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HUNTINGTON'S DISEASE PATIENTS AND FAMILIES FACING COVID-19 EMERGENCY IN ITALY

Marcella Solito [1,2] Martina Petracca [2] , Paola Zinzi [2,3],
Anna Rita Bentivoglio [1,2], Maria Rita Lo Monaco [4]

1 Institute of Neurology, Università Cattolica del Sacro Cuore, Rome, Italy; 2 Movement Disorders Unit, Fondazione Policlinico Universitario Agostino Gemelli IRCCS, Rome, Italy; 3 Clinical Psychology Unit, Fondazione Policlinico Universitario Agostino Gemelli IRCCS, Rome, Italy; 4 Geriatric Day-Hospital, Fondazione Policlinico Universitario Agostino Gemelli IRCCS, Rome, Italy;

Background

Italy was the first country in Europe to deal with **Coronavirus Disease 2019 (COVID-19)** epidemic since the first autochthone case in February 2020. The COVID-19 pandemic could be a condition of increased vulnerability for patients and families with **Huntington's disease (HD).** Social isolation with loss of the usual support system may worsen the chronic assistance burden and, if protracted, may exhacerbate the risk of distress and mental suffering.

Materials & methods

A consecutive cohort of 2167 outpatients with chronic neurological conditions followed at onr Hospital was enrolled into a telephone survey, between April 1st and April 15th 2020[1-2] , and we report the survey data on the impact of the COVID-19 pandemic outbreak in a subsample of eighty HD patients and their families. HD patients whose appointments scheduled in the lockdown period from March to May 2020 were deleted and postponed to an undefined date, were consecutively contacted by phone for the interview and all patients (and in case of advanced disability, their carers) gave their consent and accepted to participate the survey.

Results

Out of 80 HD patients, apparently no patient had contact with COVID-19 positive cases, no one directly linked with the virus nor swab confirmed infection, even if flu-like symptomatology was experienced in first trimester 2020, with fever reported by 8,7% and cough/sore throat by 27,3 %. Even if in 12.5% of our sample were reported two or more flu symptoms, only one patient underwent the swab test, with negative result.

Regarding disease management during the pandemic outbreak, five individuals needed urgent neurological care, and in all these cases medical staff promptly dealt their requests , contacting them and arranging videoconsultation.

Fourteen suspended physiotherapy or other treatments, seven individuals reported subjective worsening of neurological symptoms. Three patients were long-term institutionalized, and information was collected by their next of kin. They all were reported being healthy, with no COVID cases detected in their nursing homes, safely closed to external contacts since the start of lockdown measures. Video contacts, instead of the relatives' visits, were arranged and supported by the Nursing Home staff.

Compliance with hospital decision to stop activities and openness to the proposal of telemedicine was shown. No worrying signs of crisis or distress related to social restriction rules worsening caregiving burden were evident.

Discussion

In the pandemic time, to maintain social distancing, HD families were forced to live isolated, even more than they were used to and with a loss of the usual support system. Social isolation, significantly if protracted, may increase the risk of distress and mental suffering. Along with subjective feelings of loneliness, it is associated with an increasing burden for the caregivers [3].

Our HD cohort is small and biased as being regularly followed up in one of Italy's largest specialistic sites. However, our impression is that HD families showed resilience and adaptation to the ongoing emergency status, not revealing significant distress or crisis signs. As in Italy, essential care support is mainly dependent upon the family, and we can imagine that they use previously adopted solutions to cope with this lockdown. They experience daily difficulties dealing with disability limits and medical concerns related to their condition, but maybe this has become a sort of strength and adaptability resource in the pandemic time.

Table 2: **Pandemic Covid-19 variables**

HD Outpatients Sample n=80		
Swab Test: Performed/Positive , n	1/0	
Subjective perception of worsening (neurological condition), n (%)	7 (8,7%)	
Suspension of physiotherapy or other treatments	14(17,5%)	
Difficulty in finding drugs, n (%)	6 (7,5%)	
Need of urgent consultation, n (%)	5 (6,2%)	
Reasons for requesting , n		
• Long time run since past visit	2	
• Psychiatric symptoms management	2	
• General worsening /weight loss	1	
Awareness about COVID 19 emergency, n(%)	74 (92,5%)	
Compliance social restriction	Before March 11th	After March 11th
	46 (57,5%)	77 (96,2%)

Conclusion

In general, an excellent attitude to cope with the emergency and social restrictions was observed in our HD patients and families during the COVID-19 first pandemic wave in Italy . The offering of telemedicine support was highly appreciated by them once being reassured that the medical team would be remotely available for any urgency and emergent needs.

Telemedicine implementation will be an unavoidable consequence of pandemic but HD population followed at our hospital outpatient service has proven itself being ready to benefit.

Table 1: Demographic and clinical characteristics of the HD outpatients'.

HD Outpatients Sample n=80	
Male/Female ratio, n	37/43
Full sample	mean± SD
Age, mean± SD (years)	59 ±12,4
Disease Duration, mean± SD (years)	8.3 ± 6.1
Age at onset, mean ± SD (years)	51 ±11,3
	n(%)
HD Shoulson stages	
❖ early (I-II ; TFC 10-13)	23 (28,7%)
❖ intermediate (III; TFC 4-9)	34 (42,6%)
❖ late/advanced (IV-V; TFC 0-3)	23 (28,7%)
Recovered in long term institution	3 (3,8%)
Treatments for HD symptoms	77(96,3%)
Flu-related symptoms in 2021 first months	
❖ Fever	7 (8,7%)
❖ Cough/Sore throat	19 (23,7%)
❖ Asthenia	10(12,5%)
❖ Asthenia	6 (7,5%)
❖ Myalgia	3(3,7%)
❖ Dyspnoea	1(1,2%)
❖ Hyspomia/Hypogeusia	
COMORBIDITY	
❖ Diabetes	6 (7,5%)
❖ Hypertension	9 (11,3%)
❖ Pulmunary diseases	8 (10%)
❖ Cancer history	5 (6,3%)
❖ Heart disease	4 (5%);
❖ Kidney disease	1 (1,2%)
❖ Obesity	-
Two or more concomitant illness	9 (11,3%)
Smokers	38(47,5%)

References

1) Italian Ministry of Health Covid-19, in Gazzetta ufficiale il Decreto #Iorestoacasa. March 10, 2020. www.salute.gov.it/portale/news/p3_2_1_1_1.jsp?lingua=italiano&menu=notizie&p=dalministero&id=4186

2) Piano C, Di Stasio E, Primiano G, et al (2020) An Italian neurology outpatient clinic facing SARS-CoV-2 pandemic: data from 2167 patients. Frontiers in Neurology. https://doi.org/10.3389/fneur.2020.00564

3) Domaradzki J (2015) The Impact of Huntington Disease on Family Carers: a Literature Overview. Psychiatria polska, 49(5), 931–944. https://doi.org/10.12740/PP/34496.

For further info mail to paolazinzi@yahoo.com