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CRITICAL COMMENTARY

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Challenges to delivering family-centred care during the Coronavirus pandemic: Voices of Italian paediatric intensive care unit nurses

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Italy has been one of the epicentres of the coronavirus pandemic since late February 2020.[1] Although the peak of the pandemic has passed, with the total number of positive coronavirus cases in decline since April, Italy remains one of Europe's worst-affected countries.[2]

Lombardy was the most affected region, with 95 459 people testing positive for severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2) and 16 788 officially registered coronavirus disease (COVID-19)-related deaths as of 21st July.[3] The spread of SARS-CoV-2 was very heterogeneous in Italy. A national response to preparing health systems was imperative, but because of the regional specificity, it was managed differently. According to regional indications, hospitals were divided into COVID and non-COVID hospitals, and where this was not possible or in the regions with low impact, COVID-dedicated wards were organized. These COVID areas could be activated according to a sequential strategy that provided for an expansion of capacity (beds, equipment, staff) based on demand.

1 | ORGANIZATION OF PAEDIATRIC DEPARTMENTS AND PAEDIATRIC INTENSIVE CARE UNITS

In general, paediatric departments had a decrease in activity because of the reduction in elective surgery and consultations.[4,5] Because of the urgent demands for adult intensive care, in terms of intensive care unit (ICU) bed capacity and critical care staff, paediatric health care professionals (HCPs) in Italy, as well as in most of Europe, were faced with three different scenarios[6,7]:

- Paediatric intensive care units (PICUs) having to admit adult patients with COVID-19;
- PICU HCPs redeployed to adult ICUs to manage adult COVID-19 patients; and
- PICUs still exclusively dedicated to children (with or without COVID-19).

The second major change in terms of reorganization was the significant redistribution of critical care staff to cover the need for intensive care competence. Several PICU nurses were voluntarily redeployed to adult ICUs, both in and outside the region, and in some cases, neonatal intensive care (NICU) nurses were involved in the care of older infants and toddlers.[7] With the exception of Lombardy, the majority of Italian PICUs remained dedicated to children because the adult ICU capacity was not overwhelmed. In the midst of the pandemic, in minimally affected regions, a huge amount of energy was dedicated to the preparation and reorganization of the units. It was considered a great opportunity to have this time during such a chaotic period. At a time when everything is new and constantly evolving, having time was a great opportunity.

2 | ORGANIZATION OF FAMILY-CENTRED CARE DURING THE PANDEMIC

COVID-19 has significantly changed our standard pathways, protocols, procedures, and also our ways of interacting with families. During the pandemic, nurses demonstrated flexibility and resilience in this

social and health care crisis, during which maintaining family-centred care is even more important. For every hospitalized child, the impact of physical, cognitive, and emotional health has a huge impact on the road to recovery.[8] Psychosocial health can easily be forgotten, but the possibility of having parents, siblings, and friends close by is a crucial part contributing to psychological well-being. Patient and family-centred care is defined as "working" with patients and families rather than just doing things "to" or "for" them.[9] In this situation, the need for social distancing and public safety leads to important restrictions on the physical presence of families of hospitalized children,[10] with reduced time for children to spend with parents and siblings. Indeed, in most parts of Italy, only one parent could visit and often only for restricted hours. For some units, this did not require a substantial change, but for the staff of open PICUs, where parents can normally stay with their children at any time without restrictions, this was a dramatic change, with the loss of parents as important partners that collaborate in care. Despite progress in recent years to more open parental visitation, in Italy, there are still only few PICUs with facilities and access for parents on a 24-hour basis.[11] In response, health systems had to adapt family-centric procedures and tools to overcome the restrictions to physical presence.[12] Internet-based solutions and telemedicine facilitated daily communication between children, parents, and the rest of the family. These resources, as well as online schooling or virtual teaching support, were implemented. Encouraging parents to be creative and produce artefacts such as diaries, letters, and/or text messages or be a part of social media groups are ways of engaging them and also other family members to start up a different communication model, not only based on live communication but also empowering an asynchronous one.[13] These resources can be beneficial not only for children but also for parents as they can have a "record" of their experiences to reflect on later.

