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COVID-19: A family's perspective

4

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The emergence of a new virus of the Coronaviridae family, called severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2) which was detected for the first time in December 2019 in Wuhan (China), has led to the definition of a new disease known as coronavirus disease 2019 (COVID-19).¹

Up to date, this condition has affected over 90 million patients in 188 countries around the world, with almost 2 million deaths.² In its more severe presentation, the SARS-CoV-2 infection causes acute respiratory failure that requires mechanical ventilation in a high proportion of cases.³⁻⁶ In Spain, more than 11,500 persons have been admitted to intensive care units (ICU) due to COVID-19, typically with prolonged stays and a high percentage of mortality.⁶

The characteristics of this highly contagious and lethal disease have compelled governments to adopt extraordinary measures in most countries, including a declaration of a state of emergency, the general confinement of the population, the encouragement of social distancing, the isolation of patients and their close contacts, and the implementation of restrictive visiting policies both in social and health-care facilities.⁷⁻⁹

Although these measures have demonstrated to be effective to flatten the epidemic curve, they have resulted in radical changes in social and health-care practices.¹⁰ These new policies have caused patients and their relatives to suffer through the disease in isolation and family separation, even in challenging and unique moments such as end-of-life events. These and other factors have altered the family unit and its dynamics during the pandemic.

Post-intensive care syndrome (PICS-P) affects many critically ill patients (30%–50%). It encompasses physical (mainly respiratory and neuromuscular systems), cognitive (memory and attention deficits), and psychological [depression, anxiety, stress, and post-traumatic stress disorder (PTSD)] sequelae that appear after discharge from the ICU and impact negatively their quality of life.¹¹

This syndrome also affects family members (PICS-F), a vulnerable population that suffers negative physical, psychological, and social effects which also lead to a deterioration in their quality of life.¹²

Data from several studies show a high prevalence of anxiety (73%),¹³ depression (35%),¹⁴ PTSD (56%),¹⁵ and complicated grief (52%)¹⁶ in relatives of ICU patients.¹⁷ These sequelae can be long lasting. The Randomized Evaluation of COVID-19 Therapy (RECOVER) study revealed that 16% of relatives had not reduced their level of depression 1 year after the discharge of their patients.¹⁷

They also exhibit physical symptoms such as fatigue and health risk behaviors such as sleep disturbances, insufficient rest, sedentarism, unbalanced diets, and non-compliance with medical treatment. The burden of caring for a patient who has been severely ill can affect personal aspects of the family's life plans and their social and professional relationships; it also tends to foster family conflicts.¹⁸

A study assessing the components of PICS-P's impact on the family members who care for the patient found a low burden level in 34.5% of caregivers and a moderate-high level in 15.5% of caregivers. The presence of psychological components of the PICS-P (anxiety and depression) 3 months after discharge from the ICU affected negatively the burden of the caregiver. Neither physical sequelae nor other measured variables had any significant impact of the caregiver burden.¹⁹

The Society of Critical Care Medicine assumes the concept of family as defined by the patient, or in the case of minors (who have no legal decision-making capacity) by their surrogates.²⁰ In this context, "family" may or may not be actually related to the patient. Rather, they are supportive individuals with whom the patient has a meaningful relationship.

A person's admission to the ICU causes an alteration of the family structure and function, creating a series of disorders and feelings and an overall experience that is almost always described as traumatic. When this occurs, family members must deal with emotional, cognitive, and social stressors that generate feelings of shock, uncertainty, denial, anger, despair, hope, guilt, anxiety, and fear of the patient's death. If the stressors exceed the family's coping ability to handle the situation (and in many cases the family has limited adaptation resources or a lack of habit to use them), they become subjects in need of care.²¹

The primary needs of families who have a patient in the ICU include (1) receiving truthful and understandable information about the patient's status; (2) assurance that their loved one is not alone and that as family members they can reassure, protect, and support their patient; (3) receiving some hope about the possibility of recovery or at least, in the event of a hopeless situation, the assurance of a painless and dignified death; (4) the perception that their patient is well cared for; and (5) the perception that the professionals caring for their relative have the necessary skills to perform an effective job.

