attention received from the nurse specialist than with the attention from the rheumatologist. Having more time, being a better listener and giving more suitable advice were the reasons mentioned most. In general, all patients were satisfied with the care received. Kindness, being given the possibility to have telephone contact with the nurse specialist and a listening ear were the reasons most often mentioned for this overall satisfaction.

Chapter 8

In chapter 8, an editorial called "Fatigue in patients with Rheumatoid Arthritis: what is known and what is needed" is presented. In this editorial results of published studies on RA-related fatigue are systematically presented: 1) concept and definition of fatigue; 2) assessment instruments; 3) prevalence, course, severity and predictors of fatigue; 4) the patient's experience; 5) current care of fatigue by healthcare professionals and finally 6) treatment of fatigue.

Chapter 9

In chapter 9 the findings of the studies in this thesis and the implications for nursing care and future research are discussed.

Fatigue is a common, severe and chronic symptom in patients with RA. Due to the lack of a clear definition and the causes of RA-related fatigue, testing of specific therapeutic anti-fatigue strategies is hampered. RA patients and healthcare professionals showed differences in "beliefs" about RA-related fatigue. Where RA patients reported that they seldom discuss their fatigue with healthcare professionals, the rheumatologist and the nurse specialist believed the opposite. Knowledge and attitudes of healthcare professionals towards RA-related fatigue are not problematic, but in clinical practice it is important to explore fatigue systematically rather than wait until patients mention the symptom spontaneously. A validated assessment instrument for RA-related fatigue is needed to make it easier to compare results of different studies. Furthermore, the choice of a questionnaire should closely match the goal of the assessment, for example research versus clinical assessment. A brief and simple assessment instrument would be most appropriate to use in a clinical setting. In research other standards can apply. The amount of research on RA-related fatigue has been growing in recent years. For healthcare professionals, there is a need for research on causes and effective interventions, to help them inform and support RA patients to manage their fatigue.

With this thesis, the first step in the recognition of fatigue as a very serious problem for RA patients is made. Furthermore, the need for more information about causes and interventions for fatigue is expressed by RA patients and healthcare professionals. Further efforts have to be made to test the effectiveness of interventions to treat fatigue in RA patients. Implementing actual knowledge in daily practice of healthcare professionals is needed to help RA patients to manage fatigue.

FATIGUE

SAMENVATTING

Vermoeidheid is een veel voorkomende klacht bij patiënten met Reumatoïde Artritis (RA) en heeft grote gevolgen voor de kwaliteit van leven van deze patiënten. De onderzoeken, die in dit proefschrift zijn beschreven, richten zich op de ernst en het beloop van vermoeidheid, op vermoeidheid zoals die ervaren wordt door RA patiënten, op attitude en kennis van zorgverleners alsmede op de huidige door hen verleende zorg t.a.v. vermoeidheid en tenslotte op de communicatie tussen patiënten en zorgverleners ten aanzien van vermoeidheid.

Hoofdstuk 1

In de algemene inleiding van dit proefschrift worden de begrippen Reumatoïde Artritis, vermoeidheid en verpleegkundige zorg toegelicht en worden tevens de resultaten van eerder onderzoek naar vermoeidheid bij RA patiënten beschreven. De inleiding eindigt met het doel van dit proefschrift, namelijk:

1. het vaststellen van de ernst en het beloop van vermoeidheid bij RA patiënten;
2. het beschrijven van vermoeidheid vanuit het perspectief van de RA patiënt (ervaring en zelfmanagement) en de zorgverleners (kennis, attitude en huidige zorgverlening) en
3. het inzicht geven in de communicatie over vermoeidheid tussen RA patiënten en zorgverleners.

