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In recent years there have been some projects in Europe for highlighting the role of patients with musculoskeletal conditions in the training of health professionals. Examples include the Patient Partner project in which patients participated in the training of general practitioners for identifying the early symptoms of rheumatoid arthritis, and the Osteoarthritis Communicator project (OAC), in which people suffering from osteoarthritis participated in the training of physiotherapists.

Similar projects have been carried out in Finland, too. About a decade ago a project was launched for training members of twelve different groups of long-term conditions to give lectures to professionals of the social and health care sector. The activity started in nine localities in eight vocational health care schools and one medical faculty. The experiences were good. Feedback from teachers and students was positive. As is often the case in fixed-term projects, however, the activity faded out in about half of the participating teaching units after the project funding stopped, but in five localities the activity still continues.

Experience in the core

A year ago a new project was launched in Finland with an aim to make this so called experience-based education a systematic part of teaching in all vocational social and health care schools and medical faculties. The project is backed by as many as 24 non-governmental organizations representing,

FROM THE EDITOR

Patients as teachers

For two decades I have worked in various tasks with people suffering from musculoskeletal conditions. During that time I have heard hundreds of stories about how it feels to live with arthritis/rheumatism and what the condition involves in one’s life. I firmly believe that hearing those stories has helped me become a better health professional. Each story has increased my understanding about the effects of the condition, about receiving help, about making lifestyle changes and about the joy when the changes are successful, and – above all – about patients’ wishes on how to be encountered and heard.

Most of us probably remember, perhaps especially from the early days of our careers, patients and clients who have made a great impression on us so we still vividly recall when we first met them. By sharing their own experiences they have given us new insights, summed up issues in such a manner that it has deepened our perspective to the daily life of a patient and thereby to one’s own work as well. Should not all health professionals have a similar opportunity to encounter the patient also as a guide and teacher? At best a patient could offer his/her experiential knowledge already during the early stages of education, to supplement and perhaps concretize the professional knowledge received from other experts/teachers.

From sporadic to systematic

For as long as professional health education has existed, patients have been used to provide concrete examples and demonstrate the subject matter. Especially in clinical training it is important to encounter “real” patients, to consider their symptoms, possible diagnosis and treatment. Patients have given talks during lectures to supplement other teaching. Sometimes the patients have been “interesting cases” found at the ward; sometimes they have been acquaintances of the teacher. All in all, the activity has been sporadic, and the method has not necessarily always been patient-oriented or holistic.

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A year ago a new project was launched in Finland with an aim to make this so called experience-based education a systematic part of teaching in all vocational social and health care schools and medical faculties. The project is backed by as many as 24 non-governmental organizations representing,
for example, musculoskeletal conditions, neurological conditions, sensory disabilities and mental health problems. The aim is to make experience-based education part of the curricula of different professional groups and establish it as a permanent part of teaching. This naturally requires lobbying at the Ministry of Social Affairs and Health, at the Ministry of Education and in various units of the educational administration as well as long-term interaction with rector's and teachers of educational establishments.

One practical obstacle to an expansion of the activity has been that experience-based educators should also get a reasonable pay for their work. Schools often cannot afford to pay even for a travel expenses allowance. Another challenge has been on the level of attitudes: How can we assure that an experience-based educator knows his/her job and that s/he really has something to contribute to the teaching? For example, I recently heard a comment, while explaining the activity to a group of physicians, that if a patient is allowed to talk freely, “s/he will just go on complaining and telling what’s wrong.” This misconception, however, will usually change quickly after becoming familiar with experience-based education.

Certificate as guarantee of quality
To provide assurance about the quality of the operation to the educational administration and teachers, in health care schools and medical faculties alike, a nation-wide certificate is being created for experience-based education and a new training programme is being designed for experience-based educators. The aim is to build the operation on the same principles and quality standards irrespective of the location in Finland. The training programme is designed both by educational professionals and people who have worked as experience-based educators representing various groups of disorders. The training programme is scheduled to be completed during the present weeks after which it will be tested next autumn at five localities. The aim is to train 250 new experience-based educators.

During the project all possible efforts are taken to ensure that the experience-based education will continue even after the project. One of the outcomes of the project will be a web portal containing information with which educational facilities and patient organizations can co-operate to launch and develop experience-based education. Educational establishments will also have access to a data base with contact information of all trained and qualified experience-based educators.

As the project progresses I am increasingly convinced that experience-based education is a great idea and should be part of various curricula, but a lot of work still remains to be carried out. And as we now have rolled up our sleeves, why not promote the issue also on the European level. This could be a great opportunity for a joint European project. Interested? Do not hesitate to contact me!

Jaana Hirvonen
Editor
jaana.hirvonen@reumaliitto.fi

In this Issue
This AHP Newsletter is a special edition which will be in distribution at the EULAR Congress in Copenhagen. We will introduce a wide scale of topics related to health professional work in the field of rheumatic diseases and musculoskeletal conditions. Jackie Hill will highlight a cross-European health professional research project which will further develop a questionnaire called the Educational Needs Assessment Tool (ENAT). Susan Oliver tells about mind mapping as a means to explore the RA patients’ journeys in the health care system. We also have an interview with Milena Gobbo who will discuss a psychologist’s role in the multidisciplinary team. In her article, Christina H. Opava asks if rehabilitation is still needed in the era of biological drugs. We will also introduce an important thesis by Han Repping-Wuts on the impact of fatigue in RA – to mention only a few subjects of this issue. Enjoy the Newsletter!

