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Challenge of rare diseases for health care professionals

Jaana Hirvonen is the new editor of EULAR AHP newsletter. Ulla Nordenskiöld, the former editor, left a great legacy to build on.

Everyone working in the realm of musculoskeletal disorders may have met many people suffering from rheumatoid arthritis or fibromyalgia, but how many has encountered a person suffering from Ehlers-Danlos syndrome or scleroderma? Does it make any difference whether a person suffers from an ordinary or a rare rheumatic disease? Does the rarity of a disorder somehow affect the way in which a patient is encountered or services are organised?

People suffering from rare diseases encounter a higher than average number and rate of challenges related to diagnostics, care and coping with the disease. Diagnoses are often delayed and effective treatments are missing for many rare diseases. The number of units specialised in the care of these diseases is small or they are located far away. Up-to-date information expressed in plain language is either non-existent or difficult to find, and other persons suffering from the same disease may perhaps never be met, and yet it is precisely access to information and peer support that have emerged as especially important issues in service need queries put to people suffering from rare diseases.

What amounts to rare?

Rare diseases are a heterogeneous group. The estimated number of them is from six to eight thousand. Even though the number of people in individual diagnosis groups is not great, even as many

as 6 % of Europeans are estimated to suffer from some rare disease taking into account all diagnoses. There is, however, no standard definition for rare disease as yet. According to the most common definition, applied in the EU, a disease is considered to be rare if the maximum number of people suffering from it is five per a population of ten thousand. In the Nordic countries the criterion used has been stricter: one per a population of ten thousand. In addition to occurrence, the definition provides that, in addition to its rarity, the disease hampers daily life – the mere "exotic" diagnosis is not enough. Indeed, rare diseases are, by nature, often chronic, systemic, and progressive if not treated efficiently, and may even be causes of premature death.

Need of action plans

The special needs of people suffering from rare diseases have gradually raised awareness in various parts of Europe. When organising various service entities and operations such as care paths and peer support to people suffering from rare diseases, a more aware and systematic working method is needed than is the case for the major diseases affecting the general population. Service must possibly be concentrated in few care units, for some diseases expertise can perhaps be found only in a few units in all Europe. A person suffering from a rare disease may also slip through the net in social security issues; an effective drug may not be

Editorial office:

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 Layout & printing work: Heikki Hjelt. Markkinointipörssi Oy. Helsinki, Finland

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On the cover: Rehabilitation at Klinik Valens Rehabilitation center in Switzerland.

compensated for the treatment of a rare disease as it is for some more common disease, in which case the person suffering from a rare disease must pay a higher rate for the medication. Special action plans are needed for securing the care, social security and quality of life of people suffering from rare diseases. The development is most advanced in Norway where rare diseases and care rights of people suffering from them were defined in the legislation already some years ago. Action plans have been carried out in other countries, too, such as in France and Portugal.

EU and Rare diseases

The status of people suffering from rare diseases has been under consideration also in the European Union. A public consultation document has been prepared for summing up the elements of the EU policy concerning rare diseases and for facilitating the possibilities of patients to get access to appropriate and prompt diagnosis, care, and information. The goals section of the document presents 14 questions e.g. about the classification of rare diseases, availability problems of rare medication, and recommendations concerning social and education services. The Commission expects answers to the questions, from people interested in the matter, by 14 February 2008 – Valentine's Day. Does your work community have thoughts about developing services to people suffering from rare musculoskeletal disorders? It pays to influence, now it is possible on the European level. The document can be found at http://ec.europa.eu/health/ph_threats/non_com/cons_rare_dis_en.htm.

Another important date will occur in February. On the leap day, 29 February 2008, the 1st European Rare Disease Day will be celebrated with the motto "A rare day for very special people." The day is co-ordinated by Eurordis, European Organisation for Rare Diseases. The goal is to promote the status of people suffering from rare diseases and to raise awareness about rare diseases by means of various media campaigns and events in various parts of Europe.

It is great that Europe is becoming increasingly aware of the special needs of people suffering from rare diseases. Ultimately the people who suffer from rare diseases crave for the same things as those suffering from any disease: timely, competent and multidisciplinary care, and support and resources for coping with the disease. These are familiar and basic thoughts also to the Allied Health Professional operation.

Jaana Hirvonen
Editor



Examples of rare rheumatic diseases

- Ehlers-Danlos syndrome
- MCTD
- Myositis
- Relapsing polycondritis
- Scleroderma
- (Adult onset) Still's disease
- Vasculitis: for instance Takayasu Arteritis, Wegener Granulomatosis etc.

Web sites dealing with rare diseases:

- www.eurordis.org (English, French, German, Italian, Portuguese, Spanish)
- www.orpha.net (English, French, German, Italian, Spanish)
- www.rarelink.dk (Danish)
- www.rarelink.se (Swedish)
- www.rarelink.no (Norwegian)
- www.rarelink.fi (Finnish, under construction)
- <http://iier.isciii.es/er/> (Spanish)
- <http://www.cafamily.org.uk/dirworks.html> (English, UK based)

In this Issue

The special theme of this EULAR AHP newsletter is co-operation and communication in their broad sense. Topics include e.g. a doctoral thesis about the use of IT technology in multidisciplinary interaction, and a multinational project about people suffering from osteoarthritis as trainers of health care professionals. This issue also introduces three national Allied Health Professional organisations and discusses preparations of the Paris congress. Enjoy your reading! The editors are glad to hear from story tips about interesting perspectives to multidisciplinary work and about ongoing research projects and projects developing rheumatic care.



The art of multidisciplinary teamwork?

Mobilizing the planet – EULAR on its way towards 2012

ULLA PALONEN-TIKKANEN



Peter Oesch is a member of EULAR Executive Committee.

