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# Management of spasticity in individuals with spinal cord injury in the era of COVID-19 pandemic societal restrictions

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# STUDY DESIGN: Cross-sectional telephone interviews.

**OBJECTIVE:** The coronavirus disease (COVID-19) pandemic placed unprecedented pressure on healthcare systems worldwide. Here, we aimed to investigate the disruptions in management of spasticity and activities of daily living (ADL) in individuals with spinal cord injury (SCI) during the COVID-19 pandemic.

SETTING: Two university hospitals in Istanbul, Turkey.

**METHODS:** Twenty-four individuals with SCI exhibiting moderate and severe spasticity were enroled. All participants underwent ultrasound-guided botulinum toxin type A (BoNT-A) injections at two centres. A self-rated spasticity survey prepared by the authors was conducted. We questioned whether there was an increase in spasticity and the need for new BoNT-A injections during the societal restrictions of the COVID-19 pandemic. Spasticity severity in the previous week was rated using a numeric rating scale (NRS). ADL disrupted by spasticity were assessed by asking open-ended questions.

**RESULTS:** In total, 75% participants reported a moderate increase in spasticity, 12.5% reported a severe increase, and 12.5% reported no difference. The mean spasticity NRS score was 6 (standard deviation = 2). Further, 87.5% (21) participants reported the need for BoNT-A treatment because of symptom re-emergence. When spasticity-induced deterioration in ADL was assessed, individuals mostly reported difficulties in walking, sitting on a wheelchair, and sleep disturbance due to spasticity.

**CONCLUSIONS:** Most (87.5%) individuals with SCI reported a moderate or severe increase in spasticity during COVID-19 restrictions. Individuals with disabilities are an especially sensitive group and require specialised care during extraordinary circumstances, such as pandemics, hurricanes, or earthquakes.

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# INTRODUCTION

The emergence of the novel coronavirus severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2), which is responsible for the coronavirus disease (COVID-19) pandemic, has swept the world and left serious concerns for public health and the need for significant modifications in healthcare. Apart from the imminent risk of contracting the virus, quarantine measures, increased personal protection procedures, and the overall restrictive nature of the past 2 years have created psychological and physical impacts across all demographics, especially among people with disabilities [1]. A severe lack of information currently exists on individuals with spinal cord injuries (SCI). Access to healthcare for individuals who depend on caregivers or require long-term symptom management has been halted during the surge of the pandemic, leaving these patients in a vulnerable situation. Inaccessibility to hospitals or healthcare services for routine follow-ups and treatments and psychological distress due to quarantine may be common problems faced by individuals with SCI during the COVID-19 pandemic.

The first case of COVID-19 was reported on11 March 2020. Healthcare and rehabilitation services declined after the first case due to pressure placed on the healthcare system from the increasing number of cases. Outpatient and home-based services were disrupted. Inpatient services decreased and interrupted their usual activities, leading to early hospital discharge. Physiotherapy, occupational therapy sessions, and botulinum toxin type A (BoNT-A) injections were postponed [2].

Spasticity is a sign of damage to the upper motor neurones. It is one of the most common complications of SCI [3]. The level of injury and completeness of the lesion affect the spasticity and functioning domains (e.g. ambulation, positioning, hygiene, wheelchair sitting, transfers, and sleep). Spasticity may result in muscle pain, spasms, contractures, and pressure ulcers and may negatively affect the quality of life of individuals with SCI [4]. The treatment modalities for spasticity include stretching exercises, splinting, oral medications, local treatments such as BoNT-A injections, and surgical procedures. Treatments are typically adjusted according to the patient. BoNT-A injections are used to manage focal/segmental spasticity in individuals with SCI, similar to many other neurological disorders [5].The peak effect occurs within weeks4–6 after injection, and the duration of the effect lasts 3–6 months [6].

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 Table 1.
 Demographic and clinical characteristics of the participants.

Male/Female n(%)	20 (83.3)/4 (16.7)
Age (years) mean ± SD	43.1 ± 13.6
Time since injury (years) mean $\pm$ SD	$13.8 \pm 10.3$
Married/Single n(%)	16 (66.7)/8 (33.3)
Employment	
Not officially employed	19 (79.2)
Working	3 (12.5)
Student	2 (8.3)
Etiology n(%) Traumatic/Nontraumatic	17 (70.8)/7 (29.2)
Paraplegia/Tetraplegia n(%)	9 (37.5)/15 (62.5)
ASIA Grade N(%)	
Α	7 (29.2)
В	1 (4)
С	4 (16.7)
D	12 (50)
Ambulation n(%)	
Wheelchair dependent	12 (50)
Household ambulator	4 (16.7)
Community ambulator	8 (33.3)
Spasticity Medication n(%)	
Oral baclofen	22 (91.7)
Tizanidine	2 (8.3)
Botulinum toxin-type A injection	24 (100)
Intrathecal baclofen pump	0 (0)
Spasticity NRS mean±SD	$6.0 \pm 2.0$

NRS numeric rating scale, ASIA American Spinal Cord Injury Association.

