OP0284-PARE THE INFLUENCE OF FUNCTIONAL TRAINING AND PSYCHO-SOCIAL SUPPORT

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Background: Treatment of chronic noncontagious diseases in which we include RMD implies usage of medicines and non medicine (changing bad lifestyle habits like losing nutrition, physical activity, smoking...).¹ Unwanted cardiovascular and cerebrovascular states are the most common cause of shortening of life of people with RMD.² None of the chemical drugs can replace physical activity. Physical activity dosage is individual, and depends on aerobic capability and heart rate increase, taking in account age, type of noncontagious diseases, level of tissue and organs damage as well as the type of work the person is engaged in. Patients with RMD have common symptoms, such as stiffness, fatigue, poor mobility, joint pain and muscle pain, anxiety and depression, and lack of fitness. In addition to physical medicine and rehabilitation and balneoklimatology, various forms of physical activity are recommended, such as walking, swimming, functional training. Today, moderate physical activity is known to help reduce fatigue, strengthen muscles and bones, improve flexibility and endurance of the joints, and improve general health. It is necessary to find the best combination of rest, activities and exercise programs to prevent deformities of the joints, the development of disability, improve the quality of life, and the mental health of patients with RMD.³

Objectives: 1. By practicing Cigong, an increase in the volume of movement in the joint, the strengthening of joint muscles and the improvement of general condition, pain relief, fatigue reduction is achieved and also, it helps patients look and feel better.

2. The goal of Yoga is to neutralize and remove all obstacles that stand in the way and disturb the function of the body and the mind and achieves inner peace.

3. Changing the psychological state during exercise also led to a positive way of thinking.

4. Psycho-physical support for the people with RMD

Methods: From 2011, we organize two times a week functional training of Cigong.⁴

Since January 2016, twice a week persons with RMD have been practicing Yoga.⁵

From 2015, one per week four psychologists volunteer hold workshops for psycho-social support for persons with RMD.^{6,7}

Participants of the training and psycho-social sessions took a survey.

Results: 1. Joint pain reduction – 50% of total number of participants

2. Joint mobility increase – 95% of total number of participants

3. General fitness improvement – 73% of total number of participants

4. Less pronounced negative emotions – 59% of total number of participants

Conclusion: Practicing cigong, yoga and psycho-social support workshops help patients look better and feel better. Changing the psychological state during exercise also led to a positive way of thinking. All of this increased the effectiveness of drug treatment and improved the quality of life of patients with RMD.

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OP0285-PARE SARCOPENIA IN PATIENTS WITH RHEUMATIC DISEASES

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Background: Sarcopenia is a rather new term, coined in 1989: only in 2016 the International Classification of Disease (ICD) code was established for this disease. Sarcopenia describes a state of reduced muscle mass together with reduced muscle strength and reduced muscle performance that comes with aging. The topic is of great relevance for people with rheumatic diseases, because chronic inflammations and lack of exercise, among others, have been identified as risk factors for the development of sarcopenia. To shed additional light on this emerging field, the German Rheumatism League has funded a participatory research project for the investigation of sarcopenia.

Objectives: The aim of the study was to investigate the prevalence of sarcopenia in patients with rheumatoid arthritis. In addition, the study aimed at identifying risk factors and biomarkers for the development/diagnosis of sarcopenia. The results of the study are intended to enhance the diagnostic tools for recognising sarcopenia in patients with rheumatoid arthritis and to allow the formulation of specific exercise recommendations for the prevention of sarcopenia. Based on the results of the study and additional information from the literature, an information leaflet or brochure for patients will be prepared.

Methods: Participants were screened by medical questionnaires. Blood chemistry was analysed. Body composition was assessed by dual-energy X-ray absorptiometry (DXA). Muscle area and muscle density were measured using peripheral quantitative computed tomography (pQCT). Various neuromuscular tests were performed to assess muscle performance, muscle strength and sense of balance. Additional information on treatment options, prevention and detection were retrieved in a comprehensive literature search. Two "Patient Research Partners" are involved in the study.

Results: The study has not yet been completed. So far, 269 patients (age 18 and older; 216 female, 53 male) were recruited until December 2018. Mean age of participants was 59 years, mean DAS-28 was 2.4 (remission). The control group consisted of an existing cohort of 280 individuals without chronic inflammatory diseases or muscle paralysis (153 females, 127 males, mean age 63 years). Preliminary data show that prevalence of sarcopenia is higher in patients with rheumatoid arthritis compared to the control group. Literature revealed that physical exercise has a positive effect on sarcopenia. In addition, amino acid supplementation, nutritional interventions and hormones might be effective in the treatment of sarcopenia.

Conclusion: The higher prevalence of sarcopenia in patients with rheumatoid arthritis illustrates the urgent need to provide education on sarcopenia for patients with rheumatic diseases.

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OP0286-PARE DEVELOPING A VIRTUAL ASSISTANT TO PROMOTE EDUCATION ON OSTEOARTHRITIS

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Background: Osteoarthritis (OA) is one of the most prevalent chronic rheumatic diseases (24% in Portugal, according to the Portuguese Society of Rheumatology) accounting for significant years of disability. Optimal management of OA requires active patient participation. A recent systematic review concluded that more effective information strategies are needed to respond to the needs of OA patients.¹

Interactive computational simulation with Virtual Humans (VH) has been used with the purpose of educating or promoting lifestyle change in healthy people or in

the management of chronic illnesses, such as diabetes treatment, including good users' acceptance and an increase in their knowledge.² Knowledge acquisition is generally seen as a necessary condition for behavioral change. Applications with virtual humans offer a dynamic, interactive and easily accessible approach to enhance users' knowledge. We did not find published literature on the use of virtual humans to educate people with OA.