Hoofdstuk 2

In dit hoofdstuk wordt het prioriteitenonderzoek voor verpleegkundig onderzoek binnen de afdeling reumatologie beschreven. Er is gebruik gemaakt van kwantitatief onderzoek met een schriftelijke vragenlijst waarin verpleegkundigen is gevraagd naar onderwerpen voor verpleegkundig onderzoek en waarbij patiënten is gevraagd naar klachten van hun ziekte waar ze de meeste hinder van ondervinden. De resultaten laten zien dat er een verschil bestaat tussen onderwerpen die verpleegkundigen belangrijk vinden voor verpleegkundig onderzoek en klachten die patiënten moeilijk vinden om mee om te gaan. Het verschil zit vooral in psychosociale onderwerpen die door verpleegkundigen voornamelijk gekozen zijn als onderwerp voor verpleegkundig onderzoek maar die door patiënten niet genoemd worden als erg lastig om mee om te gaan. Patiënten benoemen vooral vermoeidheid en pijn als klachten van hun ziekte waarvan zij de meeste hinder ondervinden.

Hoofdstuk 3

In hoofdstuk 3 worden de ernst, het beloop en de predictoren van vermoeidheid bij RA patiënten beschreven. Er is, over een periode van een jaar, een longitudinaal onderzoek met schriftelijke vragenlijsten uitgevoerd. Buiten ziektegerelateerde variabelen (het hebben van pijnlijke en gezwollen gewrichten, algemeen welbevinden en lichamelijke beperkingen) is aan 150 patiënten gevraagd de Checklist Individuele Spankracht (CIS) bij het begin van het onderzoek en vervolgens na 12 maanden in te vullen.

Op basis van de scores onderscheidt de CIS-vermoeidheid drie categorieën vermoeidheid:

- normale vermoeidheid (score tussen 8-27),
- matige vermoeidheid (score tussen 27-34) en
- ernstige vermoeidheid (score van 35 of hoger).

Uiteindelijk hebben honderddrieëntwintig patiënten deelgenomen aan dit onderzoek. Van deze populatie heeft 50% een score hoger dan 27 op de CIS-vermoeidheid. Bovendien heeft 40% van de onderzoekspopulatie zowel bij de start als na twaalf maanden een vermoeidheidsscore van 35 of hoger, hetgeen in dit onderzoek ‘aanhoudende ernstige vermoeidheid’ wordt genoemd.

Het onderzoek toont tevens aan dat ‘algemeen welbevinden’ en ‘lichamelijke beperkingen’ predictoren zijn voor deze aanhoudende ernstige vermoeidheid.

Hoofdstuk 4

In hoofdstuk 4 wordt vermoeidheid vanuit het perspectief van de RA patiënt beschreven. Hierbij is gebruik gemaakt van een combinatie van kwantitatief en kwalitatief onderzoek met behulp van schriftelijke vragenlijsten en een semigestructureerd interview. Negenentwintig RA patiënten hebben thuis, voorafgaand aan een gepland poliklinisch consult, de volgende vragenlijsten ingevuld: de CIS (gericht op vermoeidheid), de HAQ (gericht op lichamelijke beperkingen), de SF-36 (gericht op de kwaliteit van leven) en de Groninger slaapscore vragenlijst. Vervolgens zijn de patiënten geïnterviewd tijdens hun bezoek aan de polikliniek waarbij ook de ziekteactiviteit is gemeten met behulp van de DAS-28.

Alle interviews zijn op band vastgelegd en vervolgens geanalyseerd met behulp van het softwareprogramma ‘The Observer’. De resultaten laten zien dat RA-vermoeidheid zich onderscheidt van ‘normale’ vermoeidheid door de extreme aard en het vaak onverwacht optreden van deze vermoeidheid. Uit het onderzoek blijkt tevens dat RA patiënten door ‘trial and error’ leren om te gaan met hun vermoeidheid, zonder hulp van professionals en in de veronderstelling dat vermoeidheid hoort bij de ziekte en dat deze niet verholpen kan worden.

Hoofdstuk 5

In hoofdstuk 5 zijn de resultaten beschreven van een onderzoek naar kennis en houding van Nederlandse Reumatologen ten opzichte van RA-vermoeidheid. Tevens is hen gevraagd naar hun huidige zorgverlening ten aanzien van vermoeidheid bij RA patiënten. Hierbij werd gebruik gemaakt van een cross-sectioneel kwantitatief onderzoek met een schriftelijke vragenlijst.