“You just need to exercise everyday, choose a sport of your liking, follow a special diet, take you meds, work on your psychological issues and stress levels, adapt self-help methods, relax daily, obtain proper aids, furnish and modify the setting at work and at home to your needs, apply for social benefits, discuss the situation with your family and friends, contact peer support, join a patient organization, and set goals for your future – that’s basically it – and you will be good as new in no time.”
Tanja Alexandra Stamm is the Chairperson elect of the EULAR Standing Committee of the Allied Health Professionals (AHP). She was born on the 10th of December in 1973 in Vienna, Austria. She has studied occupational therapy and educational science in Vienna. In 2002, she completed the European Master of Science Programme in occupational therapy which took her to Sweden, Denmark, the Netherlands, and UK. She completed another master degree for business administration and management at the Technical University of Vienna in 2003. In the same year, she started her doctoral studies in Munich, Germany, and Eastborne, UK, which she completed in 2005 and become PhD in 2007. In December 2007, she was awarded the postdoctoral lecture qualification as a Private Docent\(^1\) (in German: Privatdozentin) at the Medical University of Vienna for Health Sciences (Gesundheitswissenschaft).

Since 1999, Tanja Stamm has been a research scientist and a leader of the clinimetry (clinical studies) team at the Department of Internal Medicine III, Division of Rheumatology, at the Medical University of Vienna. Her research interests are outcome measures, the WHO International Classification of Functioning, Disability and Health (ICF) in rheumatology and rehabilitation, occupational science and qualitative studies related to the experiences of people with chronic rheumatic diseases. Furthermore, Tanja Stamm coordinates international multi-centre clinical trials called Stop Arthritis Very Early (SAVE) and Definitive Intervention in New Onset Rheumatoid Arthritis (DINORA).

How long have you worked as an occupational therapist and how did you get involved with scientific research?
– After graduating from occupational therapy (OT) school in 1995, I worked for two years in an orthopedic hospital on a children’s ward and meanwhile studied educational science at the University of Vienna. Our OT team in this hospital tried to start research on the effectiveness of our interventions in patients with osteoarthritis. However, we were not very successful due to the limited time and knowledge. Besides, we were not working in an academic environment. This is when I noticed that I wanted to get involved in research, and I finally applied for a position at Josef Smolen’s rheumatology department at the Medical University of Vienna.

Is the Austrian academic climate friendly towards health professional research?
– Few health professionals in Austria are involved in research. Austria is a very traditional country and the first master courses for health professionals started only in 2009! Students have to pay for their studies themselves, unlike in most other professional fields, where the students receive state funding for their master

\(^1\) Private docent is a title used in some European university systems, especially in German-speaking countries, for someone who holds all formal academic qualifications to become a university professor.
courses. One of my aims is to contribute to increasing the professional status of health professions in Austria. One possibility to do so is being involved in international activities, such as EULAR.

Is multidisciplinary teamwork common in Austria?
– Multidisciplinary teamwork is not very common in Austria because of the low professional status of health professionals. It is more common that medical doctors “prescribe” what should be done by health professionals. Furthermore, if any teamwork should exist, medical doctors are the leaders of these multidisciplinary teams.

How could we in practice emphasize the importance of multidisciplinary teamwork in Europe?
– I think that health professionals should have equal opportunities in terms of education, status, and employment all over Europe. This can be our future goal. This would also upgrade the quality of our services in health care system and offer our patients the possibility to receive the best and state-of-the-art multidisciplinary care available.

Are there some aspects in multidisciplinary work that we should be critical about?
– In my opinion, multidisciplinary work should be truly multidisciplinary – not exclusive in terms of some professions not being represented – or in terms of one profession being always the leader of a team. Furthermore, I think there should be an open atmosphere for self-reflection within each profession, but also within a multidisciplinary team.

What kind of issues would you like to bring up as the next Chairperson?
– As the Chair of the Standing Committee of AHPs, I would like to facilitate the funding of health professional research projects in EULAR. I would also like to start a mentor programme and a platform for exchange for young researchers in the health professions. My dream would be to increase the number of PhDs within the health professionals and thus, to have AHP supervisors and mentors working as a consultants in clinical work and in research for young researchers. Also, we should aim to have equal academic environment for all AHPs in Europe.

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Presently, seventeen European countries have a representative in the AHP Standing Committee. At the moment, EULAR has four national AHP member organisations: the British Health Professionals in Rheumatology (BHPR), the health professionals in rheumatology Switzerland (hpr), the Netherlands Health Professionals in Rheumatology (NHPR), and the Swedish Rheuma Forum (SveReFo).

New members are welcome to join. Please contact the EULAR secretariat for further information, anja.schoenbaechler@eular.org.

Websites:
The British Health Professionals in Rheumatology
www.rheumatology.org.uk/bhpr

The health professionals in rheumatology Switzerland
www.rheumaliga.ch/ch/hp_health_professionals

The Netherlands Health Professionals in Rheumatology
www.nhpr.nl (only in Dutch)

The Swedish Rheuma Forum
We all know that time runs fast. Indeed, sometimes surprisingly fast. Four years have already passed since Peter became EULAR’s Vice-President representing the Allied Health Professionals and two years since John began his term as the Chairperson of the EULAR AHP Standing Committee.

