Objectives: To evaluate the validity and responsiveness of the 8-item Neuro-QoL UEF in RA. We hypothesized scores would be strongly (>0.70) associated with MHAQ, MD-HAQ, and PROMIS PF, moderately (r= 0.4 to 0.7) to symptoms, disease activity, and QoL indicators, and be responsive to change in disease activity and PF.

Methods: Data were from the 0 and 6-month visits of adults with early RA (≤1 yr) enrolled in the Canadian Early Arthritis Cohort, a prospective real-world study at 16 sites across Canada. Participants completed the Neuro-QoL UEF, MHAQ, MD-HAQ, PROMIS-29, and PT Global at each visit. Rheumatologists recorded joint counts and MD Global. To evaluate content validity, we examined descriptive statistics across CDAI disease activity levels, and Pearson correlations between the Neuro-QoL UEF, legacy measures, CRP & ESR. Responsiveness was assessed by correlating change scores from visits 0-6 between Neuro-QoL UEF, disease activity and legacy PF scores.

Results: The 262 participants were mostly white (83%) women (71%) with a mean (SD) age of 55 (13). Summary statistics at 6-months are shown in Table 1. Neuro-QoL UEF was moderately-strongly correlated with MHAQ, MD-HAQ, PROMIS-PF (r= 0.63-0.75) and moderately correlated with pain and stiffness, (r= 0.59, -0.64), and CDAI, SDAI, PT&MD Global, TJ & SJ (r= -0.39-0.58). Neuro-QoL UEF was moderately correlated with PROMIS QoL domains Pain, Fatigue, Anxiety, Depression, Sleep & Participation (r= -0.39-0.60).

Conclusion: Neuro-Qol UEF has initial evidence of validity and responsiveness and support use of Neuro-QoL UEF to self-assess inflammatory activity in the hands and day-to-day experiences of living with RA.

Table 1. Summary statistics of physical function and RA disease activity indices at 6 months.

<table>
<thead>
<tr>
<th></th>
<th>Mean</th>
<th>SD</th>
<th>Mdn</th>
<th>25%</th>
<th>75%</th>
<th>(Min, Max)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Physical Function</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Neuro-QoL UEF</td>
<td>46.5</td>
<td>9.7</td>
<td>53.8</td>
<td>37.5</td>
<td>53.8</td>
<td>(21.8, 53.8)</td>
</tr>
<tr>
<td>MHAQ (0-3)</td>
<td>0.29</td>
<td>0.43</td>
<td>0.13</td>
<td>0.00</td>
<td>0.38</td>
<td>(0.00, 2.25)</td>
</tr>
<tr>
<td>MD-HAQ (0-10)</td>
<td>1.39</td>
<td>1.64</td>
<td>0.70</td>
<td>0.00</td>
<td>2.00</td>
<td>(0.00, 8.00)</td>
</tr>
<tr>
<td>PROMIS-PF</td>
<td>46.4</td>
<td>8.5</td>
<td>46.2</td>
<td>39.5</td>
<td>56.0</td>
<td>(23.3, 56.0)</td>
</tr>
<tr>
<td>RA Disease Activity</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>CDAI</td>
<td>9.3</td>
<td>9.9</td>
<td>6.0</td>
<td>3.0</td>
<td>13.0</td>
<td>(0.0, 56.0)</td>
</tr>
<tr>
<td>SDAI</td>
<td>10.7</td>
<td>10.9</td>
<td>6.8</td>
<td>3.1</td>
<td>15.2</td>
<td>(0.0, 70.0)</td>
</tr>
<tr>
<td>Patient Global</td>
<td>3.0</td>
<td>2.5</td>
<td>3.4</td>
<td>1</td>
<td>5</td>
<td>(0.0, 10.0)</td>
</tr>
<tr>
<td>MD Global</td>
<td>1.8</td>
<td>2.2</td>
<td>1</td>
<td>0</td>
<td>3</td>
<td>(0.0, 9.0)</td>
</tr>
<tr>
<td>Swollen Joints (28)</td>
<td>2.1</td>
<td>3.7</td>
<td>0</td>
<td>0</td>
<td>2</td>
<td>(0.0, 20.0)</td>
</tr>
<tr>
<td>Tender Joints (28)</td>
<td>2.4</td>
<td>3.8</td>
<td>1</td>
<td>0</td>
<td>3</td>
<td>(0.0, 20.0)</td>
</tr>
</tbody>
</table>