Extraordinary conditions such as pandemics, hurricanes, or earthquakes may affect individuals with disabilities more than they affect non-disabled people [7, 8]. This study aimed to investigate the effects of disruptions on spasticity management in individuals with SCI during the COVID-19 pandemic Accessibility to health services and medications was also examined.

#### **METHODS**

A telephone interview with questions based on prior research was performed. Individuals with SCI exhibiting moderate or severe spasticity were included. All patients with SCI who received ultrasound-guided BoNT-A injections at two university hospitals between September 2019 and March 2020 (26 patients) were contacted by phone. The patients underwent a single-injection session during this time frame. Among the 26 patients, two were excluded because one did not want to participate, and another could not answer questions adequately due to a mental disorder. Twenty-four (92.3%) volunteers were finally included in the cross-sectional study. Demographic data and neurological classification of SCI according to ASIA standards were recorded [9].

The included patients were community-dwelling individuals with SCI aged  $\geq 18$  years who were receiving BoNT-A injections for spastic muscles. The exclusion criteria were unwillingness to participate, mental disorders (not answering questions properly), and SCI with mild spasticity. The survey was prepared by the authors, pre-tested on 10patients, and revised accordingly. All participants were interviewed by a single author (KG) between 15 June and 15 July 2020. Ethical approval was obtained from the local ethics committee.

The most common indications for BoNT-A injections were difficulty in performing intermittent catheterisation (41.7%), difficulty in walking (33.3%), difficulty in sitting on a wheelchair (16.7%), and transfer problems (8.3%). The most commonly injected muscle groups were the hip

adductors for intermittent catheterisation; ankle plantar flexors for preventing contractures, standing up, and ambulation; and knee extensors for positioning, dressing, and enabling easier sitting.

The demographic characteristics of the 24 participants were recorded. Participants were asked if they experienced an increase in spasticity under the societal restrictions of the COVID-19 pandemic and were given a choice of the following answers: no difference, moderate increase, or severe increase in spasticity. The need for new BoNT-A injections was also investigated. The spasticity severity over the previous week was assessed using a numeric rating scale (NRS), where feeling no muscle spasm was rated as0, and the most severe muscle spasm ever experienced was rated as 10. Other medications used for spasticity were also recorded. In addition, we questioned the participants regarding whether they regularly performed stretching exercises during the pandemic.

Activities of daily living (ADL) complicated by spasticity were assessed with open-ended questions, and the participants were allowed to provide more than one answer. Sleeping, sitting in a wheelchair, and walking were the most frequent responses. Sleeping disorders due to aetiologies other than spasticity were excluded.

Disruptions in accessing healthcare services were also investigated. If the answer was yes, open-ended questions were asked to determine the reason for difficulty. Participants were allowed to provide more than one reason. In addition, accessibility to medications was evaluated.

Descriptive statistics were used to summarize the collected data in the study.

#### RESULTS

The demographic characteristics of the participants are presented in Table 1. Among the volunteers, eight (33.2%) had complete motor injuries and 16 (66.7%) had incomplete motor injuries. The patients had used oral medications for a mean of 9.2 (standard deviation [SD] = 5.8) years and had occasionally participated in exercise therapy for a mean of 10.4 (SD = 6.3) years. The indications for injections in the motor complete-injury group were as follows: difficulty in performing intermittent catheterisation, positioning, dressing, preventing contractures and pressure sores, sleeping problems, and difficulty sitting in a wheelchair. The indications for injections in the motor-incomplete injury group were as follows: prevention of contractures, enabling easier wearing of orthoses, difficulty in standing and walking, and transfer problems.

Eighteen (75%) patients reported a moderate increase in spasticity, three (12.5%)reported a severe increase, and three (12.5%) reported no difference in spasticity during this time period. The mean NRS score for spasticity severity was 6(SD = 2). Twenty-one (87.5%) patients reported the need for reinjection because of symptom re-emergence. The most important symptoms prompting the need for BoNT-A reinjection were difficulty in performing intermittent catheterisation in nine patients, difficulty in walking in seven patients, difficulty in sitting in a wheelchair in three patients, and transfer problems in two patients.

When spasticity-induced deterioration in ADL was questioned, 10(42%) individuals reported problems in their walking pattern, and 10(42%) individuals reported difficulty while sitting on a wheelchair. Eleven (46%) patients experienced a lack of sleep due to spasticity symptoms (e.g. muscle spasms and muscle pain). Only three (12.5%) individuals reported that spasticity did not affect their ADL.

