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Right to personalised treatment

The world is full of local, regional or global theme days, weeks and months. The goal of many such theme events is to raise awareness about important issues or to raise funds for good causes. As people working in the field of musculoskeletal conditions ought to know, World Arthritis Day takes place annually on 12 October. Perhaps fewer know that World Lupus Day takes place on 29 May. And two days from that, on 12 May, it is time for Fibromyalgia Awareness Day. Several other musculoskeletal conditions have their own theme days, too.

Theme day for patients' rights

This spring I heard for the first time about an important theme day bringing together different diagnosis groups for a common cause. On 18 April the Active Citizenship Network organised the fifth European Patients' Rights Day. The network consists of 100 civic organisations from 30 countries. The network has defined 14 basic citizens' rights related to health care services.

The goal of the day is to highlight, discuss, and act for the improvement of patients’ rights throughout Europe.

The regulation of the Directive will be force late in 2013. An EU citizen must be compensated for treatment equal to that of native citizens. Patients from the EU countries must receive compensable care in his/her own country. An EU citizen must be compensated for his/her treatment in another member state, if corresponding treatment falls under compensable care in his/her own country. The regulation of the Directive will be binding by the end of 2013, which means that within a relatively short period national legislation and social security systems must be adjusted to enable the rights provided by the Directive, let alone harmonising the varying national systems.

Projects like this survey provide important information about the challenges faced in the patients' rights situation on the European level, enabling joint action to be taken to improve the rights.

By the way, do you know why 25 May will be an important day? It is the first day of EULAR congress held in London this year. I hope we will meet there.

Jaana Hirvonen
Editor
Nine questions for the chair-elect

Dr. Thea P.M. Vliet Vlieland is the chair-elect of the EULAR Standing Committee of Health Professionals in Rheumatology. She works as an associate professor at the Leiden University Medical Center in the Netherlands. In the following interview, the new chair unveils her thoughts on research, HP priorities, and HP Committee goals in EULAR.

Do you define yourself as a theoretical researcher or are you more focused on the practical developments in the healthcare field?

— I would say that I am a researcher on practical developments in health care.

Do you think that patient-centered care is already a self-evident goal in health care?

— Patient-centredness is indeed an important attribute of care, but it is insufficiently achieved in many cases. We have a strong tendency to design and deliver care from the provider's perspective. Therefore, this topic is still a challenge for patients, providers, researchers, and other stakeholders.

What are your main interests in the care of people with rheumatic diseases?

— The development, evaluation, and implementation of non-pharmacological interventions.

The Netherlands is often seen as a forerunner in the development of new healthcare approaches. What would you like to bring with you to EULAR as a typically “Dutch method”?

— Enthusiasm and energy. Practical experience as well as research experience in the field of arthritis care. We need a well-functioning network of clinicians and researchers in arthritis care meaning both health professionals and rheumatologists, closely collaborating with patients.

In your personal view, what are the main differences between inter- and multidisciplinary health care approaches?

— I find the distinction a little artificial, collaboration and communication among all team members (health care providers and the patient) needs to be optimised. How this is achieved depends on many factors, such as the goal of the treatments, health care providers’ level of knowledge and skills, preferences of the patient, opportunities and facilities to communicate and so on.

Some seem to think that there is not enough dialogue between physicians and other HPs. Do you find that this is the case?

— In EULAR, we have various possibilities to enhance collaboration with physicians. Rheumatologists are involved in projects initiated and executed by HPs such as the development of HP recommendations and courses. Vice versa, HPs are invited to contribute to many EULAR activities initiated by physicians. It is important to make use of every opportunity to collaborate.

Where would you like to see the HPs within 10 years’ time?

— Over the past years, the HPs in EULAR have achieved a lot. For example, a structured organisation (having Vice-president, Standing Committee, and a Scientific Sub-committee); a growing number of member organisations; a high-quality scientific programme during the annual EULAR congress; various international projects funded by HP grants from EULAR.

— In 10 years’ time, I would like to see an even more professional and effective organisation, offering a core curriculum of education for HP in rheumatology as well as evidence-based recommendations, more new HP organisations in Europe, and thus more members of the HP Committee.

What are your goals as the new chairperson?

— I would like to build further on the work that has been accomplished by my predecessors. An important goal for the short-term is, in line with the strategic goals of the HPs, to establish a sub-committee for education.

