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A couple of years ago we applied for support and it was granted to us from EULAR for renewing the newsletter of the Allied Health Professional (AHP) Standing Committee. We needed more resources for editorial and layout work. This newsletter is the fourth one in the renewed series. Ulla Nordenskiöld, whose idea the newsletter originally was, participated as editor in chief in the editing of the first renewed newsletter. After that, the editorial team has been composed of myself as the editor, Mikko Väisänen as editorial assistant and Heikki Hjelt who has been in charge of graphic design.

Without articles and their writers the newsletter would not exist. Health professionals living and working around Europe who have been interviewed or who have written about their work, their research projects, or themes important to them, have formed a very important group alongside the editorial team. In addition we have provided news about current issues of EULAR’s AHP Standing Committee in Rheumatology, information about grants and about educational visits to research and care units, and reported about the AHP programme at the annual EULAR Congress.

We aim at presenting a balanced picture of current themes and work of people working in the field of rheumatic and musculoskeletal disorders around Europe. I myself have a pretty good idea about the situation in the Nordic countries, and I would be especially interested in hearing about topical issues and ongoing development projects in the Southern Europe.
Moreover, even though Europe is integrating, working methods vary in different countries. It would be interesting to hear about that, too. You probably have themes in mind you would like to read more about.

Bringing readers together and working as a catalyst
Has our newsletter reached its potential readers, and how does it serve its readership? AHP Newsletter is a generic newsletter aiming at presenting current themes about various aspects of rheumatic and musculoskeletal care and rehabilitation, reporting current research results and providing information about various development projects and good practices. Optimally our newsletter might act as a link between health professionals working around Europe, highlight important themes for general discussion, and even act as a catalyst for collaboration projects in order to understand health as a complex phenomenon and find commonly agreed practices and solutions to various issues. Our goal is to make everyone working in the field of rheumatic and musculoskeletal disorders adopt the newsletter as their own and to make the newsletter useful in taking a multidisciplinary tack and even in strengthening one's own professional identity. Our newsletter is not and does not aim at being a scientific publication, as there are already several creditable, established scientific journals dealing with multidisciplinary research.

The status of our newsletter is assessed once a year by EULAR Executive Committee which decides on possible support for the next year. We have received a grant for publishing two issues in 2009 as well, for which thanks goes to EULAR.

Give us a news tip
Will an interesting newsletter serving us all and providing new information be published next year as well? Your contributions are needed, too! Our following issue will be published in June before the EULAR Congress in Copenhagen. Why not take time to prepare an article for our next issue? Language should not be a problem either, as all articles undergo a language check before publication. Even if you would not write an article (yet) but you have a theme in mind worth hearing more about, give us a tip for an article.

Jaana Hirvonen
Editor
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P.S. The newsletter is sent to the members of the Allied Health Professional Standing Committee in Rheumatology with the wish that they forward the newsletter as widely as possible in their own countries. You can make sure you receive the newsletter in the future by registering directly on the newsletter mailing list at: www.eular.org/st_com_health_professionals.cfm.

In this Issue

This Newsletter provides a retrospective picture tour to EULAR’s Congress in Paris last summer. As usual, we deal with a large scale of issues related to health professional work from different angles. The articles discuss the use of life stories in health research, the management of work ability, and the Canadian model of recruiting patients to take an active role in advocating the best possible care. We also examine sexuality as a source of energy for people with rheumatic diseases and MSDs. Finally, we shed light on the essential role of a social worker in the multidisciplinary team – to mention only a few subjects of this issue.

Enjoy the Newsletter!

Choosing members of the multidisciplinary team

Moreover, even though Europe is integrating, working methods vary in different countries. It would be interesting to hear about that, too. You probably have themes in mind you would like to read more about.
FROM THE CHAIRMAN

Evaluating the first Teach-The-Teacher course

n May 2008, the first EULAR Teach-The-Teacher course was held at the Leiden University Medical Center, the Netherlands. The course was organized by Peter Oesch and John Verhoef in collaboration with the EULAR Secretariat and the Boerhaave Committee of the Leiden University Medical Center. A detailed course report was given at the EULAR Congress.

Ms. Agnès Verbay carried out the evaluation of the course in order to get her Master of Science degree on Medical Education at the University of Bern, Switzerland. The title of her master’s thesis is "Identifying Learning and organizational Needs of Physiotherapists in Rheumatology in Eight European Countries". The following presents a summary of her thesis.

Physiotherapists in focus
EULAR fosters state-of-the-art care for patients with rheumatoid arthritis (RA) and osteoarthritis (OA) within European countries. Recently, its activities have also concentrated on Allied Health Professionals (AHP). In order to further develop multidisciplinary educational programmes, EULAR designed a pilot Teach-the-Teacher course for physiotherapists, nurses, and occupational therapists. The course was also conceived as a vehicle for the investigation of learning and organizational needs of physiotherapists. Specifically, the following questions were asked during the course: Which barriers in the health care system and the hospital settings reduce patient care below state-of-the-art levels? Which competences of physiotherapists should be improved? How could EULAR support physiotherapists?

