

Poster Presentations

THURSDAY, 15 JUNE TO SATURDAY, 17 JUNE 2017

Building patient led organisations

PARE0001 GROWING STRONGER TOGETHER: IMPLEMENTING EULAR YOUNG PARE'S STRATEGY

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Background: In a recent European youth survey, 53% reported that rheumatic and musculoskeletal diseases (RMDs) affected their ability to work, while 75% reported that RMDs interrupted their education. Therefore, in 2017 and 2018, while continuing to achieve the objectives reached in 2015 and 2016, EULAR Young PARE will focus on two key points from EULAR Young PARE's strategic objectives: work and education.

Objectives: In 2017, in line with EULAR's efforts to raise awareness of the needs of people with RMDs among employers and other stakeholders, the specific and still unmet needs of young people with RMDs will be highlighted, so that employers and other stakeholders will be more aware of the needs of young people with RMDs and young people will receive better support to find a suitable job. In 2018, education for young people with RMDs will be in focus, so that educational institutions across Europe will be more flexible and assistive in supporting high quality education for young people with RMDs.

Methods: In 2017, we will support EULAR's lobbying activities by raising awareness among employers and other stakeholders about the needs of young people with RMDs. We will also provide information to support young people in finding suitable jobs and to be aware of their rights in the workplace. Best practices concerning ergonomics, support programmes, career counselling and suitable jobs will be collected and shared. In 2018, we will support educational institutions across Europe to be more flexible and assistive in providing high quality education for young people with RMDs by offering training and support to national youth leaders.

Results: Thanks to the results achieved in 2015 and 2016, it is anticipated that structures will be in place to continuously raise awareness among employers, medical staff in schools, teachers and unions about the competencies and limitations of young people with RMDs. These activities enable EULAR Young PARE to expand and strengthen the active network of youth groups across Europe. Every PARE organisation will have a PARE youth liaison person, who will be encouraged and supported to take active roles in their national organisations and in the EULAR community.

Conclusions: The objectives reached by EULAR Young PARE in 2015 and 2016 are closely related to its future aims and achievements, allowing EULAR Young PARE to grow stronger and continue its work by the side of young people with RMDs, in order to improve their quality of life.

References:

[1] EULAR Young PARE. Available from: <http://www.youngpare.org> [accessed on 30 January 2017].

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Arthritis research

PARE0002 CELEBRATING TEN YEARS OF SUCCESSFUL PATIENT INVOLVEMENT IN RESEARCH OF INFLAMMATORY CONDITIONS

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Background: In 2016, the Research Institute (RI), Primary Care and Health Sciences, Keele University, UK, celebrated 10 years of Patient and Public Involvement and Engagement (PPIE) in research of musculoskeletal and other long term conditions. Our Research User Group (RUG) with over 90 members with a range of long-term conditions, actively work with research teams on studies. Many of whom have been involved in ten studies of different inflammatory conditions. We provide two case studies: 1) CONTACT: a trial comparing the effectiveness and side-effects of two commonly-used drugs (Naproxen and low-dose Colchicine) to treat acute gout in primary care; 2) A qualitative interview study with people with rheumatoid arthritis (RA) who had attended a nurse-led review clinic, which included identifying people at risk of anxiety and depression.

Objectives: To describe how PPIE helped shape the design and delivery of the CONTACT and qualitative interview studies.

Methods: 1) For the CONTACT trial, two RUG members with experience of gout joined the Trial Steering Committee. Another seven RUG members formed an advisory group to provide the patient perspective on trial procedures.

2) For the qualitative interview study, a group of eight people with RA from a local rheumatology centre (*Haywood User Group*) commented on the documents for the ethics application and met to discuss data analysis and dissemination.

Results: 1) In the CONTACT trial, RUG members made a difference by:

- Commenting on the trial design and acceptability of the drug intervention
 - Helping to produce clear and user-friendly information sheets for participants in the trial.
 - Provide practical advice regarding how participants were recruited
- Future RUG involvement will include helping to interpret the trial findings planning further dissemination and discussing future research studies.

2) In the qualitative interview study, the PPIE group:

- Contributed to the development of readable patient questionnaires for use in the clinic
- Offered their perspectives on the interpretation of the qualitative data
- Helped develop a leaflet to inform patients about mood problems related to rheumatoid arthritis and where help could be sought
- Contributed to the establishment of an RA annual review clinic at the local hospital
- Advised on the dissemination of results to a lay audience
- Generated ideas for a study about the delivery of RA annual review clinics in primary care, supporting a related grant application

Conclusions: Both studies demonstrated the wide-ranging benefits of PPIE input throughout the research cycle of identification, designing, managing and disseminating research. The RI will continue to involve patients with long-term conditions in studies for the benefit of the wider patient community.