According to EULAR's Executive Committee: "EULAR gathers together the most diverse and talented people in the rheumatology world. Many of our members have created major advances in our field. Our scientists and doctors, together with our clinicians, healthcare professionals, patients, and supporting staff have made extraordinary work possible. Few disciplines have achieved so many changes in recent years. Diseases are now modified. People experience mobility where

before there was morbidity.

But how are we going to create the next major step? What is the best way to channel our efforts?

We have created a platform of eight areas in which we think effort could best be focused. Some are purely medical, such as finding new solutions to old diseases. Some are political: gaining awareness, recognition and resources from the wider public. Others are more about how we work. We want to see more collaboration across professional bodies, and also international borders. We want our discipline to become the most attractive to young minds.

After all, if we don't mobilize the planet, who will?"

Under the leadership of the EULAR President, Professor **Ferdinand C. Breedveld**, EULAR is defining its objectives and goals for the next five years. In early 2007, the EULAR Executive Committee defined eight overall objectives for EULAR to achieve by 2012.

The AHP are, as topical subgroup, part of this strategy planning process. Under the leadership of **Peter Oesch**, a first draft of AHP goals supporting the EULAR overall objectives was defined (see EULAR Health Professionals' news Vol.8, No 1/2007, p.3).

On September 28th and 29th 2007, the EULAR strategy workshop with the aim to review the drafts of the 13 subgroups was held in Zurich. The AHP goals were then well received and will be considered by the strategy implementation teams reviewing EULAR's

activity portfolio in order to reshape and refocus it for the years to come. Already in early 2008, the Executive Committee will be able to approve a first set of specific projects and measures in the field of rheumatology that will contribute to further "mobilizing our planet".

The AHP goals within the EULAR strategy

First steps to achieve the defined AHP goals have already been taken. One of the AHP's aims is to achieve a closer partnership with international health professional's organisations. We had the pleasure to have **Karen Kerr**, President of the Association of Rheumatology Health Professionals (ARHP) attending our Standing Committee Meeting and Scientific Committee Meeting in Barcelona. In return, the EULAR AHPs were invited to the ARHP international relations luncheon held during the ACR meeting in November 2007. We were there represented by Professor **Kristina Opava** from Sweden. Professor Opava is a very well-known international researcher in the fields of rheumatology and member of the AHP scientific committee. We are very happy that Professor Opava volunteered to represent the EULAR AHP at the ACR. As a result from these initial contacts, it was decided to have one representative in either congress planning committees. The practical details will be discussed in December 2007 and should take place for the planning of the Copenhagen congress programme 2009. We also want to establish closer relations with other international health professional organisations. A next step can hopefully be taken by Peter Oesch representing the EULAR AHP at the next CARE conference held in Oslo from 23rd to 25th of April, 2008.

However, we also want to establish closer relationships with European AHP organisations. Further improvements were already possible here! It is our pleasure to announce two more official health professional member organisations within EULAR. The EULAR General Assembly held in June 2007 accepted the Swedish Rheumatology Forum SveReFo and the Netherlands Health Professionals in Rheumatology as new member organisations. In this newsletter, you will find more information on some of our official member organisations. Together with the national AHP organisations, we also intend to share a booth at the next EULAR congress in Paris 2008. This will allow them and us to get in a personal contact with the attending AHPs and hopefully stimulate our colleagues from other countries to establish their own national organisation.

A further goal of the AHP within the EULAR strategy 2012 is to have working groups developing products, such as educational courses, publications, policies,

recommendations for care, etc. The AHP Educational Committee is well on its way with the development of the “teach the teachers course”. The other working group is the AHP Scientific Committee which will meet for two days in January 2008 in Zurich. The aim of this meeting is to further establish the annual congress planning and to work out a long term plan regarding the AHP congress programme content as

well as to discuss the feasibility of joint research projects. The goal is to have AHP research projects ready for presentation to the EULAR Executive Committee to be considered in its strategy to mobilize the planet!

Peter Oesch
AHP Vice President

Which future role shall the AHP Committee have within EULAR?



EULAR Secretariat staff members from the left: Education Programme Coordinator Caroline Pasche, Congress Manager Ernst Isler, Executive Assistant Anja Schönbächler, Finance Coordinator Marie-Louise Huwiler, Executive Director Heinz Marchesi and former Executive Director Fred Wyss. Also Project Coordinator (Social Leagues) Florian Klett is a member of the staff.

Allied health professionals in rheumatology have made significant progress within EULAR in recent years, both in terms of membership as well as programming. During the relatively short two-year period I have been with EULAR, I have seen that the AHP Committee is a very active body; one that is willing to shape and strengthen the position of allied health professionals in Europe by acting as initiator, enabler, and developer of activities in various fields. At the General Assembly in Barcelona, again two new AHP associations (Netherlands and Sweden) could be welcomed to the EULAR family. We would like to interpret this enlargement of the AHP community as a first step towards a truly pan-European membership. Still, compared to scientific associations and patient organizations, the allied health professionals have by far the smallest number of member countries in EULAR. More efforts are needed. We do hope, therefore, that the current momentum will stay and inspire health professionals in other countries to apply for membership. No doubt, this would also strengthen the AHP Committee: if it can count on affiliates from more countries, it will have a better base to broaden its activities and include more talented people in its programmes.

Educational activities are ranking high on the agenda of the EULAR Health Professionals. Right now, a major new project is being prepared: an international post-qualification course aimed at nurses, occupational therapists, and physical therapists in Europe. The newly founded AHP Scientific Committee is also making special efforts to develop an attractive AHP programme for the EULAR congress that caters to the diversity of skills and interests of health professionals in various countries. The AHP programme for the 2008 congress in Paris is the largest ever. Rightly so: the fact that the number of AHP participants at EULAR congresses has almost doubled since 2001 is good evidence that there is substantial interest in AHP sessions. With these achievements and activities, the health professional community has laid a foundation for a prosperous and meaningful future within EULAR. Strategically, goals and objectives have been set for the five-year period 2008 to 2012. Special focus is on education, recommendations for treatment and the further development of the international AHP network. The EULAR community will support you in making it happen.