Discussions and questionnaires
The course was attended by 23 health professionals; twelve physiotherapists, eight nurses and three occupational therapists. They came from six Middle-Eastern (Czech Republic, Croatia, Estonia, Hungary, Lithuania, and Poland) and three Southern European countries (Italy, Portugal, and Spain). The 12 physiotherapists came from the six mentioned Middle-Eastern countries and from two Southern European countries (Italy and Portugal). All participants had previous experience working with patients with RA and OA.
At the beginning of the course, a focus group discussion was held with six physiotherapists and an open space discussion with 14 health professionals addressing the above-mentioned questions. During the course, all participants filled in questionnaires immediately after each presentation. They had to indicate the percentage of the content of the lecture that was new and the percentage that was useful to them. In addition, they had to describe the new and useful contents, respectively. With the help of additional questionnaires, human, physical and financial resources needed for the best possible care and teaching were assessed. Qualitative data were analyzed by categorizing, coding, mind mapping, and organizing into system levels.

**Mutual co-operation**

Co-operation between the investigator and the course participants was excellent. The two discussion groups and the questionnaires were consistent in showing that the current organization of health care systems and hospitals in the countries of origin do not support optimal care for patients with RA and OA. The main reasons appear to be cultural, tariffication, and economical factors. There is a demand for improvement concerning clinical reasoning, guidelines, evidence-based practice, psychosocial aspects of RA and OA, knowledge about scientific principles, and the use of digitalized media.

Physiotherapists also felt that their practical and interpersonal skills could be further developed. Patient empowerment and interprofessional co-operation were not thought to be up-to-date. Participants were surprised how much they could learn about teaching. They estimated that a median of 40 percent of the contents of all the presentations during the course were new and 65 percent was considered useful. The range was from 20 to 100 percent. Physiotherapists experienced an urgent need for more support from rheumatologists.

The study has confirmed pressing learning needs of physiotherapists in eight European countries. Consequently, organizing further multidisciplinary Teach-the-Teacher courses would be important and should be implemented with urgency. If EULAR intends to improve the care of patients with RA and OA, it should not only consider the competence of physiotherapists and other health professionals but it should also pay attention to the deficiencies arising at higher system levels, such as the health care system and the hospital organization. This implies that the physicians play a key role in the process on improving the co-operation between all members of the system.

**John Verhoef**
Chairman of EULAR Standing AHP Committee

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.
The management of work ability in people with arthritis and rheumatism

The management of work ability in people with arthritis and rheumatism has been neglected until the end of the last century. For instance, the second edition of Kelley’s textbook of rheumatology states that if a patient with rheumatoid arthritis is planning to return to work, but cannot, due to his/her condition, an application for disability should be considered after a few visits to the rehabilitation department. There is no reference to the possible rehabilitation strategies enabling the patient to return to work! Such a way of thinking cannot be explained by then lacking pharmacological possibilities for the treatment of rheumatoid arthritis since other diseases, such as non-specific musculoskeletal disorders were treated in the same manner. Work-related rehabilitation programmes for these conditions were first introduced in the late eighties with so-called Functional Restoration Programmes aiming at an improvement of the individual’s work ability.

Neglecting work ability in people with rheumatic diseases is a major failure in modern medicine and is against the right to work as stated by Universal Declaration of Human Rights. It also neglects the enormous costs that work inability causes to the society. Although precise figures do not exist, estimates from EU member states concerning the economic costs of all work-related ill-health range from 2.6 to 3.8 percent of the Gross National Product. In Switzerland, the number of pensioners from 1993 to 2003 has grown annually by an average of 3.5 percent. Musculoskeletal disorders were one of the two causes for disability with the most significant annual growth and are, at 31 percent, the second largest reason for receiving disability pension.

This raises many questions: where modern management of work ability in rheumatic diseases stands today, and what is the role of health professionals in the return to work process? Do we routinely discuss return to work as a treatment goal with our patients and do we know enough about the required steps in the return to work process? This article wants to give a short overview of important steps in the return to work process.

Requirements for a successful return to work
Ergonomics is concerned with the design and evaluation of jobs, tasks, products, working environment, and system in order to make them compatible with the needs, abilities and limitations of the employee. These principles of ergonomics also apply to people with arthritis and rheumatism planning to return to work. The primary question is whether the requirements of work match the needs of the person. If not, the health professional must consider whether work conditions and/or person’s functioning can be changed. This requires not only a medical assessment but also a thorough assessment and, consequently, understanding of the work requirements. This basic information is essential for a successful return to work.

Assessment of a person’s work ability and work demands
To enable a comparison of the work demands with the physical capacity of the individual, new assessments are needed. The traditional medical examination focusing on impairment will not allow such comparison. Evidence has been found already in the 1980s that only few objective physical or biomechanical measures were associated with return-
to-work\textsuperscript{2}. A recent study to determine the prognostic value of a comprehensive medical assessment for the prediction of return to work came to a similar result. The authors were unable to identify any medical variables that accounted for significant proportions of variance in return-to-work\textsuperscript{3}. Due to these shortcomings of the traditional impairment-based medical measures in the evaluation of work ability, performance-based assessment systems, so called Functional Capacity Evaluation (FCE), have been developed to measure work-related physical capacity. Physical capacity as found in the FCE testing is compared to required physical job demands of the patient’s occupation. Such testing reflects the WHO model of functioning acknowledging that having a disease does not consequently mean having a disability. However, there has also been criticism on the psychometric properties of such tests. The Department of Work and Pensions in the United Kingdom modified the personal capacity assessment which is accused to be lacking scientific reports on its validity. More research on the psychometric properties of work-related assessments has just recently been strongly requested\textsuperscript{4}.