We would like to take the opportunity to thank all the people who have helped to further develop the EULAR Allied Health Professionals organization in the last years. We have seen a tremendous growth of activities which would not have been possible without the support of the EULAR Secretariat in Kilchberg Switzerland, the Executive Committee members, and our health professional colleagues from different European countries.

The EULAR support includes grants for AHP travel bursaries and educational visits but most of all, the provision of the yearly AHP research grant of 30 000 Euros. In addition to this grant, EULAR decided at its March Executive Committee meeting in 2009 to support the research project of Dr. Jackie Hill on the validation of the Educational Needs Assessment Tool (ENAT). This European project will involve colleagues from eight different countries. Please read more on this project in this Newsletter.

The interest for co-operation
We are especially pleased to notice the growing number of the national health professional member organizations in EULAR. At the moment, Switzerland, the Netherlands, the United Kingdom, and Sweden have official member organizations in EULAR, and Norway, having established in 2008 a national HP organization, will apply for membership this year at the General Assembly. This is in line with one of the Strategic Goals of the Standing Committee of Allied Health Professionals within the EULAR strategy 2012 stating: “We will have encouraged local initiatives for establishing the foundation of five new national AHP organizations in Rheumatology thus enabling them to become official members in EULAR”. We very much hope there will be more national HP organizations to follow. We have heard rumours that Denmark and Spain are also in the process of establishing a national organization.

A further highlight for us was to witness the increasing interest of European health professionals to actively contribute to the annual AHP scientific programme at the EULAR congress. Also the accelerating volume of AHP abstracts submitted to the congress makes us very proud. This kind of AHP input and international co-operation enables the creation of an impressive multidisciplinary congress programme which hopefully attracts AHP colleagues to attend the congress and thereby raises the awareness for the importance of high standard care for people with arthritis, rheumatism, and other musculoskeletal conditions.

The Teach-the-Teacher Course
In May 2008, another highlight for us was the implementation of the AHP course providing an evidence-based post-qualification introductory education programme on osteoarthritis and rheumatoid arthritis which meets the clinical needs of AHP’s working in the field of rheumatology. This course, developed by us and sponsored by EULAR, was a pilot Teach-the-Teacher Course for physiotherapists, nurses, and occupational therapists. The 23 participants from nine countries gathered for four days at the Leiden University Medical Center, the Netherlands.

There were twelve physiotherapists from the Czech Republic (1), Croatia (1), Estonia (1), Hungary (1), Lithuania (3), Poland (3), Italy (1) and Portugal (1), eight rheumatology nurses from the Czech Republic (1),
Estonia (1), Hungary (2), Italy (2), Portugal (1), Spain (1) as well as three occupational therapists from the Czech Republic (1), Estonia (1), Portugal (1). The course was a great success and a similar course will be held at the end of 2009 in Brno, Czech Republic.

Making connections
Most importantly, we want to congratulate Editor Jaana Hirvonen and Editorial Assistant Mikko Väisänen for the AHP Newsletter you are now reading. It is in our opinion an excellent tool to facilitate networking between the European health professionals as well as with our colleagues around the globe. Please make use of the newsletter, send it to your colleagues and give suggestions to the editor about interesting health professional themes.

We wish our successors the very best for the future and very much hope you will continue to support them in their activities.

Peter Oesch and John Verhoef

Dear AHP colleagues

The AHP booth is an excellent meeting point for the health professionals attending the EULAR Congress.

For the second time after the congress 2008 in Paris, it is our pleasure to invite you all to the official Allied Health Professional (AHP) booth. This is your opportunity to meet your colleagues from other European countries and the United States during the congress. The AHP booth will be located in the EULAR Village in hall C5.

The EULAR village is a new invention at the congress. The idea is to regroup all EULAR social activities to a same floor and to create an area for informal meetings. Most of the EULAR-related activities and sister societies will be displayed in the village.

European AHP organizations as well as the Association of Rheumatology Health Professionals (ARHP) from the U.S. have the opportunity to present their national organizations and interact with other representatives. Please take advantage of this special occasion.

See you there!

Peter Oesch
AHP Vice-President representing the Allied Health Professionals

John Verhoef
Chairperson of EULAR AHP Committee

Tanja Stamm
Chairperson elect of EULAR AHP Committee

10–13 June 2009: The preliminary programme at the AHP booth

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<td>16:30 – 17:00 Welcome Meeting Chair: Tanja Stamm (A) &amp; Kare Birger Hagen (N)</td>
<td>17:00 – 18:00 Network Meeting for Physiotherapists Chair: Carina Boström (S)</td>
<td>17:00 – 18:00 Network Meeting for Occupational Therapists Chair: Ingvild Kjeken (N)</td>
<td>10:15 – 11:15 Network Meeting for Nurses Chair: Heidi Zangi (N)</td>
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<td>12.00 – 13:00 Network Meeting for Psychologists Chair: Erik Taal (NL)</td>
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Helping patients to understand their disease - The Educational Needs Assessment Tool (ENAT)

The major rheumatic diseases are progressive, disabling conditions causing significant levels of pain, reduced psychosocial status, and morbidity. Health professionals spend much of their time giving advice and information to help patients understand and self-manage their condition.