Heinz Marchesi
EULAR Executive Director

Introducing national AHP organisations

BHPR



British Health Professionals aim to promote the role of the multidisciplinary teamwork.

A new milestone in the history of EULAR is the official membership of national health professional organisations in rheumatology. The organisations work closely with the EULAR Standing Committee of the Allied Health Professionals to achieve its aims and objectives. EULAR's Allied Health Professionals have four national organisations as members: the British Health Professionals in Rheumatology (BHPR), the health professionals in rheumatology Switzerland (hpr), the Netherlands Health Professionals in Rheumatology (NHPR), and the Swedish Rheumatology Forum (SveReFo). In the following, three of these member organisations are introduced.

The British AHP organisation

British Health Professionals in Rheumatology (BHPR) was founded in 1985. The organisation is a charity and represents all health professionals in rheumatology including nurses, occupational therapists, physiotherapists, podiatrists, and rheumatologists to name but a few. The primary aim of BHPR is to promote the key role of the multi-disciplinary team in delivering best quality care for people with musculoskeletal conditions. It also aims to support health professionals and allied care workers in their roles as members of the multi-disciplinary team. BHPR informs, influences and facilitates health policy and practice to ensure that the needs of people with musculoskeletal conditions are met. Although BHPR is a viable and effective organisation with its own unique identity, it is closely associated with the British Society of Rheumatology (BSR). BHPR has eight elected committee members and a number of associate members representing other organisations such as the Chartered Physiotherapists Association, Occupational Therapy

Association, The Royal College of Nursing Rheumatology Nursing Forum, and the Podiatry Association. At present, BHPR has approximately 550 members, all of whom pay a small yearly fee. The close relationship with the BSR allows BHPR to share their administrative staff and offices, and they also share a chief executive. BHPR has a representative on all BSR committees and each year, one major conference is held jointly in the spring. Although they have their separate sessions they also have joint sessions and all sessions can be attended by BHPR or BSR members. The two organisations have jointly published a number of guidelines including the Management of Rheumatoid Arthritis (the first 2 years) and the Management of Hot Swollen Joints in Adults. In addition to its conferences, the BHPR produces Newsletters each year, and in 2005 launched its website in collaboration with the BSR. This can be found by visiting www.rheumatology.org.uk and then clicking on the BHPR tab on the left-hand side. BHPR also offers a number of prizes and bursaries for its members to attend conferences both in the UK and abroad. Recently, a number of applications have been received from health professionals from Europe and even Hong Kong, and BHPR would welcome even more applicants with open arms! Information can be found on the website.

AHP a division of Dutch society for rheumatology

To be better able to reach common objectives, the Netherlands Health Professionals in Rheumatology



Position of NHPR within the Dutch Society for Rheumatology, DSR

In NHPR, there are 220 members in Nursing section, 76 in Physical therapy, 27 in Occupational therapy, 10 in Social work and 16 members in the Psychosocial Research section.



The beautiful view from Interlaken's world famous Jungfrau distracted attention just slightly from the interesting hpr congress program dedicated to soft tissue disorders.

(NHPR) was established as a new division of the Dutch Society for Rheumatology (DSR). Although within the DSR, a good cooperation existed between the rheumatologists and the five health professional sections, the five sections as well as the rheumatologists considered it desirable to give the health professionals a clearer profile. Since 2005, the NHPR brings together health professionals from the sections of Nursing, Physical therapy, Occupational Therapy, Social Work, and the interdisciplinary working group called Psychosocial Research of Rheumatic Diseases. The new division strengthens the cooperation between health professionals which has been increasing in the past years.

The main goals of NHPR

The aim of the NHPR is to organize disciplinary and multidisciplinary activities aimed at the enhancement of prevention and early detection of rheumatic diseases as well as the enhancement of high quality treatment, care, and education of patients with rheumatic diseases. The NHPR will reach this goal by enhancing the knowledge and skills of health professionals, promoting cooperation and exchange of knowledge within and between health care disciplines, and managing and disseminating information about research, care, and education. NHPR organizes Educational as well as Scientific Meetings and publishes a newsletter in the Netherlands Journal of Rheumatology. In the future, NHPR plans to start a Educational development project to find out the present educational needs in order to better formulate of professional and educational standards and then implement and evaluate these new standards. NHPR will also develop a website for maintaining and disseminating information and strengthen of international cooperation of health professionals within EULAR. During the last EULAR congress, the NHPR was ratified as a member of the EULAR by the General Assembly.

The allied health professionals in Switzerland

The health professionals in rheumatology switzerland (hpr) founded in September 2004 is a relatively young association of health professionals in rheumatology. Nevertheless in 2006, it became, together with the British Health Professionals in Rheumatology (BHPR), the first official AHP member organisation in EULAR. It also cooperates with the Social League Switzerland, the Swiss Society for Rheumatology, and the Swiss Society for Physical Medicine and Rehabilitation. The objectives of the hpr switzerland are to optimize the treatment and care of rheumatism patients and to promote an interdisciplinary team approach. It is guided in this objective by scientific principles and by the professional ethics of the professions involved. hpr switzerland fulfils its objective by supporting healthcare professionals involved in rheumatology. The hpr switzerland organises an annual joint conference with the Swiss Society for Rheumatology and the Swiss Society for Physical Medicine and Rehabilitation. This year's conference was held in the town of Interlaken at 30th of August 2007. A joint session was held in the afternoon on "Molecular and cellular basis of pain – Novel aspects for therapeutic interventions" followed by an hpr abstract session and the award ceremony for the annual poster prize. The hpr switzerland were able with the help of the sponsor ABSORIN Switzerland to award 1000 SFr. for the best poster presented. Winner of the poster prize 2007 was **Roger Hilfiker** and his scientific team with their work titled "Improving a home-based balance exercise programme by means of Rasch analysis" (more on page 13).

