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**LIVING WITH A DISABILITY DURING THE PANDEMIC.  
“Instant paper from the field” on rehabilitation answers to  
the COVID -19 emergency**

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**6° WEBINAR SIMFER**

***LIVING WITH A DISABILITY DURING THE PANDEMIC.***

**“Instant paper from the field” on rehabilitation answers to the COVID -19 emergency**

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**Key words:** rehabilitation, disability, COVID19

## Abstract

COVID-19 pandemic is creating collateral damage to persons with disabling conditions of different aetiology. The restrictions imposed to contain the spread of infection is limiting the access to many health services, including rehabilitation. It is expected that such situation will lead to long lasting negative consequences for persons with disability, increasing functional limitations in chronic conditions and hindering the recovery after acute events. The aim of this paper is to explore the impact on people with disability, reporting the contents of the sixth Italian Society of Physical and Rehabilitation Medicine (SIMFER) webinar on the COVID -19 impact on rehabilitation (“Covinars”). Seven representatives of Associations of persons affected by different disabling conditions described the difficulties they are facing during the pandemic, the initiatives undertaken to support their members and their future perspectives and expectations. The users’ inputs will be helpful in planning the future phases of the emergency and improve preparedness for other emergencies.

## Introduction

The COVID-19 pandemic is currently spreading rapidly throughout Europe and other parts of the world, (1) putting unprecedented pressure on the health systems. After a first huge impact on the acute sector of the healthcare system, also the area of post-acute care and rehabilitation have been involved (2-4). Rehabilitation professionals need to provide adequate care to persons who survive the COVID-19 with disabling sequelae (3,5). increasing evidence is emerging that many patients are left with significant functional limitations, not only related to respiratory impairments (6-7). Patients usually treated in rehabilitation settings, are left behind due the shift of resources to the emergency sector and the limited outpatient and home-based services imposed by the lockdown (3,8-10). A survey by the European scientific societies ESPRM and UEMS-PRM found that up to 2,2 million people in Europe so far had to interrupt rehabilitation treatments due to the epidemic (11). This is expected to have a negative impact in the short term, with functional deterioration in persons with chronic diseases, and hindrance of recovery in patients suffering from acute disabling conditions.

The Italian PRM Society (SIMFER) organized weekly webinars, so-called “Covinars”, to share instant information from the field, summarized in a series of instant papers (12) (Figure 1). In a previous webinar, ways for a rapid and effective recovery of rehabilitation services were discussed from the perspective of professionals (13). To properly organize this, it’s important to listen to the voice of those who are facing this situation first-hand. Therefore, the 6<sup>th</sup> webinar hosted speakers of

different Associations representing persons affected by different disabling conditions and their relatives, asking them to illustrate their needs, expectations and proposals to plan future services.-This paper reports the content of this Covinar, held on April 27<sup>th</sup>, 2020 that focused on the impact of the pandemic on people living with disability.

### The Covinar

Seven representatives of Italian Patient Associations were interviewed during a 120 minutes webinar (Table 1).

Insert table 1 about here

Table 2 shows the situation of the pandemic in Italy on that day (14). One author (PB) prepared and sent in advance a series of questions to the participants and acted as an interviewer, asking also questions received live during the Covinar. Similar to the previous Covinars, out of about 5,000 PRM physicians in Italy, and 3,300 SIMFER members, there were 200 live attendants. Up to May 2<sup>nd</sup> about 500 more persons viewed the recorded version, including other specialists and health professionals.

### **The current impact of the epidemic on the persons living with disability**

Associations complained that many inpatient services decreased or interrupted their usual activity, arranging early discharge plans and/or stopping new admissions. A critical situation was reported for acute health conditions (e.g. stroke in adults), with a significant decrease in hospital admissions (partly explained by the fear of being infected by SARS CoV-2), but also for conditions needing specialized inpatients rehabilitation services, such as Spinal Cord Injuries, or rare diseases where diffuse expertise is lacking, and patients rely upon few specific units in the Country (e.g. Charcot Marie Tooth disease). The difficulty in getting advice from medical specialists and in obtaining a coordinated care plan addressing the different needs of persons affected by chronic disabling diseases was a major concern. Some examples were: how to manage immuno-depressant drugs or episodes of active inflammation in rheumatic diseases; rehabilitation for relapses in multiple sclerosis. Also, the epidemic exacerbated pre-existent critical aspects in the organization of care, such as the lack of coordination between the General Practitioner and health services, and the inadequacy of home based and community services.

The social isolation and the sense of loneliness and discrimination often experienced by persons with disability were amplified by the lockdown. An overall inadequacy of social protection measures, was perceived. One representative called “an emergency within the emergency”.