Research has shown that patients and health professionals can have different beliefs about what information is needed and when. The ENAT questionnaire can help to provide the right information at the right time, and as it was developed with patients with arthritis, it includes topics that patients deem important.

The questionnaire is easy to fill in and takes about five minutes of the patient’s time. When I was testing the ENAT in Leeds, a number of patients told me that they thought it was an excellent questionnaire and they wished they had been able to complete it before.

In the UK, our research has shown that the ENAT questionnaire can be used with patients with rheumatoid arthritis (RA), osteoarthritis (OA), psoriatic arthritis (PsA), ankylosing spondylitis (AS), systemic lupus erythematosus (SLE), scleroderma (SSc), and fibromyalgia (FMS). As well as its use in clinical practice, the ENAT can be used as an outcome tool for research or audit, thus having the potential to promote evidence-based practice in all professions.

A major European research grant

In 2004, I was awarded the EULAR AHP grant to work with European colleagues to translate the ENAT questionnaire into Dutch, Finnish, Norwegian, Portuguese, Spanish, and Swedish. We tested the translated versions with patients with RA and performed a Rasch analysis to make ensure the measurement properties remained stable. The translated ENAT questionnaires were successful, as was the experience of working with my European colleagues. I think we all gained such a lot from the collaboration and when I approached them asking if they would be willing to undertake a further study they were all eager to be involved. The next logical stage for the ENAT work is to assess its use in other major rheumatic diseases and so I applied for a second EULAR grant in 2009. I was surprised and very happy that this multidisciplinary European research project application was accepted.

The study requires patients to complete the translated versions of the ENAT on just one occasion. We will need between 125 and 150 patients from each of the disease categories (AS, FMS, OA, PSA, SSc and SLE) from each of the seven countries (Austria, Finland, the Netherlands, Norway, Portugal, Spain, and Sweden). Patients will be recruited from rheumatology outpatient clinics, day units, inpatient wards, data bases, and from the community; in fact, any location in which the patient can be contacted and providing they have a definite diagnosis of the target disease.
The ENAT questionnaire has seven sections:

1. **Managing pain** – medications, using heat/cold, distraction, relaxation, exercise, acupuncture, hydrotherapy
2. **Movement** – practical devices, lifting, energy conservation, rest/sleep, joint protection
3. **Feelings** – dealing with stress, moods/depression, fatigue
4. **Arthritis process** – cause, type of arthritis, heredity, treatments, disability
5. **Treatments** – need for medication, how to take it, side effects, blood tests, X-rays, surgery, appliances
6. **Self-help measures** – alternative therapy, vitamins, what to avoid doing, exercises, how much exercise, when to contact a doctor or nurse
7. **Support systems** – helpful organisations, financial help, coping groups, getting the most out of consultations

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**A network of researchers**

The grant is for three years starting in July 2009, and will involve health professionals and patients from eight European countries. I will co-ordinate the study from Leeds, **Mwidimi Ndosi**, my research nurse, will undertake the Rasch analysis, and **Helen Greenwood** will undertake data inputting and administrative duties. We will be working with **Tanja Stamm** (Austria), **Marja Leena Kukkurainen** (Finland), **Thea Vliet Vlieland** (the Netherlands), **Heidi Zangi** (Norway), **Arménio Cruz** (Portugal), **Jenny de la Torre** (Spain), and **Elisabet Welin Henriksson** (Sweden) and their teams.

If all goes to plan, we should have a well validated questionnaire in the not too distant future to help patients from a number of European countries to identify their educational needs. However, there are other benefits from the two research projects that we have undertaken. We are building a European network of researchers who are learning much from each other. I envisage that even when this project is completed, the links that we have forged will establish the foundations for further and expanding collaboration between health professional researchers throughout Europe.

**More information:** www.leeds.ac.uk/acumen/

**Dr Jackie Hill**
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**Visit the AHP website**

The EULAR AHP Standing Committee’s website is available at www.eular.org/st_com_health_professionals.cfm.

At the website you can find information concerning the AHP Committees activities and goals. The AHP committee encourages health professional research in rheumatic and musculoskeletal diseases and works also for improving the patient’s role as the key expert of his/her own treatment.

You can also read the previously published on-line issues of the AHP Newsletter and join the e-mailing list of the newsletter.
There have been many exciting developments in the field of rheumatology. However, to me, the most fascinating journey we have been on in the last decade has been the increasing recognition of how vital it is that clinicians recognise the patient’s perspective and that the patient’s voice should be integral to care and, in fact, the patient must be a partner in the decision making process.

Last year at EULAR, I presented some of the key findings from the National Rheumatoid Arthritis Society Mapping project. We all use maps from time to time – some of us are better than others at interpreting and managing maps. In this project, we used the principles of process mapping used in industry to explore the real experiences of patients who had sero-positive Rheumatoid Arthritis (RA). We used both process mapping and qualitative research to explore the true experience of participants from first presenting symptoms to the first three years of diagnosis and treatment. The reason we were motivated to undertake this work was that, in many cases, as chair of the Royal College of Nursing Rheumatology Forum in the UK and Chief Nurse Adviser for the National Rheumatoid Arthritis Society (NRAS), I represented nurses or the patient organisations in relation to developing standards and guidelines. Yet, when exploring with NRAS some of the reports and queries received from the NRAS helpline it was clear that not everyone received the high quality care frequently cited as being what happened in clinical care and we wanted to understand more about this issue and how these differences impacted upon the individual with their condition.

