

Impact of the COVID-19 pandemic on neuromuscular rehabilitation setting. Part 2: patients and families' views on the received health care during the pandemic

Lorenza Magliano¹, Giulia Citarelli², Maria Grazia Esposito², Vito Torre², Luisa Politano²

¹ Department of Psychology, University of Campania "Luigi Vanvitelli", Caserta, Italy; ² Associazione Centro "Gaetano Torre" per Le Malattie Muscolari, Unità di Ricerca, Naples, Italy

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Correspondence

Luisa Politano

"Gaetano Torre" for Muscular Dystrophies Association, via C. Guerra 10, Marano di Napoli (NA) Italy.

E-mail: luisa.politano@unicampania.it; poli3295@gmail.com

Orcid: 0000-0002-0925-7158

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This study explored views of users with muscular dystrophies and their caregivers on staff-user relationships and the treatments provided by a Rehabilitation Centre during the pandemic. Patients and relatives were asked to anonymously complete an open-ended questionnaire exploring their views on these aspects. Fifty-four patients and 40 caregivers gave their informed consent and participated in the survey. Fifty-three patients were adults, 28% suffering from Duchenne/Becker muscular dystrophy. Patients reported 269 comments on health care services provided during the pandemic, 132 (49%) concerning positive aspects and 137 (51%) negative aspects. The prompt restart of the rehabilitation therapies and the staff closeness over the pandemic were the practical aspects most frequently appreciated (46.9%), while closer family contacts and the perception of being able to rely on the Centre's constant support were the most cited psychological aspects (53.1%). Architectural barriers, difficulties in accessing public health services, economic difficulties, and lack of support from welfare and other agencies were the practical critical points most frequently reported (89%). In addition, social isolation, and loneliness due to fear of contagion were the most negative psychological aspects (10.1%). As regard the caregivers' views, participants reported 151 comments. Of these, 86 (56.9%) were positive and 65 (43.1%) were negative. Among the positive aspects, the psychological ones – such as closer family contacts, not feeling abandoned and counting on the constant Centre's professional support prevailed (53.5%). As for the negative aspects, most caregivers (92.6%) believe that the pandemic exacerbated their financial and bureaucratic difficulties, particularly in poorer families.

Key words: COVID-19 pandemic, muscle diseases, benefits and difficulties, activities of daily living, rehabilitation setting

Introduction

Since the beginning of 2020, severe acute respiratory syndrome coronavirus-2 (SARS-CoV-2) has become a worldwide pandemic that has had a significant impact on not only medical treatments, but also on society and economy.

In muscular dystrophies (MDs) – multisystem diseases that often affect heart, respiratory system, and other organs – many patients require ongoing assistance in their daily life. It follows a demanding burden^{1,2} and an inevitable close contact with caregivers. Patients with MDs are at high risk of developing severe disease if they get COVID-19. Therefore, the prevention of the contagion is of greatest importance for their life²⁻⁴. In addition, for patients who require medical care, the number of people needed for care can be large, making it especially difficult to balance infection control, conducting activities of daily life and providing medical care. A number of studies have examined the impact of COVID-19 on the life of people with MDs and the care these patients received during the pandemic. Bertrand Recasens and Rubio³ identified in 1) direct SARS-CoV-2 effect on different neuromuscular pathologies; 2) limitation of physical rehabilitation (one of the essential aspects of myopathies treatments) due to safety measures and 3) economic difficulties for patients and their families – due to the scarcity of resources in terms of public healthcare – the main effects of COVID-19 on neuromuscular diseases care. Another study by Matsu-mura et al.⁵ reported the results of a web-based survey exploring the influence of COVID-19 on the care of 542 patients with MDs. Approximately 30% of patients had to postpone regular clinical follow-up, and 25% to use telephone consultations. A shortage of ventilator accessories and infection protection equipment, occurring during the pandemic, had a serious impact on medical care and infection prevention measures. Nishizara et al.⁶ investigated changes in motor function in a group of 85 DMD patients after travel restriction due to COVID-19. They found that a more sedentary lifestyle and lack of regular physical therapy services most likely contributed to negatively affect the ankle dorsiflexion ROM, but not other motor functions. To this regard, Sobierajska-Rek et al.⁷ investigated the rehabilitative situation of 69 young patients with DMD in the pandemic, to establish an online rehabilitation program and motor assessment and determine the usefulness of telerehabilitation in these patients. They concluded that patients, under the physiotherapist guidance and caregivers' help, can continue home based rehabilitation. Kenis-Coscun et al.⁸ compared telerehabilitation or home-based video programs in patients with DMD who have lost their access to on-site rehabilitation, due to pandemic. They showed that telerehabilitation was better in improving muscle strength than a video-based home exercise, although none was able to improve functional outcomes.