Job analysis is a measurement tool that can be used to estimate the work demands. It quantifies the range of the physical tasks performed in the occupation concerned, and identifies the physical attributes required as well as the critical levels of demand. Different job analysis techniques are used, such as direct observations of the range of tasks, administration of questionnaires and checklists, biomechanical assessments, recording of heart rate and oxygen consumption, blood lactate measurements and interviews with experts, supervisors and incumbents. The interview technique is most feasible for health professionals.

**Fitting together the work and the worker**

Once the work-related deficits are identified, appropriate steps must be taken to overcome work-related disability. According to the principles of ergonomics, two major approaches can be differentiated. The primary option to avoid or correct mismatch between work demands and the needs, abilities and limitations of people is to redesign, reallocate, or develop the job according to the needs of the worker. Ergonomic improvements in work design may be characterized as fitting the work to the worker. A secondary option is to train the worker in order to fit the worker to the work. Measures aimed at increasing the capacities of the working population include most conventional forms of selection and training, as well as therapeutic interventions such as exercise programmes aimed at increasing the individual’s fitness for work.

**Fit the work to the worker**

Ergonomic interventions at the work place were evaluated to be effective in returning sick listed patients with lower back pain to work. The multinational cohort study conducted in Denmark, Germany, Israel, Sweden, the Netherlands, and the United States enrolled 1631 workers 3 to 4 months fully sick listed. The people were recruited from sickness benefit claimants’ databases. The ergonomic interventions applied consisted of either adaptation of the work place, job tasks, or working hours. These varied considerably (15 to 63 percent) in occurrence between the national cohorts\textsuperscript{5}. A recent systematic review confirmed that ergonomic interventions are effective workplace interventions\textsuperscript{6}.

**Fit the worker to work**

Exercise is recommended for the treatment of various musculoskeletal diseases to improve function and decrease pain. Exercise is also a major treatment component of functional restoration programmes aiming at an improvement of work ability. Two recent reviews investigated whether exercise reduces sick leave and long term disability in patients with non-specific back pain. Both found evidence of the
effectiveness of exercise in reducing the number of sick days\textsuperscript{7–8}.

There is evidence that a combination of clinical interventions and modified work interventions are effective in returning workers with work-related lower back pain to work faster, reducing pain and disability, and decreasing the rate of back injuries\textsuperscript{6}. Vocational rehabilitation programmes have also been conducted in patients with chronic rheumatic diseases. These programmes also combined ergonomic interventions at the work site as well as medical interventions for the worker to improve his or her work ability. However, there is currently only scant evidence for the benefit of such rehabilitation approaches in chronic rheumatic diseases\textsuperscript{9}. There is a clear need for further research on this subject.

The future role of Health Professionals in work ability management

Health Professionals in Rheumatology can take a leading role in work ability management of people with arthritis and rheumatism. We can perform Functional Capacity Evaluations to assess work-related functioning and have the expertise to perform interviews to define the demands of work. Interventions at the work place to overcome work barriers can be initiated by health professionals and rehabilitation programmes can be conducted. Health professional researcher must further evaluate the psychometric properties of work-related assessments as well as the efficacy of work-related interventions in patients with chronic inflammatory rheumatic diseases. These efforts will further develop work ability management in people with arthritis and rheumatism and thereby reduce the burden of work disability on the people with arthritis and rheumatism as well as reduce costs that work inability causes to society!

Peter Oesch
EULAR AHP Vice-President

References:

POSITIVE EXPERIENCES:
the life stories of people with rheumatoid arthritis

Health professionals can learn a great deal from the life stories of people with rheumatoid arthritis. These stories need to be heard and analyzed.

\textbf{Interviews and narratives}

In the interviews, we asked the participants of the biographic narrative study to describe their whole life story. The story told by each participant and the specific life events (biographical data) were analysed both individually and in comparison to each other. All participants were expected to have work experience but no regular paid work at the time of the interviews due to the chronic disease. These criteria were given on purpose because we were interested in potential experiences on a balance of different types of activities in the lives of people with rheumatoid arthritis. We expected that people who had lost their paid work would have more experiences of changes in their daily activities and thus might have gone through a so-called “occupational imbalance”.

P
redominately, negative consequences of rheumatoid arthritis have been reported in the existing literature. In contrast, we found positive experiences in a recent qualitative study as described by some participants with rheumatoid arthritis\textsuperscript{1}. In this study, a qualitative method, namely, semi-structured interviews combined with a constant comparative content analysis was used. However, the resulting analysed data were not of sufficiently profound to provide a possible explanation or interpretation of these positive experiences. Therefore, we conducted another qualitative study using a less structured and more open qualitative method, namely, the narrative biographic method\textsuperscript{2} that would potentially lead to more detailed data analysis and explanation. By using a narrative interview style, we expected to generate more data on the lifeworld of individuals with rheumatoid arthritis. Our further objective was an analysis of greater depth by implementing a biographic perspective on what the participants told us in the interviews\textsuperscript{3}.

Peter Oesch
EULAR AHP Vice-President

References:
Compared to our earlier study with semi-structured interviews, the participants in the narrative biographic study enjoyed the narrative open interview style more and explained and described their life stories with rich details. Data analysis involved building a relation of the emerging concepts to each individual life story and thus allowed an in-depth explanation of positive experiences in close connection to the biography.

Some participants regarded rheumatoid arthritis as a challenge for mastery of their lives. They valued the chance which they had been given, and viewed their condition overall positively. These people were active self-responsible individuals, while others, adapted to the disease, were less active and “made the best out of a bad situation”. Especially in countries where the medical model predominates in health care, our findings can also be used to broaden the current view that some health professionals have towards patients and stress the importance of patients being self-responsible, active, and striving for mastery in their lives. Both types of life stories (active mastery and adaptation) highlight the importance of patients being self-responsible and active and thus, show the need for a change in attitude in predominately biomedical health care systems, such as Austria.

