THURSDAY, 14 JUNE 2018

It's your move: promoting physical activity in people with RMD's

SP0077

NEW INSIGHTS INTO STRATEGIES TO EFFECTIVELY PROMOTE PHYSICAL ACTIVITY

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Physical activity is generally safe and beneficial for people with rheumatic diseases. Despite this, people with rheumatic diseases commonly engage in physical activity at levels which fall below common recommendations. Recent advances in behavioural science and health psychology offer healthcare professionals new tools and methods for promoting physical activity among people with rheumatic conditions. This lecture will present the most recent evidence on the interventions and behaviour change techniques that are most likely to increase motivation for physical activity, help individuals translate their motivation into action, and promote long-term maintenance of physical activity.

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SP0078

THE PATIENTS PERSPECTIVE ON PHYSICAL ACTIVITY AND WORK PARTICIPATION IN RMDs

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Fatigue and musculoskeletal symptoms are shared features of many rheumatic and musculoskeletal diseases (RMDs) that often impact on physical activity and work participation. Physical activity is particularly important in the management and quality of life of people with RMDs. Participation in regular exercise can facilitate positive adaptations¹, but people with RMDs tend to be less physically active than the general population.^{2,3}

Two hundred and sixty-eight individuals with antiphospholipid syndrome (APS) participated in a cross-sectional online survey (85% female, mean age 47±11 years, 59% primary APS) on physical activity and exercise. It was found that 82% of participants wanted to increase the amount of physical activity and exercise that they do and 71% of participants were either motivated or very motivated to participate in physical activity and exercise. However, a range of barriers to increasing levels of physical activity and exercise were expressed as summarised in table 1.

Abstract SP0078 – Table 1. What is preventing you from increasing the amount of physical activity and exercise that you do?

Energy Levels	Exhaustion, tiredness, no energy after work, ADLs draining, 'payback', fatigue, mentally and physically exhausted, stressful job
Symptoms	Pain, aching, flare, muscle spasms, headaches, migraines, stiffness
Strength, balance and mobility	Bad falls, jelly legs, legs dead weight, balance, dizziness, giddiness, loss of control, mobility, light headed, lack of strength
Fitness	Level of fitness poor, lack of stamina/endurance, overweight, deconditioned
Psychological	Anxiety, depression, worry about side effects, stressful, scary, uncertain what can do, not sure if safe, no willpower, no motivation, no confidence, laziness, worry about negative effect on work
Environment	Resources, membership cost, travel costs
Time	Lack of time, work, carer, dependents, family demands, life too hectic, busy life, have to balance activities, do enough already

From a patient perspective, managing home and work priorities to get things done without compromising health is a tricky task! Self-management is an important skill for anyone with an RMD, but it is a challenging skill to learn as RMDs are often unpredictable and the art of listening to your body takes time and experience. Having the flexibility to adjust the cumulative load and stressors placed on your body and mind in response to your current health status is crucial. Exercise interventions need to be personalised and, importantly, be flexible so that they can be easily adjusted to reflect the health uncertainties and disruptions associated with many RMDs. These adjustments can be made to a variety of parameters including scheduling, type of exercise, volume, frequency, intensity or duration all of which need guidance for the patient. Flexibility can also be incorporated into work participation through changes to work tasks, location, start/finish times, breaks and working from home. In many countries, it is now a legal right to request flexible working and employers have legal obligations to provide reasonable adjustments for individuals with health conditions such as RMDs.

In our APS study, two-thirds of people said that they had not been given any advice regarding participation in physical activity and exercise and of those who

had received advice only 30% thought they had received adequate advice. The latest BMJ Best Practice for APS recommends in patient instructions "exercise regularly".⁽⁴⁾ However, evidence from our study suggests that people are uncertain as what physical activity they can or should do and the specifics of exercise in terms of type, frequency, duration or intensity. People wanting to exercise looked for guidance from health care professionals as well as online, but found a lack of information regarding the types of exercise they should be doing and how to determine if they were doing too much or too strenuous exercise.