Neuro-QoL scores declined in a dose-response manner across worsening CDAI DA states reflecting increasing impairment (Table 2). Persons with HAD reported the highest disability, scoring nearly 0.5 SD lower on the Neuro-QoL UEF than PROMIS PF. Change from baseline to 6 months in Neuro-QoL UEF was moderately correlated with changes in PROMIS PF, MHAQ, PT Global, and CDAI (r= -0.44-0.65). The mean change and range from 0-6 months in Neuro-QoL was significantly larger than in PROMIS (8.9 [95% CI 7.5, 10.4] vs. 5.4 [95% CI 4.4, 6.4]) (see Figure).

Table 2. Mean scores (% CI) at 6 months by CDAI level.

<table>
<thead>
<tr>
<th></th>
<th>Mean</th>
<th>SD</th>
<th>Mdn</th>
<th>25%</th>
<th>75%</th>
<th>(Min, Max)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Physical Function</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Neuro-QoL UEF</td>
<td>65.1</td>
<td>5.2</td>
<td>63.7</td>
<td>60.7</td>
<td>67.7</td>
<td>(57.6, 73.0)</td>
</tr>
<tr>
<td>MHAQ (0-3)</td>
<td>0.05</td>
<td>0.02</td>
<td>0.09</td>
<td>0.14</td>
<td>0.24</td>
<td>(0.00, 0.48)</td>
</tr>
<tr>
<td>MD-HAQ (0-10)</td>
<td>6.86</td>
<td>1.15</td>
<td>7.17</td>
<td>6.00</td>
<td>8.33</td>
<td>(5.33, 8.33)</td>
</tr>
<tr>
<td>PROMIS-PF</td>
<td>62.8</td>
<td>5.42</td>
<td>61.8</td>
<td>58.3</td>
<td>65.3</td>
<td>(56.3, 65.3)</td>
</tr>
</tbody>
</table>

Acknowledgements: The CATCH study was designed and implemented by the investigators and financially supported through unrestricted research grants from: Amgen and Pfizer Canada - Founding sponsors since January 2007; AbVie Corporation and Hoffmann-LaRoche since 2011; Medexus Inc. since 2013; Merck Canada since 2017, Sandoz Canada, Biopharmaceuticals since 2019, Gilead Sciences Canada since 2020 and Fresenius Kabi Canada Ltd. since 2021. Previously funded by Jansen Biotech from 2011-2016, UCB Canada and Bristol-Myers Squibb Canada from 2011-2018, Sanofi Genzyme from 2016-2017, and Eli Lilly Canada from 2016-2020.

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REFERENCES:


Disclosure of Interests: None declared.

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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. for myself and family, social isolation and lack of personal freedom, more time with family) ii) health settings (e.g. unclear 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

Work & Community
 Persistent stress: Mass media
 Lack of awareness and disclosure of RMD
 Hope vs suspicion about vaccines

Health settings
 (Unclear information about risks
 Medications: shortages and fear about risks
 Traveling and self-managing
 Telecare: friend or foe?

Individual Person
 Fear for myself and family
 Home isolation/lack of freedom
 Missing physical/human contact
 Psychological difficulties
 Coping strategies
 Opportunity to slow-down
 Time to family

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.

REFERENCES:


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Disclosure of Interests: None declared.

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OP0265-HPR 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 investigation [1]. A recent study suggested caution may be required with rituximab and sulfasalazine in COVID-19 patients [2].

OP0264-HPR “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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