Gender differences in the life stories
In a secondary analysis of the life stories of people with rheumatoid arthritis, we explored possible gender differences. In addition, we interviewed more people with rheumatoid arthritis because not enough men participated in our earlier studies.

“Knowledge of the differences between life stories of women and men could be taken into account in the goal setting and intervention process of health professionals.”

We then returned to each life story and extracted possible similarities and differences between women and men. The concept “rheumatoid arthritis as a source for new challenges in relation to positive experiences” was found in women’s life stories only. Some women experienced rheumatoid arthritis being the reason for a new relationship to their physical body, such as a new form of balance of activities without stress being essential for the physical body. “Developing a career as a patient as a rather passive receiver of medical care” was found in men’s life stories only, while “lack of control over the physical body” and “making the best out of a bad situation by adapting to the disease” were found in the life stories of both women and men.

Knowledge of the differences between life stories of women and men could be taken into account in the goal setting and intervention process of health professionals. Further research is needed both on the life stories of people with rheumatoid arthritis and other chronic diseases but also on the differences between women and men. These findings may challenge health care systems where patients are regarded as passive receivers of medical care but they may also improve understanding and treatment goals of health professionals when treating either women or men with rheumatoid arthritis.

Tanja Stamm

PhD, MSc, MBA, Mag. Phil., OTR Tanja Stamm will be the next Chairman of EULAR’s Standing Committee of Allied Health Professionals in Rheumatology. She works currently at the Vienna University. Her major research interests are outcome research, qualitative methods, and occupational therapy research. In the future, she hopes to increase the role of research among the health professions in traditional countries such as Austria.

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References:
A rendez-vous at the AHP booth

Allied Health Professionals had their own booth at the EULAR Congress for the first time. In previous congresses, there have been several requests to establish an AHP meeting point where colleagues from various countries could meet.

– The AHP committee was thrilled to make this wish came true with such a good turnout, Vice-President Peter Oesch said.

Most of the EULAR-related activities and sister societies were displayed in the same area. The AHP booth offered a splendid opportunity to present the national AHP organizations and interact with other representatives after AHP lectures and poster sessions. Nurses, physiotherapists, occupational therapists and psychologists had their own Networking Meetings at the booth.

– This will be a new AHP tradition. The Committee will have a similar booth also in the next EULAR Congress in Copenhagen, Oesch was happy to inform.

See you there!
Norwegian Health Professionals Aase Frich, Liv Rognerud Eriksson and Anne Christie were glad to find information about the AHP Committee.

Vice-President Peter Oesch and Kimberly F. Kimpton from the U.S. representing the Association of Rheumatology Health Professionals (ARHP) exchanged ideas on AHP issues.

The official AHP member organizations presented in shifts the work of the AHP Committee and their own national organization at the booth. Charlotte Klinga, Emelie Horn-Widman, and Inga-Mai Wångberg are from the Swedish Rheuma Forum (SveReFo).

The Networking Meeting For Occupational Therapists was also a success.

Urs Gamper representing Switzerland (hpr). All the member organizations had their posters at the AHP booth.

Carine Vogel, Hanneke Voorneveld, Susan Oliver, and Jackie Hill were pleased to see each other at the Networking Meeting For Nurses. Chairman John Verhoef smiles in the background.
Love-ly sexuality

Sexuality is a basic human drive involving a need for emotional expression, pleasure, satisfaction, gentleness and love. According to sexologist Tarja Sandberg, a musculoskeletal condition does not erase the experience of one's own sexuality, even if having sex might call for finding new ways and means. According to Sandberg, you can feel sexy just by letting yourself realise it.

The media is often strongly criticised for parading sex in excess and for perpetuating stereotypes. Tarja Sandberg, however, sees positive aspects in how the media operates. Sandberg, who works at the Family Federation of Finland, is a specialist nurse and an advanced-level, authorised clinical sexologist. In her view, sexuality has become more open, more valued and accepted than previously, thanks to the media. Sexuality is not just a bunch of problems, but it is usually experienced as a positive thing and an integral part of life.

– The genders have become more alike and equal, and women, too, are openly allowed to want sex and take initiatives. According to research, masturbation and other practices of sex have increased, says Sandberg.

Everyone determines the expression of his or her own sexuality individually. Sexuality is part of one's personality irrespective of age, gender, sexual orientation or physical capacity.

– Sexuality is not about positions, as mere sex might be, but about attitudes. Sexuality means an overall experience about oneself as well as about one's own eroticism and pleasure-seeking aspect, maintains Sandberg.

Through one's presence one may express one's sexuality as sexiness. Everyone has met people who do not meet narrow standards of beauty or good looks, but who nevertheless radiate that special something which electrifies the atmosphere.

– They have found their own sparkle of eroticism and sensuality. Everyone is allowed to nourish their sexuality and sexiness. I venture to claim that no one is so ill or disabled as to be excluded from sexual experiences – so handicapped that one could not feel sexy, says Sandberg.

Overcoming prejudice

Sandberg describes sexuality as a journey with phases, border-crossing and barrier-breaking. Along the journey it is good to assess one's situation from time to time. According to Sandberg, falling ill is such a time for self-assessment. Disease may distort one's idea of one's sexual identity, and one may unnecessarily start to limit one's potential. A person may feel that he or she is no longer desirable, if the body image has changed due to the disorder or if musculoskeletal symptoms have affected one's motor functions. According to Sandberg, falling ill may serve as a halting place that helps a person map his or her own resources.