Palazzo et al.⁹ recently explored the usefulness of religious faith and assistance of associations on patients' capacities to deal with critical times. They found that closeness of family and activities promoted remotely by

the associations played a crucial role, allowing the participants to feel united, to discover new aspects of themselves and to give more value to life.

In a study aiming to explore the staff views on the care provided by a Rehabilitation Centre during the pandemic and the impact on the professionals assistance, we recently reported¹⁰ that participants, most of them physiotherapists, highlighted 169 aspects, 48.5% referring to the resources used to cope with critical issues, and 51.5% concerning the difficulties encountered. Emotional aspects prevailed on practical aspects, both in terms of resources (52.4 vs 47.6%) and difficulties (57.5 vs 42.5%).

As the second part of the study, here we present the results of a survey aimed to explore the views on the care provided by the same centre during the pandemic from the perspectives of patients with MDs and their caregivers.

Patients and methods

The survey was carried out at the “Gaetano Torre” Centre (G. Torre) for MDs, a rehabilitation centre, operating within the framework of a regular agreement with the Northern Health District of Naples, Italy. The Centre provides a range of outpatient and at-home clinical and rehabilitative care to persons with MDs over their life span. Patients assisted by G. Torre Centre (n = 105) and their caregivers were invited to complete an anonymous open-ended questionnaire of seven/eight items exploring the practical and psychological aspects emerged during the pandemic in relation to the healthcare services provided by the Centre (see Tables I and II for the items list). The questionnaire was given to participants during the routine follow-up visits between September and December 2021 by a social worker, who was available to clarify questions upon request. Participants were free to fill in the questionnaire immediately or later, depositing it in a special box. The study protocol was approved by the Ethics Committee of the Naples 1 Local Health Authority, (Prot. 362/2021).

Results

Patients' clinical and social demographic variables

Fifty-four patients (participation rate: 51.4%) and 40 caregivers gave their informed consent and participated in the study. Fifty-three out of 54 participating patients were adults and affected by several types of MDs. In particular, 28% had Duchenne/Becker MDs, 17.5% Limb-girdle MDs, 17.5% Myotonic Dystrophy type 1, 17.5% Facio-Scapulo-Humeral-Dystrophy, 5% Spinal Muscular Atrophy type 3, and 14.5% had other neuromuscular dis-

Table I. Patient version of the Questionnaire.

As a person with a neuromuscular disease, we invite you to answer the following questions about the services you received at the Gaetano Torre Centre and your experience during the COVID-19 pandemic.
Your answers will be useful for: a. Improve the quality of services offered. b. Obtain more guidance in dealing with similar experiences
Please note that the questions refer to situations that occurred during the pandemic.
1) Based on your experience as a person with a neuromuscular disease, how did the pandemic affect and influence the service and performance received at the G. Torre Centre?
2) Based on your experience as a person with a neuromuscular disease, what are the positive aspects of the services received from the G. Torre Centre?
3) Based on your experience as a person with a neuromuscular disease, what are the critical aspects of the services provided by the G. Torre Centre?
4) Based on your experience, what are the positive aspects in the daily life of people with neuromuscular diseases?
5) In your experience, what are the problematic aspects in the daily life of people with neuromuscular diseases?
6) In your experience, what are the positive aspects in the families of people with neuromuscular diseases?
7) Based on your experience, what are the main difficulties faced by families of people with neuromuscular diseases?
8) In your opinion, what could be the changes to improve the service offered by the G. Torre Centre?

Table II. Caregiver version of the Questionnaire.