Thirteen (54.2%) individuals reported a disruption in accessing healthcare services. Among these 13 individuals, 10(41.7%) did not request any healthcare access in person because they were worried about COVID-19 contagion. Four (16.7%) participants complained that they could not schedule their appointments. One participant (4%) participant reported problems with caregivers and transfer. All patients confirmed that they had easy access to their medications.

Twelve (50%) participants stated that they did not exercise regularly during the social restrictions. Among participants who exercised regularly, 10 (43.7%) exercised at home, nine exercised

with their caregiver, and one exercised with help from a physiotherapist. Two (8.3%) patients received exercise services at the outpatient clinic of a hospital.

# DISCUSSION

The COVID-19 pandemic has caused interruptions in both outpatient and community-based rehabilitation services. In addition to many elective procedures, BoNT-A injections were postponed [2], which caused a loss of function due to increased spasticity in individuals with disabilities [10]. During the COVID-19 pandemic, the effects of disruptions in accessing health services and discontinuation of BoNT-A treatment in patients with spasticity due to stroke, traumatic brain injury, cerebral palsy, and dystonia have been investigated [11–13]. However, to our knowledge, this is the first study to specifically focus on individuals with SCI.

Santamato et al. concluded that discontinuation of BoNT-A treatment was associated with worsening of activities, participation, and perceived spasticity in patients with hemiplegic and traumatic brain injuries [11]. In our research, most (87.7%) individuals with SCI reported a moderate or severe increase in spasticity during the societal restrictions of the COVID-19 pandemic. Although spasticity may help with some ADL, it negatively affects functioning [14]. In our study, most individuals with SCI reported that an increase in spasticity negatively affected their ADL.

Mental stress has been reported to increase spasticity [15, 16]. Individuals with SCI may experience psychological distress due to quarantine, similar to non-disabled individuals. In this situation, an increase in spasticity is expected. Staying at home during lockdowns may cause psychological problems and lower selfefficacy. We did not investigate the psychological status of patients in this study; however, two community ambulatory female patients reported depressive symptoms and lower selfefficacy. In their words: 'As if I will never be able to walk outdoors again'.

Individuals with SCI had some problems reaching medical professionals, and the most common reason was COVID-19 transmission anxiety. The second reason was the difficulty in scheduling appointments to visit doctors, but all patients had access to their medications. Because Turkey has a universal health care system, patients with chronic diseases had access to medications without the need for a prescription during the quarantine period.

Evidence shows that stretching exercises can help decrease spasticity during rehabilitation of upper motor neuron lesions [17]. Only half of the participants exercised regularly during societal restrictions. 9 (75%) caregivers in the exercise group performed stretching exercises. Most individuals could not undergo professional physiotherapy. Only 12.5% patients were able to visit professional physiotherapists or occupational therapists.

Sköld et al. concluded that problematic spasticity was significantly correlated with incomplete cervical injury defined by the American Spinal Injury Association (ASIA) as B–D [18]. Most patients enroled in this study had tetraplegia and an ASIA impairment scale (AIS) score of D. Oral baclofen is often used to manage SCI spasticity, and if the patient still has focal/segmental spasticity, we combine it with local treatment modalities such as BoNT-A injections. If the patient has severe generalised spasticity intractable to oral and local treatment, then intrathecal baclofen therapy is prescribed. We encourage exercise therapy in addition to pharmacological treatment.

Twenty-four individuals were included in the study, lower than the number of patients treated for SCI at our centre. We aimed to identify patients with problematic spasticity; therefore, we chose those who had received BoNT-A injections and excluded those with mild spasticity. Patients using intrathecal baclofen pumps were not excluded. We contacted almost all our patients via telephone-based surveys because older and uneducated people could not be reached through internet-based surveys. Previously, telephonebased surveys have provided better patient responses and reported outcomes [19].

In conclusion, 21 (87.5%) individuals with SCI reported a moderate or severe increase in spasticity during the societal restrictions of the COVID-19 pandemic. Spasticity negatively affects performing intermittent catheterisation, sitting on a wheelchair, transfers, walking and sleeping. During the pandemic, the global and local health authorities partially neglected people with SCI and other disabilities. People with disabilities are a vulnerable group and require greater attention under extraordinary conditions such as pandemics, hurricanes, or earthquakes. The widespread use of telemedicine and telerehabilitation may help solve this problem. Moreover, monitoring exercises and home-based therapies may improve functionality.

### DATA AVAILABILITY

Raw data were generated at University of Health Sciences and Istanbul Medeniyet University. Derived data supporting the findings of this study are available from the corresponding author (K.G.) on request.