— Your term will be for the next 2 years, what would you like to accomplish in that time together with the HP Committee and the Vice-president?

— Increase educational activities for HP through EULAR, e.g. by means of more teach-the-teacher courses and an online course. Also further improve the HP programme during the EULAR Annual Congress, e.g. by providing more sessions, including workshops for clinicians. It is also vital to foster collaboration among researchers in HP care by means of encouraging joint, international projects. With all activities, it is very important to take the possible differences in approaches among member states into account and to work closely together with patients and rheumatologists.

Thank you Tanja!

Dr. Tanja Stamm’s term as the chair of the HP Committee is coming to an end. She has enjoyed working within EULAR for HPs. She will advise and assist Thea P.M. Vliet Vlieland with taking over the duties of the chair. Rewardingly, the status of HPs within EULAR has notably risen during the last decade which gives good ground for handling the responsibilities of a chair in a productive way.

According to the soon resigning Chair Tanja Stamm, even deepening cooperation with scientific associations (rheumatologists) and patient organisations (PARE) is essential for a prosperous HP future in EULAR.

Picture source: Petra Spijka

“itan is vital to foster collaboration among HP researchers by encouraging international projects.”
Welcome to London!

EULAR-funded HP project

How to proceed

The steering group preparing the development of the recommendations determines a maximum of 10 propositions for non-pharmacological management of hip and knee osteoarthritis through a Delphi procedure. A systematic literature search on the selected topics will then be conducted, using for instance the Cochrane library and Medline and other databases. The plan is to carry out a methodological evaluation concentrating on studies on effectiveness of relevant interventions. All evidence will be reviewed and expert opinion will be documented to find out where the evidence is insufficient or absent. We hope that results of this project will contribute to the quality of care for people with hip and knee osteoarthritis across Europe, Thea says.

The HP Vice-president Kåre Birger Hagen, chair of the HP Committee Tanja Stamm and chair-elect Thea Vliet Vlieland were delighted to welcome all health professionals to the EULAR Congress in London.

Find us at the HP booth

The health professional booth is located in the EULAR Village at stand no V1-V2-V3. As in the previous congresses, the village interlinks all EULAR social activities in the same location and creates a favourable atmosphere for informal meetings. Most of the EULAR-related activities and sister societies will be displayed in the village. National health professional member organisations of EULAR present their activities at the booth.

– All HPs can pop in for a cup of tea or coffee at the booth, that is recommended British way to have a break, Lindsey Hawley suggests warmly.

HP information

At the booth, new national representatives from Europe can learn more about the ongoing HP member campaign, get information on how to become a member, update their knowledge on EULAR and the HP Committee work, and leave their contact information for further details.

Wii Station

This year we have arranged to have a Wii station at our HP stand, where everyone can test their balance on a Wii board. Physiotherapists in Great Britain have been using this as method of rehabilitation of patients with arthritis affecting their feet. We hope to see lots of colleagues in London.

The preliminary health professional networking programme and activities at the HP booth

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The EULAR Congress provides an exclusive opportunity for European health professionals, researchers, and colleagues to interact.

Both as a member of the Local Organising Committee and the BHPR, it is an honour for us to invite you all to the HP booth at the EULAR Congress, says Diana Finney.

EULAR Congress in London provides an exclusive opportunity for European health professionals, researchers, and colleagues to interact.

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Join in!
The EULAR Member Campaign for Health Professional Associations in Europe

EULAR Health Professionals News

EULAR seeks more national health professionals (HP) organisations to become member of EULAR and participate in the work of the EULAR Standing Committee of Health Professionals in Rheumatology. All interdisciplinary health professional organisations specialising in the care and treatment of rheumatic and musculoskeletal diseases in European countries are welcome to join in.

In spring 2011, EULAR had seven health professionals associations as members:

- the British Health Professionals in Rheumatology (BHPR)
- the health professionals in rheumatology Switzerland (hpr)
- the Netherlands Health Professionals in Rheumatology (NHPR)
- the Swedish Rheumatology Forum (SweReFo)
- the Norwegian Interdisciplinary Organisation in Rheumatology (NIOR)
- the Danish Interdisciplinary Forum (DIRF)
- the Serbian Association of Health Professionals in Rheumatology (SAHPR)

Delegates from EULAR member organisations in the Committee of HPs in Rheumatology

EULAR Standing Committee of Health Professionals in Rheumatology endorses multidisciplinary collaboration in the treatment of rheumatic and musculoskeletal diseases in Europe. The Committee was established in 1989 as a European platform for cooperation and shared information among the different health professionals working with rheumatology. The Committee encourages health professional research in rheumatic and musculoskeletal diseases and works also to improve the patient’s role as the key expert of his/her own treatment.

