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Building patient led organisations

PARE0018 ENABLING PATIENT-CENTRED CARE IN RHEUMATOID ARTHRITIS AND ASSOCIATED COMORBIDITIES

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Background: Patients with rheumatoid arthritis (RA) have an increased risk of comorbidities such as diabetes (IR of 8.6 per 1000 person-years⁽¹⁾; 20% prevalence⁽²⁾), interstitial lung disease (7.7% incidence⁽³⁾; up to 60% (interstitial lung abnormalities in early RA)⁽⁴⁾), depression (up to 200%⁽⁵⁾; 16.8%⁽⁶⁾), and cardiovascular disease (40-70%⁽⁷⁾; 5-12.9%⁽⁸⁾) which contributes to increased long-term morbidity and mortality⁽⁹⁾. However, despite advances in treatment there are few established recommendations on the management of RA-related comorbidities.

Objectives: This study aimed to identify examples of good practice in the care of RA and associated comorbidities meeting standards of patient-centred care, and consider how these could be implemented in other European centres.

Methods: Following a literature review, multidisciplinary teams including specialists in rheumatology, cardiology and internal medicine, nurses, physiotherapists, psychologists, patient liaisons and care coordinators at 12 selected specialist centres across Europe (1 centre per country) were interviewed (approx. 180 interviews). The models identified were critically reviewed by a group of experts including a patient representative, and the degree to which the interventions impacted patient care and could be implemented in other centres was evaluated.

Results: Several care model interventions were identified which may improve quality and the patient's experience of care, e.g. fully integrated screening and diagnosis of comorbidities; coordination and sharing of care across different disciplines of comorbidity management; tailored individual education of patients and family members on lifestyle; enabling virtual engagement between patients on lifestyle management; and optimised convenience for patients having to attend multiple specialty appointments.

Conclusion: This study identified and evaluated interventions that may improve patient outcomes and quality of care in RA and associated comorbidities. The next steps will be to disseminate and implement these examples of good practices in a variety of European healthcare systems and settings.

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Patient information and education

PARE0019 LIVING WITH SYSTEMIC SCLEROSIS: EXPLORING ITS IMPACT ON CAREGIVERS: A QUALITATIVE STUDY

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Background: Systemic sclerosis (SSc) is a rare, chronic and heterogeneous disease with many possible outcomes and an uncertain horizon which presents difficulties not only for patients, but also for caregivers.

Objectives: To gain more insight in the experiences and unmet needs of caregivers for people with SSc in the Netherlands.

Methods: The study had a qualitative design. Participants were recruited by the Dutch patient organization (NVLE) using social media. One focus group and two individual interviews with a semi structured approach were held. Participants were asked to note down their associations with the disease, which lead on to a group conversation moderated by two researchers (MRS, CHE). The focus group was audiotaped and transcribed. Individual telephone interviews were summarized. All participants verified and approved the reports afterwards.

Results: Eight caregivers (4 males, 4 females: 4 partners, 2 widowers, 1 parent and 1 friend) of patients with SSc participated. Six attended the focus group session, two were interviewed over the phone. Several challenges were reported by the participants. The first challenge is coping with the chronic disease course, unawareness of treatment options and lack of information about limitations in treatment modalities. Furthermore, the witness of patients' ailing, changing bodies, decreasing mobility and poor energy levels without being able to provide a cure, was experienced as a huge burden by caregivers. Alongside this distress, caregivers personal lives are also affected; future opportunities are cut off, such as starting a family or continuing an active life style.

Caregivers addressed invalidation and the decrease in support from others due to misjudgment and misconceptions about severity, duration

and impact of the illness. Over time, this resulted in a dwindling network of social and emotional support, affecting family-life, relationships and mental health of both patient and caregiver.

Another strain was the complex mutual process of coping and the lack of frank communication about the condition between the partners, towards their social network and the medical staff. This is partly due to the indolent course of the disease, but also due to fear of what the future would hold and lack of insight in prognosis.

Caregivers reported that care provided at the hospital did not actively involve caregivers, nor provided them with the much-needed information with regard to prognosis, long-term treatment plans or daily care.

Conclusion: SSc has a major impact on the lives of caregivers, however, current care does not actively inform, include or support them to relieve some of this burden. Further research should focus on the modalities in which caregivers can be involved in the care and which information and support is required.

Figure 1. Word cloud/associations by participants, as part of the method used in focus group discussion.

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PARE0020 EXERCISE FOR LUPUS PATIENTS

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Background: Up to 80% of all Lupus patients experience fatigue and most of them report this as the most severe symptom. One of the major

causes of morbidity in SLE patients is chronic, debilitating fatigue, decreasing quality of life, increasing risk of work disability with associated cumbersome healthcare costs.

Several research papers show that the only thing clinically proven to have an effect on Lupus fatigue is moderate exercise. If you tell this to a Lupus patient experiencing fatigue, however, you will find it very difficult to motivate them to exercise. The challenge is to make them realise that exercise does not necessarily mean running a marathon or going to the gym – a little movement goes a long way.

Objectives: To get lupus patients to exercise and thereby experience less fatigue/better manage their disease.

Methods: Develop an exercise program, that is approved by physiotherapists and leading lupologists, easy to do and inspires Lupus patients to keep active even when they feel exhausted.

Results: In collaboration with physical therapists Lupus Europe has developed an exercise program from our own experiences and had it approved by leading European lupologists. The program has five levels; from lying in bed up until being able to run and jump. All exercises can be done at home without training tools. In order to make it accessible we have planned to make five videos (with Lupus patients), showing how to do each exercise and five connected pamphlets. We have already recorded the first three levels and are planning to finish the entire “package” in 2019. The materials will be made available to all Lupus patients on the Lupus Europe web site and YouTube channel free of charge.

Conclusion: We have already seen good results within the Lupus community, where people are finding the program easy to use and a help to keeping them active. Our hope is, that researchers will use our program to investigate its effectiveness on Lupus fatigue.

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