– One may relearn how to enjoy one's sexuality within the boundaries set by the condition – within the present moment and under its circumstances, Sandberg points out.

Sexuality is not always a two-way street. As a single you have the chance in peace and privacy to get to know your own body, your desires and fantasies, and use various tools if desirable.

– Singles are free to fulfill their sexuality. A musculoskeletal condition does not necessarily change the situation, but in a relationship there are always two viewpoints to be taken into account, Sandberg says.

A relationship is based on trust, mutual understanding and positive emotional bonding. Lack of feelings and emotions disturbs the basis of sexual expression. Mutual caring and respect of the other are cornerstones of a relationship, constituting a good foundation for a shared experience of sexuality after one or both members of the relationship have musculoskeletal symptoms.

– I know couples who have rediscovered one another after illness had stepped into the picture. The disease allowed touching, gentleness and care in a new way. On the other hand, in faded relationships illness has been used as a pretext to end an unsatisfactory sexual relationship, explains Sandberg.

In a relationship agreements and compromises are needed about the rules of sex, exactly as about other aspects of life. Successful satisfaction of sexual needs calls for compromises from both parties. Rules can be changed according to the situation.

– "Oral sex" is essential, i.e. sex should be discussed openly. It is important to talk about one's desires and needs, and to listen about and take into account the desires and needs of the other party. Boundaries must be set together. You should not merely assume, if it is possible to know. The surest way to destroy a sexual relationship is speechlessness or being lulled into false assumptions, says Sandberg.
What is real sex?
It is said that the brain is the most important sexual organ and that orgasm takes place in the brain. Sex should not be a choreographed acrobatic feat, disregarding one’s back and joints or pains inflicted. In fact sex need not have anything to do with sexual intercourse.

– Why should sex only mean penetration into a bodily orifice? Fully satisfactory sex may mean being very close to each other, caressing and emotional kissing. Good sex does not equal erections or overwhelming passion — it may blaze up in time, by surrendering to intimacy and letting yourself attune peacefully without forcing, says Sandberg.

Musculoskeletal symptoms, fatigue, and medication may reduce sexual desire. Falling ill may change the way you express, set the pace with or fulfil your sexuality. Even though sexuality is primarily an emotional issue, use of common sense is allowed, too. During the acute phase it is quite natural that sex is not on the top of the agenda. A pause is justified, but you should see to it that the interruption will not be a permanent one.

– Sexual pleasure is a source of well-being. It is a resource that heals and brings a person close to him or herself and to their possible partner. At best sexual pleasure is a painkiller that lifts the mood and the overall sense of satisfaction. Sexuality is lovely, once you have found your own thing, correct timing and suitable boundaries, maintains Sandberg.

Health professional responsibility
According to Sandberg, the health care system should be available for discussing concerns related to sexuality.

– After the appearance of a musculoskeletal condition, the possible effects of the new situation on sexuality must be discussed with the new patient. Talking about sexuality should be a normal part of the health care system’s operation, emphasises Sandberg.

People are unnecessarily hesitant to deal with sexual issues, while it is essential, for the new patient, to discuss how much the condition affects his or her sexual expression or, for instance, establishing a relationship.

– It is not for the patient to bring up the issue; that is a task for the health care system. The matter could be introduced, for example, by saying that at our health care centre the practice is to ask this from all clients. A tolerant and unprejudiced discussion about sexuality helps, and the matter can be brought up again. If need be, the patient can be referred to a sexual therapist. The most important thing is to bring up the issue as a natural aspect of life, says Sandberg.

Medical certificate on sex aids
In Finland sex tools can be applied for as aids, in the same way as, for example, reaching aids etc. Sex aids can help in the process of change in sexual function caused by a handicap or musculoskeletal disorder. A health care professional or sexual therapist can assess, together with the client, the changes resulting from the handicap or disease. They can then discuss the types of sex aids that might facilitate the sexual fulfilment of the client. At the same time they assess the possible need of customising the aids, a task usually carried out by an occupational therapist or a prosthetist. An expert’s opinion on the need of the aid is usually written by the person who assessed the patient’s capacity. A recommendation about the usefulness of the aid from the physician in charge is often required as well.

More information:
The Declaration of sexual rights: www.worldsexology.org/about_sexualrights.asp

More literature:
J. Hill, The impact of rheumatoid arthritis on patients’ sex lives, Nursing Times 2004; 100(20):34-35.
Consumers in Canadian arthritis research

Traditionally, patient involvement in research has been limited to providing the bodies or “guinea pigs” for clinical trials for the investigators. At the Canadian Arthritis Network (CAN), the model for patient involvement in arthritis research moves far beyond these limitations. Arthritis patients, or consumers as we call ourselves, are involved in every aspect of research and take an active role in monitoring and advocating for the best possible care, treatment and research for people with arthritis.

CAN was established in 1998 and is currently one of 18 Centres of Excellence funded by the Canadian government. CAN is unusual in its structure, governance, and research mandate because it includes people with arthritis on all of its committees as well as its funded research. Dr. Robin Poole, the Network’s recently retired Scientific Director, stated, “CAN is unique in the world because we involve, as equal partners, people with arthritis, the pharmaceutical and biotechnology industries, government and non-governmental organizations in the development, conduct and implementation of our research in the marketplace, thereby ensuring its relevance and application.”