The contact information of the national member organisations:

www.eular.org/member_health_professionals.cfm



John Verhoef is the Chairman of EULAR Standing Committee of the Allied Health Professionals in Rheumatology.

Is using a rehabilitation tool mediated by Information Technology the answer to more effective patient care and teamwork?

THESIS BY JOHN VERHOEF, LEIDEN UNIVERSITY MEDICAL CENTER, NETHERLANDS



Rheumatoid arthritis (RA) is an autoimmune disease affecting approximately about one percent of the adult population in the Western countries. Despite advances in medical treatment, RA requires the services of various health professionals, e.g., rheumatologists, nurses,

physical therapists, occupational therapists, and social workers. Ideally, all physicians and health professionals involved are systematically coordinating their activities to maximize the continuity and cohesiveness of care. In daily practice, access to comprehensive arthritis care and the coordination of services are often insufficient.

Name of the thesis: Integrated Care for Patient with Rheumatoid Arthritis, 2007

Objectives:

1. To describe the feasibility of a system of networks and continuing education for primary care physical therapists as regards arthritis care.
2. To evaluate the impact of the introduction of a rehabilitation tool (the Rehabilitation Activities Profile; RAP), including a computer application, in multidisciplinary team care in rheumatology with respect to clinical effectiveness, patient satisfaction, team members' satisfaction and measurement properties.
3. To develop and apply a measurement instrument to evaluate the communication during multidisciplinary team conferences in an arthritis team care setting.

Design: Descriptive study (feasibility study regional network implementation) and pretest posttest design (implementation of the RAP).

Setting: Day patient and inpatient wards of a rheumatology rehabilitation clinic.

Subjects: Patients admitted to both wards and members of two multidisciplinary teams.

Main measures: Patient-oriented measures of functional ability, measures of physical and mental functioning, quality of life, disease activity, patient satisfaction, team functioning, and team satisfaction.

Read the whole thesis:

www.openaccess.leidenuniv.nl/dspace/bitstream/1887/12300/5/fulltext.pdf

A shortage of specialized health care practitioners and facilities and increasing cost-constraints in health care are creating challenges for arthritis care. Many countries are beginning to develop new models for arthritis care involving information technology, educational interventions, patient-initiated care, and extended roles for health professionals.

In the thesis, an arthritis care model concerning a system of networks and continuing education for physical therapists in primary care is described (in this article this will not be further elaborated). Furthermore, the thesis focuses on the evaluation of the introduction of a rehabilitation tool, the Rehabilitation Activities Profile (RAP), including a computer application in multidisciplinary team care. The process of communication has an essential role in effective teamwork. Further research is required as regards the definition and measurement of mutual understanding in different situations, as well as the relation between the communication measures (process assessments) and the outcome measures. This thesis presents an elaborated case study, offering a clear example of an approach into the importance of fluent communication.

Clinical outcomes versus patient satisfaction and team satisfaction

This thesis contains a study comparing the impact of the use of an International Classification of Functioning, Disability and Health (ICF)-based rehabilitation tool (RAP) on clinical effectiveness and patient satisfaction in a rheumatology

multidisciplinary team care setting. Overall, patients improved significantly between admission and discharge and between admission and six weeks after discharge; however, there was no significant difference between the improvements in the two periods. Patient satisfaction was significantly higher in the period after the introduction of the RAP; however, the absolute difference was small. It was concluded that in RA patients admitted for multidisciplinary team care, the introduction of the RAP did not change clinical effectiveness but had a modest beneficial impact on patient satisfaction.

With respect to the impact on the health professionals involved, the process of communication, team functioning in general, and the administrative workload appeared to be influenced, with conflicting results for the two multidisciplinary teams involved in the study. In the day patient setting, the introduction of a rehabilitation tool had a positive effect on team members' satisfaction with team functioning and team conferences, whereas in the inpatient setting, the effect was absent or the opposite.

The mixture of results pertaining to different outcome measures and two different settings (day patient and inpatient) make it difficult to draw a firm conclusion on whether the usage of the rehabilitation tool should be recommended in rheumatology rehabilitation settings. With respect to its impact on staff satisfaction, the clear distinction between its impact on team functioning and team satisfaction with conferences in the inpatient and day patient setting indicate that a rehabilitation tool such as the RAP is more suitable for a "true" rehabilitation setting than for an inpatient nursing ward. In that respect, it needs to be borne in mind that economic considerations are also important to outweigh the advantages and disadvantages of interventions in health care.

Considerations should also include an analysis of factors that may have played a role in the lack of clinical effectiveness among patients and conflicting experiences among health professionals. With the RAP it is predominantly focused on the ICF level of Activities and Participation, however, the spectrum of

problems encountered by patients with RA is broad, and includes a number of aspects on the level of Body Functions, Body Structures, Environmental and Personal Factors as well. Limitations and problems on the level of Activities and Participation must always be seen in connection with the other levels of disease consequences, so that the focus of the RAP may be too narrow. The RAP in its present form may, therefore, be less suitable for the monitoring of progress and evaluation at discharge in settings in which admissions are brief. All of these reflections point into the direction of consideration of adjustment of the contents of the RAP according to those areas that have been previously identified to be relevant by patients with RA and expert health professionals and to the rehabilitation setting in which it is to be used. In this respect, it could be worthwhile to study the qualities of other rehabilitation tools.