A further challenging issue was the management of the acute phase of critical illness (including procedures like cardiopulmonary resuscitation), considering the absence of parents/primary carers because of precautional guidance.[14] This was perceived to have had a great impact on these children and their families during such acute events. Cardiopulmonary resuscitation or other critical procedures increased the amount of stress related to the personal risk of exposure not only for the HCPs but also for the parents. In this context, one of the principal concerns for parents and carers was the possibility of becoming infected with SARS-CoV-2 themselves.

Another difficulty for the families was the interaction between different services within a hospital, that sometimes had different criteria and protocols regarding the surveillance procedure for suspected cases. The use of full PPE was extensively enforced for all suspected cases, especially in the early phase of hospitalization. This often coincided with the most acute phase of hospitalization, and children were often visibly scared by the appearance of physicians and nurses wearing full PPE. This protective equipment, although essential, can be seen as a barrier by children but was also a barrier for HCPs as well, depriving them of the possibility of touching and nonverbally reassuring the patients by smiling.

The shortage of HCPs, especially nurses, during the pandemic also led to a reinterpretation of the roles in multidisciplinary teams. Once more, communication with families was supported and delivered not only by nurses but also by medical or nursing students and even volunteers with some training. These volunteers were helpful in promoting coping strategies and coordinating communication efforts between the families and the clinical team. A strong and enhanced partnership with community or social organizations facilitated the delivery of essential items and technological devices for videoconferencing and helped the families to use low-cost or free internet programmes to assist and mediate such communication.

3 | NEW CHALLENGES FOR THE FUTURE AND LESSONS LEARNED

The COVID-19 pandemic is not over. This situation led nursing professionals to adapt to a rapidly changing clinical culture. The following can be considered lessons learned with implications that extend beyond the pandemic:

- The importance of parents as partners in care remains a key point of family-centred paediatric intensive care, even in a social-distancing context. If their physical presence is not possible, it is the duty and responsibility of the clinical team to maintain this vital presence in terms of daily communication for transparency, accountability, and consistency.
- Alternatives to physical family presence must be encouraged and stimulated by the clinical team; for instance, creative and artistic resources may engage the family in a different communication model. In this context, it is important to consider the child and family's story to facilitate the conversation between the clinical team and the patient in the absence of mediation by wider family members.[15]
- Widespread use of PPE must continue, and education (often through play) for hospitalised children is necessary to reduce their fear and anxiety. Clear guides for kids with images and a short explanation discussing why hospital workers are wearing some extra gear can be helpful.
- COVID-19 is an opportunity to reconsider the roles and responsibilities of HCPs using all available resources, including social workers, volunteers, relatives' associations, and other non-governmental organizations in daily clinical practice.
- Internet-based solutions can facilitate communication, but the use of technology needs to be controlled, paying particular attention to patients' privacy. Virtual family/parent/patient teaching should be integrated into the usual routine. The lack of availability of technical devices or technological illiteracy, however, can underline disparities for some categories of the populations. It is the responsibility of the clinical team to intervene to support families in this regard with tailored resources.

In a time of crisis, such as the COVID-19 pandemic, there is an opportunity to rethink and restructure ICUs and look at problems from a fresh perspective. Sharing experiences, even if virtually, via social media makes it possible to influence a wider and more diverse group of professionals to share experiences, find ideas, and try new solutions. This energy has led many of us to find new ways of interacting with patients, and thanks to our PPE, we all still look like astronauts on a trip to the moon!

AUTHOR CONTRIBUTIONS

Brigida Tedesco, Giulia Borgese, Umberto Cracco, and Pietro Casarotto wrote their commentary and reports based on their clinical experience during the pandemic. Anna Zanin collected the drafts, translated them into English, and prepared the final manuscript. Each author provided critical care expertise based on their disciplines of interest. All authors have read and agreed on the final manuscript.

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