CAN’s Consumer Advisory Council (CAC) is comprised of a diverse membership of volunteers representing a wide range of professional experiences, ages, cultures, languages, geographic regions, and types of arthritis. The members of the Council are selected for their commitment to arthritis research excellence and their ability to participate in a fairly rigorous agenda. The majority of members have a wide background of experience from within their own provinces providing arthritis self-management courses, demonstrating musculoskeletal examinations to medical students, or working with arthritis advocacy organizations. When they become part of CAN and the CAC, they also receive two training days each year to increase their understanding of research requirements such as research proposals, peer review protocols, ethics, and lay summary requirements, as well as information on current arthritis research. The combination of the members’ backgrounds and this extensive training has resulted in CAN developing “Highly Qualified Consumers” (HQC).

At CAN, CAC members are involved in governance, policy making, research prioritizing, providing consumer consultants to research teams, peer review activities, knowledge translation, and exchange activities, and they also act as presenters at research conferences and workshops. These roles are explained more fully below.

Role in Governance

CAN includes members of the CAC on each of its committees: the Research Management Committee (RMC), the Scientific and Medical Advisory Committee (SMAC), the Training and Education Committee (TEC), the Training Adhoc Review Committee, and the Board of Directors. There are two CAC members on the Research Management Committee (RMC) and one CAC member has observer status on the Board. RMC is responsible for determining the strategic vision of CAN while the Board administers the general and financial affairs of CAN. TEC includes two CAC members as well, and oversees the development of policies and strategies to create innovative training programs which will promote the recruitment, training, and retention of outstanding new arthritis investigators.

Role as Research Advisors

CAC members assist with problem identification, research study design, and survey development and serve as collaborators and co-investigators on research projects. Their impact was felt at the 2002 Osteoarthritis Consensus Conference in which consumers identified pain and fatigue as priority concerns for research. As a result, CAN and the Institute for Musculoskeletal Health and Arthritis (IMHA) co-funded three peer reviewed grants on osteoarthritis for a total of $4.4 million. In 2006, CAN held a pain workshop that prominently featured consumers as speakers and focus group participants. Following the workshop, consumers produced their own “Perspective on Pain and Arthritis” that complements a scientific White Paper on the topic. Dr. Marc Pouliot, Associate Professor at the Université Laval in Quebec stated, “By understanding how consumers feel pain, I can target my research to the specific area that will help the most.” More recently, the CAC provided HQC members as consultants or collaborators for every research team.
that prepared a proposal for CAN’s Strategic Research Initiative in Bioengineering for the Restoration of Joint Function competition.

Role as Peer Reviewers
CAC members sit on the Scientific and Medical Advisory Committee, an external peer review committee for CAN’s investigator-driven research. This committee consists of an international group of leading scientific and medical experts as well as two CAC members who have equal voting privileges in relation to reviewing the research proposals. Additionally, three CAC members sit on the Adhoc Training Application Committee which reviews research proposals submitted by new investigators who are working on their post graduate or doctoral degrees.

Role as Knowledge Brokers
The members of the Consumer Advisory Council have many and varied connections to other arthritis groups throughout Canada. Some of these organizations include The Arthritis Society (TAS), the Canadian Arthritis Patient Alliance (CAPA), the Alliance for the Canadian Arthritis Programs (ACAP), Patient Partners in Arthritis (PPIA), and other disease specific groups such as the Ankylosing Spondylitis Association and Lupus Canada. CAC members make every effort to disseminate the results of research through newsletters, websites, community education forums, and outreach activities. A new initiative that is being piloted by the CAC is called CAN CARES.3

CAN CARES is a conference for people with arthritis that will feature some of the Canadian Arthritis Network’s researchers for one day of dialogue and networking. It will offer the opportunity for patients, their families and friends to listen to a number of researchers present their findings, pose questions related to each presentation and provide written feedback on each topic. The CAN CARES event is a valuable knowledge translation and exchange tool. CAC members hope to raise the profile of arthritis research in Canada and promote its importance. The long term goal is to create a demand for “a cure for arthritis” and focus attention on the need for more arthritis research funding.

Role as Co-Presenters
CAC members have presented at various international conferences with CAN researchers. Additionally, for the past several years, consumers have presented in each symposium at CAN’s Annual Scientific Conference as well as at the Training Day for new investigators that precedes the conference. Originally, CAC members revealed their own experiences living with arthritis but more recently, they have been recognized for the unique contributions they make in the arthritis community and have been asked to share their expertise. For example, in 2008, one consumer demonstrated the musculoskeletal examination for shoulders that medical students are taught, and another presented the topic of “Progressive Licensing in Clinical Trials” as a result of her work with the Public Health Committee on tracking negative side effects. Other topics included “Writing a Good Lay Summary” and “The New Highly Qualified Consumer Database”.

A Model to Emulate
The Canadian Network of Centres of Excellence wrote in its 2004 report, “the integration of the Consumer Advisory Council at all decision-making levels is forward thinking and could be an inspiration to all other Networks of Centers of Excellence”4. CAC members think that the CAN model of consumer involvement in research is one which can and should be duplicated in all disease areas and in other countries. Consumer participation increases the legitimacy of health research which is primarily pursued for the benefit of the public. The principle of democracy and the right to participate must be considered in all decisions that directly affect the health and lives of consumers. Their knowledge and experience is invaluable.