Alle reumatologen (N=204) en reumatologen in opleiding (N=49), die lid zijn van de Nederlandse Vereniging voor Reumatologie, hebben een vragenlijst met 52 vragen toegestuurd gekregen. Voor de analyse is gebruik gemaakt van beschrijvende statistiek.

De respons was 44%. De kennis van reumatologen met betrekking tot vermoeidheid bij RA patiënten is grotendeels in overeenstemming met eerder gepubliceerde resultaten van onderzoek. Opvallend is, dat bijna alle reumatologen aangeven een kennistekort te hebben over oorzaken van vermoeidheid en van evidence-based interventies om vermoeidheid te voorkomen of te behandelen. Reumatologen hebben over het algemeen een positieve houding ten opzichte van vermoeidheid bij RA patiënten, hoewel ze aangeven vermoeidheid minder vaak te bespreken in vervolgconsulten ervan uitgaande dat patiënten zelf hun vermoeidheid benoemen. De meeste reumatologen erkennen dat zorgverleners minder aandacht besteden aan vermoeidheid dan aan pijn of stijfheid.

Hoofdstuk 6

In hoofdstuk 6 zijn de resultaten beschreven van onderzoek naar kennis, houding en huidige zorgverlening ten opzichte van vermoeidheid bij RA patiënten onder verpleegkundigen uit Nederland en uit de UK.

Hierbij is gebruik gemaakt van een survey met een schriftelijke vragenlijst. De vragenlijst is per post verstuurd naar alle Nederlandse verpleegkundigen (N=227), die lid zijn van het platform Reumatologie van V&VN, en naar alle Britse verpleegkundigen, die lid zijn van de “British Health Professionals in Rheumatology” (N=267). De totale respons is 48% (39% UK en 57% Nederlandse verpleegkundigen). In het algemeen is de kennis van Nederlandse en Britse verpleegkundigen met betrekking tot vermoeidheid bij RA patiënten in overeenstemming met eerder gepubliceerde resultaten van onderzoek en blijkt uit het onderzoek dat alle verpleegkundigen een positieve houding ten opzichte van RA-vermoeidheid hebben.

In de zorg voor vermoeidheid geven verpleegkundigen blijk van een drietal tegenstrijdigheden:

- Hoewel verpleegkundigen geloven dat andere zorgverleners patiënten kunnen helpen met vermoeidheid verwijzen zij patiënten niet door naar andere disciplines.
- Ondanks de erkenning dat communicatie over vermoeidheid slecht is, geven verpleegkundigen aan dat het meestal de patiënt is die de vermoeidheid ter sprake brengt en
- Ondanks dat verpleegkundigen weten dat naast het vinden van een balans tussen activiteit en rust andere interventies mogelijk kunnen helpen bieden zij deze niet aan patiënten aan.

Hoofdstuk 7

Hoofdstuk 7 richt zich op de communicatie over vermoeidheid tussen patiënten en zorgverleners, waarbij gebruik is gemaakt van kwantitatief en kwalitatief onderzoek. Twintig RA patiënten die de polikliniek van Reumatologie bezochten voor een gepland consult, zowel met de reumatoloog als met de reumaverpleegkundige, hebben deelgenomen aan het onderzoek. Alle consulten (N=40) zijn opgenomen op video en geanalyseerd op de communicatie over vermoeidheid op basis van impliciete “cues” en expliciete “concerns” van de patiënt met behulp van de Medical Interview Aural Rating Scale (MIARS). Bij de analyse is tevens is gekeken naar de respons van de zorgverlener wat betref een adequate (doorvragen en erkennen) of inadequate (overstappen op en ander onderwerp) reactie op een door de patiënt geuite ‘cue’ of ‘concern’.

Aansluitend op beide consulten is aan patiënten gevraagd om op een lijst van 21 ziektegerelateerde aspecten aan te geven hoeveel zorgen zij zich daarover maken (geen zorgen tot heel veel zorgen) en hoe tevreden (ontevreden of zeer tevreden) zij zijn met de aandacht van zowel de reumatoloog als van de reumaverpleegkundige betreffende deze zorgen. Tenslotte hebben zij in een interview kunnen aangeven waarom zij niet of niet helemaal tevreden zijn met de aandacht die ze hebben gekregen.