Starting the research process
The study was set up with qualitative researchers, clinicians (doctors, nurses, occupational therapists, physiotherapists, and podiatrist) working together with patients as members of an advisory panel overseeing the research processes and guiding the project. Patients were recruited with an open invitation. The researcher contacted the participants and asked for them to collect all their notes together about their RA. Details about the participant were collected including age, sex, employment, geographical location, and whether they had been admitted to hospital or had surgery. Participants had been diagnosed for three years or less at the time of recruitment.

What we wanted to do was ask about particular time points in the person’s journey with RA but we also wanted to hear what each person thought about their experiences at key points in the journey. If you would like to know more about the study process and look at individual patient maps you can see them all by going to the NRAS website www.rheumatoid.org.uk and putting in ‘mapping patient journeys’ in the search section.

So what did we learn?
We mapped 22 participants’ journeys and collected a wealth of information about the true consequences of delays in being referred to a specialist; time to get treatment benefits or access to treatments and how to negotiate their specific healthcare needs. The study looked at more than just the clinical perspective but also how this could lead individuals to make personal and early decisions to change jobs or stop work and in some circumstances retire early. To many patients, in the beginning the whole issue of healthcare and what was happening was a bit of mystery and rather confusing (see the picture of a mind map).

The study demonstrated that in this group of RA participants access to rapid diagnosis and early treatment (< 6 weeks) was only being achieved for a small group of patients (7 participants) and of those the majority used private healthcare to access rapid diagnosis and treatment (6 participants). Two participants waited just less than 12 months before they were seen by a specialist.

Each person’s healthcare journey was mapped – that is, it was made into a real map showing the time from one step of the journey to another. The costs of the journey were calculated with the help of researcher from the London School of Economics.

It was clear from this small study that some patients with aggressive disease were costly to the economy very early on in their disease with one patients diagnosed > 2 years and < 3 years 5 months had been
an inpatient for a total of 21 days. Yet, in the UK, patients are not eligible to receive anti-TNFα therapies until they have failed two disease modifying drugs and have achieved a high level of disease activity (based upon the Disease Assessment Score counting 28 joints) of over 5.1 twice (one month apart).

What did the patients say about their journeys?
One participant recounted how she first heard her diagnosis. She stated that the doctor took her to the nurse and handed the file to the nurse and he then told the nurse that the patient had RA. That was when she knew she had RA.

Another recounted about who she managed to get information: ‘You need to ask, nothing offered’. But others had stated that they had ‘nothing but praise’ for the way they had been looked after by all the health professionals and the health service.

One patient said: ‘the first GP [general practitioner] was very helpful but I was not diagnosed at this time ….the current GP has a specialist interest in RA….which is wonderful’.

Another RA patient who had been diagnosed less than a year recalls the words used when she was diagnosed: ‘yes, I think you have RA, of the things you can get this is what you did not want…you won’t get better’.

One participant recounted how her illness rapidly caused a significant problem to her work and salary: ‘…On long term sick leave since July 2004 [when she should have returned to work after maternity leave.] After 13 weeks, the basic salary was reduced by 25 percent. This resulted in a loss of earning as well as a loss of company car’.

The car allowance amounted to the equivalent of £ 4,800. It took six months from first presenting symptoms before she was diagnosed and treated. Earlier treatment might have kept this lady at work.

Another participant struggled with her relationship, the burden of a new diagnosis, loss of self esteem, changes in work, and ultimately financial challenges followed by depression. Having just got married during the three year period, received her diagnosis of RA, lost her job and ended up divorced living back at home with her parents caring for her.

Hearing the patients’ voice
Importantly, the journeys were very variable depending upon the first healthcare professional they saw and whether they had the knowledge and empathy needed the provision of the local specialist team and whether they had access to a full multidisciplinary team, in many cases access to teams and information varied.

A wealth of information has been collected using this approach although it has to be remembered there are limitations to this work. We do not always recall events as clearly as we might believe – so recall can be flawed and effected by how upset or anxious we are at the time but also the level of information given and whether at the time the information was given we were receptive to hearing the messages being given and if the information seemed relevant and meaningful at the time.

The participants in this study were already members of a patient organization and therefore, had already demonstrated their ability and wish to access additional resources and support so they are probably not truly representative of the general RA population. The study was small in terms of quantitative research and the process used were unique at the time as process mapping had not been used in this way to explore how care varied from standards and guidelines. Combining qualitative research principles allowed us to hear the patient’s voice through the process of this research and still despite the limitations shows us we still have much to do to ensure we provide care that is consistent and represents the best in high quality care for all.

Susan Oliver
Nurse Consultant Southampton University NHS Hospital
Joint chair of the Rheumatology Futures Project

More information:

The mind map shows why the healthcare system may seem very confusing to patients.
The psychological point of view from Spain

Psychologists often help people solve questions of everyday life. They attempt to understand the role of mental functions in individual and social behaviour, and to explore the underlying psychological processes. Psychologists have a great deal to offer for the multidisciplinary team work.