The Consumer Advisory Council is convinced that in order to ensure the relevance of any research, to ensure the research results are broadly disseminated, to ensure the results are implemented in current health care policies, and to ensure that unmet needs are met within the arthritis community, consumers must be an integral part in all aspects of any research organization.

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Canadian Arthritis Network
Delia_Cooper@telus.net

More information: www.arthritisnetwork.ca

References:
1. Dr. Robin Poole. Canadian Arthritis Network 2005 Renewal Application. P. 1
2. Dr. Marc Pouliot. Centre de Recherche en Rhumatologie et Immunologie, University Laval, Quebec, Canada.
3. CAN CARES – Canadian Arthritis Network’s Canadian Arthritis Research Exchange Seminars is based on the successful “Roundtable on Arthritis Research” (ROAR) event developed by Colleen Maloney of the Consumer Advisory Board in the Arthritis Research Center of Canada (ARC) based in Vancouver, BC 2004.
Social workers work to make the system work

We were invited to write an article about our work as medical social workers in the Jan van Breemen Institute (JBI), based in Amsterdam, the Netherlands. The JBI is an outpatient centre for rheumatology and rehabilitation serving Amsterdam and the surrounding area. The patient population consists predominantly of people with rheumatic diseases and chronic pain disorders. The objective of the treatment for our patient population is to make the patient regain his/her place in the society - depending of course on his/her specific needs. Care includes diagnostics, advice, and treatment regarding functional disorders, activity limitations, and the stimulation of participation in the society. The department of Social Work within the Institute is a part of the paramedical department, and is comprised of four social workers, each working between 60 to 80 percent of a full-time position.

The social work department is a participant in the rehabilitation and arthritis teams. We work together with colleagues from different disciplines as much as possible, which requires a thorough knowledge of other disciplines’ areas of expertise (e.g. physiotherapists, podotherapists, occupational therapists, speech therapist, rheumatologists, psychologists, psychiatrists, and rehabilitation doctors) and demands good communication skills.

Guiding the social process

Because social work concentrates on the social context of the patient in rehabilitation, we often have contacts with other organisations such as the Social Services, unemployment centres, homecare, the housing agency, and the organisation that specifies the level of care necessary at home. The Social Work department at the JBI treat patients with psychosocial and emotional problems related to their illness, handicap, or rehabilitation process, and all the resulting changes in the life of the patient and his/her direct relationships.

If rehabilitation can be seen as the process of returning back to everyday life, social work has the job to guide all related aspects of this process. It forms the bridge between the institute and the daily life of the patient, the link towards further help if needed and it is the team that is best equipped to defend the interests of family members and next of kin.

Interventions take place on a micro-level: the patient, his/her family, and next of kin; on a miso-level with regards to relationships with the neighbourhood, work, and at the housing level; and on a macro-level in the context of the patient as a citizen and a consumer of, e.g. welfare facilities, legitimate benefits, and rights among other issues.

Professional expectations

In order to fulfill the purpose of a social worker in the JBI, one has to conform to specific requirements.

These requirements can be put next to the general quality criteria for social workers working in the health care sector. The basic functional profile of the social workers in the JBI are that they possess a Bachelor’s Degree in Social Work, preferably with extra schooling in the health care sector, and that they are professionally registered.

The target of social work is to promote quality of life and independence of the patient through accompaniment and treatment of the patient. Work has to be done in a methodical and process-like manner, and, if needed, it involves persons from the direct environment of the patient, working to improve and prevent immaterial and material problems and to contribute to enforcing the problem-solving abilities of the patient.

It is important that the social worker is capable of working in an independent, socially adequate, responsible and attentive manner. Expressing oneself well, both verbally and in writing, is of the utmost importance, as are characteristics such as perseverance, patience, integrity, reliability, and the ability of working systematically.

We are both very content to be working at the JBI, as it is a very lively and challenging multidisciplinary working environment. Not only do we as social workers treat individual patients, we also share responsibility for group activities such as the treatment programme for chronic pain patients, assertivity training, relaxation training, and informative meetings for people with arthritis and osteoarthritis.

It was our honour to provide you with some information about our work. If you have any comments, remarks or questions, please feel free to contact us at l.wassenberg@janvanbreemen.nl or m.v.hout@janvanbreemen.nl.

Lara Wassenberg and Marjan van Hout
Swedish Rheuma Forum

Swedish Rheuma Forum (SveReFo) is an interdisciplinary organisation for health professionals working in the field of rheumatology in Sweden. According to the Chairman Carina Boström, the primary goals for SveReFo are to stimulate development and research for individuals and between different professional groups, create economical conditions for health professional research with focus on interdisciplinary research, and to work for national and international collaboration between health professionals in rheumatic care.

– Our long-term goal is to improve care and rehabilitation for patients with rheumatic disorders, says Boström.

The organisation was established in 1989 and it has members from the following professional groups: nurses, occupational therapists, physical therapists, rheumatologists, and social workers. SveReFo is economically supported by the patient organization Swedish Rheumatism Association which also has a representative associated to the board.

Grants, Newsletter, and educational meetings

SveReFo allocates travel grants and promotes small grants for health professional research in rheumatology. The scholarships are announced once a year in the board meetings and about 5 to 10 applicants per year receive grants.

A Newsletter is distributed to the members by e-mail twice a year. In the future, the Newsletter will only be distributed to the members through SveReFo’s website. The members will receive an e-mail informing when a new Newsletter is published.

– The Newsletter contains reports from meetings, conferences, scholarship-reports, calendar, web site addresses, and other actual information such as new treatment strategies and guidelines, Boström tells.