Acknowledgements: We thank all of our Research User Group members for their valuable time and contribution to the RI's research. CONTACT was funded by the NIHR School for Primary Care Research. The RA qualitative study was funded by the Scientific Foundation Board of the Royal College of General Practitioners and the Haywood Foundation. KD is part-funded by a NIHR Knowledge Mobilisation Research Fellowship (KMRF-2014-03-002). CCG is part funded by the NIHR Collaborations for Leadership in Applied Research and Care West Midlands.

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Work and rehabilitation

PARE0003 ASSESSMENT OF PAIN AND IMPORTANCE OF EXERCISE IN HIP OSTEOARTHRITIS

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Background: Osteoarthritis (OA) of the hip is a common condition which affects men and women of all ages. The cartilage becomes damaged. Stiffness and reduced range of movement are common. The pain experienced from OA of the hip may be felt in your lower back, buttocks and groin. You may also feel pain from your hip in your leg and down into your knee. This is called referred pain. The goals of OA treatment include alleviation of pain and improvement of functional status. Optimally, patients should receive a combination of nonpharmacologic and pharmacologic treatment. A physiatrist may help in formulating a nonpharmacologic management plan for the patient with OA.

Guidelines from Osteoarthritis Research Society International (OARSI) advise that nonpharmacologic treatment of hip and knee OA include the following: patient education; heat and cold; weight loss; exercise; physical therapy; occupational therapy; unloading in certain joints (eg, knee, hip).

Objectives: The aim of this study was to investigate the importance of exercise and TENS (Transcutaneous electrical nerve stimulation) therapy in patients with OA of the hip on the pain and functional status.

Methods: This was a prospective clinical study involving 20 patients with primary hip OA treated stationary at the Center for Physical Medicine and Rehabilitation during 2016. On receipt of all the respondents filled out the social survey, quantification of pain was conducted by visual analogue scale (VAS) and function was evaluated through measurement of the range of motion in hip joint. After that, they received physical therapy (exercise and TENS therapy) for 21 days. TENS was applied once a day for 30 minutes on both hip joints, with the frequency of 85 Hz and with short-term pulses (4 ms) (appliance TENS-2, Electronic Design Medical, Serbia). Exercise was applied once a day for 30 minutes, according to individually customized protocol; active and active-assisted exercises were used to the point of pain for strengthening the muscles of the lower extremities and to increase range of motion in the hip joints. One month after the inspection we tested functional status and pain.

Results: There was 100% of women, mean age 64.15±4.06 years. The most represented were retirees, 60%, followed by workers and unemployed 10% and 30%. BMI was 27.3±4.22 kg/m². After a month there was a statistically significant reduction in pain measured by VAS (at the beginning it was 6.7; at the end 3.2; $p < 0.001$). At the end of the study there was a statistically significant increasing range of motion for active flexion ($p < 0.05$) and active abduction ($p < 0.05$), while there was no statistically significant increasing for active extension, adduction, internal and external rotation in the hip joint ($p > 0.05$).

Conclusions: The ACR strongly recommends the following nonpharmacologic measures for patients with knee or hip OA: cardiovascular or resistance land-based exercise, aquatic exercise, weight loss, for overweight patients. TENS may be another treatment option for pain relief. Our study showed that exercise and TENS therapy led to a statistically significant reduction in pain as measured by VAS pain scale and improving range of motion in hip joint.

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Patient information and education

PARE0004 PATIENT REPORTED LONG TERM EFFECTS OF SIX WEEK PROGRESSIVE RESISTANCE TRAINING PROGRAMME FOR RHEUMATOID ARTHRITIS

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Background: We introduced six week physiotherapy led progressive resistance training (PRT) programme for Rheumatoid arthritis (RA) patients to improve physical function and prevent the muscle loss (rheumatoid cachexia). Six week data showed improvement in body composition, physical function and fatigue scores¹. There is little published data about the longer term benefits of short exercise interventions and therefore we wished to study longer term effects on exercise behaviour in our patient group.

Methods: We surveyed 79 RA patients who had completed the six weeks PRT programme between 2013 and 2016 using two methods: Anonymous postal questionnaire; Direct telephone questionnaire. Patients were asked the same following questions: 1. Describe the best you feel at present following the exercise programme? Same/ Better/ Worse. 2. Have you continued with progressive resistance exercises? Yes/ No. 3. Do you feel the programme was worthwhile? Yes/No. 4. Did you feel the programme was too long, just right or too short?

