Telemedicine and Health Humanities for Children with Rare Diseases: A Lesson from COVID-19 to e-Psychology

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The outbreak of Coronavirus (COVID-19) disease has been a public health emergency of international concern that has limited the access to hospitals and medical services to many people with chronic and non-emergent diseases worldwide [1]. Rehabilitation has constituted one of the most affected branches of medicine and psychology, with clinical units that have been temporarily closed to outpatients due to strict rules against contagion [2].

In this scenario, e-Health, which provides at distance general care and services by using information-communication-technologies (ICTs), emerged as a fundamental tool to ensure the continuity of caring services while keeping outpatients, inpatients and health providers safe during COVID-19 outbreak [1-3].

E-Health endeavours many different branches, including Telemedicine (namely, the practice of medicine using technology to deliver care at distance), Telerehabilitation (namely, the branch of Telemedicine focused on rehabilitation), and e-Psychology (that uses technologies for psychological evaluations, consultations and treatments at distance).

The World Health Organization reported that Telemedicine using ICTs to overcome geographical barriers and increase access to health care services, could be particularly beneficial for rural and underserved communities in developing Countries and groups that traditionally suffer from lack of access to health care [4]. More generally, for many patients, particularly those with rare diseases of the nervous system, Telemedicine represents an indispensable and unique opportunity to pursuit.

RDs are complex and heterogeneous conditions affecting less than 1 person per 2000 individuals in the general population. Despite this definition, globally, there are from 6000 to 8000 recognised RDs affecting more than 300 million persons [5]. Affected people experience multisystem diseases, multiple accesses to different health services and multifaceted often not conclusive treatments. More than 50% RDs affect children with different phenotypes and onsets due to genetic variability, mostly manifesting neurological involvement. Centres for RDs own advanced capabilities in diagnosis, management, therapy, research and transition to adult age, but they are often located far from the patients' homes and unevenly distributed across countries [6].

Children with RDs and their families could benefit from the empowerments related to the use of personal computers and tablets and this will hold true also after the end of COVID-19 pandemics thanks to Telemedicine.

However, Telemedicine is a modality of medicine that could also turn out to be alienating. During COVID-19 pandemic, Telerehabilitation has been a viable opportunity for reducing the risks related to the infection, while offering solutions to the constant demands of care. It also showed that the physical absence was identified as a limit for the work by professionals and even children's caregivers who perceived Telemedicine as just medially effective [3].

If rehabilitation and psychology can be more effective in presence, their use could remain limited for children with RDs and their families, even after the end of pandemic for the likely distance of their homes from the specialized centre for that specific RD.

However, too often a simple telephonic of video call between a clinical professional and a patient or his/her caregiver has been called Telemedicine. It is extremely reductive, first of all because Telemedicine needs security measures as the cryptography in the transmission of data taking into account privacy requirements. Secondly, e-Health is a new methodology that could be less effective if based only on traditional contents related to the visual (video) and audio interaction: it cannot be based, for example, on touch, that is a fundamental aspect for physiotherapists and physiatrists. Conversely, e-Health should benefit from new visual and auditory approaches, such as Health Humanities, gamification, and video-analysis techniques.

Health Humanities can be defined as a common ground between arts and humanistic culture, health and social sciences, ideal mixture to support health care and well-being of children and for reducing the stress of their caregivers [7,8]. They include (but are not limited to) the narrative medicine, with specific methodologies aimed at analyzing the narratives of patients, family members and health professionals in the medical records, the visual thinking strategies, based on the use of visual arts to empower medical and psychological interventions, and the use of music as a therapeutic approach. A recent study highlighted how art could improve the motor performance of patients with neurological disorders, reducing the perceived fatigue and increasing the movement precisions. The authors called it Michelangelo's effect [9], similarly to the Mozart effect related to the use of music for improving performances [10]. Musical and acoustic stimulations were also reported as effective for locomotor performances of neurological patients [11,12].

Specific software could be also used for recognizing and analysing motion gestures performed in front of the cam. They can exploit a large palette of techniques for video analysis (including machine learning) sometimes combined with wearable sensors for having a real-time processing of movements and providing feedback to the child and caregivers. Such signals can be recorded, stored, and remotely transmitted to physicians, allowing them to make effective decisions concerning therapy and rehabilitation [13].

Lastly, gaming is an excellent trait d'union between technologies related to human movement analysis and a virtual scenario resorting to the Health Humanities that can enhance motivation, participation, engagement and learning of children [14,15].

The end of COVID-19 should not turn off the spotlight on Telemedicine. The need of a continuity of special care will remain a challenge for children and adults with RDs, often living far from their specialised clinical centres. Their particular situation should encourage health professionals, in particular physiatrists, psychologists and therapists to use Telemedicine, e-Psychology and Telerehabilitation developing new strategies, combining innovative learning approaches and emerging technologies, for being effective at least as (or even more than) interventions administered in presence and for the reduction of the stress experienced by caregivers.

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