As a EULAR member organisation you can:

- interact with colleagues on European and international levels
- retrieve first-hand information on the latest recommendations in the state-of-the-art care and treatment of rheumatic and musculoskeletal diseases
- contribute and participate in the development of health professional research
- organise and participate in health professional educational courses
- promote your national HP association’s work at the yearly EULAR congresses (networking meetings, HP booth, etc.)
- have an easy-access to the information on EULAR’s facilities for health professionals such as educational visit grants and research grants
- and most of all be part of a European health professional network with direct connections to other national HP organisations

The current national representation in the EULAR Standing Committee of Health Professionals in Rheumatology. The representatives of the co-opted member countries (marked with green on the map) can be contacted for further discussions on building a national organisation.

Delegates from EULAR member organisations in the Committee of HPs in Rheumatology

Each member organisation can delegate a representative to work on the EULAR Standing Committee of Health Professionals in Rheumatology. In addition, the committee also includes interested professionals from other European countries who are planning to establish a national HP organisation that could subsequently apply for EULAR membership. Do not hesitate to ask for further information on this process.

WELCOME!

Five steps to get involved for a national HP activist:

1. If a national interdisciplinary health professional organisation already exists in your country, please find out first whether this organisation has a co-opted representative in the Standing Committee of HPs. If so, please contact this person regarding your involvement in EULAR. You will find the member list of the Committee at www.eular.org/st_com_health_professionals.cfm.

2. In case there is no organisation representing health professionals in your country, you can establish a national organisation first. Bear in mind that this organisation’s bylaws should be in accordance with the EULAR bylaws. You can obtain the bylaws from the EULAR Executive Secretariat, contact: eular@eular.org.

3. Importantly, this national organisation should represent different health professional groups (such as nurses, occupational therapists, physiotherapists, podiatrists, nutritionists, social workers, psychologists, and others) and should have a clear multidisciplinary perspective. All the professional groups mentioned above do not have to be represented in the organisation, but an open attitude towards all health professionals in the organisation is required.

Join in!

HP member campaign flyer available at: www.eular.org/st_com_health_professionals.cfm
HP Educational Visit Grant

EULAR awards up to 10 bursaries for educational visits to health professionals other than physicians working in the field of rheumatology to enable them to visit colleagues in another EULAR member country. The amount of each bursary is between €750 and €1,500. 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. In 2010, EULAR received 8 applications for a health professional visit. The HP Committee encourages health professionals to use this great opportunity to widen horizons in the professional sense.

How to apply?
The next application deadline is 31 March 2012. Applications should be submitted by e-mail to the EULAR Secretariat at gabriele.klug@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. Recipients are required to submit a one-page overview as a report to the EULAR Secretariat after the visit, focusing on the results that have been achieved.

The application form and the contract to be signed with terms and conditions are available at: www.eular.org/health_professionals_educational_visits.cfm

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Nursing Science Summer School at Witten-Herdecke University, Germany

Advanced Nurse Practitioner in Rheumatology Patricia Minnock from Our Lady’s Hospice and Day Services, and a PhD clinical research fellow at the School of Nursing and Midwifery, Trinity College Dublin received a EULAR grant to participate in the European Academy for Nursing Science (EANS) summer school. The methodology school was especially organised for nurses undertaking PhDs.

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The EANS 2010 summer school implemented a new curriculum to ensure that mixed research methods will become a norm in nursing research exploring the whole complexity of the profession.

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More information is available at: http://www.european-academy-of-nursing-science.com/

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References

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The Nursing Science Summer School is a 3-year programme which is designed for an individual nurse scientist to participate in the European Academy for Nursing Science, and is recognised by the European Academy of Nursing Science, Minnock explains. She completed the first year’s 2 week programme in 2009 at Turku University, Finland which was funded by the European Union’s Framework 6 Marie Curie Scheme. My second year’s one week programme at Witten-Herdecke University, Germany, was covered by the EULAR HP educational visit grant. Next year’s school takes place in Lund University, Sweden, for 1 week in July, tells Minnock.

