

## COVID-19 Intensive Care Unit: the emotional experience of family members

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### SUMMARY

#### Objective

This study describes the psychological counseling offered to family members of SARS-CoV-2 patients in an intensive care unit (ICU). The purpose of this study is to describe the emotional burden experienced by families, and describe the first contact and counseling services.

#### Methods

Family members of patients admitted to the IRCCS ISMETT COVID-19 ICU were contacted by telephone by the IRCCS ISMETT Clinical Psychology Service. After this first contact, the families who accepted the service were offered periodical counseling by the psychologists. The clinical psychological interview was used to manage and support their emotional burden. The stress thermometer was used as a tool to assess the stress experienced by the family members, who were followed by the psychology team until the patient was discharged or transferred to another hospital, or until his or her death. A follow-up telephone psychological counseling was planned six months after the patient's discharge.

#### Results

We contacted 60 family members of patients admitted to the IRCCS ISMETT COVID-19 ICU. Of these, 23 accepted the telephone psychological counseling. The level of perceived stress of family members was high ( $M 7 DS 1.6$ ). The main cause of distress was described as related to an emotional issue (fear, depression). Family members were encouraged to manage the emotional burden and supported at the time of the patient's discharge or death.

#### Conclusions

Our experience with telephone psychological counseling for family members of COVID-19 ICU patients highlights the emotional burden of families and the importance of this service. Our study encourages additional research on the post-traumatic sequelae of family members forced to deal at a distance with the hospitalization of a beloved one, and suggests the need for a patient- and family-centered model of care, even during a pandemic.

**Key words:** COVID-19 pandemic, psychological support, family members

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### Introduction

The importance of the family caregiver in the clinical setting has long been recognized for the fundamental role of supporting patients with complex clinical conditions and helping patients to adapt to their path of care. The patient-centered model of care<sup>1</sup> places not only the patient but also the family member at the center of care. The World Health Organization (WHO) encourages to keep family members constantly informed and involved in the patient care process, and recognizes their emotional burden and psychological needs<sup>2</sup>. Indeed, health systems are committed to identifying strategies to encourage and facilitate the active and participatory role of family members in the clinical management of the patient<sup>3-6</sup>. This applies in particular to family members of critically-ill patients admitted to the ICU.

ICU patients are often unconscious patients losing most of their communication skills. This forces family members to deal with a strong physical and emotional detachment that over time determines high levels of stress, leading them to experience forms of anticipatory mourning related to the prolonged absence of their loved one.

Family members of ICU patients often present psychological symptoms such as anxiety and depression that can lead to real traumatic experiences, recently described with PICS-F (Post Intensive Care Syndrome Family) <sup>7-12</sup>.

In the last several years, studies on the psychological sequelae of long-term ICU patients have been extended to include the emotional effects not only on patients, but also on their families. These considerations are intended to describe the variety of symptoms and disorders related to the critical clinical conditions of the loved one (Family Intensive Care Unit Syndrome) and to identify paths to support family members and prevent similar relapses <sup>13,14</sup>.

To this regard, attempts have been made to identify strategies for the care and active involvement of family members of patients admitted to the ICU <sup>15</sup>. Furthermore, recent scientific evidence associates a better adaptation of family members of ICU patients to an improved post-discharge patient management by family members during home care <sup>16</sup>.

One of the strategies to improve the emotional burden of family members is attention to communication <sup>12,17-19</sup>. The advent of the SARS-CoV-2 pandemic and social distancing and isolation regulations, have further complicated the emotional burden of relatives of critically-ill ICU patients. Furthermore, the spread of COVID-19 and the severe respiratory complications reported by some patients who contracted the virus, forced many hospitals to open dedicated intensive care units for critical COVID-19 patients. The traumatic experience and the psychological repercussions of this new patient population is the subject of many studies that increasingly extend the range of observation to include family members. In particular, families of patients admitted to a COVID-19 ICU experience the strong emotional distress associated with the critical clinical condition of their loved one, amplified by the social resonance of the COVID-19 infection. Also, these family members have no physical contact with the patient or with the hospital, resulting in an experience of loneliness/abandonment that contributes to worsening their emotional burden <sup>20-22</sup>.