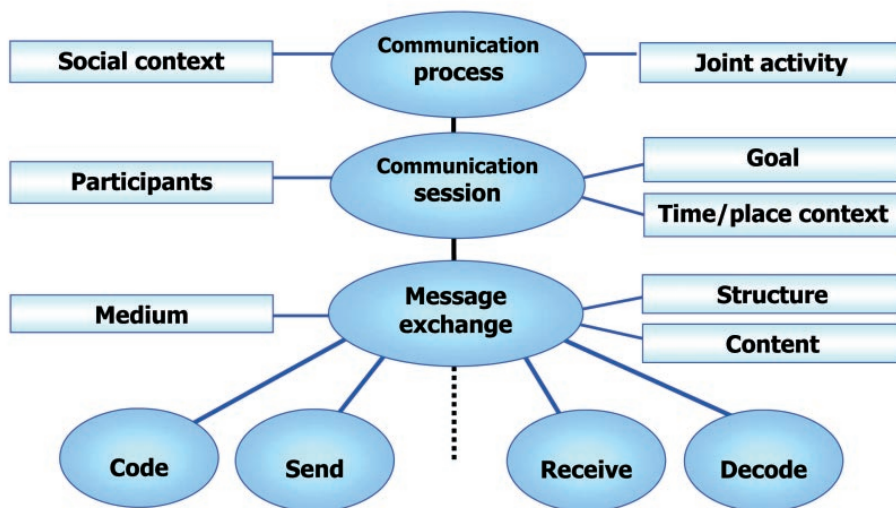
The impact of Information Technology in health care

In this thesis, we assessed the impact of information technology (IT) by focusing on the way it changed communicative behaviour in a well-defined setting. In general, we can say that changing communicative behaviour is one of the major effects of the usage of IT in an organizational setting. The impact on communication can be assessed by taking into account both its efficacy as well as its efficiency.

Concerning Te'eni's observation that the main goal of communication is to achieve mutual understanding, it could be hypothesized that the level on which this is achieved determines the efficacy of the communication. This leaves us with the problem of defining and measuring mutual understanding. In this thesis, we have based our judgment on the efficacy of the team conference communication on the proposition that mutual understanding is achieved when team members are able to agree on common treatment goals. The analysis of the communication during multidisciplinary team conferences demonstrated that in the rheumatology setting, the introduction of a rehabilitation tool with accompanying IT application facilitated the process of mutual agreement on treatment goals.

Efficiency of communication boils down to the effort and time it takes to reach mutual understanding. In this thesis, we have assumed that a team conference – a face-to-face meeting that consumes considerable time from the health professionals – should be used primarily for discussing and negotiating common team goals. All other communication activities, such as informing each other about the patient's health status, should be as limited as possible. This implies that other means must be sought for exchanging information on the patient. In our case, we

Decomposition of the communication process by Te'eni and Clark



made this exchange asynchronous, by mediating it by using an IT-application. This enabled health professionals to assess and register the information at a time and place that would best suit them. Indeed, for the initial team conferences, the proportion of time spent on grounding decreased significantly. Grounding can be defined as achieving a shared view of the current health status of the patient, such as a description of the severity and extent of disease activity and the presence of comorbidities. This thesis demonstrated that especially for the initial team conferences in which,

before the introduction of the RAP and accompanying IT application consigned for a considerable part of information exchange, transference of the process of information exchange was indeed accomplished. In our view, outcome measures, such as patient satisfaction or improvement of health status or health professionals' judgments of team functioning and team conferences, are indirect measures for the impact of IT. This impact must also be assessed in terms of both the efficacy and efficiency of the communication processes it affects.



Promising future for collaboration

PARE (EULAR standing committee of people with arthritis/rheumatism in Europe) has started an important restructuring process. One of the purposes of this process is to create better conditions for a closer collaboration with other parties of EULAR. PARE is convinced that new partnerships are necessary for establishing patient centred health care services that enable people with arthritis to lead full and independent lives.

One way of doing this is by increasing the incorporation of the patient perspective in all areas of life affecting people with arthritis. Research, patient advocacy, the development of recommendations for the treatment of rheumatic diseases as well as arthritis health care provision are better and more relevant when people with direct experience with living with the disease are involved.

As the vice-president of EULAR PARE, I appreciate the dialogue with the AHP. It is of utmost importance to intensify our collaboration. Organising the so-called Joint sessions at the EULAR congress is a first example of the benefits of working together. There is a common body of scientific and personal knowledge that needs to be shared. By exchanging best practices, patient representatives as well as health professionals can learn from each other. Because health professionals often have a closer and more intensive contact with people with arthritis than clinicians or researchers, this direct communication is most valuable. We hope that our collaboration on a European level will have a spin off in our respective member countries. Patient education and awareness campaigns like World Arthritis Day are

areas in which we would like to cooperate with health professionals.

There are other joint interests: When it comes, for instance, to research of non-pharmalogical interventions like physiotherapy, life style recommendations, self management or the use of aids, it is difficult to acquire sufficient sponsors. Joining forces can help to obtain funding for projects that are highly relevant for patients and health professionals. Patients are starting to contribute to the development of such a research agenda, e.g., during OMERACT, or the CARE-conferences. There is no reason why their involvement should be limited to the phase of identifying research priorities. Their involvement could be furthered also beyond research. In the Netherlands, we have started to collaborate with health professionals in a number of interesting projects. For this purpose, a network of well-selected patient representatives receives training on how to present the patient perspective and on how to contribute constructively to a project. On an international level, we hope to develop a similar network of competent patient representatives that are willing and able to participate actively in international studies, working groups, or advocacy work.

In short, there are plenty of challenges for collaboration between health professionals and PARE. We hope the future will bring promising opportunities to work together more often.