Nursing as research and practice
The EANS 2010 summer school implemented a new curriculum to ensure that mixed research methods will become a norm in nursing research exploring the whole complexity of the profession.

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Nursing as a complex intervention involving a number of component parts with the potential for interactions between them which, when applied to the intended target population, produce a range of possible and variable outcomes. This is the reason why developing an evidence base is a considerable challenge, says Minnock.

The Nursing Science curriculum was based on the Medical Research Council’s (MRC 2000, 2008) framework for investigating complexity in health care delivery through an integrated process of development, feasibility, piloting, evaluation, and implementation, where there is a non-linear and dynamic interchange between stages.

The EANS programme aims to equip the next generation of nurse researchers with the methodological experience and expertise, knowledge, skills, infrastructure, and finance to undertake research which is programmatic, multidisciplinary, theory-based, and integrated, Minnock continues.

The overarching aim of this curriculum is to ensure that the complex nature of nursing will be recognised explicitly in research programmes and that these respective programmes will become increasingly multi-state, -disciplinary, and -programmatic in order to develop knowledge for practice that can be translated into everyday health professional use.

Patricia Minnock highly recommends the programme to all doctoral nursing students.

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EULAR Health Professionals News

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Example of an educational visit report:

Visiting the Leeds Institute of Molecular Medicine

Rheumatology nursing has been evolving over many years in countries like the United Kingdom and Netherlandes, however in Portugal this area just started to emerge.

Regarding this development, as a Portuguese nurse working within a multidisciplinary team in the rheumatology research area, this contact with one of the best Rheumatology centres of Europe was a unique opportunity. I was at the Leeds Institute of Molecular Medicine and the Academic & Clinical Unit for Musculoskeletal Nursing for one month. For this trip, I had received financial support from EULAR.

Team in action
During this visit, I had the opportunity to witness an excellent multidisciplinary team work: doctors, nurses, podiatrist, physiotherapists, occupational health professionals, and psychologists working all together in order to provide the best treatment and guarantee the best quality of life to the patients.

I also had the opportunity to develop my knowledge in rheumatology nursing, acquire new ideas and scientific parameters in order to improve the standard of research and care and to foster collaboration across clinical units in Europe. In 2010, EULAR received 8 applications for a health professional visit. The HP Committee encourages health professionals to use this great opportunity to widen horizons in the professional sense.

With kind regards
Andréa Ascenção Marques
Nurse in the Rheumatology Department of Coimbra University Hospital

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EULAR Health Professionals News

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Apply for a health professional educational visit 2011

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EULAR Health Professionals News
Thirty years ago, I became a member of the Rheumatology and Rehabilitation Research Unit of the University of Leeds (RRRU), and although at that time I was a very experienced senior nurse, I knew very little about rheumatology.

My first love had been general surgery, where people came into the ward very ill and usually left cured, how very different from what I was about to experience. I joined the RRRU, not through an interest in Rheumatology, but because I wanted to gain experience in research. Little did I know that this move would change my working life forever.

It did not take me long to realise that nurses and health professionals (HP) in general could make a real difference in the patients’ experience of living with their disease and that we could play a much bigger part in their care in clinics than was the normal practice at that time. However, if we were to make a real difference, we needed to disseminate our experiences and our research results much more widely.

I attended my first EULAR conference in 1987 and gave a paper “The effect of a request card on the type of container used to dispense drugs to patients with rheumatic disease”. It was at this meeting that I realised the importance of EULAR as a unique forum for exchanging ideas and experiences with nurses and HPs from other countries and I have attended almost every conference since. In those early years, the numbers of delegates at EULAR conferences were small compared to the many thousands who attend now and conferences were only held every four years. Many changes have taken place in the organisation since those early days. At that time, the HP Vice-president had to organise the whole of the HP section of the conference single-handedly, an enormous task. Subsequently, under the leadership of consecutive HP Vice-presidents, the number of HP representatives on the EULAR Scientific Programme Committee, the body which organises the yearly conference, has increased.

I believe that this, combined with the call for session proposals, has made a significant difference to the quality and relevance of the conference to HP delegates.

**Catalyst for new ideas**

There remains, of course, the thorny problem of the small number of sessions available for HPs. Unfortunately, this is a “problem of hours on seats” problem. It is hard to make the case that we need more sessions for HPs when they comprise just a few hundred delegates compared to many thousands of doctors and scientists. More recent changes include the creation of a Scientific Sub-committee, specifically for HPs, which meets at each EULAR conference to discuss the composition of the next conference. As well as assessing grant applications and the quality of conference abstracts, this committee has also been an important catalyst for new ideas, concerning research projects and education programmes.