This study describes the psychological support provided to a group of family members of COVID-19 ICU patients. In addition to describing the emotional experience of these family members, our goal was also to describe the attempt to maintain a model of care centered on patients

and their families, even during the SARS-CoV-2 pandemic and with a particular complex patient population.

## Methods and tools

Since October 2020, part of ISMETT's intensive care unit has been reorganized to treat patients with severe complications from SARS-CoV-2 infection. The data in this study refer to patients admitted to ISMETT's COVID-19 ICU between October 20, 2020 and February 2, 2021. During this time, the patients who required intensive care were 62 (10 females and 52 males).

Upon their admission in the COVID-19 ICU, these patients' clinical conditions were severe and most of them required intubation and deep sedation.

In addition to managing the COVID-19 patients, the entire clinical staff focused on communication with the families to create a feeling of trust and support, acknowledging their emotional burden.

In this context, the ISMETT Clinical Psychology Service activated a telephone counseling service for family members of COVID-19 ICU patients.

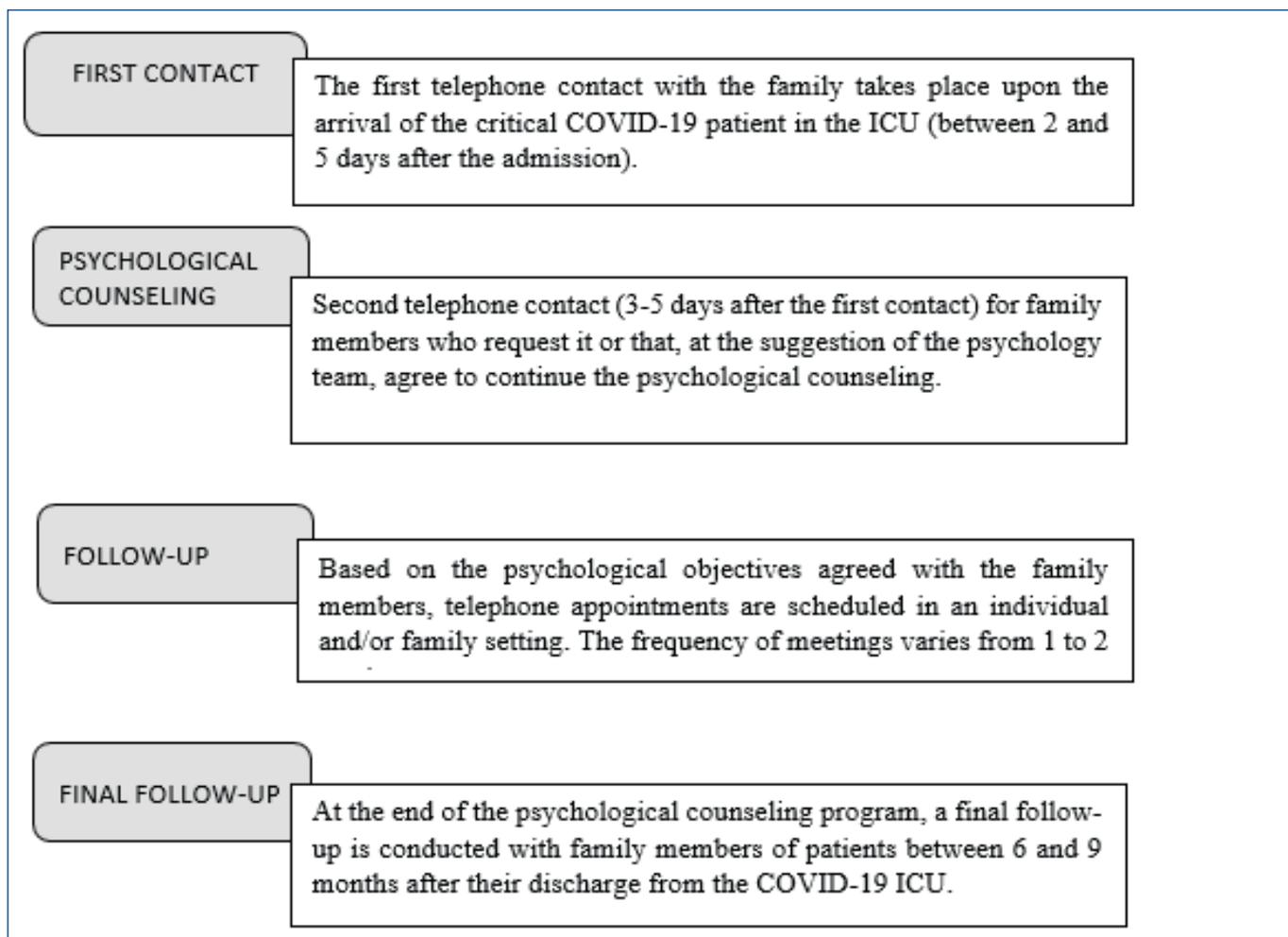
The Psychological Counseling Service was organized as follows (Fig. 1):

