Disclosure of Interests: Richard Beesley: None declared, Simon Stones Consultant for: SS has provided consultancy services to Envision Pharma Group, though this is not related to the contents of this abstract., Speakers bureau: SS has undertaken speaking engagements for Actelion, eye-forpharma, Four Health, Janssen and Roche, though these are not related to the contents of this abstract.

DOI: 10.1136/annrheumdis-2019-eular.3285

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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Disclosures: Most authors have received funding from the industry including Sanofi Genzyme who solely funded this study

Disclosure of Interests: Neil Betteridge Consultant for: Amgen, Eli Lilly, Grunenthal, GSK, Heart Valve Voice, Janssen, Roche, Sanofi Genzyme and Sanofi Regeneron, Speakers bureau: Amgen, Eli Lilly, Grunenthal, GSK, Heart Valve Voice, Janssen, Roche, Sanofi Genzyme and Sanofi Regeneron, Alejandro Balsa Grant/research support from: Abbvie, Pfizer, Novartis, BMS, Nordic, Sanofi, Consultant for: Abbvie, Pfizer, Novartis, BMS, Nordic, Sanofi, Sandoz, Lilly, Paid instructor for: Pfizer, Speakers bureau: Pfizer, Novartis, UCB, Nordic, Sanofi, Sandoz, Lilly, Maya Buch Grant/research support from: Pfizer LTD, UCB, Consultant for: Abbvie, Eli Lilly, EMD Serono, Pfizer Ltd., Sanofi, maxime dougados Grant/research support from: Eli Lilly and Company, Pfizer, Abbvie, and UCB Pharma, Consultant for: Eli Lilly and Company, Pfizer, Abbvie, and UCB Pharma, Patrick Durez Speakers bureau: Bristol-Myers Squibb, Eli Lilly, Sanofi, Celltrion, Ennio Favalli: None declared, Guillaume Favier: None declared, Cem Gabay Grant/research support from: Roche, Pfizer, AB2 Bio Ltd, Consultant for: Roche, Pfizer, Lilly, Abbvie, Sanofi, Regeneron, Bristol-Myers Squibb, Novartis, UCB, AB2 Bio Ltd, Debiopharm, Rinie Geenen: None declared, Ioanna Gouni-Berthold: None declared, Frank van den Hoogen: None declared, Alison Kent: None declared, Lars Klareskog Grant/research support from: Yes, but not for the presented study., Mikkel Østergaard Grant/research support from: Abbvie, Celgene, Centocor, Merck, Novartis, Consultant for: Abbvie, BMS, Boehringer-Ingelheim, Celgene, Eli Lilly, Hospira, Janssen, Merck, Novartis, Novo, Orion, Pfizer, Regeneron, Roche, and UCB, Speakers bureau: Abbvie, BMS, Boehringer-Ingelheim, Celgene, Eli Lilly, Hospira, Janssen, Merck, Novartis, Novo, Orion, Pfizer, Regeneron, Roche, and UCB, Karel Pavelka: None declared, Joaquim Polido-Pereira: None declared, Anne Grete Semb: None declared, Magnus Sköld: None declared, Tore K. Kvien Grant/research support from: Abbvie, BMS, MSD, Pfizer, Roche and UCB, Consultant for: Abbvie, Biogen, BMS, Boehringer Ingelheim, Celgene, Celltrion, Eli Lilly, Hospira, Merck-Serono, MSD, Novartis, Oktal, Orion Pharma, Pfizer, Roche, Sandoz, Sanofi and UCB

DOI: 10.1136/annrheumdis-2019-eular.4283

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