Two recent EULAR-funded initiatives have highlighted educational needs. Firstly, the EULAR web-based survey of the current status of extended roles, taken by HPs within Europe, showed how the state of educational programmes varied from country to country. Secondly, the Task Force established to produce guidelines for the basic and advanced role of the nurse in the management of chronic inflammatory arthritis has identified a lack of educational consistency across the EU. Whilst some countries such as the UK are well catered for educationally, in others there is little or no rheumatology education apart from in-house teaching. EULAR has a major role in the provision of HP education. In addition, EULAR is well-placed to provide on-line programmes for HPs. These would be time consuming and expensive to develop but in the long run, such courses could make a major difference to the way in which care is provided and to the quality of patient care.

**Unrecognised efforts and need for transparency**

As I reflect on the changes that have occurred within EULAR over the past 25 years, I realise how much HPs have progressed, particularly in the last decade. However, I also realise that the valuable work undertaken by the EULAR HP Committees often remains unrecognised and unreported. This invisibility even occurs within the EULAR organisation itself. This is partly because HPs are very under-represented on relevant EULAR Standing Committees, such as Education and Training, Clinical Affairs, Investigative Rheumatology, and Epidemiology and Health Care services. Our inclusion could have a big impact within EULAR and subsequently on EU practice.

There is also a problem in that there is a lack of transparency regarding the way that EULAR functions. For instance, a number of colleagues have asked me how the HP Scientific Sub-committee is chosen or how they can become members or who chooses the HP Vice-president? These are valid questions and there are no secrets but there still appears to be widespread ignorance of these matters and this information needs to be broadcast as widely as possible, perhaps on the EULAR website.

**Working as a team**

As I approach my final EULAR conference before retirement, what of the future? I believe that EULAR will continue to flourish and to improve the lot of patients by enabling HPs within Europe to develop their knowledge and skills and to share information. However, if there is one thing that I have learned over the years it is that this can only be achieved by working as a team with our rheumatology colleagues and with patients and by appreciating and encouraging their input.

Much still remains to be done but with so many knowledgeable and willing HPs, rheumatologists and patients within Europe, I have no doubt whatever that EULAR will be the “must attend” conference for HPs.

**EULAR as a unique forum for HPs**

**Our inclusion could have a big impact within EULAR and subsequently on EU practice**

**Web-survey: The first data on extended roles of non-physician health professionals and innovative models of care within Europe**

Due to the increasing prevalence of rheumatic diseases, extended roles of non-physician health professionals and innovative models of care may be important options in rheumatology in the future. Extended roles have been pioneered in the UK, Canada, USA and Australia and been found to be effective and safe. However, few data are available about mainland Europe, so the aim of this study was to explore the current status of extended roles undertaken by health professionals within Europe, and the corresponding models of care used.

**The used method**

Non-physician health professionals from various European countries were asked to complete a web-based survey using the snowball sampling technique. Data analysis involved calculating descriptive statistics and frequencies based on the countries where the participants currently worked.

**What was learnt**

Of the 479 health professionals who filled in the survey, 430 (92%) indicated that they were performing extended roles. Considerable differences between the 27 participating countries existed, in terms of which extended roles and which innovative models of care were being used. Barriers to performing extended roles were cited as the attitude of rheumatologists in all but eight countries, while attitudes of patients were less common barriers. Lack of knowledge, education and educational opportunities were also experienced in several countries.

We recommended increasing educational opportunities, as well as developing strategies to limit the barriers experienced.

Read more at Musculoskeletal Care 2011

Published online in Wiley Online Library (wileyonlinelibrary.com)

Jackie Hill is retiring from EULAR after decades of work.

Jackie Hill

Is one of the first rheumatology nurses in the UK. PhD in 2000, Fellowship of the Royal College of Nursing, co-convenor of the EULAR Nursing Task Force to produce Recommendations / Points to Consider for the Basic and Advanced Role of the Nurse in the Management of Chronic Inflammatory Arthritis.
Healthcare: Sex and sexuality for people with arthritis – a taboo subject or not?

