Self-reported Impact of the Early 2020 COVID-19 Crisis on the Healthcare Pathway During and After Lockdown in Patients With Chronic Immune-Mediated Inflammatory Diseases: A Practical Survey

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Abstract

Introduction: Global lockdown in the context of the coronavirus disease 2019 (COVID-19) pandemic is an unprecedented experience. We report here the results of an anonymous questionnaire-based survey on the healthcare and control of chronic IMIDs (chronic immune-mediated inflammatory diseases) within the IMMINENT network during the French lockdown (March 17, 2020-May 11, 2020) and the 2-month period following the end of the lockdown (July 11, 2020). Methods: Two anonymous questionnaires were sent by email to 4500 patients who were followed in a university hospital for an IMID in the departments of gastroenterology, rheumatology, dermatology, pneumology, neurology, and internal medicine. Results: A total of 921/4500 (20.46%) responded to the first survey (impact of the lockdown), and 553/4500 (12.28%) to the second (impact at 2-months post-lockdown). Concerning the impact of the lockdown, 420/915 (45.9%) reported affected follow-up. Similarly, after the lockdown, 248/544 (45.6%) declared a negative impact on their follow-up. The repartition by departments of patients’ perception of an altered follow-up during and at the end of the lockdown was not statistically different. Our study highlighted the effects of the COVID-19 pandemic and the restriction measures

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implemented on the self-reported impact felt by patients on the follow-up of their chronic IMIDs without significant differences among all departments. **Conclusion:** Our study is original by showing that patients, whatever the type of IMID, shared this same negative perception. This transdisciplinary study demonstrated the importance of a collaborative network among all departments.

**Keywords**
COVID-19, SARS-CoV-2, lockdown, healthcare management, chronic inflammatory disease, psychological impact, access to care, access to medicine, telemedicine

**Introduction**
Global lockdown in the context of the coronavirus disease 2019 (COVID-19) pandemic is an unprecedented experience in the modern era, whose consequences have still to be fully determined on many levels including physical and mental health. For example, data on the impact of lockdown on the follow-up and disease control of patients with chronic immune-mediated inflammatory diseases (IMIDs) are scarce (1), and the evolution after lifting the lockdown has not been studied. The multidisciplinary network “IMmune-Mediated INflammatory diseases aNd Targeted Therapies” (IMMINENT) is a project conducted within the university hospital of Lille aiming to improve research, care, teaching, and therapeutic education in the field of IMIDs and their treatment. We report here the results of an anonymous questionnaire-based survey on the healthcare and control of chronic IMIDs within the IMMINENT network during the French lockdown (March 17, 2020-May 11, 2020) and the 2-month period following the end of the lockdown (July 11, 2020).

**Material and Method**
Two anonymous online questionnaires (44 questions) made using Microsoft forms® platform were sent by email to patients who were followed for an IMID within the IMMINENT network in the departments of gastroenterology, rheumatology, dermatology, pneumology, neurology, and internal medicine. Among 8000 patients followed within the IMMINENT network project, 4500 had provided an email address, for whom the questionnaires were sent. Respondents to the first survey sent during the lockdown period were referred to as group 1, and participants in the survey sent 2 months post-lockdown were mentioned as group 2. The rates of patients having had an impact of lockdown/end of lockdown on their disease follow-up, symptoms, treatment, and access to information, were estimated in the overall population and in the population stratified by department with 95% confidence intervals (exact Clopper-Pearson method). These rates were compared between departments using chi-square tests. Statistical testing was done at the two-tailed α-level of 0.05. Data were analyzed using SAS software (version 9.4; SAS Institute Inc., Cary, NC). Ethical approval for the study was obtained from the French ethic committee. The primary outcome measure was the impact on follow-up of chronic IMIDs by departments, and secondary outcome measures were the impact on symptoms, supply of medication, and access to information related to the pandemic, both during the lockdown and post-lockdown periods. To measure the impact or access to information, we dichotomized the answers with “somewhat agree,” “agree,” and “totally agree” as a “yes” versus “totally disagree,” “disagree” and “slightly disagree” as a “no,” to create a binary classification relevant to the concerned question.

**Results**
A total of 921/4500 (20.46%) responded to the first survey (impact of the lockdown), and 553/4500 (12.28%) to the second (impact at 2-months post-lockdown). Diseases’ repartition is shown in Table 1. Concerning the impact on follow-up, in group 1, 420/915 (45.9%, CI 95% = [42.6%; 49.2%]) reported that the disease follow-up was negatively affected by the lockdown. Similarly, in group 2, 248/544 (45.6%, CI 95% = [41.3; 49.9]) declared that they had a negative impact on their follow-up post-lockdown without significant difference between the 2 groups (P = .91). The repartition by departments’ perception of an altered follow-up during (P = .72) and at the end of the lockdown (P = .77) was no statistically different. Concerning secondary outcome measures, respectively, 244/912 (26.8%, CI 95% = [23.9; 29.8]) and 117/547 (21.4% CI 95% = [18.0; 25.1]) patients declared having experienced symptoms of exacerbation during both lockdown and post-lockdown periods. During the lockdown, 76/913 (8.3%, CI 95% = [6.6; 10.3]) patients reported drug supply problems related to their disease, compared to only 14/545 (2.6%, CI 95% = [1.4; 4.3]) patients 2 months after the lockdown. Finally, 438/916 (47.8%, CI 95% = [44.5; 51.1]) patients have declared that they were not well informed about their potential risk of contracting COVID-19 during the lockdown period, and 230/544 (42.3%, CI 95% = [38.1; 46.6]) after the lockdown. Table 1 lists the main factors that might have influenced the patients’ overall impression throughout and after the lockdown, relating to the patient’s psychological status, disease activity, work environment conditions, and means of access to healthcare services.

