Research Article

CMT-COVID Survey

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Abstract

Introduction: Coronavirus disease 2019 (COVID-19) is a pandemic and public health emergency caused by the Severe Acute Respiratory Syndrome Coronavirus 2 (SARS-CoV-2). Our study evaluated the impact of the COVID-19 on patients with Charcot-Marie-Tooth (CMT), the most common genetic neuromuscular disorder.

Methods: A simple online questionnaire for CMT patients diagnosed with COVID-19 was developed to investigate how much the COVID-19 impacted the community of CMT patients and its consequences on the progression of CMT. With the support of the Italian CMT patient Association (ACMT-Rete) and the American CMT Association (CMTA), the survey was distributed electronically through the INC Contact Registry and the web-based Contact Registry in the US, and in Italy through the Italian CMT Registry, ACMT-Rete members newsletter and social networks.

Results: 152 individuals completed the survey. Approximately 59% of completers were female, and the average age was 49.96 (SD 12,65, range 22-76 years). 13.8% of the respondents had a COVID diagnosis and 2% (n=3) of them were health workers. Symptoms of COVID-19 were typically mild and none went to the ICU.

Discussion: These results do not show a clear increased risk of COVID in people with CMT.

Keywords: Charcot Marie Tooth, CMT, COVID-19, Survey

Introduction

Coronavirus disease 2019 (COVID-19) is a pandemic and public health emergency caused by the Severe Acute Respiratory Syndrome Coronavirus 2 (SARS-CoV-2). COVID-19 symptoms include fever, cough, fatigue, shortness of breath, sore throat, headache, diarrhea, anosmia and ageusia/dysgeusia. Severe manifestations, including pneumonia, acute respiratory distress syndrome, cytokine storm, myocardial injury, and death are more common in older patients and those with medical comorbidities [1-6]. Our study evaluated the impact of the COVID-19 on patients with Charcot-Marie-Tooth (CMT), the most common inherited neuromuscular disorder [7,8]. The COVID-19 pandemic has resulted in the reorganization of health-care settings affecting clinical care delivery to patients with CMT as well as other inherited neuromuscular disorders [6,9]. How much this public health emergency has impacted the care of patients with CMT is unclear, although there is a concern that the lockdown measures impacted on patient activity [10]. There are also concerns that people with

CMT and other neuromuscular diseases are at an increased risk for severe presentations of COVID-19.

We investigated how many participants in our online cohort were diagnosed with COVID-19, the symptoms they presented with, the presence of risk factors, and how the COVID-19 impacted the progression of their CMT.

Methods

The study was approved by the Institutional Review Board of the University of Iowa. A simple online questionnaire for CMT patients (Table 1) was developed to investigate how much COVID-19 impacted the community of CMT patients and its consequences on the progression of CMT. Then with the support of the Italian CMT patient Association (ACMT-Rete) and the American CMT Association (CMTA), the survey was distributed electronically through the INC Contact Registry and the web-based Contact Registry in the US, and in Italy through the Italian CMT Registry (http://www.registronmd.it/), ACMT-Rete members newsletter and social networks. In the

US contact registry, 53.45% have CMT1A, 3.77% have CMT1B, 4,93% have CMT1X, 9,69% have CMT 2A and 26,19% have CMT without a subtype or genetic classification. Nearly 3500 individuals participate in the registry. All registry participants between the ages of 18 to 90 were invited and provided consent to participate in this survey. Data regarding age, gender, CMT type and if participants were health workers were collected. The CMT-COVID Survey was anonymous and included COVID-19 related questions, accessible

Table 1: The Survey.

1)	What is your genetic type of CMT?
2)	What is your age (in years)?
3)	What is your gender?
4)	Did you have a test that confirmed that you had COVID-19? if no, thank you for taking the survey?
5)	Did you visit a health care professional, such as your personal doctor or nurse or an emergency department?
6)	Did you have any of the following symptoms when you were diagnosed with COVID-19 (check all that apply)? a. No symptoms b. Fever c. Headache d. Malaise e. Cough f. Shortness of breath
7)	Do you have any of the following known risk factors for a more severe COVID-19 infection (check all that apply)? a. None of these b. Diabetes c. COPD d. Asthma e. Hypertension
8)	Do you have Sleep Apnea? a. If yes, do you use CPAP or other non-invasive ventilation at night?
9)	Were your smell and taste affected when you had COVID19?
10)	Were you hospitalized because of COVID-19?
11)	Were you admitted to an intensive care unit because of COVID-19?
12)	Did you require a respirator in the hospital?
13)	Are you a health care worker?

Table 2: Symptoms/Risk Factors.