The bureaucratic burden on patients and families to obtain assistive devices and orthoses was experienced as very stressful. This was attributed to the lack of diffuse online support systems, and the huge differences between regions (or even intra-region) in rules and procedures to obtain such technical aids.

Finally, a general concern was reported on the availability of resources to face the “return wave” of persons who will need rehabilitation treatments after such a long shortage period.

### **Actions taken by the Associations to support their members**

A remarkable ability of self-management and proactivity shown by the associations emerged. Remote communication systems (from the most popular social media platforms to more professional and customized tools) were used to support patients and their families, through self-organized initiatives:

- Mitigate the effects of physical distancing and isolation (teleconferences and phone calls);
- Share information between the members of the association on how to manage different practical or clinical problems, such as pharmacotherapy, nutrition, physical activity and lifestyle;
- Promote healthy lifestyle contrasting the limitations caused by the epidemic (video-tutorials on adapted physical activity);
- Promote public awareness of the consequences of the epidemic on persons with specific conditions (social media campaign)
- Deliver telemedicine services for evaluation purposes or treatments (teleconsultation and telerehabilitation).

The Associations are advocating at a political level, often interacting with national and regional authorities in charge of health, welfare and social affairs. The plethora of different authorities and competencies involved in the different aspects of care of persons with disability, creating conflicting situations and inefficiencies caused anxiety in the users. The epidemic is seen as an opportunity to re-shape and improve this area of care according to the principles of dignity of persons with disability. The European coordination was also considered important.

### **Future perspectives and expectations**

Associations unanimously expressed a plea for rapid recovery of rehabilitation services, as well as the need for some changes in their organization and delivery (e.g. strengthening the community and home-based services, improving or creating networks where lacking, supporting the role of peers...). All participants agreed that telerehabilitation services, intended as any kind of remote digital support, should be maintained. Nevertheless, concerns were expressed on the lack of financial support, of a general normative framework to ensure the sustainability of such services, and the fragility of many projects based on goodwill or individual initiatives (in particular the role of female caregivers, under pressure managing multiple roles without a proper welfare support).

## Conclusion

The huge impact of the COVID-19 pandemic on rehabilitation services, as reported by health professionals, was confirmed by persons with disability or chronic disease. This left patients, families and caregivers alone with their needs. Associations made great efforts to assist their members offering information, advice and individual support. Some of them provided online video's with exercises for persons at home, as supported by current knowledge (15).

On top of the health-related consequences, organizational and administrative issues put an important burden on patients and caregivers. Therefore, the consumer organizations are promoting awareness in society and are advocating at the political level, nationally as well as internationally. They are calling for a strong partnership between all stakeholders to ensure integrated care and preparedness also in emergencies. Providing a disability inclusive response to the pandemic is important and is supported by WHO (16,17). WHO already produced a useful document proposing a list of actions for people living with non-communicable disease (NCD) that could be extended to people living with chronic disease or disability (18).

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**Table 1 – Participants and areas of interest**

ACMT-RETE - Marina Garcea (Charcot-Marie Tooth Disease)
AISM - Giampaolo Brichetto (Multiple Sclerosis)
ALICE ITALIA - Nicoletta Reale (Stroke)
ANMAR - Silvia Tonolo (Rheumatic Diseases)
FAIP - Vincenzo Falabella (Spinal Cord Injury)
FIGHTTHESTROKE - Francesca Fedeli (Cerebral Palsy – Perinatal and pediatric stroke)
FNATC - Anne Cnops (Traumatic Brain Injury)

**TAB 2 – Reported cases of SARS Cov-2 at April 27<sup>th</sup> in Italy**

AREA	TOTAL CASES	HOSPITALIZED	ADMITTED IN ICU
ITALY	199.414	20.353	1956

Figure 1. Evolution of the COVID-19 epidemic according to the official Italian Health Ministry data, and timelines of (1) the most important restrictions imposed to the population, (2) Italian Society of Physical and Rehabilitation Medicine (SIMFER) initiatives and (3) publications in the European Journal of Physical and Rehabilitation Medicine (EJPRM). Covinar = SIMFER “COVID-19” webinars. Italian government reactions to epidemic: (1) February 24<sup>th</sup>, 2020: red zones (total quarantine) close to Milan; (2) March 2<sup>nd</sup>: closure of schools; (3) March 8<sup>th</sup>: travel restrictions; (4) March 11<sup>th</sup>: total shutdown; (5) May 4<sup>th</sup>: start of phase 2, with reopening to 70% of the economic activities and reduction of social distancing for the population.

