

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

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The outbreak of COVID-19 has forced the health care system to undergo profound rearrangements in services and facilities, especially during the periods of lockdown. In this context, inpatient and outpatient services had to rethink and reorganize their activities to meet the needs of severely disabled patients, as those affected by Muscular Dystrophies (MDs).

We present the preliminary results of a survey aiming to explore the staff views on the changes in the care provided by the Gaetano Torre Rehabilitation Centre, and, the impact of these changes on professionals, patients and their families.

The survey was carried out using an open-ended questionnaire including six-items, on the practical and psychological aspects emerged during the pandemic in relation to the healthcare services provided by the Centre and to the patients/caregivers conditions. The participants, most of them physiotherapists, highlighted 169 aspects emerging in the pandemic, 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 resources (52.4 vs 47.6%) and in difficulties (57.5 vs 42.5%) categories. In particular, with regard to patients' resources, psychological benefits, despite the burden, 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 more resources than difficulties (72.8 vs 17.2%). Among the former, 75% concerned the emotional sphere, such as the perception of having a point of reference even in such a difficult time.

Key words: pandemic, benefits, difficulties, muscle diseases, rehabilitation setting

Introduction

The outbreak of COVID-19 has forced the health care system to undergo profound rearrangements in services and facilities in Italy, especial-

ly during the first lockdown. In this context, inpatient and outpatient services had to rethink and reorganize their activities to meet the needs of severely disabled patients, as those affected by muscular dystrophies (MDs)¹.

MDs are a heterogeneous group of genetic disorders characterized by progressive wasting of muscle tissue and substitution with fibro-adipose tissue². Age of onset and evolution range from early infantile to adult and late onset forms; loss of ambulation occurs in the first-early second decade in the more severe forms. Most of MDs are multisystemic disorders affecting heart, respiratory and endocrine system, bones, eye. Respiratory insufficiency and cardiac failure are the most frequent cause of death; in some MDs, patients may develop fatal arrhythmias with a high risk of sudden cardiac death. Beside specific drug treatment, motor and respiratory rehabilitation are the main tools to delay the evolution of the diseases. The most severe MDs require a progressive family involvement in daily care leading to demanding burden³. However, psychological benefits related to caregiving are also reported⁴.

The Italian Association of Myology has recently conducted an online survey among the affiliated neuromuscular centres, to assess changes in pharmacological therapies provision, outpatient clinical and instrumental services, support services and clinical trials provided to patients with MDs during the first lockdown⁵. On average, 40% of centres reduced outpatient clinical visits (44.5% in Northern Italy centres, 25% in Central Italy centres, and 50% in Southern Italy centres). A postponement of in-hospital therapies provision has been reported in about 20% of cases (23.4% in Northern, 13.0% in Central and 20% in Southern Italy). On average, 57% of centres suspended support services such as physiotherapy, nursing care and psychological support (66% in Northern, 43% in Central and 44% in Southern Italy). The most affected services (in 93% of the centres) were Rehabilitation's services and on-site outpatient visits.

Since May 2020, the gradual resumption of the health activities led to a change in the rehabilitation assistance procedures to guarantee the maximum safety from contagion to the staff, users and their relatives, through individual protection disposals (IPD), environment sanitation, and physical distances.

Here we present the results of a survey aiming to explore the staff views on the changes in the care provided by the centre, and, the impact of these changes on professionals, patients and their families.

Materials and methods

The survey was carried out, at one -year from the beginning of the pandemic, at the Gaetano Torre Centre (G.

Torre) for Muscular Dystrophies, a rehabilitation centre, funded by Prof. Giovanni Nigro in 1977, and dedicated to patients with MDs, that operates 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.

In the second part of June 2021, the G. Torre staff (N = 30) was invited to complete an anonymous, open-ended questionnaire including six-items, on the practical and psychological aspects emerged during the pandemic in relation to the healthcare services provided by the Centre and the patients/caregivers conditions. The study was approved by the Ethical Committee of ASL NA1 (Prot. 362 of 8/6/2021).

Results

Twenty-four professionals (80%) gave their informed consent and participated in the study. Of these, 79% were physiotherapists engaged in motor and respiratory rehabilitation. Altogether, the participants highlighted 169 aspects emerging in the pandemic. In particular, 48.5% referred to the resources used to cope with critical issues and 51.5% concerned the difficulties encountered. Within the resource category, 47.6% were practical and 52.4% were emotional aspects. Among the practical aspects, the use of IPD (41.0%) and a greater intra-team collaboration in the management of patients (12.8%) prevailed. Among the psychological aspects, the most frequently reported were the perception of a greater sense of protection/affective closeness towards users and family members (28.6%), associated with a sense of gratitude (14.3%) towards the staff.

As far as the difficulties category, 42.5% referred to practical aspects and 57.5% to emotional aspects. Among the practical difficulties, the most frequently reported were the users' reluctance to reach the Centre (13.5%) immediately after the lockdown, and the difficulties in reaching and interfacing with health districts (13.5%). The most frequently reported psychological difficulties were fear of contagion (44.0%) and patients' loneliness (14.0%).

Regarding the impact of the pandemic on staff working, more practical and psychological resources than difficulties (practical: 78.90 vs 21.10%; psychological: 76.90 vs 23.10%), emerged. In particular, the most emphasized practical resources were teamwork and the use of IPD provided by the centre, whereas the main psychological resources were a greater emotional contact with patients and the ability to reassure them about the fear of contagion.

As far as the difficulties, the participants reported feelings of uncertainty/precariousness in their practices,

related to the need of adhering quickly to the ever-changing regional and national directives. Moreover, the staff reported that the difficulties encountered by the patients were more psychological than practical (84 vs 16%), mainly fear of contagion and reduction of social contacts.

Regarding the patients' resources, the participants indicated more psychological than practical benefits (87 vs 13%), such as an improvement in intra-family relationships, feeling more cared for, and satisfaction for the received care.

As for the patients' relatives, the staff indicated more resources than difficulties (72.8 vs 17.2%). Among the former, 75% concerned the emotional sphere, such as the perception of having a point of reference even in such a difficult time. As for the difficulties, once again, those of an emotional nature prevailed (56.2 vs 42.8%), mainly fear of contagion for themselves and the loved ones.

Practical difficulties included contacts with the local health services, such as difficulties in interfacing with the offices, bureaucratic delays, and economic problems.

In line with the significance of the psychological aspects mentioned above, the ability of the G. Torre staff to reorganize services and respond to the new needs of patients during the COVID-19 pandemic emerges. In particular, the initiative of "a virtual coffee point" was appreciated, a weekly online appointment with the psychologist and other professionals during which the difficulties of the period and how to deal with them were discussed with patients and their families.

Limitations of the study

Although this study has many methodological weaknesses, it may provide useful information on the impact of a pandemic in the routine rehabilitation setting. In particular, the findings of this study highlight that, in spite of the difficulties related to COVID-19, healthcare staff, patients and caregivers were able to activate psychological and practical resources.

Future perspectives

We intend to extend this study to the perception of patients and their caregivers on the validity of the changes implemented by the G. Torre Centre during the pandemic. Their view's evaluation will be important in dealing with other events with a potential impact on the daily management of disability.

Ethical consideration

The study was approved by the Ethical Committee of ASL NA1 (Prot. 362 of 8/6/2021).

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Conflict of interest

The Authors declare no competing interests.

Author contributions

G.C.: acquisition and analysis of questionnaires.

M.G.E., C.G. and V.T.: acquisition and analysis of questionnaires.

L.M.: study design, writing and critical revision of the manuscript.

L.P.: study concept and design, writing and critical revision of the manuscript.

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