What does a taboo subject mean? Taboo for whom? For the society? But I don’t have sex with the society. I just have to live in the society. I am free to behave and do everything I can so that I and my partner are happy and strong as a couple. And sex is a very important part in this equation.

The keys to resurrecting a lagging love life are communication, planning, and a positive attitude. Communicating openly and directly with your partner, doctors and other health professionals (HP) is not always easy. People can have trouble discussing sexual issues since they can assume that they are expected to simply feel lucky to be able to manage in their daily lives and should therefore not have the need or even the right to “complain” about changes in sexual functioning.

How to approach a health professional

What would be the first logical step, if one has the courage to ask guidance in these issues? Of course, talking to your rheumatologist, or other HP involved in your treatment, because s/he is the specialist you are seeing for your rheumatic condition. S/ he knows all about your medical history, all about your chronic pain, all about your joints, all about your mobility – the lack of it – and your disease fatigue.

But does s/he know anything about your most secret anxieties? Does s/he know anything about your sexual difficulties and fears of rejection and incapacity since you got rheumatism? And should s/he or all your health care providers, a team full of people, know all this? Would they care about this? Could they be of any help in this field? So many questions…

First, consult your doctor

In the beginning, it was inconceivable for me to talk to my rheumatologist, or any other HP for that matter, about my sexual difficulties. But there are some functional problems associated with arthritis/rheumatism which are not rheumatism’s specialty. For instance, as a result of arthritis of the hip joints, it may be painful to abduct (spread) the legs in the missionary position of intercourse. This usually happens in rheumatoid arthritis, osteoarthritis, and ankylosing spondylitis.

Arthritis of the knees can also interfere with intercourse, if one person is on his or her knees. Arthritis of the back, as in ankylosing spondylitis or psoriatic spondylitis, can also interfere with one’s sex life.

Anyway, talking to a rheumatologist seemed like a dead end at first. I was too ashamed and I couldn’t know how my rheumatologist would react. Besides, my rheumatologist is a man. With a woman rheumatologist it would have been easier, I guess, but with a man… I mean, they say that women come from Venus and men come from Mars. So how would I travel a distance of millions of kilometres and be understood? For a beam of light it takes about 18 minutes and 40 seconds from Mars to Venus. Then it hit me: I happen to possess the most powerful transportation means possible, my thought, which can travel even faster than the beam of light.

I made up my mind and I decided to see my rheumatologist and talk about my sexuality and the aspects considering my rheumatic disease. When making the appointment I clearly specified that I need a bit more time than normally to discuss a personal matter. In my point of view, this was the most difficult step to make.

Once I started to talk, I saw that all my fears were in vain. My doctor was open-minded about this subject and very willing to discuss this with me. He even told me that he was surprised that I had not approached the subject of sex with him earlier. He did not consider the issue a taboo but a necessary one. At the end of the conversation, after he had succeeded to make me feel comfortable talking about everything, he said that he had wanted to approach me earlier about this, but was afraid of my reaction or was worried if I was ready for such a delicate conversation.

So he was human too, after all. My fears had had no basis. It turned out that my rheumatologist is one of those doctors who open their minds and hearts to the patients.

Talking to kineto-therapist

Later on, I also discussed with my kineto-therapist therapist, specially a woman. Having a fit muscular system is helpful in an active sex life as a person with arthritis – you can sustain your body more and with less pain and you can have a longer lasting intercourse. I found out useful things in the process of creating new, comfortable positions for intercourse with my partner.

I was surprised to hear that she had already advised many other people with rheumatism of different ages and backgrounds. This success, I thought!

Be proactive

I realised that my case was a happy one. You do not know for sure how your rheumatologist or other HPs would react when you bring such a sensitive topic on the table.

Maybe my own “how to do” list below could help people with rheumatism as well as HPs to learn from my experience.

Our attitude is everything. It is common knowledge that for instance arthritis can lead to sexual challenges that may require adjustment on the part of the individual with arthritis and her/his partner. It is essential to communicate openly, let us be proactive both ways!