As the caregiver of a person in the care of the G. Torre Centre, we invite you to answer the following short series of questions on the services (practical work and assistance) provided by the Centre during the COVID-19 pandemic, with the aim of: a. Obtain more elements for dealing with similar experiences in the future and at the same time, b. Improve the quality of services offered to patients and their families.
Remember that the questions refer to situations that occurred during the pandemic.
1) Thinking about the current situation, how do you think the pandemic has affected the service and performance provided by the G. Torre Centre?
2) What strengths and weaknesses did you find in the services provided by Centro G. Torre during the pandemic period?
3) What aspects, in your opinion, were or are most problematic for patients and their families during this phase of the pandemic? Why?
4) Were there, or are there anyway, positive aspects in the daily lives of patients and their families during the pandemic period?
5) What are the main difficulties, from your point of view, that the patients' families have faced and are facing?
6) Based on your experience, what positive aspects could there have been for patients' families during this phase of the pandemic?
7) In your opinion, what could be the changes to improve the service offered to patients at the G. Torre Centre?

orders. Males were 33 (61.1%) and females 21 (38.9%). The mean age of patients was 46.8 ± 14.4 years. No socio-demographic data on caregivers was collected due to privacy regulations.

Patients' views on health care services provided during the pandemic

Question n. 1 investigated the *impact of the pandemic on the service and the assistance provided* by the G. Torre Centre. Of the 53 patients who completed the item, 46 (86.7%) did not report any difference compared to pre-pandemic time, one participant stated that

the pandemic has had a mild impact on the services and six (11.3%) complained about the discontinuation of the physiotherapy (FKT) during the lockdown (first pandemic wave).

Question n. 2 invited patients to *identify positive aspects – if any – in the services received*. Patients reported 67 positive comments, including 44 (65.7%) practical and 23 (34.3%) psychological. Among the practical aspects highlighted by participants, best practice and professional skills prevailed, while among the psychological aspects the relationship with the health professionals (i.e., the psychological support and the perception of staff full

availability despite objective difficulties due to pandemic) was the most appreciated one.

Question n. 3 regarded the *perception of critical aspects in the services received*. Fifty-two (96.3%) patients completed the item. Of these, 37 patients (71.1%) did not identify any negative aspect, while 15 (28.8%) identified in the bureaucratic difficulties in the renewal of the approvals for treatments and the geographical distance from the G. Torre Centre the most critical points.

Question n. 4 addressed the potential *positive aspects of the pandemic on daily life activities*. Fifty-one (94.4%) patients completed the item. Twenty-seven (52.9%) reported 29 positive comments, 11 of which (37.9%) were psychological and 18 (62.1%) were practical. Among the psychological aspects, family support and resilience skills were the most appreciated, while rehabilitation and their positive health effects and the readiness of health care professionals prevailed among the practical aspects. Twenty-one patients (44.4%) did not report any positive comment.

Question n. 5 concerned the *critical aspects of the pandemic on daily life activities*. Forty-seven (87%) patients mentioned 66 general and specific negative practical aspects, mainly related to functional autonomy limitations due to the disease and architectural barriers.

Question n. 6 concerned the *positive aspects present in the families*. Forty-two (77.8%) patients answered to this item. Of these, six patients (14.3%) did not find any positive aspect, while 36 reported 36 statements on positive aspects, mainly including feeling of being loved, perception of family cohesion and family sharing of problems.

Question n. 7 addressed the *negative aspects present in the families*. Fifty patients (92.6%) indicated 56 critical issues, 15 (26.8%) concerning psychological aspects and 41 (73.2%) practical aspects. Among the psychological aspects, feeling of worry, psychological consequences of the disease on personal wellbeing, and a sense of isolation/loneliness were the most frequently mentioned points. Among the practical aspects, need for daily help in performing one's activities and the poor interest/attention to own problems by the Authorities and Institutions emerged as critical points.

Question n. 8 invited patients to suggest what changes the G. Torre Centre should implement to improve the health services offered. Thirty-two (68%) patients did not suggest any change, underlining their full satisfaction with the health assistance received, while 15 (32%) reported 17 suggestions, the most frequent being a higher psychological support in presence and/or remotely.

Caregivers' views on health care services provided during the pandemic

The caregivers' version of the questionnaire included

the same questions covered in the patient's version of the tool, except for questions n.2 and n.3, which merged.

Question n. 1 investigated the *perceived impact of the pandemic on the care and assistance offered* by G. Torre Centre. Thirty-nine (97.5%) caregivers responded. Of these, 20 (51.3%) did not mention any perceived impact on the health care provision, 10 (25.6%) pointed out a positive impact and 9 (23.1%) reported a negative impact limited to the lockdown period in which FKT was interrupted.

