

Patients' Perspective of Dystonia Symptoms during the SARS-CoV-2 Pandemic

Since the World Health Organization declared the emergence of a new coronavirus (SARS-CoV-2) in January 2020, medical care has been severely challenged. We aim to describe the effects of the 3-month complete lockdown and subsequent treatment restrictions in Spain for patients with dystonia.

We designed an anonymous online survey (REDCap platform, November–December 2020) for dystonia patients recruited through a patient association (*Asociación de lucha contra la distonía en España [ALDE]*). The study was approved by the local ethics committee. All patients provided informed consent before answering 35 multiple-choice questions covering demographic, social, clinical, and treatment variables. Changes since March 2020 (onset of lockdown in Spain) in motor and nonmotor symptoms were evaluated through a 3-point Likert scale (better, unchanged, and worse). Bivariable analyses were performed to investigate associations between changes in dystonia and other variables using R software (version 3.6.2). Significance was set at $P < 0.05$.

Seventy-one patients participated in the survey. The most frequent phenotype was focal dystonia ($n = 27$, 38%), especially cervical dystonia ($n = 19$, 27%). Most patients ($n = 46$, 65%) reported worsening of dystonia; only 3 (4%) improved and 22 (31%) remained stable. Increased anxiety, lower mood, increased pain, and insomnia were reported in 75%, 73%, 62%, and 59% of patients, respectively (see Table 1). Dystonia worsening was significantly associated with increased pain (X^2 , $P < 0.01$), less exercise (X^2 , $P = 0.02$), and the inability to contact the treating physician (X^2 , $P = 0.01$). A trend for lower mood (X^2 , $P = 0.06$) and decreased physical therapy (X^2 , $P = 0.07$) was also found. Thirty (42%) patients felt that dystonia management was not appropriate.

Botulinum toxin injections were delayed in 25 of 40 patients undergoing chemodenervation (mean \pm SD 113.5 \pm 81.0 days). This did not impact on worsening of dystonia (X^2 , $P = 0.39$) but was related to worsening of mood (F , $P < 0.01$) and patients' perception of inadequate care (F , $P < 0.05$). Eleven (15%) patients increased anti-dystonic medications or were started on new drugs. Twenty-four (34%) patients had a medical emergency but avoided seeking care due to fear of infection.

The present study suggests that the pandemic's exceptional circumstances worsened both motor and nonmotor symptoms in most dystonia patients, in line with previous reports.^{1,2}

Interestingly, nonmotor symptoms have been increasingly recognized in dystonia but are still poorly understood,^{3,4} which were most frequently reported and contributed to clinical worsening. Our results suggest that exercise and rehabilitation may also impact on both motor and nonmotor symptoms, and their role in dystonia warrants further study.⁵ We acknowledge several limitations due to the small sample size, self-selection bias, and lack of correlated neurological examination. However, our results highlight the relevance of nonmotor symptoms and exercise treatment in dystonia, and prioritizing them during neurological follow-up could be a turning point in the treatment of dystonia patients during the pandemic. ●

Acknowledgments: We thank all participants for taking the time to respond to the survey and ALDE patient association for their collaboration.

Ethical Compliance Statement

This study was approved by the Ruber International Hospital Ethics Committee. All the data obtained were anonymous. We confirm that we have read the journal's position on issues involved in ethical publication and affirm that this work is consistent with those guidelines.

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Relevant conflicts of interest/financial disclosures: Nothing to report.

Funding agency: Nothing to report.

Received: 12 April 2021; **Accepted:** 14 April 2021

Published online in Wiley Online Library
(wileyonlinelibrary.com). DOI: 10.1002/mds.28645

TABLE 1 Dystonia changes according to demographic and clinical variables before and during the COVID-19 pandemic (n = 71)

	N	Dystonia		P-value
		Unchanged or better	Worse	
Demographic variables				
Gender, N (%)	F = 51 (73) M = 19 (27)	F = 18 (35) M = 7 (37)	F = 33 (65) M = 12 (63)	1
Age (y), mean (SD)	46.2 ± 15.7	49.2 ± 11.9	44.6 ± 17.4	0.63
Unemployment, N (%)	36 (51)	11 (31)	25 (69)	0.14
Clinical variables (prepandemic)				
Type of dystonia, ^a N (%)	F = 27 (38) S = 20 (28) M = 4 (6) G = 18 (25) U = 2(3)	F = 13 (48) S = 6 (30) M = 2 (50) G = 4 (22) –	F = 14 (52) S = 14 (70) M = 2 (50) G = 14 (88) –	0.27
Symptoms duration (y), mean (SD)	16.9 ± 14.1	15.7 ± 14.6	17.7 ± 13.9	0.57
Physical therapies, ^b N (%)	38 (55)	12 (32)	26 (68)	0.72
Regular physical exercise, N (%)	55 (78)	18 (33)	37 (67)	0.49
Oral medication, N (%)	36 (51)	12 (33)	24 (67)	0.86
Botulinum toxin injections, N (%)	40 (56)	14 (35)	26 (65)	1
Clinical variables (changes during pandemic)				
Botulinum toxin injection delay	25 (35)	7 (28)	18 (72)	0.39
Increased oral treatment	11 (15)	0 (0)	11 (100)	<0.01
Stopped or decreased physical exercise, N (%)	49 (69)	12 (24)	37 (76)	0.02
Stopped physical therapies, N (%)	32 (45)	8 (25)	24 (75)	0.07
Increased anxiety, N (%)	53 (75)	15 (28)	38 (72)	0.12
Insomnia, N (%)	42 (59)	12 (29)	30 (71)	0.25
Lower mood, N (%)	52 (73)	14 (27)	38 (73)	0.06
Increased pain, N (%)	44 (62)	7 (16)	37 (84)	<0.01
PCR-confirmed SARS-Cov2 infection	1 (1)	1 (100)	0	1
Other variables				
Inability to contact your neurologist when needed	23 (32)	4 (17)	19 (83)	0.01
Perception of inadequate dystonia management	30 (42)	2 (7)	28 (93)	<0.01

^aType of dystonia: focal = F, segmental = S, multifocal = m, generalized = G, unknown = U.

^bPhysical therapies: physiotherapy, occupational therapy, speech therapy. Statistical analysis: P-value was obtained using χ^2 test/Fisher's test/T-student test/Wilcoxon test. The highlighted P-values represent a statistical significance.

Abbreviations: F, female; M, male.

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Author Roles

(1) Research project: A. Conception, B. Organization, C. Execution; (2) Statistical analysis: A. Design, B. Execution, C. Review and critique; (3) Manuscript preparation: A. Writing of the first draft, B. Review and critique.

C.D.: 1A, 1B, 1C, 2A, 2B, 3A

I.P.: 1A, 1B, 1C, 2C, 3B

M.M.K.: 1A, 1B, 1C, 2C, 3B

Funding sources and conflict of interest: No specific funding was received for this work, and the authors declare that there are no conflicts of interest relevant to this work.

Full financial disclosures for the previous 12 months: C.D. has received travel expenses to attend scientific meetings from Alter and Bial. M.M.K. has received honoraria for talks from Bial and International Parkinsonism and Movement Disorder Society and travel expenses to attend scientific meetings from Boston Scientific; she is currently participating in a Michael J. Fox Grant. I.P. has received travel expenses to attend scientific meetings from Neuroaxpharm and International Parkinsonism and Movement Disorder Society and honoraria for speaking at meetings from Allegran and International Parkinsonism and Movement Disorders Society.