How to bring up sexual issues with HPs

- Encourage your doctor to realise that we really need a multidisciplinary approach when talking about musculoskeletal diseases; we need HPs to work together for us. Different health professionals can be consulted: a rheumatologist, an orthopaedist, a kineto-therapist, a sexologist, a psychologist, a gynaecologist, a physiotherapist, an occupational therapist, a trained nurse to name only a few.
- Bring it up yourself. I believe that open communication is a necessity and it is the first step towards any solution. Talking with a trained specialist about sex or sexuality is important. Do not avoid the subject, even if you are embarrassed or uncomfortable. HPs are usually used to talking about all matters and will try to ease your possible discomfort.
- You can start the conversation by saying: ‘Is there a way we could deal with my concerns about my sex life? Could we take some time today to discuss how my condition can affect my sex life?’
- It is good to have a clear agenda of the issues you want to discuss. Write down your questions before you actually meet. Having them in writing can help you to stay on top of your sexual health care.
- It may help if you bring your partner with you.
- Ask about everything; the effects of the illness or disability on sexual function, about what influence medications or surgery may have, how to improve the intercourse positions. Find out also what is to know about the positions that are not recommended for instance for the people with joint replacements.
- Keep the door open for future discussions. Ask your doctor to refer you to another member of the multidisciplinary team who can help you further.
More training to deal with sexuality and people with rheumatic diseases
Spanish occupational therapist's point of view

EULAR Health Professionals News

Rainbow families with rheumatic symptoms

Rheumatic and musculoskeletal diseases may strike all people regardless of their sexual orientation, gender identity and/or gender expression. ILGA-Europe is the European region of the International Lesbian, Gay, Bisexual, Trans and Intersex Association. ILGA-Europe advocates equal access to health services and non-biased treatment for all people.

Planning the EULAR Congress 2012

The next EULAR Annual European Congress of Rheumatology will take place between 6 and 9 of June 2012 in Berlin, Germany. The annual EULAR congresses which began in 2000 are now a major event in the calendar of world of rheumatology. The meeting will provide a unique occasion for the exchange of scientific and clinical information. It should facilitate interactions between patients, medical doctors, scientists and health professionals in Europe and from around the world.

Abstract submission for Berlin 2012

The electronic Health professional abstract submission system will be open until the 31 January 2012. Abstracts received after the deadline will not be accepted. 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).

Health Professionals Travel Bursaries

Every year, EULAR awards a number of travel bursaries to the first or presenting author of a health professional’s abstract that has been accepted for oral or poster presentation at the EULAR Annual Congress.

A travel bursary shall facilitate attendance at the EULAR Congress and includes:

• registration (including one year free subscription to the EJRP)
• a cash amount of 350 EUR for travel and living expenses
• three nights hotel accommodation (single use), booked by EULAR

All health professionals other than physicians are eligible. There is no age limit for these bursaries.

Further information at:
www.eular.org/edu_travel_bursaries_ohp.cfm

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 mid-term report to the Scientific Sub-committee of the EULAR Health Professionals on the progress of the research project. After the completion of the project, the recipients must report the results to the EULAR Executive Committee. Furthermore, the recipients are expected to present their project in the EULAR HP 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/health_professionals_research_grants.cfm.

Applications for 2012 should be mailed to: M. Patricia Jud at the EULAR Secretariat (patricia.jud@eular.org) to arrive no later than 31 December 2011.

The following evaluation criteria will apply:

• Project’s desirability and feasibility
• Quality of work plan and methods
• Scientific value
• Potential impact and relevance for EULAR Health Professionals
• Project leadership and management
• Impact and potential for new research
• Evidence of the project's potential

Executive Assistant Patricia Jud will assist with all questions regarding the EULAR Health Professionals Research grant.

Do you have good news for the newsletter?

Since 2000, the HP Newsletter has functioned as the main information channel of health professionals in rheumatology within EULAR. The newsletter is published twice a year featuring the work of health professionals and all aspects of multidisciplinary collaboration.

Please give us tips about health professional thesis, projects, and new research themes in the musculoskeletal field. Contact the editor of newsletter for further information: juana.huirvonen@eular.fi.

Prescribe the newsletter free-of-charge at:

EULAR Health Professionals Research Grant
Experiences from implementation of an evidence-based intervention in rehabilitation

Exercise is a common non-pharmacological and non-surgical treatment strategy in rheumatoid arthritis (RA). Dynamic exercise therapy in RA has been extensively studied, and proven to be effective in enhancing cardiovascular fitness, muscle strength, physical and mental functioning, and quality of life, without detrimental effects on disease activity or radiological joint damage. As a result, exercise therapy is recommended in many sets of clinical guidelines and recommendations on the management of RA.

