Disclosure of Interests: None declared
DOI: 10.1136/annrheumdis-2019-eular.7921

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RHEUMA-VOR: A PROOF-OF-CONCEPT NETWORK STUDY FOR THE IMPROVEMENT OF RHEUMATOLOGICAL HEALTH CARE THROUGH COORDINATED COOPERATION

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Background: Rheumatoid arthritis (RA), psoriasis arthritis (PsA) and spondyloarthritis (SpA) are the most common chronic autoimmune rheumatic diseases. For all 3, the so-called "window of opportunity" [1-3] has been identified as the decisive factor affecting the outcome.

Objectives: The aim of the prospective study is to improve early diagnosis of RA, PsA and SpA and thus positively impact the quality of care for patients with the help of coordinating centers. The primary endpoint is the number of cases with an actual indication for immediate referral to a specialist in proportion to all reported cases.

Methods: The project establishes a network of the University Medical Center Mainz, the Medical School Hannover, the Center for Rheumatology Lower Saxony e.V., the University Medical Center Saarland, the ACURA Center of Rheumatology Rhineland-Palatinate, the Leibniz University Hannover and the University Medical Center Freiburg, local rheumatology specialists, the associations of statutory health insurance physicians and general practitioners and the 3 regional associations of the Deutsche Rheuma-Liga e.V. Covering 3 federal states, the network reaches approximately 13 million inhabitants.

Primary care providers are given access to screening questionnaires to document potential early cases of RA, PsA, and SpA, based on characteristic symptoms. These are evaluated by multidisciplinary teams at the regional coordinating centers. If they fulfill the criteria for referral, patients get an appointment at a cooperating rheumatology specialist within weeks. If a rheumatic disease is diagnosed, physicians and patients receive questionnaires on sociodemographic data, quality of life, functionality, medication, diagnosis and psychological aspects. After 12 months, the questionnaires are completed a second time. The collected data is compared with a matched reference group of the German Rheumatism Research Center. It is planned to screen up to 8.700 people within the 30-month survey phase that started in October 2017.

Results: Preliminary data will be presented at the conference. Currently, 2.400 patients have been screened, of which 400 patients were included in the study and 15 already underwent their follow-up screening.

Conclusion: Previous studies have shown positive results of coordinated cooperation among the relevant care providers. For example, 75 percent of the patients diagnosed with early RA within the ADAPTERA network were in remission after 2 years (DAS28<2.6) [4]. Corresponding developments are expected in all clinical pictures for participants in Rheuma-VOR.

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Disclosure of Interests: Matthias Dreher: None declared, Gunter Assmann: None declared, Kirsten Hoeper: None declared, Konstantinos Triantafyllidis: None declared, Jan Zeidler: None declared, Harald Binder: None declared, Reinhold E. Schmitt: None declared, Andreas Schwarting Grant/

research support from: GSK, Pfizer, AbbVie, Novartis, Roche, Speakers bureau: GSK, Novartis

DOI: 10.1136/annrheumdis-2019-eular.3666

AB1233

PEOPLE WITH RHEUMATIC AND MUSCULOSKELETAL DISEASES CONNECT AND LEARN ABOUT HEALTH-RELATED ISSUES USING SOCIAL MEDIA

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Background: Smartphone applications and social media (SM) are increasingly used, transforming the way in which people communicate. Peer interaction, remote information access and community building are just some of the uses of SM, presenting novel opportunities and challenges, especially for people with chronic conditions such as rheumatic and musculoskeletal diseases (RMDs).

Objectives: To explore the perspectives of people with RMDs on using SM for health-related purposes.

Methods: A questionnaire-based survey, co-designed in English by rheumatologists and patient research partners and translated into German, Italian, Spanish, Russian, French and Portuguese, was issued between May and December 2018, distributed via patient organizations and SM platforms. We report on the main quantitative exploratory analyses.

Results: A total of 992 participants started the survey; 853 (86%) participants reached at least 25 of 31 questions and were subsequently included in analyses. Participants were from 56 countries, with 50% from the UK, Germany, Portugal and Spain; 11% were outside of Europe. 60% of participants reported a good or very good experience in the use of SM. More than half (56%) were between 35 and 54 years, 90% were female, 37% had >1 RMD and 62% were multimorbid.

The use of smartphones, SM, SM for health-related purposes was affirmed by 93%, 95% and 76%, respectively. They started this in particular to connect with other people living with the same condition (58%). In general, 50% use SM to seek medical information, treatment options and to exchange experiences. Facebook (58%), Google+ (17%) and YouTube (17%) were the top three used platforms for health-related purposes; while Facebook (88%), YouTube (50%) and Instagram (47%) were most popular for general use. Platforms, that are usually used are not always the preferred one for health-related purposes, since only 16% of Instagram, 28% of YouTube and 67% of Facebook users prefer the same for health-related purposes. The greatest advantage of SM is to acquire different experiences and exchange knowledge with peers. More than half voiced concerns regarding confidentiality and 21% were hesitant of disclosing their condition. Virtual appointments are still novel, since only 4% reported experience.

SM use and education were comparable between groups with different levels of multimorbidity, although health was poorer (p=0.001) and they were older (p=0.001). Participants more frequently considered that information provided by primary care physicians was inadequate (p=0.014) and wanted to make their voice heard (p=0.006), but at the same time were more skeptical about reliability of information on SM (p=0.036).

Conclusion: The use of SM for health-related purposes is widespread among people with RMDs, mainly as a means to connect and exchange knowledge and experience, thus empowering individuals to better self-manage their health. The strong concerns about confidentiality and better guidance of patients may improve health literacy and the relationship between the patient and the health care team, addressing new avenues and challenges in healthcare.

Acknowledgement: We would like to thank PARE in their support distributing this survey study.

Disclosure of Interests: Paul Studenic: 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., Alessia Alunno: None declared, Valentin Ritschl: None declared, Elena Nikiforou: None declared

DOI: 10.1136/annrheumdis-2019-eular.6304