After COVID-19 patients were admitted to the ICU, the caregivers were contacted by the ISMETT psychologists. The purpose of this initial meeting was to contain the emotional burden of the family member and illustrate the telephone counseling service.

After the first contact, and based on the emotional needs of the family, follow-up telephone psychological counseling was initiated. The goal of telephone counseling was to assess the emotional burden of the family member (through a clinical interview and periodic administration of the stress thermometer) and provide strategies to contain and manage the emotional burden. Families were followed by the Psychology Service until their loved one was discharged from the hospital.

Six months after discharge, a psychological follow-up was arranged in a family setting, to assess the potential conditions of psychological distress.

One of the psychologists' tasks with family members was to support them in the process of caring for the critically-ill patients and helping them deal with the patient's clinical complexity. After the initial moment of shock and anger <sup>23</sup>, family members had to face the prolonged emergency condition and the physical absence of the family member, while trying to readjust, albeit temporarily, to their normal everyday life (work, school, etc.). A form of pre-loss bereavement was identified in a significant number of family members, which in some cases lasted for weeks or even months <sup>24</sup>. This condition is understandably related to high stress levels linked to prolonged alert levels.



**FIGURE 1.** Psychological counseling with family members of COVID-19 ICU patients.

### Tools

The main tool was the clinical interview in the context of psychological support and emotional containment.

The psychological interview is a critical evaluation procedure commonly used in mental health practice that involves, through the creation of a favorable relational context, collecting and using the necessary information for diagnosis and treatment<sup>25</sup>.

During the telephone counseling, unstructured psychological interviews were conducted to create a relationship of trust and functional emotional contact, contain and manage the family's emotional burden, and provide benefits in terms of emotional expression and catharsis. The Emotional Distress Thermometer<sup>26-28</sup> was administered for a quick evaluation of emotional distress. This is a single item stress detection tool that uses a Likert scale from 0 (no perception of stress) to 10 (extreme distress). Patients assess their emotional distress over the past week. The tool identifies a threshold value of

4 which represents an important and significant level of stress perceived by the patient<sup>29-31</sup>. The tool proved beneficial for the setting and the particular type of users described in our work.

Furthermore, the Emotional Distress Thermometer includes a list of 39 factors that represent the significant sources of stress perceived by the patient.

### Results

Between October 2020 and February 2021, the ISMETT Psychology Service contacted 60 family members of COVID-19 ICU patients. Patients admitted during this timeframe had an average age of 54 years (10 females and 50 males). At the time of writing the article, 21 deaths and 15 transfers to post-COVID-19 rehabilitation facilities were reported in the initial group. Out of all the contacted family members, 23 were followed by periodic telephone interviews for psychological coun-

seling. The 23 relatives that received counseling were 15 spouses (13 wives and 2 husbands), 5 sons, 1 brother and 1 daughter-in-law. Overall, 86 psychological interviews were conducted. Of the family members who received counseling, 9 had to deal with the death of their loved one in the ICU and 14 experienced a gradual improvement of the patient until discharge from hospital or transfer to another non-intensive care unit. The mean level of emotional distress detected with the stress thermometer was severe stress ( $7 \pm 1.6$ ). The area most affected was emotional problems: 21 family members indicated emotional problems as the cause of the discomfort and specifically all of them checked the "Fear" box, three also checked "Nervousness", and two "Depression". The relational problem was indicated as the main cause of discomfort for two family members both describing relationship problems with children. Follow-up data at six months after hospital discharge are not yet available.