As in the medical field, psychologists choose an area of specialization. In the best possible scenario, people with rheumatic diseases and severe musculoskeletal disorders could be referred to a psychologist, who is familiar with the characteristics of their condition. Today, psychologist is a self-evident member of the multidisciplinary team. According to psychologist Milena Gobbo, this is starting to be the case also in Spain. In the Spanish health care system, psychologists may work within the rheumatologic unit and provide psychological attention from an integral perceptive by collaborating with other professionals of the unit. They can also work as a consultant for other health professionals, for example generating a referral protocol for rheumatologist to determine which patients would profit the most from psychological evaluation. As many of the treatments require the patient’s active participation, psychological interventions are increasingly used.

Most chronic rheumatologic disorders require major psychological adaptation. An expert psychologist in rheumatic diseases can identify the processes which are part of the readjustment of a chronic illness such as anxiety, depression, or loss of self-esteem. Moreover, an expert is able to accurately discern when these processes can be considered normal or when more professional help is needed, says Gobbo.

Milena Gobbo is a new representative in the EULAR AHP Committee. She works at the Spanish Society of Rheumatology and she is the Chairperson of a local AHP organization called AEPROSER (Agrupación de Profesionales de la Salud en Reumatología). Her special areas of interest are fibromyalgia, rheumatoid arthritis (RA), and the treatment of pain.

The aim of a psychological intervention
Psychological treatment has proven its effectiveness in several aspects of rheumatic diseases. It is also cost-effective in the long run.

Working with psychologists will provide advantages not only for the patient but for the whole health care system. Research studies prove that psychological treatment reduces the direct and indirect costs of health services, including the number of days that people spend on sick leave, Gobbo notes.

Psychological approach may help the person and his or her family members to adjust and understand the impact of a disease in a comprehensive and holistic way. This is especially important when the diagnosis is unclear.

The goal is to assist the patient to become a better manager of his or her own health, which will eventually improve the overall quality of live. The healthcare team will support the person in reaching this goal, Gobbo explains.

The person’s perception of their condition is the key factor in developing an adaptive behaviour and in preventing a vicious circle of hopelessness and helplessness. It is constructive to discuss probable behavioural risk factors, anxieties, fears, or stress with...
a professional who can recommend the possible resources at hand for better adapting to the new situation.

– Many need to tackle the ways the disease may affect their social or sexual life or influence their careers. The psychological intervention can smoothen the perception of pain and the feelings of disablement by promoting an active and effective disease coping. Of course, treatment should always be adapted to the person’s individual requirements and characteristics, Gobbo points out.

Psychologists may work with individuals, couples, families, or groups. There is a great variety of psychological methods and coping techniques which can be applied.

– Nowadays, it is even possible to offer the first steps of treatment through the Internet. Some people may prefer dealing with their personal issues online before coming to a face-to-face contact, Gobbo says.

Other forms of expertise

The professional knowledge of a psychologist is especially relevant in the planning and development of patient’s guidelines and various self-care programmes which normally underline the role of psychological well-being. On the other hand, some psychologists are specialized in health professional education, in areas such as advancement of social skills related to patients, communication of bad news and burnout management.

– It is also typical for psychologists to collaborate in research projects to reveal all the psychological aspects of the rheumatic disease in question. In this respect, the EULAR Congress is an important forum for co-operation, Gobbo highlights.

She is very excited to participate in the congress in Copenhagen and meet the other members of the AHP Committee.

– I would like to share ideas about the treatment of rheumatic diseases from the different viewpoints of the specialists represented in the Committee and advance the systematic use of the techniques and procedures which have already demonstrated their positive effects in the treatment of people with rheumatic diseases, says Gobbo.

More information: aeproser.blogspot.com
www.ser.es/investigacion/Grupo_Trabajo/Aeproser.php

The Spanish AHP organization, AEPROSER, Agrupación Española de Profesionales de la Salud en Reumatología, has members from the following professional groups: nurses, occupational therapists, physical therapists, psychologists, rheumatologists, rehabilitation physicians, and psychiatrists. The picture was taken after a team meeting with most of the groups represented.
The era of biological drugs – is rehabilitation still necessary?

New biological drugs have been introduced during the past decades and dramatic improvements among those that fulfil the criteria for prescription and benefit from the drugs have been observed in clinical practice as well as reported in scientific studies.

Introduction of new drugs represents an important step towards the ultimate solutions to problems related to inflammatory diseases. It also sets the scene for changed paradigms related to the care and rehabilitation of people with inflammatory rheumatic diseases. Some even seem to think that rehabilitation is no longer necessary in rheumatology. This conception is problematic for several reasons. One is that data from many countries indicate that only some 30 percent of patients with inflammatory rheumatic diseases enjoy the benefits of biological drugs. Another is that all aspects of the patients’ health do not necessarily improve automatically as a result of effective inflammatory control. A third reason is the increased risk of cardiovascular disease and premature death that patients with certain rheumatic diseases suffer.

Physical activity and drug treatment

We studied aspects related to physical activity and physical capacity among patients with early, medically well controlled rheumatoid arthritis (RA) included in the national Swedish RA-registry. Patients were recruited at ordinary medical check-ups with their rheumatologists at 17 centres in central and southern Sweden and no exclusion criteria as to age, co-morbidity, or functioning were applied. Data collection and intervention was performed by physiotherapists within their ordinary clinical work.