If those needs are met, it will bring the family relief from anxiety and some degree of comfort.²²

The concept of person-centered medicine recognizes not only the needs of the patient but also the needs of the family members. This leads to the consideration that families cannot be viewed as mere "visitors"; indeed, they constitute an indissoluble bond that makes them relevant actors in the face of critical illness. Family-centered

care recognizes the paramount role of the family in the patient's recovery. It describes the health-care team's responsibility to provide support to critically ill patient's families, to be respectful, and respond adequately to each family's individual needs and values.

The "Guidelines for Family-Centered Care in the Neonatal, Pediatric, and Adult ICU"²³ published in 2016 established a series of recommendations based on the scientific evidence to optimize the support of ICU patients' families. These recommendations include the family's presence in the ICU, family support, open communication with the family, inclusion of specific consultants in the team such as specialists in ethics, psychological support or aspects related to the organization, and structure of these units.

The strategies to detect and prevent PICS require a structured and early multidisciplinary approach to the critical patient's admission. The measures should allow for the detection of risk factors not only for the development of sequelae both in the patient and in the family members. There are many initiatives and recommendations established to reduce PICS-P's appearance which are gradually being implemented in ICUs as standard policies.

The "ICU liberation"²⁴ concept is a quality improvement initiative based on the implementation of the ABCDEF set of evidence-based measures, which has shown that, when applied comprehensively, it improves outcomes and reduces the incidence of PICS. Pain control, adequate sedation, delirium management, keeping patients awake and breathing spontaneously, early mobilization, and family's early involvement and participation all have shown to increase patient's survival and to reduce sequelae in patients and their families after discharge from the ICU.²⁵

There is not much scientific evidence available on interventions to reduce PICS-F. A systematic review shows that proactive communication and adequate information are essential elements to ameliorate the sequelae of critically ill patient families.²⁶ Certain interventions can actually worsen the situation, for example, meetings held by external palliative teams without ICU professionals' participation. On the other hand, actions such as sending a condolence letter after a patient's death could decrease the incidence of PTSD.^{27,28}

In recent years, humanization of intensive care units has advanced significantly through different initiatives, such as the HU-CI project.²⁹ This international and multidisciplinary project spearheads a change in the paradigm of critical patient care (following eight different guidelines), offering a frame of reference for humanized intensive care.³⁰ The implementation of these initiatives has led to opening the doors of ICUs for extended hours to family members, to allow the presence and active participation of the families in the care and even specific procedures of their patient, to form "families," to communicate openly and more freely with the patient and the professionals in the attending team, and for the families to be present at the end-of-life events.³¹

The recent pandemic has put the health system in check and has shaken many of these policies that were being gradually implemented in many units. On the other

hand, it has highlighted the importance of preserving these directive strategies. The pandemic has also unveiled the emotional effect that this disease has brought to patients, families, and health-care professionals. The separation of the most severely ill patients from their families shows the cruelest side of the pandemic.³²

During this time, we have seen how patients remain isolated from their families, increasing their fears and anxiety in the face of a severe illness that could potentially lead to death and of the loneliness and isolation during their extended admission to the ICU. Families have had to live with the uncertainty of what was happening in these units, while the media showed saturated units and insufficient resources to care for all seriously ill patients.

The communication and decision-making process have been hampered by the reduction of direct contact with professionals, regarding essential aspects such as the decision to admit somebody to the ICU or the limitation of life-support treatment. Therapeutic decisions have been made regarding specific treatments, many of them as “off-label”, compassionate (if unproven) use, or the inclusion of clinical trials with great uncertainty not only from the clinical point of view but also from the decision-making process as well.³³

Finally, many families have not been able to accompany their loved ones at the end-of-life³⁴ events and have even had difficulties to say goodbye, to perform the usual rituals, or to dispose of the body after the demise of the patient. All of this suggests a significant impact on the incidence of PICS-P on those who have overcome the disease, but also of PICS-F, particularly in families of deceased patients.³⁵

Health professionals have experienced extraordinary situations in which the high demand for care, often accompanied by a shortage or scarcity of resources, has led to the health system's saturation. In response, intensive care teams have expanded their units structurally, occupying new spaces and taking in other professionals who normally do not attend critically ill patients, and even using equipment that is not always adequate.³⁶ Meanwhile, the lack or shortage of proper personal protective equipment (PPE) has exposed health professionals to the risk of infecting themselves and their families. The problem intensifies due to the strenuous, prolonged, and exhausting shifts, the reduction of the workforce, the unavailability of diagnostic tests, and the realization that the quality of care being provided is not always adequate.³⁷