Symptom/Risk Factor	# Responded Yes
Cough	20
Fever	21
Headache	21
Fatigue	17
Sore throat	17
Shortness of Breath	16
Muscular or joint pain	17
Diarrhea	16
No Symptoms	0
Smell and/or taste affected	13
Have Risk Factor Asthma	0
Have Risk Factor COPD	0
Have Risk Factor Diabetes	2
Have Risk Factor Hypertension	1
No Risk Factors	18
Sleep Apnea	1

only if the participants had both CMT and have been diagnosed with COVID-19. Participants specifically diagnosed with CMT were asked to complete the survey. The specific questions regarding COVID-19 concerned 1) symptoms from COVID-19, 2) the presence of pre-existing risk factors, 3) the presence of sleep apnea and, if so, whether CPAP or non-invasive ventilation was required, 4) if hospitalization and, if so, admission to an intensive care unit (ICU) occurred, 5) if a respirator/ventilator was required in the hospital. Demographic information on gender, age, and genetic diagnosis of the participants was obtained. Percentages were determined for all questions for each response category.

Results

A total of 153 patients completed the survey between May 2020 and January 2021. Approximately 59% (n=90) of responders were female, and the average age was 49.96 (SD 12.65, range 22-76 years). CMT types were represented as follows: CMT1A 46% (n=71), CMT1B 8% (n=12), CMTX1 6% (n=9), CMT2 16% (n=25), CMT4 2% (n=3), HNPP 2.6% (n=4) and 19% (n=29) did not specify the type of their CMT. Twenty-one patients (13%) had a diagnosis of COVID-19 (17 female); two of these were health workers. The remaining 124 individuals completed the survey even though they had not been diagnosed with COVID-19. Queried symptoms included fever, headache, fatigue, cough, shortness of breath, sore throat, muscular or joint pain and diarrhea (Table 2): 76% of the 21 patients (n=16) reported all symptoms, 5% (n=1) all symptoms except shortness of breath, diarrhea, and sore throat, 14% (n=3) only fever, headache, and cough, 5% (n=1) fever, headache and sore throat. Smell or taste affected 62% (n=13). We queried diabetes, COPD, asthma, and hypertension as potential risk factors: 85% (n=18) of participants had none of these risk factors, 9% (n=2) had diabetes and 5% hypertension (n=1). One also reported sleep apnea. All those with COVID-19 were evaluated by health care professionals, but none of the participants were hospitalized.

Discussion

The COVID-19 pandemic impacts lives in many ways, affecting work, relationships, ability to obtain healthcare and health perception [10]. Thus, there are concerns for populations such as those with CMT as to whether they are at increased risk of contracting COVID-19 and, if they do, whether they are at risk for developing the severe complications of the disease requiring hospitalization and ICU care. Our results do not support an increased risk for patients with CMT to contract COVID-19. They also do not support an increased risk of severe complications from the disease if individuals are infected with SARS-CoV-2. We recognize limitations with our study in that our data comes from individuals we have not examined who have been asked to complete on-line surveys. In fact, we only asked those who had been diagnosed with COVID-19 to respond to the survey, those who died could obviously not have completed the survey. The fact that many (132/153) completed the survey but only around 21 people with CMT actually had acquired COVID simply means that over 100 of the responders had not carefully read the instructions. Therefore, it raises questions about the actual percentages of patients with CMT and COVID-19 which is likely to be much less than the 13% of the CMT

population cited here. However, we believe that our results suggest that there is not likely to be an increased risk of acquiring severe cases of COVID-19 for most patients with CMT. In part this is based on the fact that in past queries of our USA and Italian registries there are typically hundreds of patients who rapidly respond to our questionnaires. Thus, we think it unlikely that there were many patients in the registries who had COVID-19 but simply did not complete the questionnaires and that those that did acquire COVID were not more severely affected clinically than people without CMT based on the responses to queries about disease severity. We reasonably conclude that COVID infection is not common in the CMT patient population. Whether there are increased risks for patients with rarer forms of CMT with significant respiratory compromise remains unanswered and will require investigations focusing on these subgroups. We recognize the need for health professionals to increase efforts to carefully follow individuals with CMT to determine which if any CMT subtypes or symptoms are particularly predisposed to develop more severe forms of disease.

Acknowledgements

Ethical Publication Statement

We confirm that we have read the Journal's position on issues involved in ethical publication and affirm that this report is consistent with those guidelines.

Author Contributions

Riccardo Zuccarino, study concept and design, analysis and interpretation of data, drafting and critical revision of manuscript for intellectual content Chiara Pisciotta, statistical analysis and interpretation of data, critical revision of manuscript for intellectual content Valeria Prada, statistical analysis and interpretation of data, critical revision of manuscript for intellectual content Filippo Genovese, study concept and design, interpretation of data, critical revision of manuscript for intellectual content Amy Gray, interpretation of data, critical revision of manuscript for intellectual content. Angelo Schenone, study concept and design, analysis and interpretation of data, critical revision of manuscript for intellectual content Davide Pareyson, study concept and design, analysis and interpretation of data, critical revision of manuscript for intellectual content Michael E. Shy, study concept and design, analysis and interpretation of data, critical revision of manuscript for intellectual content

Author Disclosures

None of the authors has any conflict of interest to disclose.

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