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“I LITERALLY CONVINCED MYSELF I WAS GOING TO CATCH IT AND DIE”: LIVED EXPERIENCES OF THE COVID-19 PANDEMIC BY PEOPLE WITH RHEUMATIC DISEASES FROM FOUR EUROPEAN COUNTRIES

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Background: The COVID-19 pandemic has resulted in unforeseen challenges for humanity, taking a significant toll, especially the immune-suppressed individuals. In this regard, the health and general well-being of people with rheumatic diseases, the great majority users of immunosuppressives, have been at stake.

Objectives: To explore the impact of the COVID-19 pandemic on people with rheumatic diseases on immunosuppression during the first wave, concerning a) (self-)management of their disease; b) interaction with the health care team; c) emotional well-being and d) overall health.

Methods: A qualitative study was conducted following a phenomenological approach. Adults (>18 years) with a rheumatic disease from four European countries (Cyprus, England, Greece, Portugal). Patients were recruited through patient's associations and social media and were invited to participate in semi-structured, audio-recorded interview or focus groups, between July - August 2020. Following a pilot study the information provided was transcribed verbatim, anonymized and translated into English where necessary. An inductive approach was adopted to carry out a thematic framework analysis with the assistance of ATLAS.ti to identify key themes and subthemes. Data validation strategies were employed, and Ethical approval and informed consent were obtained.

Results: Participants were 24 patients (21 women, age range 33 to 74 years) divided by 7 focus-groups and 1 individual interview. Most frequent diagnoses were rheumatoid arthritis (n=7), lupus (n=4), juvenile idiopathic arthritis (n=3).

Three key themes with 3-7 subthemes were identified within the analytical framework, centred around the impact of the Covid-19 on patients' lives (Figure 1): i) individual person (e.g. fear for myself and family, social isolation and lack of personal freedom, more time with family) ii) health settings (e.g. (un)clear information about risks of contamination, fear or risk of shortages of medication, remote consultations), and iii) work and community (e.g. persistent stress due to mass media exposure, lack of awareness by others about patients' rheumatic disease and its disclosure, hope and suspicion about new vaccine development: "I hear that they will ask vulnerable groups to have the vaccine first (...) Why is that? we will be again the innocent victims"). Findings were similar across countries, except for spirituality (i.e. the pandemic as "the hand of God"), a coping sub-theme particular to Portugal. These main themes resonated well with the social ecological model and Walsh's Family Resilience Process [1,2].

Figure 1. Lived experiences of the Covid-19 pandemic by people with rheumatic diseases



Conclusion: When experiencing a significant life-event people require some time to process the different lived experiences. This study provides insights on how patients from four countries coped with the new challenges. Such insights are invaluable for health care providers and policy makers, in guiding more meaningful support tailored to individual needs, especially at times of crisis. The study highlights the impact of COVID-19 on the lives of people with rheumatic disease. A follow-up study is currently underway to examine the effect of subsequent waves of the pandemic.

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IMPACT OF COVID-19 PANDEMIC ON RHEUMATOLOGY PATIENTS IN NORTHERN IRELAND – A WEB BASED CROSS-SECTIONAL SURVEY

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Background: Concern for the susceptibility of rheumatology patients to severe COVID-19 illness has been raised since the start of the pandemic. Rheumatic disease and their immunosuppressant therapies placed many patients into the 'clinically extremely vulnerable' group when the UK's shielding guidance commenced on 23 March 2020. The impact of DMARDs/glucocorticoids/biologics on COVID-19 remains under investigation¹. A recent study suggested caution may be required with rituximab and sulfasalazine in COVID-19 patients².