National educational meetings are arranged every other year in collaboration with different organizations such as the Swedish Rheumatism Association. These meetings provide a possibility for members to interact and attend lectures, seminars and poster sessions in different areas within rheumatological care.

– The meetings have a special focus on interdisciplinary co-operation and team work. Since 1989, at least 10 meetings have been arranged, Boström points out.

Membership and collaboration

In 2007, SveReFo become a member of EULAR and the Swedish project of the Bone and Joint Decade.

– It is our ambition to work for closer collaboration with AHP organizations in Sweden, ACR’s Association of Rheumatology Health Professionals, and with other national organizations abroad such as ours, says Boström.

Since the start of SveReFo, new professions have become a part of the rheumatic care and, therefore, SveReFo is discussing whether or not these new professional groups shall become new members.

More information: www.sverefo.nu

PARE: Launch of the Stene Prize Competition

Every other year, EULAR and the Standing Committee for PARE offer the Edgar Stene Prize for the best essay on a previously determined topic. The Stene Prize is EUR 2,000 and includes travel to the Annual EULAR Congress of that year with hotel accommodation for up to four nights as well as an invitation to attend the Opening Ceremony and the Gala Dinner at the congress.

The EULAR member organisations of PARE invite all rheumatic patients in their countries to participate in the competition. Persons who are professionally connected with rheumatology are excluded from the competition. In 2009, the prize will be awarded for the essay topic: Rare But Not Less Severe – The Challenge to Cope With a Rare Rheumatic Disease.

Competitors should submit an essay not exceeding 2 typewritten pages in English, French, or German to their national EULAR member organisation by the 31st of January 2009. The best entry from each country will be submitted for the final decision made by the jury elected by the Standing Committee for People with Arthritis/Rheumatism in Europe.

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).

The AHP preliminary programme 2009

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<tr>
<th>Session type</th>
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<tr>
<td>AHP Meet the Standing Committee</td>
<td>How to reach all people with arthritis with the best possible care?</td>
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<td>AHP Abstract Session</td>
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<td>AHP Invited Speakers Session</td>
<td>Prevention of fractures and falls in osteoporosis</td>
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<td>Hip and knee osteoarthritis: Future Directions and Innovations in Rehabilitation</td>
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<td>Can the International Classification of Functioning, Disability and Health (ICF) be of help in musculoskeletal conditions?</td>
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<td>How to improve the methodological standard in clinical trials of non-pharmacological treatment?</td>
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<td>Patient-centred research designs: How to include the patients?</td>
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<td>AHP Workshop</td>
<td>Spondyloarthropathies – assessing disease activity</td>
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<td>Joint Session</td>
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<td>Promoting lifestyle changes to reduce cardiovascular risk factors in RA</td>
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<td>Work and Rehabilitation</td>
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<td>Impact of rheumatic diseases on family life</td>
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Abstract submission for Copenhagen 2009

The abstract submission process is now open until the 31st of January 2009. Health professionals can choose to submit their abstract either for practice and clinical care (topics A1 to A5) or for health professional research work (topics 7 to 27). For further information, see the EULAR website www.eular.ch.

AHP travel bursaries

EULAR offers travel bursaries for AHP 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 www.eular.ch. The decision whether the request has been approved will not be communicated before spring 2009.

Bella Center provides a beautiful setting for the EULAR Congress in Copenhagen.
EULAR to launch Orphan Disease Programme

In 2007, EULAR defined its strategic objectives for the period 2008 to 2012. As a part of this strategy, the Executive Committee decided to launch a 4-year Orphan Disease Programme (ODP), focusing on systemic sclerosis, to strengthen its activities in areas that are currently less prioritized.

With the ODP, EULAR aims to make a leap forward in the research of pathophysiology and therapy of systemic sclerosis. It aims to fund research projects that achieve tangible benefits for patients affected by systemic sclerosis.

The programme is now being worked out in detail and the first call for proposals will be issued in January 2009 on the EULAR website www.eular.ch.

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 bursary 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 applications is the 31st of March 2009. Applications should be submitted by e-mail to the EULAR Secretariat at eular@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/myUploadData/files/AHP_EducationalVisitContract.pdf

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

ARHP Distinguished Scholar Award

Dr. Thea Vliet Vlieland, associate professor Rheumatology and Orthopedics at the Leiden University Medical Center, the Netherlands, was awarded with the Distinguished Scholar Award of the Association of Rheumatology Health Professionals (ARHP). The ARHP is a division of the American College of Rheumatology and it is a professional membership society composed of non-physician health care professionals specializing in rheumatology, such as advanced practice nurses, nurses, occupational therapists, physical therapists, psychologists, social workers, epidemiologists, physician assistants, educators, clinicians, and researchers. This award is presented to an individual who demonstrates exceptional achievements in scholarly activities pertinent to the rheumatic diseases. Mrs. Vliet Vlieland was the only European scientist who was awarded this year during the ARHP Annual Scientific Meeting from 24th to 29th of October 2008.

Visit the new AHP website

The EULAR AHP Standing Committee has opened its own pages at the EULAR website at www.eular.org/st_com_health_professionals.cfm

On 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 to improve the patient’s role as the key expert of his/her own treatment. The website provides, for instance, an interesting and detailed summary of the committee’s history written by Ulla Nordenskiöld. You can also read the previously published on-line issues of the AHP Newsletter and join the e-mailing list of the newsletter.

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 2008

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