Results:

| Patient | Continued PRT | Not continued PRT | Continued PRT | Not continued PRT |
|---------|---------------------------|------------------------|----------------------------|----------------------------|
| | 75% (27/36) (Postal) | 25% (9/36) (Postal) | 51% (22/43) (Telephone) | 49% (21/43) (Telephone) |
| Better | 81% (22/27) ($p=0.006$) | 33% (3/9) | 77% (17/22) ($p=0.009$) | 38% (8/21) |
| Same | 15% (4/27) | 56% (5/9) | 18% (4/22) | 19% (4/21) |
| Worse | 4% (1/27) | 11% (1/9) | 5% (1/22) | 43% (9/21) |

Postal questionnaire: 45% (36/79) patients returned the postal questionnaire. Time from PRT programme completion to postal questionnaire was: range (mean) 12–36 (26) months. 69% (25/36) still felt better; 25% (9/36) felt the same; 3% (1/36) worse since the programme. 91% (33/36) felt the programme was worthwhile. 75% (27/36) continued PRT exercises. 81% (22/27) of these still felt better, compared with 33% (3/9) who have not continued PRT ($p=0.006$). The duration of the programme was just right for 69% (25/36) and too short for 30% (11/36).

Telephone questionnaire: 54% (43/79) patients were contactable by telephone. Time from PRT programme completion to telephone questionnaire was: range (mean) 14–38 (26) months. 58% (25/43) still felt better; 18% (8/43) felt the same;

23% (10/43) worse since the programme. 95% (41/43) felt the programme was worthwhile. 51% (22/43) continued PRT exercises. 77% (17/22) still felt better, compared with 38% (8/21) who have not continued PRT. ($p=0.009$). 49% (21/43) had not continued PRT exercises, of whom 43% feel worse at present. The duration of the programme was just right for 47% (20/43) and too short for 53% (23/43).

Conclusions: Over 90% of patients who responded found the six week PRT programme worthwhile. More than half (51–75%) of the patients continued a PRT exercise programme. Patients who continued exercises felt better compared with those who did not continue exercises.

References:

[1] Berntzen et al A Six-Week Progressive Resistance Training Class Improves Function and Fatigue in RA Patients: *Annals of the Rheumatic Diseases* 75 (S2):254 2016.

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PARE0005 EDUCATIONAL PROGRAM FOR OLDER ADULTS WITH KNEE OSTEOARTHRITIS

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Background: Osteoarthritis is the commonest cause of disability at older ages and it is a huge burden on primary care (Peat, McCarney, & Croft, 2001). The knee joint is one of the most affected in elderly, influencing directly physical function and affecting physiological and social parameters. Therefore, it is imperative to development strategies that help individuals to change the way the disease affect their lives. International recommendations reinforce educational and exercise programs as the core of non-pharmacological approaches to enhance physical function and relieve pain and others osteoarthritis symptoms.

Objectives: The purpose was to assess the effectiveness of three months educational program for older adults with knee osteoarthritis (KOA).

Methods: Participants recruitment was done in the community using various marketing strategies. Forty individuals with 60 years or more, bilateral or unilateral KOA diagnosed according to clinical and radiological criteria of the ACR (1) and independently mobile and literate participated in the program. Educational sessions regarding exercise and joint protection strategies were offered. Telephone calls were done 15 days after each educational session. Patients received a book (2), with a core exercise section. Patients in the first attendance session were taught to do registration in an exercise training diary. Self-reported measures were pain, other symptoms, activities of daily living (ADL), and quality of life assessed by Knee Injury and Osteoarthritis Outcome Score (KOOS) questionnaire (3), Patient Global Impression of Change Scale (PGICS).

Results: Final sample included 32 adults (age: 67.8±5.3 years; bilateral KOA: 93.8%; female, 59.4%; BMI: 30.1±5.3 kg/m²). Eight participants did not complete the program (3 due to health problems and 5 for personal reasons). KOOS pain improved 10% ($p=.042$), and other symptoms 8%. Improvement in KOOS ADL (-8.7±13.6) and quality of life (-8.2±18.0) were also observed. 47% of the participants reported significant changes (scores 5–7) after intervention and a decrease in medication use of 31.3%.

Conclusions: The educational program can be an effective and suitable way for osteoarthritis management and to improve pain and health-related quality of life, leading individuals with KOA to better control their pathology and consequently living better.

References:

[1] Altman, R., Asch, E., Bloch, D., Bole, G., Borenstein, D., Brandt, K., Brown C, Cooke TD, Daniel W, Feldman D, et al. (1986). Development of criteria for the classification and reporting of osteoarthritis. Classification of osteoarthritis of the knee. Diagnostic and Therapeutic Criteria Committee of the American Rheumatism Association. *Arthritis Rheum*, 29(8), 1039–1049.

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[2] Roos, E. M., & Lohmander, L. S. (2003). The Knee injury and Osteoarthritis Outcome Score (KOOS): from joint injury to osteoarthritis. *Health and Quality of Life Outcomes*, 1, 64–64. doi: 10.1186/1477-7525-1-64.

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PARE0006 PATIENT INVOLVEMENT IN BASIC RESEARCH: A PILOT STUDY

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Background: Although the potential value of patient involvement in clinical research has been recognized [1], involvement of patient representatives (PRs) in non-clinical research is uncommon.