## Discussion

This study attempted to describe the emotional context of a group of family members facing the painful therapeutic path of their loved ones, hospitalized in an intensive care unit due to the SARS-CoV-2 infection. The 60 family members contacted by telephone reported a strong emotional distress experienced due to apprehension about the clinical conditions of their loved one and their difficulty tolerating the physical and emotional distance from the patient. A number of family members (23) agreed to receive the telephone psychological counseling service. The initial counseling interviews revealed the strong emotional burden experienced by the family members. The feeling of physical and emotional distance encouraged feelings of strong helplessness inducing negative thoughts of a catastrophic type. Some of the comments most commonly voiced during the first interviews were: *"Every time the phone rings, I imagine the doctor's voice telling me my husband is dead"*, *"Every night I suddenly wake up after dreaming my husband is dead and that I'm not there [with him]"*. Others described the difficulty coping with the absence, although temporary, of a family member, *"My husband has always been the one taking care of family matters, and now I'll have to manage my work, bills and children on my own"*.

This condition was confirmed by data that emerged after administering the stress thermometer, the perceived stress level was described as severe (M7 DS) and 21 families identified emotional problems as the only strong source of distress.

Some families had to face a real bereavement, due to the worsening of the clinical conditions of the COVID-19 patient, and death in the ICU (9 patients). The death of

a family member in an intensive care unit increases the risk of developing post-bereavement depression, causing the family member to imagine an indecorous end of life for their loved one, and this leads to worsening the bereavement processing<sup>32-36</sup>.

The other family members (14) received counseling during the difficult path of care of the COVID-19 patient, daily waiting for news and fearing for a sudden worsening of the patient's conditions until discharge from the ICU.

The availability and motivation of family members to rely on telephone counseling confirmed their need to have their emotional needs recognized and receive psychological tools to help them adapt to the complex and critical clinical conditions of their loved ones, and to be encouraged with respect to their resilience<sup>36</sup>. The attention paid to a group of family members of very critically ill patients at IRCCS ISMETT also showed how patient and family centered care can be maintained despite the pandemic and rigid isolation and social distancing measures<sup>37</sup>. Furthermore, the new model of family counseling using other communication media such as the telephone can represent an innovation that can also be implemented in other post-pandemic contexts.

Our experience of psychological support to family members of COVID-19 patients aims to help encourage new models of patient and family-centered models of care for critical patients<sup>38</sup>.

Follow-up data at six months after hospital discharge are not yet available.

## Limitations of the study

The reduced reference sample makes it difficult to generalize the data described in our study. Furthermore, follow-up data at 6 months from discharge from the COVID-19 ICU has not yet been collected and processed. This data could provide interesting results in terms of long-term psychological reaction of the patients' families.

## Conclusions

The traumatic experience suffered by relatives of COVID-19 ICU patients is another aspect of the dramatic nature of the pandemic. This goal of this study is to represent and describe a further element of the complex clinical history of the SARS-CoV-2 pandemic, focusing on and recognizing the emotional distress experienced by family members of COVID-19 patients. In addition to the psychological and psychiatric outcomes of COVID-19 patients subject to a prolonged ICU stay, future research will be required to study the post-traumatic sequelae experienced by family members during the hospitalization of their loved one<sup>39</sup> and

to develop management plans for their emotional burden.

Finally, our work aims at offering an example of patient- and family-centered care attempted despite the constraints imposed by the isolation and distancing measures imposed by the SARS-CoV-2 pandemic, especially within a hospital setting.

#### Ethical consideration

None.

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#### Conflict of interest

The Authors declare no conflict of interest.

#### Author contributions

The Authors have contributed equally to the work.

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