The emotional suffering that the restricted visitation policy has infringed on health professionals is known to be high. Generally, the population has always recognized the timely and effective response of health-care teams, and now, those teams are seeking and finding new ways to overcome the limitations set by the pandemic itself. Health-care professionals have become innovative and are offering tools such as telecommunications and videoconferencing, in an attempt to shorten the distance between patients and their families. This situation is and will continue to impact health professionals who are at high risk of suffering burnout, moral distress, compassion fatigue, and PTSD.³⁸

Restricted visitation policies

The COVID-19 pandemic response has included drastic restrictions on hospital visits with the well-intentioned goal of social distancing to reduce the risk of infection.³⁹ These decisions, adopted in a generalized way and sometimes with absolute prohibitions, could be considered ethical, based on prioritizing public health⁴⁰ protection. Unfortunately, by their very nature, they undoubtedly prevent the delivery of humanized care focused on the family, especially in the most challenging situations and at the end-of-life events. These restrictive policies have been implemented abruptly, and in many cases, without the input of key stakeholders including the patients themselves, their families, and the health-care professionals. A critical reflection has led to alternative options in which greater importance is given to the accepted normative rights of patients (such as the right to be accompanied, the right to have spiritual or religious support) and questions if the limitations imposed can be of such intensity that become a de facto deprivation of these rights.⁴¹

Restrictions on family presence should not undermine the principles of family-centered care, and for this, it is necessary to adapt tools and procedures to the new context. The goals of this type of care during the COVID-19 pandemic should be geared towards¹ respecting the family's role as team members,² collaboration between family members and health-care professionals, and³ maintaining family integrity.⁴²

As an alternative to the visit limitations, many units have developed support systems and initiatives using technology to minimize isolation and to bring families closer to their hospitalized patient. The use of these devices has led to ethical and legal debates over the availability and inequity of these resources and data privacy protection. Regulations should be established to protect patients and their families' rights and to reduce the risk of legal suits to health-care professionals.

The positive experience of some ICUs with more flexible visitation policies should be considered in the future to avoid, as far as possible, the effects derived from strict isolation. As Andrist et al.⁸ established, we should not allow severe restrictions to become routine in the ICU as it weakens the current trend of humanization. His pediatric ICU experience shows how it is possible to adapt the rules to facilitate more open and flexible visits in a safe way. These authors remind us that all administrative measures have exceptions for certain essential activities. Accompanying patients, especially as an end-of-life event, is an important activity supported by ethical and legal international frameworks. There can be no reason for a patient to die alone. For this, adequate communication plan is necessary to transparently inform the family how these visits will be carried out and to avoid conflicts, allowing the family to understand the reason for the restrictions imposed. Having specific written protocols in which these policies are clearly explained can facilitate the implementations of the visits. The protocols must be dynamically adapted as the pandemics evolve.

Certain measures can help to adopt less restrictive policies while minimizing the infection risk for everybody. It is essential to have suitable PPEs for families, to

ensure adequate training in the use of the equipment, and to adapt procedures to the structural characteristics of each unit and its resources. Specific policies should also be considered for critical patients admitted to non-COVID-19 units, where the restrictions are limited to monitoring for the disease. In cases where visits are considered a limited resource, it may be necessary for independent multidisciplinary bodies to allocate those resources. Recommendations have been proposed to maintain the connection of COVID-19 patients with their families, which help to reduce the negative impact of restricting visits.⁴³

The family's presence and company can go hand in hand with the family's participation and involvement in the care of their patient. Even though this participation is considered a voluntary individualized process that develops progressively, it should be guided by the health-care professionals. Due to the pandemic, this participation in caregiving has no longer been possible due to visit limitation and saturation of health-care facilities; many health-care teams are overwhelmed and have no time to do necessary preparations.

Recently, the family's presence during specific procedures^{44,45} such as cardiopulmonary resuscitation has shown beneficial effects, as long as it is performed in appropriate settings. Interventions like these, still limited in many units, have been questioned during the pandemic, especially in procedures with a high risk of infection or in which resources and equipment are scarce. Alternative measures such as tele-accompaniment, quarantine imposition, and even pet's⁴⁶ company have been proposed.