Our findings show that only half of the patients reached levels of physical activity recommended for maintaining good physical and mental health and avoid lifestyle-related diseases and premature death. A very high proportion of our sample had impaired muscle function and other body functions (up to over...
90%) compared to gender and age matched controls without arthritis. Low pain, enough levels of health-enhancing physical activity and good physical capacity but NOT low disease activity, were independent predictors of good health perception over one year. In a conclusive randomized controlled study, we found that a one-year coaching programme for health-enhancing physical activity resulted in improved health-related quality of life and better muscle function beyond the improvements already obtained from efficient drug treatment. The transferability of our results is probably high as the study was performed in an everyday clinical context with a patient sample fairly representative of the population in the national quality registry. The results indicate that efficient drug treatment gives opportunities for health-enhancing physical activity, improved functioning, better health perception, and probably reduced risks of co-morbidity that may not always be recognized with the present focus on remission and improved body functions within rheumatology.

Modern methods for health promotion
Thus, rheumatologist should not only aim at remission of inflammation among their patients but recognize the opportunity for further health improvements, ask their patients about health-enhancing physical activity, and refer at least every other to physiotherapy for information, motivational support, counselling, and follow-up. Physiotherapists, on the other hand, should not only focus on improved body functions but consider abandoning traditional hands-on treatment and adopting modern, efficient methods to promote health-enhancing physical activity among their patients. Medical doctors and health professionals within primary health care need education and training in order to take responsibility for the large group of patients with rheumatic diseases in need of continuous support for such lifestyle-related changes. It thus seems that rehabilitation is still necessary for the majority of patients (~70%) that do not enjoy the benefits of biological drugs but also, with a different target, for those that use biological drugs.

Christina H. Opava
Professor in physiotherapy
Karolinska Institutet
Stockholm, Sweden

References:

Karolinska Institutet is one of the 18 centres which has been approved as EULAR Centres of Excellence.
Confronting RA-related fatigue

Although fatigue is a recognized symptom of RA, only a few studies have focused on its treatment. Fatigue is a multidimensional concept in which psychological, biochemical, and physiological mechanisms play an important role. Health professionals have a need for further information how to help and encounter RA patients suffering from chronic fatigue. This is the reason why I choose fatigue as the subject of my thesis on nursing.

The impact of fatigue
The thesis provided several interesting findings on RA-related fatigue. I found that 40 percent of RA patients experienced persistent and severe fatigue. The level of fatigue was comparable to the fatigue described by patients with chronic fatigue syndrome (CFS). I did not find a relation with inflammation or a low level of haemoglobin, as often is assumed in clinical practice. Instead, disability and general well-being expressed by patients seems to be related to fatigue.

Moreover, I found that RA fatigue is different from normal tiredness because RA-related fatigue begins unexpectedly and ordinary sleeping or resting does not always suppress it. Furthermore, fatigue causes inability to perform daily activities. It has a great impact on patient’s every daily life; especially it affects the ability to maintain social contacts and leisure activities.

More communication
Patients try to manage fatigue by trial and error, often gaining poor results. They choose not to discuss fatigue with health professionals because they simply accept or assume fatigue as being part of the disease which cannot be treated and because they do not want to complain. Most of the time patients express fatigue implicitly instead of just mentioning it as a problem. Although health professionals are willing to measure and treat fatigue, they do not always respond adequately to the implicitly or explicitly expressed symptoms of the patients.

Then again, contradictory to patients, health professionals are often under the impression that patients would communicate their symptoms of fatigue with their rheumatologists or with other health professionals, such as rheumatology nurses.

Bases on this, it can be concluded that fatigue, unlike pain, is not structurally discussed with patients. This lack of communication has to be addressed. There is a need for a brief and simple assessment instrument for measuring the symptoms of RA fatigue. This kind of a tool could help patients and health professionals to communicate adequately about the causes and treatment of fatigue. Multidisciplinary team work is essential. Furthermore, it would be worthwhile to educate rheumatology nurses to treat fatigue based on the method of cognitive behavioral therapy (CGT). Further research is needed to prove the effect of such a nursing intervention.

Dr. Han Repping-Wuts
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Han Repping-Wuts hopes that health professionals will find new ways to encounter patients with symptoms of fatigue.
In 2007, I received a EULAR grant for an educational visit. I travelled to Bristol Royal Infirmary in Great Britain especially to meet Professor Sarah Hewlett and her research group. I flew to Bristol for four days and was welcomed with a splendid visiting programme compiled by Sarah. I got the opportunity to meet several researchers who are performing research on RA-related fatigue, all of them aimed at creating a better outcome for RA patients. The Bristol multidisciplinary research group focuses on developing a validated fatigue questionnaire for RA, the effectiveness of a self-management programme for RA patients, and a patient-generated core set. All researchers offered me a well-described project of their PhD or research showing the great interest in fatigue as the most important symptom in patients with RA. Moreover, I had the possibility to present and discuss my thesis with the research group. The education visit offered us an opportunity to plan feasible future collaboration on research on RA-related fatigue with the intention to develop nursing interventions and health care education to help patients to manage their fatigue.

My personal goal to overcome my fear in speaking English was achieved as I gave a presentation with replies to questions from the Bristol group and received lots of compliments. This great journey acted as a stimulus for future research. So, for me it was an inspiring, motivating and stimulating educational visit.