Van de 20 patiënten zijn 37 video opnames, 17 vragenlijsten en 15 interviews geanalyseerd. Vermoeidheid is in 42% van de consulten met de reumatoloog en in 83% van de consulten met de verpleegkundig specialist besproken.

RA patiënten maken vooral gebruik van impliciete cues in plaats van vermoeidheid echt als een probleem te melden. Reumatologie-verpleegkundigen reageren op een meer adequate manier dan reumatologen.

Bijna 72% van de patiënten maakt zich zorgen over vermoeidheid (van een beetje zorgen tot heel veel zorgen) en in het algemeen waren patiënten meer tevreden met de aandacht voor hun vermoeidheid van de verpleegkundigen dan met de aandacht van de reumatoloog.

Het hebben van meer tijd, het beter kunnen luisteren en het geven van meer geschikte adviezen zijn hiervoor de meest genoemde redenen.

In het algemeen zijn patiënten erg tevreden over de zorg. Vriendelijkheid, de mogelijkheid om telefonisch contact op te nemen met de verpleegkundige, en een luisterend oor zijn de belangrijkste redenen voor deze tevredenheid.

Hoofdstuk 8

In hoofdstuk 8 wordt een ‘editorial’ met de titel “Vermoeidheid bij RA patiënten; wat is er bekend en wat is nodig?” beschreven. In deze editorial worden de resultaten van eerder gepubliceerde onderzoeken naar RA-vermoeidheid systematisch beschreven, namelijk:

- Concept en definitie van vermoeidheid;
- Meetinstrumenten;
- Prevalentie, verloop, ernst en predictoren van vermoeidheid;
- Ervaring van de patiënt;
- De huidige zorgverlening ten aanzien van vermoeidheid door zorgverleners en tenslotte
- De behandeling van vermoeidheid.

Hoofdstuk 9

In hoofdstuk 9 worden de resultaten van de onderzoeken uit dit proefschrift en de implicaties voor de verpleegkundige zorg bediscussieerd.

Vermoeidheid is een veel voorkomende, ernstige en chronische klacht van RA patiënten. Het ontbreken van een eenduidige definitie van vermoeidheid en helderheid over de oorzaken van vermoeidheid zijn een beperking voor het testen van specifieke therapeutische strategieën. RA patiënten en zorgverleners verschillen van mening als het gaat over vermoeidheid. Terwijl RA patiënten zeggen dat zij vermoeidheid zelden bespreken met de zorgverlener beweren reumatologen en reumaverpleegkundigen het tegenovergestelde.

De kennis en kunde ten aanzien van RA-vermoeidheid is niet problematisch onder zorgverleners maar in de dagelijkse klinische praktijk is het belangrijk om vermoeidheid systematisch te meten en te onderzoeken en niet te wachten totdat

patiënten de vermoeidheid zelf ter sprake brengen.
Een gevalideerd meetinstrument voor RA-vermoeidheid is noodzakelijk om resultaten uit verschillend onderzoek met elkaar te kunnen vergelijken. Bovendien moet de keuze voor een meetinstrument passen binnen het doel van het meetinstrument, bijvoorbeeld voor onderzoek of voor gebruik in de dagelijkse praktijk.

Voor het meten van vermoeidheid in de dagelijkse praktijk is een korte en eenvoudige vragenlijst het meest geschikt. Het meten van vermoeidheid in het kader van wetenschappelijk onderzoek stelt echter andere eisen aan een meetinstrument.
Het aantal onderzoeken naar RA-vermoeidheid neemt de laatste jaren sterk toe. Zorgverleners hebben behoefte aan onderzoek naar oorzaken van vermoeidheid en naar effectieve interventies om patiënten te ondersteunen in hun zelfmanagement ten aanzien van vermoeidheid.
Met dit proefschrift is de eerste stap gezet in de erkenning van vermoeidheid als een zeer ernstig probleem voor RA patiënten. In de toekomst zal onderzoek vooral gericht moeten zijn op het testen van effectieve interventies ter behandeling van vermoeidheid bij RA patiënten. Verder hebben zowel patiënten als zorgverleners aangegeven behoefte te hebben aan informatie over oorzaken van vermoeidheid en interventies ter behandeling van vermoeidheid. De implementatie van deze actuele kennis in de dagelijkse praktijk van zorgverleners is noodzakelijk om RA patiënten te ondersteunen bij het omgaan met hun vermoeidheid.

