

A thematic framework analysis of nationwide survey on needs and perceptions of people living with dystonia during the first wave of Covid-19 pandemic in Italy

Vittorio Rispoli¹, M.E.D. Crescitelli², G. Di Rauso⁵, S. Coniglio⁵, F. Cavallieri^{3,4}, F. Antonelli¹, S. Meletti^{1,5}, L. Ghirotto², F. Valzania⁴

¹Neurology, Neuroscience Head Neck Department, Azienda Ospedaliero - Universitaria di Modena, Modena, Italy

²Qualitative Research Unit - AUSL – IRCCS di Reggio Emilia, Reggio Emilia, Italy

³Clinical and Experimental Medicine PhD Program, University of Modena and Reggio Emilia, Modena, Italy

⁴Neurology Unit, Neuromotor & Rehabilitation Department, Azienda USL-IRCCS di Reggio Emilia, Reggio Emilia, Italy

⁵Neurology Unit, Department of Biomedical, Metabolic and Neural Science, University of Modena and Reggio Emilia, Modena, Italy

Introduction: The unprecedented situation forced governments to quickly pose into action a number of countermeasures to prevent the Covid-19 spread and to tackle SARS-COV2-related syndromes. The daily life of people suffering from chronic diseases was negatively impacted and routine medical care faced a sudden shortening. This is even true for rare disease, such as dystonia. During the ongoing pandemic, dystonic patients' medical care is at risk of not being taken into consideration as before. Moreover, pandemic might play a direct or indirect role in modifying motor and non-motor symptoms.

Objective: To explore the feelings and issues of people living with dystonia, the possible consequences of pandemic countermeasures on their daily and working-life, clinics remodulation and patients' relationship with healthcare centers, and to uncover needs at risk of not being met.

Methods: A nationwide survey was publicly posted online for incentive-free self-enrolment. The survey focused on demographic and clinical features, neurological service as well as contact provision, perceptions about virus infection and healthcare-related needs, job questions, support-seeking during the first-wave of the ongoing pandemic. The collected data were analysed with descriptive statistics and thematic framework analysis.

Results: People affected by dystonia highlighted the detrimental condition experienced during the first-wave of this pandemic, mainly due to social isolation and treatment session withdrawal (i.e. botulinum neurotoxin injection clinics). They felt "abandoned" in dealing with dystonia with a worsening of dystonia related features, which had negatively impacted on daily functioning and fueled stigmatization. So, people living with dystonia sought information and support via a number of means. Nevertheless, relevant needs remained unmet.

Conclusions: These findings may foster future actions to guarantee a standard of care for people suffering from dystonia even during worldwide emergencies and to contribute to awareness-raising campaign on this rare disease.