


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 ($P = .72$) and at the end of the lockdown ($P = .77$) 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 of patients' 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

Table 1. Patients' Repartition Among Departments and Diseases.

N (%)	Lockdown N = 921	End of lockdown N = 553
Department^a		
Internal Medicine	297 (32.3)	167 (31.5)
Gastroenterology	218 (23.7)	114 (21.5)
Rheumatology	125 (13.6)	73 (13.7)
Dermatology	86 (9.3)	54 (10.2)
Neurology	157 (17.1)	99 (18.6)
Pneumology	37 (4)	24 (4.5)
Diseases^a		
Systemic lupus	111 (12.3)	56 (10.4)
Systemic sclerosis	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)
Spondylarthritis	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 disease	13 (1.4)	9 (1.7)
Main factors observed potentially related to the perception of a disrupted follow-up		
	Lockdown, n (%)	End of lockdown, n (%)
Emotional perception		
Bad experience	201/914 (21.99)	110/549 (20.04)
Stressed	630/919 (68.55)	384/546 (70.33)
Work affected	394/919 (42.87)	219/547 (40.04)
self-reported disease flare ups	243/916 (26.5)	133/546 (24.36)
Access facilities/obstacles		
Renouncement to healthcare	152/857 (17.74)	59/499 (11.82)
Teleconsultation	418/899 (46.49)	176/527 (33.40)
Transportation difficulties	77/915 (8.41)	41/545 (7.52)
Canceled consultations	346/657 (52.66)	146/542 (26.94)
Postponed lab tests	134/866 (15.47)	50/505 (9.90)
Postponed imaging tests	123/858 (14.33)	43/500 (8.60)

^aSome 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. Our data showed that almost half of responding patients perceived and experienced a poorer follow-up for their chronic disease during the lockdown, and the same applied in the period after lockdown, without significant difference among all departments. Based on our survey, patients sensing a decline in their disease follow-up and control could be explained by several factors, although the association was not proven. In fact, many viewed quarantine as a stressful experience took it hard, dealt poorly with the pressure and stress, particularly with their work environment and conditions affected, confronted with teleworking, temporary or permanent job losses, and limited social interactions. Their sense of impacted follow-up might have emerged from the state of mind at the time, but it has not been reflected concretely with more flare-ups of the disease, based on patients' reports solely rather than an objective assessment by physicians. Major reasons for canceling appointments and renouncement to healthcare included fear of infection and temporarily closed outpatient clinics during the lockdown. Our findings are consistent with previous studies, displaying a range of negative psychological impacts of quarantine, such as anxiety, distress, work disruption, self-isolation, and fear of infection (2). This fact might have contributed to sensing a disruption in healthcare, but access to medical care and appointments were possible due to teleconsultation as an alternative, which permitted a continuous care and adapted management to the needs and disease, despite all the difficulties faced in terms of transportation, fear of attending a hospital or giving priority to patients with serious illnesses and emergencies. The negative impact of COVID-19 on access to medication appears to be limited in both lockdown and post-lockdown periods, which shows sustained dispensing activities during the pandemic, reflecting a good compliance to treatments for chronic diseases. A recent study revealed strategies needed for maintaining drug dispensing and access to medication in the context of the COVID-19 pandemic (3). Unlike expected, lifting the lockdown was not associated with an improved patients' perception regarding follow-up. This may be attributed to a delay in the recovery of health services and a persistent negative psychological impact, manifested in questions 6 and 7 related to stress symptoms with comparable results in groups 1 and 2. This finding is in contradiction to a previous report by Meda et al (4) which demonstrated a normalization of depressive and anxiety symptoms after lockdown, regarding only healthy and young subjects. The main limitations of our study are data were self-reported and not based on a detailed and objective assessment of diseases' control, and the low response rate inherent to this type of study which could select patients with an impact related to the question at issue and create a nonresponse bias.

Conclusion

The COVID-19 pandemic, and the restrictive measures implemented during this period (in particular lockdown), had a significant impact on the patients' medical follow-up, during and after the lockdown, according to the opinion of patients suffering from

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 trans-disciplinary 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.”
multidisciplinary network	

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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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References

1. Singh K, Kaushik A, Johnson L, et al. Patient experiences and perceptions of chronic disease care during the COVID-19 pandemic in India: a qualitative study. *BMJ Open*. 2021;11(6):e048926. doi:10.1136/bmjopen-2021-048926
2. Zhang SX, Wang Y, Rauch A, Wei F. Unprecedented disruption of lives and work: health, distress and life satisfaction of working adults in China one month into the COVID-19 outbreak. *Psychiatry Res*. 2020;288:112958. doi:10.1016/j.psychres.2020.112958
3. Ágh T, van Boven JF, Wettermark B, et al. A cross-sectional survey on medication management practices for noncommunicable diseases in Europe during the second wave of the COVID-19 pandemic. *Front Pharmacol*. 2021;12:685696. doi:10.3389/fphar.2021.685696
4. Meda N, Pardini S, Slongo I, et al. Students' mental health problems before, during, and after COVID-19 lockdown in Italy. *J Psychiatr Res*. 2021;134:69-77. doi:10.1016/j.jpsychires.2020.12.045