F
A
T
I
G
U
E

DANKWOORD

dank je wel !

Het proefschrift is echt af!
Maar ……. dit was zeker niet gelukt zonder de steun en hulp van velen.
Allen, die me op wat voor manier dan ook hierbij geholpen hebben wil ik oprecht bedanken. Een aantal mensen wil ik bij naam noemen.

Als eerste Theo van Achterberg, mijn promotor. Zonder jouw vertrouwen in mij had ik hier nu niet gestaan. Na een moeilijke aanloopperiode wat betreft verpleegkundig onderzoek wist jij me op een positieve manier te stimuleren om door te gaan en weer vertrouwen te krijgen in mezelf. Door jouw vertrouwen en de goede en fijne wijze waarop je feedback gaf kwam ik steeds een stukje verder en uiteindelijk toch bij een promotie.
Theo, alle woorden van dank schieten hier echt tekort, dus THANK YOU!

Mijn tweede promotor, Piet van Riel, wil ik bedanken voor zijn steun en de mogelijkheid om verpleegkundig onderzoek binnen de afdeling Reumatologie tot uitvoer te brengen. Daarnaast wil ik ook bedanken Gijs Bleijenberg, hoogleraar van het Kenniscentrum Chronische Vermoeidheid, die mij bij de start van het onderzoek naar vermoeidheid duidelijk heeft gemaakt dat vermoeidheid een moeilijk symptoom is waarbij vele factoren een rol kunnen spelen. Ook Jaap Fransen wil ik bedanken. Ondanks dat onze samenwerking uiteindelijk helaas niet verder ging, heb ik erg veel van je geleerd waarvoor mijn dank.

Vervolgens wil ik bedanken mijn kamergenoten. Te starten bij Toine Smiet op afdeling hematologie. De gesprekken met jou waren voor mij altijd waardevol en getuigden van een grote mensenkennis. Ook jij hebt me altijd gestimuleerd om door te gaan met onderzoek. Daarnaast Carin Potting. Samen hebben we ons best gedaan binnen het verpleegkundig onderzoek: artikelen, presentaties, brieven etc. Jouw kritische kijk op de wereld heeft mij vaak laten zien hoe ik het een en ander ook anders zou kunnen doen. Dank daarvoor! Dan Mirjam Tromp, mijn volgende kamergenoot op afdeling EOV. Een jonge en frisse kijk op een onderzoekswereld waarin jij startte en ik al een stukje verder was. Jouw heldere en concrete aanpak van zaken gaven mij weer een nieuwe impuls. Weer iets om van te leren. Hoop dat we onze kamer nog lang mogen delen en dat ik heel snel ook bij jouw promotie aanwezig mag zijn.

De managers zorg Mieke Walenkamp en Ineke Rots wil ik bedanken voor de ruimte die ze me gaven om daar waar mogelijk tijd te besteden aan dit onderzoek binnen de functie van beleidsmedewerker en verpleegkundig expert.

Hoofdverpleegkundigen van de afdeling Reumatologie, Anita van Rossum en Peter Verbroekken (a.i.) wil ik bedanken voor hun ondersteuning en het mede vorm geven van de functie van verpleegkundig expert binnen de afdeling Reumatologie. Alhoewel mijn onderzoek zeker niet alleen klinisch was gericht hebben jullie mij toch altijd de kans gegeven om onderzoek naar vermoeidheid bij RA patiënten vorm te geven.