Maarten de Wit
EULAR Vice President PARE



At Leiden University Medical Center, the Netherlands

For ten days in September 2007, I had the opportunity to visit the department of rheumatology at Leiden University Medical Center (LUMC). I work

as a researcher at Spenshult Hospital for Rheumatic Diseases in Halmstad located in the south-west of Sweden, and at the Southern Sweden Musculoskeletal Research Center at Lund University Hospital. My main focus in research is on patient centred outcomes after team care rehabilitation and after surgery. Spenshult Hospital provides both team care and surgery. The aim of my visit to Leiden was to learn more of team care research and to visit Dr **Vliet Vlieland** and her co-workers, Dr Vliet Vlieland being a well known person in team care research worldwide.

People on wheels

When I first arrived in Leiden, I was almost run over by all the fast biking people. I read in my guidebook that 60,000 people pass through the central station in Leiden every week and almost every one of them has got to have a bike outside! I thought the Swedes were biking people – but not compared to the people living in Leiden. Well, after a day or two, I learned to look for bikes instead of being concerned about cars, it just took some practice. I stayed at the International House on the Raapenburg situated on what is supposed to be “the most beautiful canal in the world”. I totally agree.

My visit was arranged by Dr Vliet Vlieland who put a lot of effort into my program. I got to meet with most of the researchers at the department and learned of their studies. But I also met with members from the day care team and physical therapists working in the Rheumatological and Orthopaedic departments, which was of a special interest to me since I myself have worked as a physical therapist for more than 20 years, 10 of them at a rheumatology department. I was impressed by the education provided for physical therapists in primary care to be updated on

Rheumatological treatment. Many of the patients in the Netherlands, as well as in Sweden, will see a physical therapist working in primary care and not always a specialist in the hospital. At LUMC, physical therapists working in primary care have the possibility to attend an ongoing education provided by specialists which has been much appreciated. I was also impressed by the way medical students have a possibility to choose the physical therapy department for education. I will bring these and several more ideas back to Sweden and to the environment I work in.

Team care interventions

I learned more about team care research, problems, and unstudied areas. I was encouraged to go on with the research I am involved in. In Sweden, several rheumatology departments are collecting data for a common register in order to learn more of team care outcome. The major research question is to find predictors for a favourable outcome of team care. While doing this, we will have to study the structure, the process, and the outcome of team care interventions. This means a lot of questionnaires for the patients to fill out at admission, discharge, and follow-ups. I also met with **John Verhoef** who defended his thesis “Integrated Care for Patients with Rheumatoid Arthritis” only a few days before my arrival in Leiden. His thesis is an important contribution to team care research. I met several team members who all appreciated the Rehabilitation Activities Profile (RAP) discussed in Verhoef’s thesis. I would like to thank all the people I met at LUMC for making my educational visit so interesting, Dr Vliet Vlieland in particular and also Professor **Hiziega** for inviting me. Hopefully, there will be some collaboration with LUMC in the future. I would also like to thank the EULAR Standing Committee of Health Professionals for allocating the grant for my educational visit.

Ann Bremander, PT PhD

Certified Specialist in Physiotherapy in Rheumatology R&D Center, Spenshult Hospital for rheumatic Diseases Oskarström, Sweden

Call for abstracts to the CARE V conference 2008

The goal of the CARE organisation is to improve the quality of care in arthritis by

- Providing a forum for international collaboration and support for patient representatives, seasoned and novice researchers and all stakeholders in the arthritis community
- Developing and evaluating models of care
- Initiating international studies on specific issues

The fifth CARE conference will be held in Oslo, Norway 23-25 April 2008.

Allied Health Professionals are welcome to submit abstracts related to the above mentioned topics. Abstract submitters may also apply for a CARE travel grant. A total of 35 travel grants of 500 euro will be assigned to participants with approved abstracts.

For more information see www.rheumacare.org

A solution to reduce the burden of osteoarthritis



Since 2005, the Swedish Rheumatism Association and ten other partners have carried out the Osteoarthritis Communicator (OAC) project with the support of the Leonardo da Vinci programme. The OAC project is working to reduce the burden of osteoarthritis, and it brings together complementary and overlapping competence and experience from physiotherapists, patients and other professional educators to produce innovative methods and new educational material to increase the knowledge on how to take care of osteoarthritis and to find alternative treatments in medical care.

The project ended officially in September 2007 but the co-operation with education and medical care bodies will continue. According to the project co-ordinator **Rolf Greiff**, the programme has been well received across Europe.

– The programme has trained 44 osteoarthritis patients to become Osteoarthritis Communicators in Sweden, Germany, Latvia, Lithuania, and United Kingdom. These uniquely qualified OA Communicators will carry out sessions for physiotherapy students during their training or for physiotherapists during their continuing professional development. We are in discussion with new partners in Denmark and Holland about introducing OACs in their countries, Greiff says. The collaboration partners have presented the project to initial target groups in Europe, participated on international conferences, and lobbied health authorities in different countries.

– We have introduced the programme to physiotherapy training centres and to Rheumatism Associations in Europe. Our dissemination activities focused on 500 key persons within European professional training for physiotherapists, 30 central

figures within European organizations' for rheumatics and 20 decision makers within the European Bone and Joint Health Strategies Project. At the moment our Newsletter has 527 recipients, Greiff proudly reports of the well-planned information strategy.

In the future, the OA Communicators will work closer together with the whole health care sector. This brings the programme into new educational settings, for example, into medical centres, in which the training or continuing professional development of doctors, nurses, physiotherapists, or occupational therapists can take place.

– We have a recruitment programme for OA Communicators and their trainers. If you have osteoarthritis and would like to become an Osteoarthritis Communicator, please contact the coordinator or a partner in your country, Greiff advises.

