



## **Guideline for Family Oriented Care in Burns Intensive Care Centres in Europe**

### **PAM Section**

This guideline is aimed to inform all health care workers, teams and departments working with **adults** in Burns Intensive Care Units (B-ICU).

Limitations of the Guideline: Literature especially about families of adult patients with burns is rare; therefore literature about families of ICU patients in general is included in this Guideline. There are very few scientific papers to be found in the literature such as randomized and controlled clinical trials that meets the highest evidence.

In this section, 3 main questions are asked:

1. How can family needs be met by the B-ICU team in the acute phase immediately after a burn injury?
2. How can a successful cooperation with the family be established throughout the entire hospital stay?
3. Which instrument can be used to identify the aspects of quality care for patients and their family members in European burn centres?

# 1. How can family needs be met by the B-ICU team in the acute phase right after a burn injury?

a) *Possibility to be with the patient*

## Recommendations

- We suggest facilitating family presence and involvement in their relative's care in the ICU (6,7,12)
- We suggest to provide waiting rooms where families can withdraw and recover (6,12,14)

## Rationale:

Families state a strong desire to be at the bedside to see their relative's condition and to understand the complexity of the injury (7, 12).

Whereas the relationship between ICU health care workers and the patient is significantly marked by technical procedures and medical specialities, the family members initially lack knowledge for proper decision-making, are struck by emotional reactions – in different intensities and modalities of expression - and have to cope with various losses, both material and human. These and other factors must be addressed at the admission.

b) *Oral information*

## Recommendations

- We suggest updating the family daily about the treatment plan and the current status of their relative and giving the opportunity of additional information when needed
- We recommend informing the family members about general treatment of burns and about the specific situation of the patient (1,2,3,4,5,6,7,8)
- We suggest to define the roles and timing in the information process
- We suggest routine interdisciplinary family conferences to be used in the ICU (2,12)
- We recommend to give the opportunity of professional support (5,6,7,12)
- We suggest documenting the given or lacking information in the patients file

## Rationale

A severe burn injury is a distressing experience not only for the injured person but also for the family members. It leads to an -often serious- change of appearance and a long stay at the ICU with recurring critical situations. Family centred care has gradually been established as a concept also for critical care during the last decades. In family centred care family members participate in care, in information sharing and most importantly in the decision making process at the level that they choose often on behalf of the patient (1). This process might take several months and the

relationship between all parties lays the foundation for a successful cooperation throughout this period of time.

Information should be consistent, honest and understandable for family members, regarding patient progress or predicted outcome. Especially in the initial stage families do not retain information or have the ability to readily interpret information. Repetition of information is crucial for the understanding. Additionally use of images and written material can help the family to refer to in their own time (7).

Interdisciplinary family conferences improve family satisfaction with communication and reduce conflict between family members and clinicians (2, 3).

Healthcare clinicians in the ICU should use structured approaches when engaging in communication with family members, grounded in modern decision theory, to address both the affective and the cognitive challenges that are encountered by surrogate decision makers (3, 4).

#### *c) Written information*

#### **Recommendations**

- We suggest providing leaflets with information about the ICU unit and general treatment of burns (2,6)

#### **Rationale**

Leaflets with information about the ICU setting and general treatment of burns reduce family members` anxiety and stress (2).

## **2. How can a successful cooperation with the family be established throughout the entire hospital stay?**

#### *a) Multiprofessional treatment teams*

#### **Recommendations:**

- We suggest psychologists and social workers as integral parts of the treatment team (3,15)
- We suggest proactive Ethics and Palliative Care consultations (12)

#### **Rationale:**

Families of burn survivors show high levels of psychological distress. Psychological support and guidance to family members can in turn provide effective support to the burn survivors (15).

Proactive palliative care consultation and ethics consultation be provided to decrease ICU and hospital length of stay among critically ill patients for whom there is a value-related conflict between clinicians and family (12).

The adequate consideration of psychological and social needs of the family translates directly into the quality of care that the admitted patient receives.

*b) Support in self-care*

**Recommendations:**

- We recommend ICU diaries to be implemented (6, 9, 10)
- We suggest encouraging family-to-family support and networking by support groups by families of former patients (11, 13)

**Rationale:**

Communication through diaries has been shown to help reduce patients' memory gaps and distorted thoughts regarding their ICU stay. Diaries have been shown to improve psychological outcomes in both patients and families (9). ICU diaries can help to build trust with the family members (9). In a systematic review of randomized and controlled clinical trials, family members reported fewer post-traumatic stress symptoms when they received an ICU diary (9).

Support groups by families of former patients can increase communication about what to expect during or after a patient's ICU stay (11). As survivors and their caregivers have first-hand experience of the challenges that survivors face, they are well suited to educate and prepare peer survivors for certain aspects of the recovery process (13).

*c) Planning of transition*

**Recommendations:**

- We suggest to inform the family early about the plan to transfer the patient to the general ward (16)

**Rationale:**

Relocation from the ICU to the general ward is associated with a big change in care. Leaving the familiar environment and over the time well known caregivers can result into a stressful experience during the recovery phase. Informing the family members in time and organizing a visit to the department and a meeting with members of the future treatment team can help to reduce anxiety and mistrust.

### **3. Which instrument can be used to identify the aspects of quality care for patients and their family members in European burn centres?**

#### **Recommendations:**

- We recommend using instruments to measure the needs of families and the quality and quantity of their supply by team members, for example the Family Satisfaction-Intensive Care Unit questionnaire (FS-ICU) (14)

#### **Rationale:**

The current literature, although not abundant, has added interventions with the patients' social network to the individual care.

Due to the intense emotional impact of accompanying a family member admitted to the ICU, health professionals seek to prevent reactions specially, those who have been identified after hospital discharge. Among them, one known as PICS-F, "Post intensive care syndrome-family", which describes psychological morbidity in members of the patients family and decline in their quality of life. PICS-F refers to the acute and the chronic psychological effects of critical illness on the family of the patient and includes the symptoms that are experienced by family members during the critical illness as well as those that occur following death or discharge of a loved one from the ICU.

The use of instruments to measure the needs of families and the quality and quantity of their supply by team members, facilitate identified and improve them. The most widespread in use and validated in several languages is the FS-ICU. This questionnaire in the newest version FS-ICU-24, facilitate to identify family satisfaction with care in the ICU (14, 17).

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