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SP0079

MAJOR ACHIEVEMENTS AND FUTURE CHALLENGES IN PHYSICAL ACTIVITY

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Research demonstrates that physical activity and exercise yield numerous health benefits for individuals with arthritis without adversely impacting joint health. Despite these data, individuals with arthritis remain less physically active than their healthy counterparts. Over the past decade, professional organisations and researchers have synthesised these data and incorporated information on the role of physical activity in management guidelines for clinicians and patients, and developed public health campaigns to motivate individuals to become more physically active. Corporations and researchers have also created and launched new software applications to measure, monitor, and promote physical activity for persons with arthritis that are easy to use and readily accessible. This presentation will highlight the major accomplishments related to the measurement of physical activity, promotion of knowledge and self-management skills to promote physical activity at the individual and population level and discuss future challenges regarding the development of effective population-based and individualised interventions to improve physical activity engagement among individuals with arthritis.

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Data visualisation: tables and graphs for publication and presentation I

SP0080

DATA VISUALISATION: TABLES AND GRAPHS FOR PUBLICATION AND PRESENTATION

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This workshop (held both on Thursday and on Friday) is an introduction to the principles of good graph and table design as pioneered by Cleveland¹ and Tufte² and updated by Few³ so that the participant can better answer the following questions: Which of the messages in my research results requires a graph or table?

Recognising how graphs improve on simple statistics and convey much more information. Knowing when a table is better, or when to keep the data in the body text.

How can I best convey the message?

Striving for clear vision by choice of graph, scaling, discrimination of data series, minimising non-data ink, avoiding chart junk. Striving for clear understanding through a balance between data and explanation. Using order, subheadings, formatting and rules to guide your reader through your table data.

Is my graph/table truthful?

Creating a direct proportion between graph and data quantities, avoiding forms prone to misinterpretation, labels to prevent ambiguity; keeping data in context,

avoiding more dimensions in the graph than in the data. Visualisation in Tables is further discussed in my recent article that is freely downloadable.⁴

This year's course will extend introductory material available via YouTube clips on the ARD website (ard.com)! Direct link: https://www.youtube.com/playlist?list=PLXU14EQbU_V9JpmoAKsaCC0VjZbxzAN

Note that you can also sign up for a **special lecture**,

"Theory of poster design and presentation" followed by a **poster tour** after the session, devoted to poster design!

Session Title: EULAR Projects – Challenging Projects in Education and Training

Date/Time: Saturday 16.06.2018 08:30–10:00

Room: Room: E106/E107

Followed by Poster Tour, sign up required!

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Challenges of patient organisations' in the 21 st century

SP0081 PATIENT ORGANISATIONS' CHALLENGES IN A WORLD THAT IS GETTING OLDER – LESS – MORE COLOURFUL

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We have to see the demographic facts. The most important fact continues to be the birth rate, that is, how many children are born in a country. Because only when children are born, they can start their vocational training or go to college 16 to 18 years later and will be available as qualified workers a few years later. Only those people can in turn have children and bring them up in a way that is sustainable. Only those can become a member of a patient organisation, can be engaged voluntarily.

When you look at the 28 countries in the EU, you will notice that on the one hand the average birth rate is 1.55 (2013) while on the other hand there are still significant differences even within Europe. To keep a population stable, we need 2.08 children per woman aged 15 to 49 years.

The consequences are evident: in almost all European countries the population will shrink without further immigration from abroad or no longer grow on its own. In almost all countries more people will die than be born. This will also have repercussions on the ageing of society and naturally on the demand for products and services too, but also on the potential labour force. This will have consequences for patient organisations too.

At the same time the needs will change because in all countries people continue to get older and live longer. In their old age they will therefore require services for a longer period of time than previous generations: health, nursing care, culture, leisure, housing, support and assistance, travel.

The economy, all companies and professions, the public health, the organisation of daily life will have to face profound changes with long-term effects as well as the associated challenges.

This also against the background of medical doctors becoming older and scarcer as well.