Trained to train others

The Osteoarthritis Communicators have been trained by expert physiotherapists and other health professionals who themselves were trained at a pilot course in Vilnius, Lithuania in 2006. The education will give an update on Osteoarthritis and considers its causes, symptoms, burden, assessment and diagnosis, risk factors and evidence-based management.

– This programme enables those with osteoarthritis to feel that they are giving something back despite the problems they have from their condition, says **Birgit Rösblad**, the Director of Research and Development at Swedish Association of Registered Physiotherapists (LSR).

She is very optimistic about the impact of the programme since the first OA Communicators are now educated and study materials have been produced.

– This will most certainly improve the quality of the education of physiotherapists.

Physiotherapists now have the opportunity to be educated by people living with osteoarthritis. This will deepen the knowledge and understanding of the disorder, says Rösblad.

The Registered Physiotherapists (LSR) has worked to promote the Osteoarthritis Communicator programme in the national level.

– All activities performed by LSR have been aimed towards spreading information about the project. In Sweden, we have been able to reach more or less all physiotherapists.

Our magazine, *Physiotherapy*, published an article about the project in November 2005. Our magazine is distributed to approximately 11,000 physiotherapists, which represents some 85 per cent of all physiotherapists. Our members have also retrieved more information on our homepage on several occasions, and through newsletters distributed in email, tells Rösblad.

Information has also been disseminated to

representatives from all eight physiotherapy education departments in Sweden. Moreover, keeping the physiotherapy school informed has been considered as an important activity since the OA communicator sessions should be an integral part of the education. – It is crucial that physiotherapists manage the disorder and continue their professional development. The Osteoarthritis Communicators programme is good way to do that, says Rösblad.



Dialogue between the health professionals and patients:

What can the patient do?

- Formulate treatment goals
- Find pleasant activities
- Exercise regularly
- Train with “acceptable pain”
- Evaluate symptoms, function, and activity level

What can health professional do?

- Give individual recommendations about weight loss, exercise, use of painkillers
- Consider the patient’s preferences, goals, and fears
- Give advise about self-exercise
- Motivate to compliance
- Give feedback through evaluation of symptoms, function, and level of physical activity

THE HPR SWITZERLAND’S POSTER AWARD WINNER

Improving a home-based balance exercise programme by means of Rasch analysis

The scientific team members:

Roger Hilfiker, HES-SO, Fachhochschule Westschweiz/Wallis, & Schweizer Paraplegiker Forschung, Nottwil
 Marielle Tschopp, Rehasentrum Leukerbad
 André Pirlet, Rehasentrum Leukerbad

Strength, balance and agility contribute to the reduction of falls. Patients can improve these features with a home-based exercise programme but adherence to such programmes is low. If the difficulty of exercise does not match the capacity of the exercising patient and the difficulty does not increase with the improving patient, he or she will probably not adhere to the programme. A sound progression of home based exercises might improve adherence and effectiveness. Rasch analysis puts the ability of the patients and difficulty of the exercises on the same metric continuum and provides information on difficulty levels and targeting of the exercises. Therefore, we wanted to use Rasch analysis in evaluating the progression of an existing home based test, exercise programme for the prevention of falls.

In the study, 29 healthy persons and 34 patients with musculoskeletal problems performed the balance related exercises and rated the difficulty level of each exercise. In our cross-sectional study, we performed a Rasch analysis to evaluate the targeting of the tests, exercises, and the progression of the difficulty level.

Results and conclusion

The Rasch analysis revealed that the order of the exercises had to be changed. Furthermore, there was a lack of difficult exercises. The test and exercise programme has now been changed and will be submitted to a new set of patients with musculoskeletal problems. The main limitation was the low sample size.

This analysis detected a suboptimal progression of the difficulty levels of the tests & exercises as well as a lack of difficult exercises. The order of the exercises can be improved, based on the information from the analysis but more difficult exercises should be devised by gait and balance experts.

AHP grant and bursaries in 2008

Since 2003, EULAR has awarded research grants for Health Professional research projects in the field of rheumatology. Despite an increased effort to advertise the AHP research grant, for two successive years EULAR has received only 2 applications per grant.

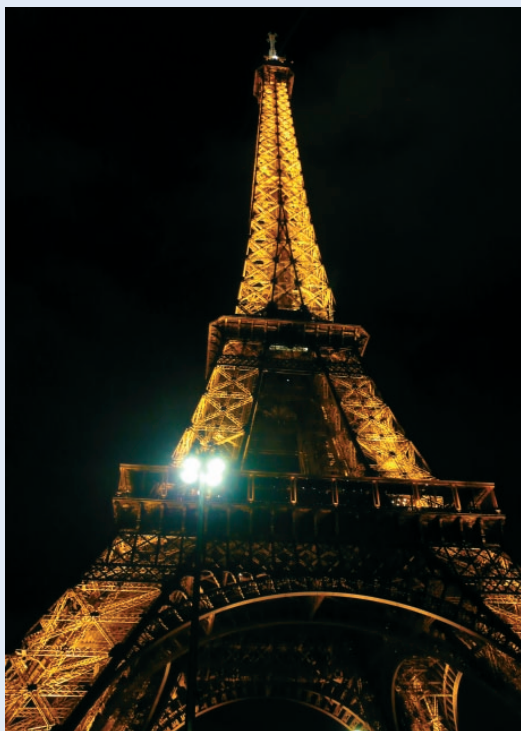
A survey among AHP researchers revealed that distributing this grant over three successive years is a major disadvantage, which prevents them from applying for it. It was, therefore, decided by the members of the EULAR Executive Committee during their meeting in October 2007, to offer an annual grant for an AHP research project of maximal 30,000 without setting a time limit. Grant application forms

are available at the EULAR website (www.eular.ch).