Other aspects related to family care has been the need to transfer patients to other hospitals (which may be located in a different geographic area) to optimize the use of resources.⁴⁷ Factors like distance, limitation of traveling and even communicating with the family, and the epidemic controls imposed on traveling all contribute to increase the family's suffering and emotional trauma. In this context, prior and open communication with the family is recommended to explain clearly the reasons for the transfer, the patient's final destination, and the ways to keep in contact with the new facility (including a phone contact number).

Communicating with the family

The appearance of PICS-F has been related to ineffective communication between the health-care teams and the family, which naturally influences the family's perception and the experience during and after their relative has been in the ICU.⁴⁸ Lack of or inadequate information is related to the development of PTSD.⁴⁹ Adequate timely information and open communication with family members are essential aspects of the care in critically ill patients, especially on the occasions when the family takes the decision-making role on behalf of a patient who may not be able to do so on its own. In those instances, it is vital to provide information from the beginning and update the family regularly, especially when changes in the treatment are expected.

In the context of the pandemic, there are diverse activities that can be implemented to improve communication with the family: question and answer meetings, general information about the health-care process, a visit to the ICU to show the family what is actually done there (including interventions such as mechanical ventilation or tracheostomy),⁵⁰ information about PICS and its components such as delirium or the emotional response to being discharged from the ICU,⁵¹ and the setting of a system to send and receive texts, messages, and videos all with the goal to bring closer the family to their patient.

Synchronous communication refers to communication between the patient and his/her family or the family and the health-care team. Structured communication must be carried out proactively, daily and, in situations that demand it due to their severity. Families must know the established communication plan either in person or online to reduce the uncertainty and stress generated by waiting for a call. Communicating with the patient and the family includes not just getting clinical information about the patient but also serving as a form of therapy by providing assurance, comfort, and a measure of dignity. Moreover, it can help to get to know the patient better as an individual and to know his preferences to help the family to take the best decisions possible regarding the patient's therapy, particularly in complex situations. Also, it can help to set therapeutic goals based not only on the clinical progress of the patient but also on his preferences too.⁵²

During the pandemic, many initiatives have been promoted by different associations and by the health-care teams to bring families and patients closer using calls and videoconferencing.⁵³ The latter facilitates emotional ties through facial expressions and nonverbal communication. To achieve effective communication, the technology itself is not enough; specific training for health-care professionals to appropriately use the gadgets and guidelines to ensure their effectiveness are necessary.

End-of-life event

The end of life constitutes a traumatic event for families of patients who die during their stay in the ICU, particularly in those surrogates of patients who are incapable of taking their own decisions. The presence of the family and an adequate communication with the health-care team are essential, the more so in end-of-life care situations.¹⁶ There is evidence that families who cannot say farewell to a relative present a higher risk of complicated grief. At the end of life of a patient, the physical, psychological, emotional, and spiritual needs of the family must be addressed, informing them of the changes in care as the disease evolves and tailoring the treatment of the patient to his preferences and those of the family.

Family's accompaniment in moments like this constitute a right in which no person shall be deprived of his life. Consequently, restrictive policies must be flexible as much as possible, allowing the family to say their farewell. Of course, to facilitate these visits require appropriate PPE as well as to train and prepare the family and to

provide them with an adequate space that allows for intimacy and privacy. Whenever that is not possible, distance accompaniment by means of teleconferencing must be encouraged, always following the family's preferences. Honestly, open communication can help families⁵⁴ to understand better the death process and to deal and prevent pathological states of grief. Facilitating emotional support to the family by the mental health specialists can prevent psychological sequelae and ensure mental well-being. There are established recommendations and tools that help families and health-care professionals to deal with grief, including quality communication, advance planning and writing of a will, and self-care.⁵⁵

Conclusion

The restrictions imposed by the COVID-19 pandemic should not decrease the family-centered care. In fact, in these circumstances, care for the family has become even more relevant. The health-care system and its professionals must adapt the established strategies to the new circumstances to become innovative through the use of technology keeping humanization of care as a key element to offer the best possible care to patients and their families. All of this will yield better results in health care and will help to reduce the prevalence of PICS both in patients and their families.

Finally, these initiatives can also have a positive impact on the health-care professionals, decreasing emotional suffering, compassion fatigue, and burnout.

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