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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 spondyloarthritides (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-Palatinat, Bad Kreuznach, Germany; Leibniz University Hannover, Center for Health Economics Research Hannover, Hannover, Germany; University Medical Center Freiburg, Institute of Medical Biometry and Statistics, Freiburg, Germany; Medical School Hannover, Department of Clinical Immunology and Rheumatology, Hannover, Germany.

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 ADAPThERA network were in remission after 2 years (DAS28<2.6) [4]. Corresponding developments are expected in all clinical pictures for patients in Rheuma-VOR.

REFERENCES

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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. 83 (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, 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 (56%), 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 accept 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. RMDs and their experiences empower 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.

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