Objectives: To develop a web application to support education of caregivers and people with OA.

Methods: This is a proof of concept study, which builds on our previous experience with virtual assistant applications. For example, "Virtual Pharmacy"⁴ is intended to improve self-medication consultation skills between students/pharmacy professionals and community pharmacy clients, whilst "VASelfCare"³ aims to facilitate self-care of older people with type 2 diabetes (REF?).

The main principle underpinning the development of our application is the use of gamification embedded in a narrative with a double purpose of maintaining user engagement and enhancing the play experience. This option has in consideration that OA is more prevalent among the seniors and is supported by a study showing that embedding narratives in mobile games enhances the play experience of this age group.⁵

In our approach, the narrative comprises dialogues aiming to ease and stimulate the search for new knowledge, and to educate for disease management and health promotion.

Results: So far, we have developed NOA, a virtual assistant that interacts with users through speech (voice and subtitles) plus facial and body animations. NOA is a 2D cartoon female model that plays the role of a character who suffers from OA and provides information about her own experiences with the disease. At the end of each dialogue, a quiz tests users' knowledge. Awarding points and digital badges for correct answers, or showing the right answers when the user fails, are expected to motivate users to play and learn more. This application will be placed in the "Portuguese League Against Rheumatic Diseases" website to convey easy access.

Conclusion: Development of a virtual assistant web application to promote education on OA, resorting to a narrative approach and gamification principles, is ongoing. Future work includes testing the application with experts and patients.

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OP0287-PARE SETTING UP A EUROPEAN FEDERATION OF SJÖGREN'S SYNDROME PATIENT ASSOCIATIONS: HOW WE BUILT UP SJÖGREN EUROPE IN LESS THAN ONE YEAR

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Background: Despite its considerable prevalence among CTDs, SS has been devoted less research, interest, time and effort compared with other close conditions. Active and synergistic involvement of patients, clinicians and scientists in the definition of unmet needs and areas of future research is crucial.

Objectives: To set up a perennial European Federation of SS patient associations to address the lack of visibility and the unmet needs, foster patient training and involvement in research and articulate patient voices throughout Europe.

Methods: Sjögren Europe was conceived during the 2018 ISSS and the decision to materialize the Federation was launched during the EULAR 2018 congress, where several meetings with key entities representatives were organized to get advice on various aspects. A medical advisory board was also set up. By-laws, a logo and a website were created. The task force is composed of patients already involved in patient advocacy at a national and international level. The first step

was to set a mindset and to communicate on a regular basis to ensure a common spirit. We set priorities and down-to-earth objectives and focus on them. Although there is a leader for supervision and to take final decisions, the governance is mainly based on shared leadership sustained by trusted connections. Personal initiatives are encouraged, and failure is considered as a learning experience. We build a culture of compromise. As members experience debilitating fatigue, they achieve the tasks they can, whenever they have time and energy, and report them to the others: Sjögren Europe adapts to its members. We also welcome anyone sharing our mission principles and wanting to be involved in the project.

Results: On the 23rd of February 2019, Sjögren Europe was officially set up with more than 8 countries as founders. Being flexible not only allows patients with debilitating fatigue to work for the federation but also leads to lean and efficient procedures and tasks. An enthusiastic and supportive environment makes the commitment sustainable and meaningful. Face to face meetings, a good network and collaboration are imperative. The way we respond to mistakes is also crucial for motivation.

Conclusion: This project empowers the SS patient community, brings hope, injects a new energy in patient advocacy and breathes motivation for collaboration to researchers, scientists and clinicians. This presentation aims to share our story and the key learning points about the way we work and to spread the positive atmosphere.

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OP0288-PARE WHAT DO YOUNG PEOPLE THINK ABOUT CONTINUOUS DATA COLLECTION IN CLINICAL RESEARCH AND THE TYPES OF ELECTRONIC DEVICES?

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Background: The use of wearable devices are of increasing interest to enable continuous data collection during drug trials. This is particularly pertinent when involving young people who are "digital natives" and have grown up with such technologies.

Objectives: To ascertain opinions from young people regarding the design of wearable devices and the use of continuous data collection for a future clinical drug trial for juvenile idiopathic arthritis (JIA).

Methods: A three hour face-to-face patient involvement session was held in a young person friendly venue in central Manchester on the 8th December 2018. Young people with a rheumatic disease were invited to participate using event flyers provided in local rheumatology clinics. Members of a national youth advisory panel, Your Rheum, were also invited to attend. Data was collected in both large and small group discussions and included a ranking exercise involving the use of voting cards, emojis and pictures of electronic devices to aid conversations. In addition, an online survey was also developed and uploaded to <http://your-rheum.org> for young people to complete if they could not attend the event in person. Open questions (requesting free text answers) ranged from general thoughts and concerns about continuous data collection, device preferences and features, to examples of unattractive devices.

Results: Eight young people attended the event (M=5, F=3, 11-19 age range). All males were under 14 years of age. One young person completed the online survey (F=1). All participants regularly used some form of an electronic device and were generally willing to use a wearable device for continuous data collection, although consideration of school regulations (e.g. uniform policies) and potential bullying was necessary. Participants reported that they would choose a device based on its viability, look, comfort and functionality. For instance, the device would need to be discrete in terms of size, muted (no sounds or vibrations) and removable. The preference of device type differed by gender though a watch and patch were in the top three favourite devices for all. Key features included the