AHP travel bursaries

EULAR offers again travel bursaries for AHPs presenting their work in the congress. These travel bursaries will only be granted for the first author of an accepted oral or poster presentation. The application can be sent before a decision on acceptance of the abstract is made, as long as the reference number is given. The application forms are available at the EULAR website (www.eular.ch). The decision on the approval of the request will not be communicated until spring 2008.

HEIKKI HIELT



The AHP programme at the EULAR Congress 2008 in Paris

Paris will see the largest AHP programme ever, starting on Wednesday afternoon and ending at Saturday afternoon with the AHP highlight session. The programme includes a total of 13 sessions involving EULAR Allied Health Professionals. Four of these are joint sessions with the rheumatologists as well as PARE (People with Arthritis/Rheumatism in EULAR) and nine AHP sessions. There will be oral presentations of submitted abstracts during the invited speakers' sessions. However, there is a new session for purely AHP abstracts in order not to disadvantage abstracts not in line with the planned topics of the invited speakers' sessions. Therefore, this abstract session will be a mix of different topics and will give an excellent overview of the research work done by allied health professionals.

Educational Visits 2008

EULAR awards up to 10 bursaries for educational visits to Allied Health Professionals other than physicians working in the field of rheumatology to enable him/her to carry out an educational visit to colleagues in another EULAR member country.

The amount of each of the bursaries is between € 750 and 1500. The annual total amount granted is € 7500. The objective is to improve the standard of research and care and to foster collaboration across clinical units in Europe. The deadline for applications is **31 March 2008**. Applications should be submitted by e-mail to the EULAR Secretariat at eular@eular.org.

Applications should include a CV with date of birth, objectives of the educational visit, a budget, a written confirmation from the host hospital or institute, and the tentative time frame of the training stay. The application form and the contract to be signed with terms and conditions is available on:

www.eular.org/myUploadData/files/AHP_EducationalVisitContract.pdf

Recipients are required to submit a report to the EULAR Secretariat after the stay, focusing on the results that have been achieved.

The AHP preliminary programme 2008 in Paris

Session type	Session title
AHP invited speakers session	Tailored cognitive-behaviour therapy and exercise therapy for patients with fibromyalgia: Innovative approaches and future directions Overcoming work limitation and joint pain The Foot in Rheumatoid Arthritis Multidisciplinary care and research demonstrated by Systemic Sclerosis Promoting exercise and physical activity in patients with rheumatic diseases: How to begin?
AHP Abstract session	AHP abstract session
AHP Meet the Standing Committee	The AHP teach the teacher course
AHP Highlight session	Highlights of the Allied Health Professional sessions Paris 2008
AHP Workshop	Writing for Publication including how to carry out literature search, write an abstract & write for publication
Joint Session	What and how to Measure Quality of Life - A Team Perspective? Innovative models of delivering care Pregnancy and rheumatic diseases Patient partnership, could we do better?



Abstract submission for Paris Congress 11–14 June 2008

The abstract submission process is open until the 31st of January 2008. Allied Health Professionals can choose to submit abstracts either for practice and clinical care or for Health Professional research work. There have been uncertainties among the AHP research community whether abstracts should be submitted to the scientific topics or to the Allied Health Professionals. The AHP researchers can rest assured that after being submitted as an Allied Health Professional they still can choose all the scientific topics as before. Their abstracts will be reviewed by scientific reviewers and will be selected for oral presentation in a scientific session if they achieve a high score. AHP researchers are still able to display their poster in the associated scientific research topic. The reason to indicate researcher's submission as an AHP is that the AHP Scientific Committee can choose

from all AHP abstracts for oral presentation during the AHP programme. This way it also is easy to count the AHP abstracts submitted to the congress. Thanks to the new abstract submission process, the numbers of AHP abstracts have gone up from 75 in Vienna 2005 to 181 in Barcelona 2007. This is not because there were more AHP abstracts submitted but because the actual figure can be accurately calculated. This figure adds credit to the Allied Health Professionals. Allied Health Professional submitting an abstract related to their practice in clinical care are strongly advised to submit into abstract topics A1 to A5. These abstracts are not in competition with the scientific abstracts. High scoring abstracts can be selected for oral presentation during AHP sessions or will be displayed as posters in the AHP poster sessions.

Topics of the Allied Health Professional abstracts

Practice and Clinical Care

- A1 Nursing
- A2 Psychology / Social sciences
- A3 Physiotherapy
- A4 Occupational therapy
- A5 Miscellaneous forms of clinical care

Health professional research work

CLINICAL TOPICS BY DISEASE

- 07. RA – epidemiology, prognosis and predictors
- 08. RA – other clinical aspects and comorbidity
- 09. RA – anti-TNF therapy
- 10. RA – other biologic treatment
- 11. RA – non-biologic treatment
- 12. SLE, Sjögren's and APS – clinical aspects and treatment
- 13. Vasculitis
- 14. Scleroderma, Myositis and related syndromes

- 15. Spondylarthropathies
- 16. Psoriatic Arthritis
- 17. Osteoarthritis- clinical aspects and treatment.
- 18. Osteoporosis
- 19. Bone diseases other than osteoporosis, metabolic diseases and crystal diseases
- 20. Infection-related rheumatic diseases
- 21. Fibromyalgia
- 22. Back pain, mechanical musculoskeletal problems, local soft tissue disorders
- 23. Management of pain in rheumatic diseases
- 24. Paediatric rheumatology
- 25. Miscellaneous rheumatic diseases

CLINICAL TOPICS BY AREA OF RESEARCH

- 26. Diagnostics and imaging procedures
- 27. Health service and outcome research
- 28. Rehabilitation
- 29. Education

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H E A L T H P R O F E S S I O N A L S