Question n. 2 concerned the *strengths and weaknesses in the health services received*. Thirty-two (80%) caregivers highlighted 43 positive aspects, 32 (74.4%) practical and 11 (25.6%) psychological. Among the practical aspects, the continuity of health care provision, even at home, the use of the personal protective equipment (PPE) provided for, the monitoring of the patient's health conditions – even at a distance – were the most appreciated ones. Among the psychological aspects, the continuous support provided to the patients by the health professionals even remotely, was perceived as a main strength. Looking at the weaknesses, 32 caregivers completed the item. Of them, 21 (65.6%) did not find any negative element, while 11 (34.4%) identified as negative aspects the suspension of the rehabilitation during the lockdown, and the bureaucratic delays.

Question n. 3 concerned the presence of potential *positive aspects of the pandemic on daily life activities*. The caregivers identified 19 positive aspects, mainly psychological. Among them, the continuous presence of family members at home and the closer family contacts were the most cited ones. Four caregivers did not report any further change in family daily life due to pandemic.

Question n. 4 focused on the *critical aspects on daily life activities*. The caregivers identified 26 negative aspects, 17 (65.4%) of which were practical and 9 (34.6%) were psychological. Among the practical aspects, reduction of social contacts, difficulties in doing daily shopping and in travelling for medical visits were the most frequently reported ones. Among the psychological aspects, the fear of contagion prevailed.

Question n. 5 concerned *positive aspects present in the families*. Twenty-four positive aspects were underlined, of which 8 were practical and 16 were psychological. Among the practical aspects, home assistance and support for the disabled people were the most frequently mentioned, while among the psychological aspects to be together at home, not feeling abandoned, counting on the staff professional support, were those most appreciated. One caregiver stressed the importance of religious faith in dealing with daily troubles.

Question n. 6 concerned the *negative aspects present in the families*. Caregivers identified 28 negative aspects,

both practical (19, 67.8%) and psychological (9; 32.2%). Architectural barriers, difficulties in accessing health services, economic difficulties, and lack of support from the Institutions were the most frequently mentioned practical aspects. Loneliness, isolation due to fear of contagion, lack of psychological support and increased burden due to patient's management were among the most negative psychological aspects.

Question n. 7 invited caregivers to *report any change that G. Torre Centre should implement to improve the health service offered*. On this question, the caregivers were equally divided, as 20 (50%) did not suggest any changes and underlined their full satisfaction with the received health assistance, while 20 (50%) reported 13 suggestions. The most frequent suggestions included the reinforcement of the multidisciplinary team and of the psychological support for patients and their families. From a practical point of view, caregivers strongly recommended strategies to guarantee greater help in dealing with the bureaucratic procedures (access to economic benefits, renewal for physiotherapy prescription, etc.) as a priority.

Discussion

The COVID-19 pandemic had a deep impact on individuals' life, particularly on that of patients with MDs and their families due to the clinical characteristics of these disorders and the need of continuous rehabilitative treatments^{3,6-9}. As underlined by Bertrand Recasens and Rubio³, "COVID-19 pandemic has pushed health systems to their limit and forced readjustment of standards of care for different pathologies. Management of neuromuscular diseases becomes a challenge since most of them are chronic, disabling, progressive, and/or require immunosuppressive drugs."

We have previously shown¹⁰ that, despite the critical issues emerging in the pandemic period, professionals of the G. Torre Centre highlighted 82 aspects (48.5%) referring to the resources used to cope with critical issues, and that emotional aspects prevailed on practical aspects both in resources (52.4 vs 47.6%) and in difficulties (57.5 vs 42.5%) categories. In particular, regarding patients' resources, the staff indicated that psychological benefits were greater than practical ones (87 vs 13%), in the form of improved intra-family relationships, feeling more cared for, and satisfaction for the received care. As for the patients' relatives, the staff indicated again more resources than difficulties (72.8 vs 17.2%), mainly concerning the emotional sphere, such as the perception of having a point of reference even in such a challenging time.

In this second part of our study, addressing the impact of COVID-19 pandemic on the rehabilitation care

received from the perspective of patients and their caregivers, we found that patients highlighted both positive (prevailing) and negative aspects. Among the psychological positive aspects, closer family contacts, not feeling abandoned and counting on the constant professional Centre's support were the most cited. The prompt restart of rehabilitation services, the compliance of the professionals with the anti-COVID-19 rules, and their closeness always, were the most appreciated positive practical aspects. On the other hand, architectural barriers, difficult access to health services, economic difficulties, and lack of support from the Institutions were the most frequently mentioned negative practical points, while social isolation and isolation due to fear of contagion were the most signalled negative psychological aspects.