**Discussion**
Our study analyzed the effects of the COVID-19 pandemic and the restriction measures implemented on the self-reported impact felt by patients on the follow-up of their
Diseases

Some patients were followed-up in one or more departments and suffered from one or more diseases. Values are expressed as numbers (%).

| Diseases                      | Lockdown N=921 | End of lockdown N=553 |
|-------------------------------|----------------|-----------------------|
| Systemic lupus                | 111 (12.3)     | 56 (10.4)             |
| Systemic scleroderma          | 81 (9)         | 46 (8.5)              |
| Sjögren’s syndrome            | 76 (8.4)       | 47 (8.7)              |
| Vasculitis                    | 20 (2.2)       | 19 (3.5)              |
| Myositis                      | 0 (0)          | 3 (0.6)               |
| Crohn’s disease               | 166 (18.4)     | 111 (20.6)            |
| Ulcerative colitis            | 60 (6.7)       | 30 (5.6)              |
| Rheumatoid arthritis          | 80 (8.9)       | 45 (8.3)              |
| Spondylarthrits               | 66 (7.3)       | 38 (7.1)              |
| Atopic dermatitis             | 27 (3)         | 16 (3)                |
| Psoriasis                     | 62 (6.9)       | 38 (7.1)              |
| Psoriatic arthritis           | 20 (2.2)       | 18 (3.3)              |
| Hereditary angioedema         | 12 (1.3)       | 4 (0.7)               |
| Hidradenitis Suppurativa      | 1 (0.1)        | 1 (0.2)               |
| Multiple sclerosis            | 152 (16.9)     | 100 (18.6)            |
| Parkinson’s disease           | 2 (0.2)        | 0 (0)                 |
| Severe asthma                 | 29 (3.2)       | 17 (3.2)              |
| Diffuse interstitial lung     | 13 (1.4)       | 9 (1.7)               |

Main factors observed potentially related to the perception of a disrupted follow-up

| Main factors observed | Lockdown, n (%) | End of lockdown, n (%) |
|-----------------------|-----------------|------------------------|
| Emotional experience   | 201/914         | 110/549                |
| Bad experience         | 21/99           | 20/04                  |
| Stressed               | 630/919         | 384/546                |
| Work affected          | 42/87           | 40/04                  |
| self-reported disease flare ups | 243/916 | 133/546 |
| Access facilities/obstacles | 152/857 | 59/499 |
| Renouncement to healthcare | 418/899 | 176/527 |
| Teleconsultation       | 134/866         | 134/866                |
| Transportation difficulties | 346/657 | 146/542 |
| Canceled consultations | 52/66           | 26/94                  |
| Postponed lab tests    | 123/858         | 50/505 (9.90)          |
| Postponed imaging tests | 14 (33) | 43/500 (8.60)          |

*Some patients were followed-up in one or more departments and suffered from one or more diseases. Values are expressed as numbers (%).

Concerning departments, there were one missing data in Group 1 = lockdown and 22 missing data in Group 2 = end of lockdown. Concerning diseases, there were 21 missing data in Group 1 and 14 missing data in Group 2.
chronic IMIDs within the IMMINENT network. Our study is original by showing that all patients shared this same negative perception, regardless of the type of IMID. Moreover, this transdisciplinary study encourages remote collaboration between departments within a single network by sharing information and enhancing communication with patients, which provide the opportunity to identify gaps, and consequently develop solutions to ensure better care and unified management in times of crisis.

Abbreviation
COVID-19   coronavirus disease 2019
IMIDs      chronic immune-mediated inflammatory diseases
IMMINENT  “IMmune-Mediated INflammatory diseases aNd Targeted Therapies.”

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Authors’ Contributions
JN and FD carried out and built the study. JN and FD wrote the first draft of the manuscript with validation from all authors. CP helped supervise the project. CT performed the statistical analysis.

Ethical Approval
Ethics approval and consent to participate: Ethical approval for the study was obtained from the French ethic committee “Comité de Protection des Personnes Sud-Ouest et Outre-Mer II” and was recorded under the no. ID-RCB: 2020-A01596-33.

Consent for Publication
By participating in the survey, patients were informed and consented to the use of the anonymous data collected for research purposes.

Availability of Data and Material
The data that support the findings of this study are available upon request from the authors.

Declaration of Conflicting Interests
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