Daarnaast natuurlijk Ria van Mierlo, hoofdverpleegkundige van afdeling E30. Ongeveer gelijktijdig startten we onze functies binnen het CIS en eigenlijk toevallig mocht ik vanaf de start van mijn functie op jouw afdeling projecten begeleiden en werd ik in 2008 ook verpleegkundig expert op jouw afdeling. Jouw warme belangstelling, ondersteuning en coaching hebben mij mede de mogelijkheid gegeven om te groeien en te komen op de plek waar ik nu sta.

Dan de PhD groep en allen die mij in een promotietraject binnen Verplegingswetenschap in Nijmegen zijn voor gegaan, Lilian, Erik, Maud, Marian, Monique, Maria, Marian, Peter, Anke, Getty, Ingrid, Mark, Anita, Betsie, Gerda, Marie-José, Maaike, Jacqueline, Greet, Ruud en Maarten. Het bespreekbaar maken van diverse onderwerpen en methoden van onderzoek inspireerden mij ook weer voor mijn onderzoek.

Verder natuurlijk alle RA patiënten die, vaak tot mijn eigen verbazing, altijd weer bereid waren om deel te nemen aan onderzoek naar vermoeidheid. Zonder hen was mijn promotie niet mogelijk geweest. Vervolgens ook alle reumaverpleegkundigen in Nederland en de UK en de Nederlandse Reumatologen die mijn onderzoek naar kennis, attitude en huidige zorgverlening t.a.v. vermoeidheid mogelijk hebben gemaakt. Een speciaal woord van dank is hiervoor op zijn plaats voor Sarah Hewlett die door mijn vragenlijst gemotiveerd werd om vanuit de UK ook deel te nemen aan mijn onderzoek, mij vervolgens ook nog stimuleerde om subsidie aan te vragen voor een "Educational Grant" bij EULAR waardoor ik een bezoek kon brengen aan de onderzoeksgroep in Bristol. Haar motivatie, enthousiasme en kennis m.b.t. het onderwerp vermoeidheid gaven mij een enorme impuls om door te gaan. So, Sarah thank you for inspiring me. The visit to Bristol was for me a challenge to continue research on fatigue.

Ellis de Groot-Vos, Jacqueline Deenen, Joke Alberts-Pijnenborg en Carine Vogel, wil ik bedanken voor de kennis die ze met me gedeeld hebben t.a.v. Reumatoïde Artritis maar ook voor de ruimte voor een praatje op jullie kamer als ik weer eens vragen had. Aggie Smetsers wil ik bedanken voor alle taalcorrecties. Vol enthousiasme ging je telkens weer aan de slag en binnen afzienbare tijd had ik alles weer terug. En natuurlijk ook Jolanda van Haren, die met een kritische blik alles wat ik op papier had gezet voor mijn proefschrift bekeek en het geschikt maakte voor de manuscriptcommissie.

Alle vrienden, kennissen en familie wil ik bedanken voor de steun maar nog belangrijker voor de broodnodige afleiding, Annemieke, Martha, Anneke, Tante Truus en Tante Nel.

Tot slot maar eigenlijk natuurlijk op de allereerste plaats mijn ouders. Zij hebben mij dit leven gegeven en de ruimte en mogelijkheden om me te ontwikkelen. Beiden stonden achter mijn keuze voor de opleiding tot verpleegkundige waarmee ik in de voetsporen trad van mijn moeder. Mijn vader zei echter altijd "jij kunt veel meer". Hij heeft mijn studies en deze promotie helaas niet meer kunnen meemaken maar hij heeft wel gelijk gekregen! Mijn moeder heeft me haar hele leven gesteund als moeder en als vriendin bij alles wat ik deed maar ook zij heeft helaas deze laatste stap niet meer mogen meemaken. Wat zouden ze trots zijn geweest!
Etelka en Elaine, mijn schoondochters en Gijsje, Zaza en Moos, mijn kleinkinderen, bedankt voor alle steun, waardering en leuke en lieve momenten met jullie.
Mijn beide zonen die vandaag hier naast me staan als paranimf, een betere keuze had ik hierin niet kunnen maken. Dank voor jullie liefde, interesse en waardering en voor al het andere wat jullie mij geven.

