Fighting a family tragedy: family-centred care in times of the COVID-19 pandemic

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Dear Editor,

The COVID-19 pandemic poses unprecedented challenges to intensive care medicine worldwide. Anticipating a mass casualty imposed by COVID-19, intensive care unit (ICU) resources have been increased considerably. Unfortunately, despite great efforts, and even if the best individual medical care can be provided, long-term hospitalisation, disability, and death cannot be prevented with certainty. This situation poses particular emotional challenges for relatives of patients affected by COVID-19.

The post-intensive care syndromefamily (PICS-F) was proposed to refer to acute or chronic psychological effects on the relatives of ICU patients [1]. Uncertainty about the patients' future, the course of illness, his/her survival, and the unfamiliar environment of an ICU may have an impact on the relatives' psychological conditions (e.g. anxiety, stress, depression, sleep disturbances). In fact, family members may show a high prevalence of anxiety, depression, and posttraumatic stress disorder (PTSD) [2]. In the pre-COV-ID-19 era, family-centred care concepts were used to address PICS-F (Table 1) [3]. Currently, the burden among relatives of ICU patients may be high, with the current situation posing new challenges for family-centred care.

Dedicated communication is regarded as a key concept of family-centred care and a cornerstone for PICS-F prevention [4]. During the COVID-19 pandemic, face-to-face communication with family members in the ICU is scarce. Thus, building a trusting re-

lationship with the ICU team may be difficult. Visiting restrictions and the enormous workload among ICU staff further limits the ability to provide sufficient communication and information to relatives [5]. Therefore, opportunities for relatives to address needs, to take part in decision-making, and to receive support measures (family care concepts, spiritual support, social worker) are often limited, which may support the development of PICS-F [3]. Additionally, reduced family presence and caregiving at the bedside due to restricted visiting hours may worsen PICS-F [3]. In cases of dying patients, end-of-life conferences and support of the dying can often not be facilitated, which may augment PICS-F [3].

In light of available guidelines for family-centred care in the ICU, it must be noted that several of these concepts may not be feasible during the COVID-19 pandemic (Table 1) [4]. Hence, novel unconventional strategies should be implemented that enable family-centred care concepts. Proposed cornerstones are 1) providing adequate information/communication, 2) family support, 3) family presence in the ICU and, 4) use of specific consultations [4].

Providing dedicated information and communication is key in family-centred care [4]. For example, conventional telephone calls may help to provide timely information to relatives. Moreover, arranging appointments for telephone calls may help relatives to establish routines and a daily structure. Structured telephone calls according to checklists and/or com-

Anaesthesiol Intensive Ther 2020; 52, 4: 336–338

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TABLE 1. Intensive care unit (ICU) family-centred care in pre-COVID-19 and COVID-19 pandemic

ICU family-centred care concept	Pre-COVID-19 pandemic	COVID-19 pandemic
Communication		
Face-to-face communication	+	_
Structured communication (VALUE mnemonic)	+	+
Family conferences	+	(-)
End-of-life conference	+	(-)
Telephone calls*	+	+
Family video conference*	+	+
Videotelephony*	+	+
Family support		
Peer-to-peer support	+	(-)
Family education programs (videos, brochures)	+	+
Information leaflets	+	+
Patient-diaries by ICU-staff	+	_
Family-authored diaries	+	+
Family presence		
Flexible family presence at the bedside	+	_
Participating in team rounds	+	_
Option of being present during resuscitation	+	_
Special consultations		
Social worker	+	(-)
Psychologists	+	(-)
Family care specialists support	+	(-)
Family navigators (e.g. communication facilitator)	+	(-)
Spiritual support from spiritual advisor or chaplain	+	(-)

Adapted to Guidelines for family-centred care in the Neonatal, Paediatric, and Adult ICU [4]

munication guidelines may enhance effectiveness. Using videoconferences/videotelephony can enable ICU staff to recognise concerns of relatives and to address them adequately.

Family support as a second cornerstone of family-centred care needs to be adapted to the current COVID-19 pandemic [4]. Specific family-oriented educational programs for relatives may be provided [6–8]. However, such educational programs or interventions to reduce PICS-F should be questioned critically and applied with appropriate caution [9]. Videos, leaflets, brochures, web sites, or web-based chat forums can provide general information about critical care during the COVID-19 pandemic. Pre-filmed virtual tours of the ICU may help rela-

tives to familiarise themselves with the specific ICU setting. Diaries written by the ICU-team for patients are regarded as an established family-centred care concept. However, the opportunity for relatives to read respective diaries in a timely manner may not currently be feasible. Instead, family-authored diaries could be implemented. This might support coping strategies through a reflective writing process. Peer-to-peer chat for relatives may also allow for sharing of experiences and thoughts.

The third cornerstone of family-centred care is family presence [4]. Due to restricted visiting regulations, family presence in the ICU is often not feasible during the COVID-19 pandemic. Alternatively, videotelephony

with handheld mobile devices might be used to visualise ICU settings and patients to relatives. However, it seems particularly important to ensure that visualisation take place according to the specific needs of relatives (who are usually unfamiliar with an ICU setting). In any case, relatives should be able to ask questions and address their own anxiety, uncertainty, and worries.

Fourth, use of specific consultations should still be possible [4]. Support by social workers, psychologists, chaplains, family care nurses, or family navigators can be provided by telephone calls, videotelephony, videoconferences, or emails. Individual coping strategies could be explained and mediated, as required.

Provision of family-centred care in times of the COVID-19 pandemic seems to be a challenging task for all ICU professionals, especially, when the pandemic has a large impact on the psychological conditions of ICU professionals [10]. Here, prevention and psychological coping strategies should be provided. Further, structured coordination of human resources in and outside of the ICU seems paramount to cope with the increased workload. In this challenging and unprecedented situation, fighting against PICS-F requires the best efforts of all team members.

ACKNOWLEDGMENTS

- 1. Assistance with the article: none.
- 2. Financial support and sponsorship: none.
- 3. Conflicts of interest: The Department of Intensive Care Medicine has or has had in the past research & development/consulting contracts with Edwards Lifesciences Services GmbH, Phagenesis Limited, and Nestlé. The money was paid into a departmental fund, and none of the authors received any financial gain. The Department of Intensive Care Medicine has received in the past unrestricted educational grants from the following organisations for organising bi-annual postgraduate courses in the fields of critical care ultrasound, management of ECMO

⁺ concept widely applicable, - concept challenging to apply, parentheses refer to concepts, which could be technically adapted (telephone calls, video telephony/conferences)

 $VALUE\ mnemonic-value\ comments\ made\ by\ family,\ acknowledgement\ family\ emotions,\ listen,\ understand\ the\ patient,\ elicit\ family\ questions$

^{*} Use of alternative communication media should be adapted to specific requirements in accordance with local data protection regulations

and mechanical ventilation: Pierre Fabre Pharma AG (formerly known as RobaPharm), Pfizer AG, Bard Medica S.A., Abbott AG, Anandic Medical Systems, PanGas AG Healthcare, Orion Pharma, Bracco, Edwards Lifesciences AG, Hamilton Medical AG, Fresenius Kabi (Schweiz) AG, Getinge Group Maquet AG, Dräger Schweiz AG, Teleflex Medical GmbH.

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