Enrolment and practical obstacles
Over an enrolment period of 24 months, 223 informed patients made inquiries on the program, of which 73 (33%) did not start, mostly because of the travelling distance to the practice. Eventually, 150 patients started with the program, which was by estimation a result of 2.0% in the target population. Thirty-six patients ended the exercise program prematurely. The mean (Standard deviation, SD) attendance rate per patient was 55% (23%). The relatively low reach in the target population is comparable with the proportion of about 1% that can be extrapolated from the implementation studies of the AFAP (Arthritis Foundation Aquatic Program) and PACE (Patients with Arthritis Can Exercise) program, developed by the Arthritis Foundation in the United States. There are a number of possible explanations for the low number of participants that were already also identified in previous studies. An attendance frequency of two times per week is time-consuming. As the program was provided during working hours, patients with a day job may not have been able to participate. The distance from the patient’s home to the physical therapist’s practice may also have played a role. Moreover, health insurance companies only funded the program for patients with a supplemental insurance package. In the Netherlands, there is a single statutory basic healthcare insurance policy for everyone. The statutory basic healthcare insurance covers the costs of basic medical care. Healthcare insurers offer supplementary packages to cover the costs of additional healthcare which may or may not include reimbursement of individual or group exercise therapy.

Attainable goal
The patients’ reasons for not starting with the Rheumatoid Arthritis Patients in Training (RAPIT) program, for ending the program prematurely and the overall relatively low attendance rate in this implementation study suggest that engagement in intensive exercise therapy twice a week may not be an attainable goal for many RA patients. The very low proportion of RA patients participating in a supervised exercise program with a frequency of two times a week suggests that the attainment of physical activity at a moderate intensity level, incorporated in daily activities, could be a more realistic target of future interventions. For RA patients, this would have the advantage that patients with cardiovascular co-morbidity as well as patients with weight-bearing joint prosthesis could also engage in this type of exercise. Currently, research into the health benefits of moderate intensive exercise programs as compared to vigorous intensity programs in patients with RA is lacking. In addition, these findings highlight the need for studies on more effective patient recruitment strategies.

Effects on real life
Regarding the programs’ effectiveness in real life, it is difficult to draw an overall conclusion from this study. Except for the positive effects on muscle strength, effects on aerobic capacity, functional ability, and psychological functioning as found in the original randomized controlled trial could not be substantiated. A possible explanation may be insufficient intensity, as in 6 providers the intervention was not appropriately carried out with respect to its intensity. This may have had an impact on the improvement in functional capacity. Indeed, it was found that patients exercising in groups with higher quality showed more improvement in physical functioning. The self-reported disease activity scores did not significantly change over time, indicating that the intervention did not exacerbate the disease activity.

Motivated stakeholders
As regards the adoption of the program by stakeholders, it can in part be considered a success; a considerable proportion of all stakeholders supported the implementation.

Lessons learnt
In general, the limited-scale implementation of an intensive exercise program for RA patients as described in this study can be considered moderately successful. The reach of the program was fair; however, this study concerned a first implementation attempt with limited project duration. On the other hand, adoption and implementation quality of the intervention were relatively good. Both the limited effectiveness and the lack of data to draw conclusions regarding actual maintenance in the future however warrant additional research.

This research project was funded by the Dutch Arthritis Association (Grant no. IMP-05-1).

Regarding the future of the program, all providers were willing to continue with the program, provided that health insurance companies maintained the funding and that there would be sufficient number of participating patients. The provider of the training course confirmed the availability of the training course in the future. On the other hand, it was observed that the majority of patients that finished prematurely did so during the first 6 months. None of the 10 health insurance companies could answer the question “will you continue to fund the program in the future?”, due to the rapid changes in health care funding policy on government and insurance company levels in the Netherlands.

The program in a nutshell
Prior to the start of the program, the providers received a three-day training course and during the execution of the program, the quality of the intervention, as delivered by the providers, was measured on a quality scale from 1 to 15 (higher is better). Five of 12 providers who started one or more groups obtained the maximum possible total score of 15 points, 4 providers had a score between 11 and 14 points and 3 providers a score of 10 points or less. Attendance rate and quality of the program were significantly associated, with a higher mean attendance rate in patients treated in the high-quality practice (61%, SD 18) than in the practices with sub maximal quality (51%, SD 24) (p<0.015). These results highlight the need for adequate provider training when considering program implementation in real life.
### The Health Professional Programme

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