En tenslotte Theo, geschenk van God! What is in a name? Heel veel dus! Je was er altijd voor me, dacht met me mee en stimuleerde mij ook als ik het soms moeilijk of druk had. Beiden zijn we workaholics maar ook dat heeft me gesteund en gestimuleerd om door te gaan. Daarnaast straalde je al die tijd rust uit, een rust die ik vaak zelf niet kon vinden en samen vulden we onze vrije tijd in met dingen waarvan we genoten en die het mogelijk maakten om op maandag weer enthousiast aan de slag te gaan. Laten we vooral blijven genieten van elkaar, onze zonen, schoondochters en kleinkinderen want daar gaat het in het leven toch eigenlijk om. Mijn dankwoord begint met Theo en eindigt er ook mee. Dat kan geen toeval zijn!

Han

F
A
T
I
G
U
E

CURRICULUM VITAE

Han Wuts werd op 13 januari 1952 geboren in Horst. Na het behalen van haar diploma aan de Middelbare Meisjes School (MMS) in Venray (1970) startte zij haar verpleegkundige carrière met de inservice opleiding tot verpleegkundige aan het UMC St Radboud te Nijmegen (UMCN). Na haar diplomering (1974) werkte zij als gediplomeerd verpleegkundige op de afdeling gynaecologie van het UMCN.

Na een onderbreking van 5 jaar, waarin zij het leven schonk aan twee zonen, hervatte zij in 1980 haar functie als verpleegkundige binnen het UMCN. Vervolgens werkte zij 20 jaar als kinderverpleegkundige. In die periode volgde zij de opleiding tot kinderverpleegkundige (1987), de docentenopleiding (1989) en de tweedegraads lerarenopleiding verpleegkunde (1990), waarna ze bijna twee jaar werkzaam was als praktijk-theoriedocente aan de opleiding tot kinderverpleegkundige.

In 1995 startte zij met de deeltijdopleiding Verplegingswetenschap in Maastricht welke zij in 1999 met succes afsloot. In 2000 werd zij beleidsmedewerker en verpleegkundig onderzoeker binnen het Cluster Inwendige Specialismen van het UMCN. In haar functie als beleidsmedewerker begeleidde zij de projecten 'Methodisch Handelen', de ontwikkeling en implementatie van 'het ziekenhuisbrede verpleegkundig dossier' en de 'Functiedifferentiatie'. Op afdelingsniveau begeleidde zij binnen de specialismen Hematologie, Oncologie en Reumatologie het project "Continuïteit van zorg tussen kliniek en polikliniek" en binnen de afdeling Reumatologie gaf zij ondersteuning aan het project ter verbetering van informatievoorziening aan Reumapatiënten die worden opgenomen voor een operatie.

In 2004 werd zij verpleegkundig expert binnen de klinische afdeling reumatologie en vanaf 2008 vervult zij deze functie ook binnen de klinische afdelingen medische oncologie, endocrinologie, nucleaire geneeskunde en algemene interne geneeskunde. Binnen haar functie als verpleegkundig expert Reumatologie verrichtte zij onderzoek naar vermoeidheid bij patiënten met Reumatoïde Artritis (RA). Dit onderzoek resulteerde in de totstandkoming van dit proefschrift.

Han is lid van SWORA (Sociaal Wetenschappelijk Onderzoek bij patiënten met Reumatoïde Artritis), VNO-CHROVER (Vlaams-Nederlandse Onderzoeksgroep, Chronische Vermoeidheid) en V&VN (Verpleegkundigen en Verzorgenden Nederland; afdeling Reumatologie en Wetenschap in praktijk). Sinds september 2008 is zij bestuurslid van V&VN Reumatologie.

Han Repping-Wuts woont in Grave en is sinds 1973 getrouwd met Theo Repping. Samen hebben ze twee zonen: Sjoerd (Amstelveen) en Jorik (USA), twee schoondochters: Etelka en Elaine en drie kleinkinderen: Gijsje, Zaza en Moos.