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.

patients' concerns regarding family planning and pregnancy (FPP) were inadequately or inconsistently addressed.¹

Objectives: To investigate the general level of information on FPP and the potential concerns among Danish patients with CIDs.

Methods: An online survey to identify FPP issues was designed, and CID patients aged 18–50 years (yrs) were included. Respondents were recruited through patient organisations providing their members with a link to the questionnaire. In addition to demographics, information relating to time of diagnosis, treatments received, pregnancies, and course of disease were collected along with access to and concerns regarding FPP. Descriptive statistics were applied.

Results: Eligible patients included 368 with rheumatological diagnoses (RA, PsA, JIA, nr-axSpA, or AS; 304 [83%] female, mean age: 40 yrs; 64 [17%] male, mean age: 42 yrs) and 95 with dermatological diagnoses (PSO or PsA; 64 [67%] female, mean age: 37 yrs; 31 [33%] male, mean age: 42 yrs). Among the rheumatic patients, 43% of females and 53% of males were currently receiving systemic treatment and 37% of females and 22% of males had received >3 different systemic treatments (other than painkillers and non-steroidal anti-inflammatory drugs [NSAIDs]). Lack of access to FPP information was consistent across age groups, but higher in those with dermatological diagnoses (Table).

In total, 68% of patients with rheumatological and 73% with dermatological diagnoses had biological children and among these 18% and 23% of patients, respectively, indicated their disease had affected how many children they had or planned to have. The most frequent concerns among patients with rheumatological diagnoses were the potential physical impact of a pregnancy, disease worsening, heredity and being able to take care of the child (19, 16, 16 and 13%, respectively), whilst disease worsening and heredity (12 and 16%, respectively) were the most frequent concerns in those with dermatological diagnoses. Many patients experienced disease worsening during or after pregnancy (rheumatologic diagnoses: 16% and 34%; dermatologic: 20% and 59%, respectively).

Conclusion: Danish CID patients of reproductive age have concerns related both to their disease and to FPP, which affect their decisions around family planning. The majority of patients responding to this survey reported limited access to information about FPP, pointing to a need for healthcare professionals to provide standardised family planning information.

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Table. Proportion of patients with rheumatological or dermatological diagnoses who reported having little or no access to FPP information, stratified by age

Age	Rheumatological diagnosis N (%)	Dermatological diagnosis N (%)
18–29 yrs	19 (49)	14 (74)
30–39 yrs	61 (58)	16 (73)
40–50 yrs	134 (60)	34 (63)

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SATURDAY, 06 JUNE 2020

RMD research

PARE0025 “RA - DON'T GIVE UP” - LIFE WITH RHEUMATOID ARTHRITIS FROM PATIENTS' PERSPECTIVE

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Background: Rheumatoid arthritis (RA) as chronic and progressing to disability disease decreases a quality of life of every person suffering from it. Knowledge about this influence from patient perspective is important to limit burden of RA and organize appropriate care for patients.

Objectives: RA has input on every area of individual and social lives. Recognition of patients' situation in daily life, professional life, participation in treatment, taking life decision gives possibilities to better understanding of diseases and starting activities to change lives with RA. Aim of research was to learn attitudes, knowledge and experiences of people living with RA.

Methods: The study was initiated by KnowPR in partnership with Polish Rheuma Federation ‘REF’. Main researcher was Tomasz Sobierajski PhD., sociologist from Warsaw University. The first stage of the study was a workshop with patients with RA organized by REF. It was brainstorming to identify main problems, appropriate understand life with RA and discussion on questionnaire. After small pilot study on questionnaire, research was made by CAWI technique. Questionnaire had been linked on professional websites, facebook, Twitter, health forums. The data had been completed during one month - January 2019.

Results of survey were presented in booklet with comments. Opinions introducing results were done from persons represented patronages of project: minister of patient rights, president of Polish Society for Rheumatology, national consultant in rheumatology, directors of National Institute of Geriatrics, Rheumatology and Rehabilitation. Publication was enriched by stories of people with RA living full lives. Publication was launched during press conference and disseminated in hard copies and on-line with free access.

Results: In survey took part 619 respondents with RA - mostly women (90%). The biggest group of respondents (34%) was in age 46-60 years old. Duration of disease was different – from few months to more than 40 years. More than half of respondents are suffering from RA more than 10 years. Disease influences of every life area. Only 38% of respondents participate in decision about their treatment and took it together with rheumatologist. There are different opinions about way of taking medication. There are not differences among age groups and duration of disease in this. Majority of patients suffer from pain (73%), from limited abilities (68%) and from permanent fatigue (69%) in everyday lives. Rheumatologist has the biggest confidence among patients like a source of information about disease (73%). Other health professionals have lower confidence (35-40%). Majority of respondents (68%) note his knowledge about diseases like rather good and better. Respondents didn't connected their decision of having a child with disease how it has been before (59%). Part of respondents had to change or resign of professional work (30%). Part of them resigned from social life and hobbies before disease. In opinion of 57% of respondents RA changed totally their lives (57%).

Conclusion: Results of survey was used like a tool in lobbying for accessibility in newest treatment in RA. Further recognize of quality of life in RA is needed. Interviews of focus groups and individuals are planned.

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PARE0026 WHICH PATIENT-REPORTED OUTCOMES DO RHEUMATOLOGY PATIENTS FIND IMPORTANT TO TRACK DIGITALLY? A REAL-WORLD LONGITUDINAL STUDY IN ARTHRITISPOWER

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Background: Development of a standardized approach to assess key elements of disease activity in rheumatology clinical trials has been the goal of Outcome Measures in Rheumatology Clinical Trials (OMERACT), American College of