A prevalence of positive aspects (56.9% vs 43.1%) during the pandemic was reported also by caregivers who underlined the same psychological aspects reported by the patients. As for the negative aspects, most caregivers (92.6%) complained about increased bureaucratic and economic difficulties. This was particularly evident in poorer families.

Limitation of the study

Although this study may have methodological weaknesses, it is nevertheless the first study exploring the impact of the COVID-19 pandemic on a routine rehabilitation setting from the point of view of patients and their caregivers. In particular, the findings of this study highlight the resilience of patients and caregivers, and their ability to activate psychological resources even in such a difficult pandemic time.

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Conflict of interest statement

The Authors declare no conflict of interest.

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Authors' contributions

LM and LP conceived the project, wrote and revised the paper; GC contributed to the drafting of the questionnaires and analyzed the data; MGE and VT distributed and collected the questionnaires.

Ethical consideration

This study was approved by the Ethics Committee of the Naples 1 Local Health Authority, (Prot. 362/2021).

The research was conducted ethically, with all study procedures being performed in accordance with the requirements of the World Medical Association's Declaration of Helsinki.

Written informed consent was obtained from each participant/patient for study participation and data publication.

References

- ¹ Mercuri E, Bönnemann CG, Muntoni F. Muscular dystrophies. *Lancet* 2019;394:2025-2038. [https://doi.org/10.1016/S0140-6736\(19\)32910-1](https://doi.org/10.1016/S0140-6736(19)32910-1)
- ² Veerapandiyan A, Wagner KR, Apkon S, et al. The care of patients with Duchenne, Becker, and other muscular dystrophies in the COVID-19 pandemic. *Muscle Nerve* 2020;62:41-45. <https://doi.org/10.1002/mus.26902>
- ³ Bertran Recasens B, Rubio MA. Neuromuscular diseases care in the era of COVID-19. *Front Neurol* 2020;11:588929. <https://doi.org/10.3389/fneur.2020.588929>
- ⁴ Eichinger K, Lewis L, Dilek N, et al. A patient-focused survey to assess the effects of the COVID-19 pandemic and social guidelines on people with muscular dystrophy. *Muscle Nerve* 2021;64:321-327. <https://doi.org/10.1002/mus.27349>
- ⁵ Matsumura T, Takada H, Kobayashi M, et al. A web-based questionnaire survey on the influence of coronavirus disease-19 on the care of patients with muscular dystrophy. *Neuromuscul Disord* 2021;31:839-846. <https://doi.org/10.1016/j.nmd.2021.04.008>
- ⁶ Nishizawa H, Nakamura A. Changes in motor function in Duchenne muscular dystrophy patients after travel restrictions due to COVID-19. *Muscle Nerve* 2021;64:357-361. <https://doi.org/10.1002/mus.27348>
- ⁷ Sobierajska-Rek A, Mański Ł, Jabłońska-Brudło J, et al. Establishing a telerehabilitation program for patients with Duchenne muscular dystrophy in the COVID-19 pandemic. *Wien Klin Wochenschr* 2021;133:344-350. <https://doi.org/10.1007/s00508-020-01786-8>
- ⁸ Kenis-Coskun O, Imamoglu S, Karamancioglu B, et al. Comparison of telerehabilitation versus home-based video exercise in patients with Duchenne muscular dystrophy: a single-blind randomized study. *Acta Neurol Belg* 2022;1-12. <https://doi.org/10.1007/s13760-022-01975-4>
- ⁹ Palazzo L, Pompele S, Rossi M, et al. Facing muscular dystrophy during COVID-19 Pandemic: the role of support associations and spirituality. *Pastoral Psychol* 2022;3:1-15. <https://doi.org/10.1007/s11089-022-00997-2>
- ¹⁰ Citarelli G, Garofalo C, Esposito MG, et al. Impact of the COVID-19 pandemic on rehabilitation setting. Part 1: professionals' views on the changes in routine care provided by a rehabilitation centre for patients with muscle diseases. *Acta Myol* 2021;40:132-134. <https://doi.org/10.36185/2532-1900-054>