#### REFERENCES

- Boldrini P, Garcea M, Brichetto G, Reale N, Tonolo S, Falabella V, et al. Living with a disability during the pandemic. "Instant paper from the field" on rehabilitation answers to the COVID-19 emergency. Eur J Phys Rehabil Med. 2020;56:331–4.
- Yagci I, Sarikaya S, Ayhan FF, Bahsi A, Bilir Kaya B, Erhan B, et al. The effects of COVID-19 on physical medicine and rehabilitation in Turkey in the first month of pandemic. Turk J Phys Med Rehabil. 2020;66:244–51.
- Erhan B, Kocer S. An approach to spasticity in spinal cord injured patients. Turk J Phys Med Rehabil. 2012;58:21–7.
- Vural M, Yalcinkaya EY, Celik EC, Gunduz B, Bozan A, Erhan B. Assessment of quality of life in relation to spasticity severity and socio-demographic and clinical factors among patients with spinal cord injury. J Spinal Cord Med. 2020;43:193–200.
- Palazon-Garcia R, Alcobendas-Maestro M, Esclarin-de Ruz A, Benavente-Valdepenas AM. Treatment of spasticity in spinal cord injury with botulinum toxin. J Spinal Cord Med. 2019;42:281–7.
- Ward AB. Spasticity treatment with botulinum toxins. J Neural Transm (Vienna). 2008;115:607–16.
- Shapiro LT, Gater DR Jr, Shultz JM. It is time to put hurricane preparedness on the radar for individuals living with spinal cord injury. Spinal Cord Ser Cases. 2020;6:34.
- O'Connell CM, Eriks-Hoogland I, Middleton JW. Now, more than ever, our community is needed: spinal cord injury care during a global pandemic. Spinal Cord Ser Cases. 2020;6:18.
- Kirshblum SC, Burns SP, Biering-Sorensen F, Donovan W, Graves DE, Jha A, et al. International standards for neurological classification of spinal cord injury (revised 2011). J Spinal Cord Med. 2011;34:535–46.
- Negrini S, Grabljevec K, Boldrini P, Kiekens C, Moslavac S, Zampolini M, et al. Up to 2.2 million people experiencing disability suffer collateral damage each day of COVID-19 lockdown in Europe. Eur J Phys Rehabil Med. 2020;56:361–5.
- 11. Santamato A, Facciorusso S, Spina S, Cinone N, Avvantaggiato C, Santoro L, et al. Discontinuation of botulinum neurotoxin type-A treatment during COVID-19 pandemic: an Italian survey in post stroke and traumatic brain injury patients living with spasticity. Eur J Phys Rehabil Med. 2021;57:424–33.
- Tarantino D, Gnasso R, Migliore F, Iommazzo I, Sirico F, Corrado B. The effects of COVID-19 pandemic countermeasures on patients receiving botulinum toxin therapy and on their caregivers: a study from an Italian cohort. Neurol Sci. 2021;42:3071–7.

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- Teuschl Y, Bancher C, Brainin M, Dachenhausen A, Matz K, Pinter MM. COVID-19related delays of botulinum toxin injections have a negative impact on the quality of life of patients with dystonia and spasticity: a single-center ambulatory care study. J Neural Transm (Vienna). 2022;129:49–53.
- Tibbett J, Widerstrom-Noga EG, Thomas CK, Field-Fote EC. Impact of spasticity on transfers and activities of daily living in individuals with spinal cord injury. J Spinal Cord Med. 2019;42:318–27.
- Bhimani RH, McAlpine CP, Henly SJ. Understanding spasticity from patients' perspectives over time. J Adv Nurs. 2012;68:2504–14.
- Phadke CP, Balasubramanian CK, Ismail F, Boulias C. Revisiting physiologic and psychologic triggers that increase spasticity. Am J Phys Med Rehabil. 2013;92:357–69.
- Bani-Ahmed A. The evidence for prolonged muscle stretching in ankle joint management in upper motor neuron lesions: considerations for rehabilitation—a systematic review. Top Stroke Rehabil. 2019;26:153–61.
- Skold C, Levi R, Seiger A. Spasticity after traumatic spinal cord injury: nature, severity, and location. Arch Phys Med Rehabil. 1999;80:1548–57.
- 19. Greene J, Speizer H, Wiitala W. Telephone and web: mixed-mode challenge. Health Serv Res. 2008;43:230–48.

# **AUTHOR CONTRIBUTIONS**

KG designed thework, acquired data, played an important role in interpreting the results, drafted the manuscript, approved the final version, agreed to be accountable for all aspects of the work. BE conceived the work, acquired data, played an important role in interpreting the results, revised the manuscript, approved the final version, agreed to be accountable for all aspects of the work.

#### COMPETING INTERESTS

The authors declare no competing interests.

#### ETHICAL APPROVAL

Ethical approval was obtained from the ethics committees of two hospitals.

# ADDITIONAL INFORMATION

Supplementary information The online version contains supplementary material available at https://doi.org/10.1038/s41394-023-00573-7.

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