Han Repping-Wuts

The objectives for my visit

- To discuss the current practices for fatigue in RA patients
- To exchange knowledge and future research on RA-related fatigue
- To set up a research network for RA-related fatigue
- To compose a joint article
- On a personal level, to conquer my fear for speaking English

More information:


Educational visits

EULAR awards up to 10 bursaries for educational visits to Allied Health Professionals other than physicians working in the field of rheumatology to enable them to make an educational visit to colleagues in another EULAR member country. The amount of each of the bursaries is between € 750 and € 1500. The total annual amount granted is € 7,500.

The objective is to improve the standard of research and care and to foster collaboration across clinical units in Europe.

The deadline for the next applications is the 31st of March 2010. Applications for 2010 should be e-mailed to Ms. Caroline Pasche at the EULAR Secretariat (caroline.pasche@eular.org). Applications should include a CV with the 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 visit. The application form and the contract to be signed with terms and conditions are available at: www.eular.org/health_professionals_educational_visits.cfm.

Recipients are required to submit a report to the EULAR Secretariat after the visit, focusing on the results that have been achieved.
The AHP programme at the EULAR Congress 2009 in Copenhagen

There will be a total of 13 sessions comprising the EULAR Allied Health Professionals programme at the next EULAR Congress in Copenhagen, Denmark, from 10 to 13 June 2009. Four of the sessions will be joint sessions organised with rheumatologists and the Standing Committee of People with Arthritis/Rheumatism in Europe (PARE).

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Planning the EULAR Congress 2010

The next EULAR Congress will be held in Rome, Italy from 16 to 19 June 2010. The aim of the Congress is to provide a forum of the highest standard for scientific, educational and social exchange between physicians, health professionals and researchers involved in rheumatology and liaising with patient organizations to achieve progress in the care of patients with rheumatic diseases.

Abstract submission for Rome 2010
The health professional abstract submission process is open until the 31st of January 2010.

Health professionals can choose to submit their abstract either for practice and clinical care (topics A1 – A5) or for health professional research work (topics 7 – 27).

For further information see the EULAR website www.eular.ch.

AHP travel bursaries
EULAR offers travel bursaries for AHPs presenting their work during the congress. These travel bursaries will only be granted to 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.
A distinguished nomination to a Czech AHP Committee member

In February 2009, Jana Korandová, chief nurse of the institute of Rheumatology, was awarded the honor of the Nurse of the Year 2008 in the category research and education. The Nurse of the Year competition is a highly respected event in the Czech Republic. The candidates compete in three categories: nurses in the home care, in the hospital and/or inpatient care and nurses in research and education. According to the jury, there was an especially large number of nominees with notable references in this year’s competition. However, Ms. Korandová received full points from all the jury members.

For eighteen years, Ms. Korandová has been actively involved in the care and of research of rheumatologic diseases. She is devoted to improve the role of health professional work in the Czech Republic and she is a dedicated member of EULAR AHP Committee. In October, Ms. Korandová will organize an AHP course on the management of Rheumatoid Arthritis (RA) and Osteoarthritis (OA). The course will be held in Brno, Czech Republic.

The EULAR Health Professionals Research Grant

Every year EULAR funds one health professional’s research project in the field of arthritis/rheumatism that is in line with the mission, objectives and goals of EULAR. Projects will be funded up to a maximum of € 30,000.

Recipients of a research grant must submit a midterm report to the Scientific Committee of the EULAR Health Professionals on the progress of the research project. After completion of the project the recipients must report to the EULAR Executive Committee on the results achieved. Furthermore, the recipients are expected to present their project in the EULAR AHP newsletter and may be invited to present their findings at the annual EULAR congress.

Application process

Applicants must complete the official application form (including detailed budget), and include the full CV of the project leader as well as a project plan. For further instructions see the official application form available at: www.eular.org/myUploadData/files/AHP%20Research%20Grant%20Application%20Form.doc.

Applications for 2010 should be e-mailed to Ms. Caroline Pasche at the EULAR Secretariat (caroline. pasche@eular.org) to arrive no later than the 31st of December 2009. Applications will be evaluated by the Scientific Committee of the EULAR Health Professionals in early 2010. Applicants will be informed by e-mail.

The following evaluation criteria will apply:

- Scientific value
- Implementation and relevance for EULAR Health Professionals (i.e., how the project may improve the non-pharmacological management of patients in a short and/or long-term perspective, and/or whether the project may foster the development of a research network of relevance for the future beyond the period of the project)
- Quality of the work plan and methods
- Feasibility of the study within the planned timeframe
- Patient-centered approach (if applicable)
- Budget realistic for the planned project
- Planned dissemination and implementation of the research results

Do you have good news for the newsletter?

Since 2000, the AHP newsletter has functioned as the main information channel of the Allied Health Professionals in Rheumatology within EULAR. The newsletter is published twice a year featuring the work of Allied Health Professionals and all aspects of multidisciplinary collaboration in rheumatology.

Let us know about recent AHP dissertations, health professional projects, research plans on AHP-fields (nurses, occupational therapists, physiotherapists, podiatrists, nutritionists, social workers, and psychologists). Also news about the multidisciplinary development on the European level would be an interesting theme or an interview with a specialist on AHP approach. Contact the Editorial office of AHP newsletter for further information at www.eular.org/st_com_health_professionals.cfm.
MEMBERS OF THE EULAR STANDING COMMITTEE FOR HEALTH PROFESSIONALS 2009

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