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SP0082 HOW A USER-LED ORGANISATION FOR RMDs ENABLES CITIZEN PARTICIPATION IN PORTUGAL

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One of the first challenges faced by patients' organisations may be to become a user-led organisation. In Portugal, for instance, there is still a strong culture of paternalistic relationship between doctors and patients, which can be a barrier when it comes to recognising leadership skills in a patient. This means that

achieving a user-led model within the organisation depends on a) at least one person (patient or carer) feeling able to come forward and assume the leadership, b) this person's ability to gather more peers for the governing bodies, and c) that this team is accepted by the members of the organisation who are used to the paternalistic model. The important role of PARE and EULAR in providing tools and opportunities for developing skills for the empowerment of patients in advocacy, lobbying and as research partners, will be addressed in this lecture, since it can contribute to overcome some of the identified barriers.

Another challenge may be that the desirable concept of patients' organisations as user-led organisations should be duly recognised, for their acknowledgement as stakeholders in the decision-making processes, representing the people affected by those processes. In Portugal, although the National Health Plan for 2012–2016 and its extension to 2020 considers citizenship-based strategies, the predicted involvement of patients/citizens and their representatives, as a key strategic axis to maximise health gains, had been limited to a couple initiatives without significant patient or public. Several patient and citizen organisations have been advocating for increased and meaningful involvement in health decision-making. In 2015, a working group was established with representatives from 13 patient organisations (including the Portuguese League Against Rheumatic Diseases – LPCDR), one consumer organisation and a research centre. The main objective was to develop a Charter for Public Involvement in Health that could be widely accepted and recognised by health stakeholders. However, the group also felt the need to define a consensus on Eligibility Criteria for the Representation of People with or without Disease in Health Decision-Making in Portugal. The final version of the Charter was discussed with political and health stakeholders in a Forum held at the Portuguese parliament that count about 150 participants. The document will now be presented for a legislative procedure in Portugal and it has been accepted in the public consultation on information to be considered during the preparation of the draft guidelines on the effective implementation of the right to participate in public affairs by the Office of the United Nations High Commissioner for Human Rights (OHCHR). This lecture will also focus on lobbying with several tools, from EULAR EU Affairs, Stene competition, PARE conferences and engagement programme, to patients' organisations networks, as a process for a user-led organisation to be acknowledged as such.

The final challenge to be addressed will be the need to empower the citizens' involvement, through education, training and networking for patient advocacy, patients' involvement on health policy decision-making processes and on research. Several empowerment tools to help applying the «users'» arguments and getting involved in multiple areas, to improve access to care, social protection, sustainability, citizens' rights and patients' quality of life will be presented.

This lecture aims to address some strategies, sharing the Portuguese League Against Rheumatic Diseases (LPCDR) experience on engaging the «users'», changing mindsets and tackling the citizen participation of people with Rheumatic and Musculoskeletal Diseases (RMDs) in Portugal.

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SP0083 GAPS IN PATIENT TREATMENT – WHAT PATIENT ORGANISATIONS CAN DO?

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Background: Access to healthcare is a basic human right and one of the fundamental principles of European health systems, together with safety, quality, and equity. Unfortunately due to economic crisis and the cuts in healthcare budgets in many countries, inequalities in healthcare have been made worse. Furthermore the healthcare systems are facing increasing demands due to demographic change and the fact that the number of patients with chronic diseases is growing.

Objectives: To identify the inequalities in healthcare system and the degree to which the standards of care are affected.

To outline patients organisations challenges in such a demanding environment and their efforts to overcome the gaps in patients' healthcare.

Methods: Describe the gaps in patients' access to health care and the degree of their satisfaction from the offered health care services as reflected by the relative EPF survey conducted in 2016 among patients in European countries.

In these challenging conditions, patient organisations should help to fill the gaps and suggest specific solutions by raising awareness about the problems of the patients and the consequences of inadequate healthcare. At the same time they should develop collaborations with the scientific and academic community as well as with other patients' organisations.

Conclusion: Patients with chronic and long term conditions have valuable experience as a result of their interaction with the healthcare system and can identify important gaps and propose solutions in order to improve access to healthcare.

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