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PARE0020

REUMAWERKT - PROMOTING PROFESSIONAL REINTEGRATION OF PEOPLE WITH A RHEUMATIC DISEASE

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Background: In Belgium, people with Rheumatic and Musculoskeletal Diseases (RMDs) are a large group of patients on sick leave receiving an allowance as their condition does not allow them to remain at work. In order to reduce costs, the Belgian National Institute for Health and Disability Insurance (NIHDI) has reached out to social partners to jointly start up projects to promote the professional reintegration of people with RMDs. ReumaNet is one of these partners and has, in close collaboration with the NIHDI, started up a research project 'ReumaWerk' to promote professional reintegration of people with a rheumatic disease.

Objectives: Via the 'ReumaWerk' research, ReumaNet wanted to identify, as from a patient's perspective, which support patients need in order to stay at work or to start working again:

1. Information: identify and assess patients' available information about professional reintegration
2. Resources: evaluate resources people with RMDs have at their disposal to stay at work and/or to return to work
3. Assess if a Patient Expert (a trained patient) is an added value in supporting peers in their professional reintegration
4. Assess if a certified return to work coordinator is an added value in supporting people with RMDs towards professional reintegration

Methods: - Surveys questioning people with RMDs to assess their satisfaction regarding available information flows, resources and support (127 respondents)

- Survey questioning stakeholders (rheumatologists, health professionals) about information on professional integration they use and share (79 respondents)

- Coaching and supporting people with RMDs via personal contacts, mail, skype, phone calls,... in order to jointly define tailored answers on professional reintegration

Results: 1. There is a discrepancy between where patients expect to find information about professional reintegration and where information is given. There is plenty information available, but not customized, sometimes inconsistent, mostly too general and the legislation is too complex.

2. People with RMDs do experience physical obstacles at work. In addition, the Belgian government provides financial support, which is unfortunately (a) not well known and (b) too limited.

3. 80% of the respondents rated 7/10 and more as satisfaction rate. 82% of the respondents (N=127) would recommend the support of a Patient Expert to other patients.

4. The certified return to work coordinator applies disability management principles, focusing mainly on job retention and stimulating professional reintegration, taking into account each patient's personal bio-psycho-social context.

Conclusion: 1. People with RMDs, and their health professionals, are in need for straightforward and correct information about professional reintegration possibilities. Information flows need to be improved and provided information needs to be more specific, i.e. disease related.

2. People with RMDs have specific needs to allow them to return to or stay at work such as flexible working hours, functional adaptations in their working environment and financial support.

3. Patient expertise is an added value in supporting people with RMDs: respondents felt more understood by a peer, appreciated the opportunity for a more open, candid dialogue and felt encouraged to return to work.

4. Working via the principles of disability management is an added value: it is important to support people with RMDs as soon as possible and provide personalized tailored information on professional reintegration opportunities.

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SATURDAY, 06 JUNE 2020

Patient information and education

PARE0021

TARGETED INITIATIVE TO FACILITATE THE IMPLEMENTATION OF EXISTING EFFECTIVE GOUT TREATMENT IN SWEDEN

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Background: Gout is a very painful rheumatic condition origin from excess uric acid in the bloodstream, which results in an accumulation of uric acid crystals in the joints and a severe local inflammatory response. Gout is treated in primary care and the current treatment has satisfactory results on disease management, thus patients can expect a controlled disease without flares. In Sweden however, only 30-40 % (1) of the patients receives adequate urate lowering treatment and prevent the disabling flares.

Objectives: As a patient association, the Swedish Rheumatism Association (SRA) has identified an opportunity to use scientific evidence and data to improve awareness in both patients and physicians in order to make the existing treatment available and to shift the gout treatment from flare management to prevention.

Methods: With SRA funding we created the Gout network, consisting of researchers, health professionals and patient research partners. Through meetings and operational support developed strategies to educate patients suffering from gout and to alert physicians in the primary care of the most recent research to aid the management of gout. We also fund a specific research project aimed to create an implementation plan to establish a treatment routine for gout in primary care with already existing resources.

Results: A high quality patient education material is under development and consists of an information video lecture and a comprehensive online patient school providing information about the diagnosis, preventive treatment, possible life style change along with other resources that will support the gout patient, both for self-care and in relation to healthcare. For the healthcare profession we have together with a clinical research expert and a patient research partner developed a fact sheet with the latest scientific updates on gout.

Conclusion: Accessible, high quality diagnosis information about gout is currently missing in Sweden. This collaboration initiative provides high quality facts to raise the general awareness and to educate and empower patients to get the effective therapy that is available today.

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PARE0022

TARGETING FATIGUE IN RHEUMATOID ARTHRITIS: A SELF-HELP BOOKLET

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Background: Fatigue in rheumatoid arthritis (RA) is prevalent, intrusive, and disabling [1-3]. It has been shown that fatigue can be reduced, in at least some people with rheumatoid arthritis, using group interventions based on cognitive-behavioral principles [1]. However, the vast majority of the (about 40% [2]) severely fatigued people with rheumatoid arthritis does not have or does not want access to group therapy.

Objectives: To develop a self-help booklet aimed at targeting fatigue in rheumatoid arthritis based on cognitive-behavioral principles.

Methods: Based on the assumption that the most strongly influencing factors of fatigue differ between people [3], a comprehensive patient-centered approach was chosen. The booklet should be easy to read (big fonts,

text boxes, bulleted text, and illustrations). Needed materials should be included.

Results: In the booklet, factors that may influence fatigue are demonstrated by a hanging mobile toy, a device with stars or other figures hanging from the ceiling. If one piece moves, all the other pieces move as well. Every individual piece that is part of the mobile influences the other. However, every mobile is different. The large differences in balance between components of mobiles can be compared to the large variety of influences on fatigue in people. Patients first need to identify which factors seem especially important influencers of their own fatigue by sorting seven cards that are included in the booklet. They put the factor of which they think that it most influences their fatigue at the top and the factor that least influences their fatigue at the bottom. The seven cards are:

- 1) severe overweight,
- 2) disease activity,
- 3) day-night rhythm and sleep,
- 4) physical activity,
- 5) emotions and negative thoughts,
- 6) pain, and
- 7) another influence.

Interventions targeting these factors are discussed in separate sections of the booklet. Users are invited to start reading the sections with advice regarding the factors that most influence their fatigue. The foldable back cover of the booklet includes the set of seven cards of influencing factors, a diagram to make a 7-day 24-hours day-night rhythm schedule, and instructions to make an action plan.

Conclusion: In the Netherlands, the text can be obtained online and as a booklet in rheumatology departments of hospitals and through a national patient association, free of charge. The booklet was translated into English, which makes it accessible to a larger group of patients. It may take up to two months to successfully change lifestyle. It's an, as yet not empirically verified, hope that the booklet will be more successful than a traditional educational brochure.

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PARE0023 ORAL HEALTH IN RHEUMATOID ARTHRITIS: LISTENING TO PATIENTS

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Background: Rates of periodontal disease and tooth loss are increased in rheumatoid arthritis (RA). Periodontal disease may exacerbate RA inflammation and complicate RA care. Understanding factors that contribute to the increased burden of periodontal disease in RA is critical to improving oral health and possibly arthritis outcomes. People with RA may have unique needs and/or barriers to maintain oral health.

Objectives: To determine from people with RA what are their experiences and perceptions about their oral health, their most important questions relating to oral health, and how they wish to receive oral health information.

Methods: Semi-structured interviews were conducted with RA patients. Recorded interview transcripts underwent iterative content analysis. Transcripts were initially reviewed to develop a coding guide. Latent content, or larger themes, were then applied to the transcripts. Constructs were considered saturated when no new themes were identified with subsequent interviews. We report identified themes with representative quotes.

Results: Interviews with 11 RA (10[91%] female; all on RA medication) averaged 19 minutes (range 8-31 minutes) and were mostly conducted face-to-face. Many believed RA medication contributed to dry mouth. Most participants had not previously considered other links between oral health and RA. Themes identified included the need for complicated oral health routines, barriers of cost and access to dental care, and shame relating to oral health (Table 1). Participants preferred to receive oral health education from their rheumatologists or dentists over printed or online resources.

Conclusion: RA patients have unique needs relating to oral health and report poor oral quality of life. Strategies to optimize oral health in RA may include educational tools for optimizing oral self-care appropriate for RA, and improved access to oral care professionals who are aware of the needs of arthritis patients.

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PARE0024 AWARENESS ABOUT FAMILY PLANNING AND PREGNANCY EXPECTATION AMONG PATIENTS WITH CHRONIC INFLAMMATORY DISEASE OF THE SKIN OR JOINTS

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Background: Patients affected by chronic inflammatory diseases of the skin or joints (CIDs; including psoriasis [PSO], rheumatoid arthritis [RA], juvenile idiopathic arthritis [JIA], psoriatic arthritis [PsA], non-radiographic axial spondyloarthritis [nr-axSpA]; reported in the survey as 'axSpA'], or ankylosing spondylitis [AS]) may be challenged in their attempts to have children. A multinational survey conducted in Europe and the US, including 969 patients, revealed that most

Table. Thematic analysis and quotes

Theme	Description	Quote
Oral-RA links	RA medications caused dry mouth	The medications, really, really are awful on your mouth, in particular prednisone. I get very raw gums... it [was] painful to brush my teeth.
Complicated oral care	Time-demanding oral care routines. Multiple oral health care tools and adaptations used depending on current oral health, and RA activity.	We don't have saliva to wash things away. We have a different mouth flora The severe pain made it very hard to open my mouth to brush my teeth. The joint damage [makes it] really hard to handle a toothbrush. We have to have toothbrushes with a wide handle... and different attachments when we need them.
Access to professional oral care	Lack of dental insurance and costs of care Logistical access: multiple dental visits. Physical access: attending appointments; prolonged sitting in a dental chair.	Even with those [special] products, the pain sometimes was just overwhelming. I'm dedicated about brushing my teeth, but boy, it was a struggle. It took me a long time to brush my teeth. I have a hygienist, and a dentist, and a gum dentist and a bunch of dentists with fancy names. I see them every 3 months. Dental offices have dental hygienists. And some of them are an A+, and some of them are C...it's important that hygienists are trained, that they really understand the tools.
Shame due to oral health	Shame relating to poor oral health. Seeking oral care possibly considered unusual for their age.	When I go back in the [dental] chair, it was uncomfortable [when first diagnosed]. I struggled. I couldn't keep my mouth open. I would feel ashamed. Something's wrong. Everyone around me has these beautiful teeth. I don't, and something is wrong. I'm getting braces. At my age, I'm getting braces.