

# Familienzentrierte Pflege bei Langzeitkindern auf der Intensivstation

## Soins centrés sur la famille & les patients long séjour aux soins intensifs

23.10.2018

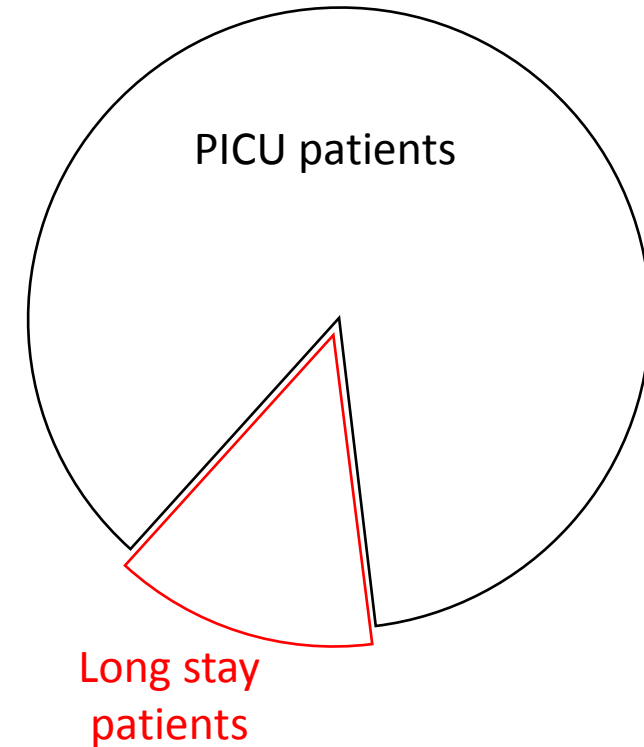
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Department Woman-Mother-Child  
Institute of Higher Education and Research in Healthcare-IUFRS  
Lausanne University Hospital, University of Lausanne

# Objectives of the presentation

- What is Family-centered care in Pediatric intensive care unit (PICU) ?
- What should be Family-centered care in PICU long stay patients and families ?

The OCToPuS study



# Family-centered care in Pediatrics

## ANTECEDENTS

Family **presence**

Family **willingness** to collaborate & participate

Nurse **competency** and willingness to negotiate care

Sufficient **time** for communication and development of family-nurse partnerships

**Environment** conducive to family presence and participation

## CHARACTERISTICS



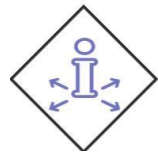
**Respect** for unique family characteristics



**Support** provided to patients and family



**Family participation** in care at their level of comfort



Open **communication**



Nurse-family **partnerships**



**Cultural** competence and appreciation

## CONSEQUENCES



**Individualized flexible** care

Family **comfort and confidence**

Family-provider **communication**

Family **adaptation and function**

Family **satisfaction**

Family **empowerment**

# Family-centered care in PICU

## FCC in PICU is fundamental, **because...**

- Family intensive care unit syndrome (FICUS), post-intensive care syndrome (PICS-F)
  - General stress: 25-31%
  - Acute stress disorder: 49-54%
  - Post-traumatic stress disorder (PTSD): 12-68%
  - Depression: 15-27%
- ↓ Psychological health outcomes of families == ↓ family functioning == ↓ child's recovery
  - Risk of the child's PTSD development significantly higher
    - maternal & paternal PTSD
    - low social and parental support & poor family functioning

Netzer and Sullivan, 2014; Davidson et al., 2012; Colville et al., 2012; Muscara et al., 2015; Woolf et al., 2016; Kolaitis et al., 2011; Trickey et al., 2012

## **... but observation of a poor implementation**

- Specific nursing focus on the child
- Short PICU lengths of stay
- Unstable, unpredictable medical conditions == Challenging relationships
- Traditionally limited family visitations
- Clinicians barriers to FCC practices: negotiation, involvement in direct care

Hill et al., 2018; Richards et al., 2017; Butler et al., 2013



# Family-centered care in PICU: Evidence-based recommendations



## COMMUNICATION

- Routine interdisciplinary family conferences
- Standardized communication techniques
- Caregivers' training

## PARTNERSHIPS

### ENVIRONMENT & FUNCTIONING

- Standardized protocols of sedation & analgesia
- Noise reduction - family sleep - hygiene
- Nurses' involvement in multidisciplinary decision-making
- Hospitals' implementation of FCC policies

### SPECIFIC CONSULTATIONS

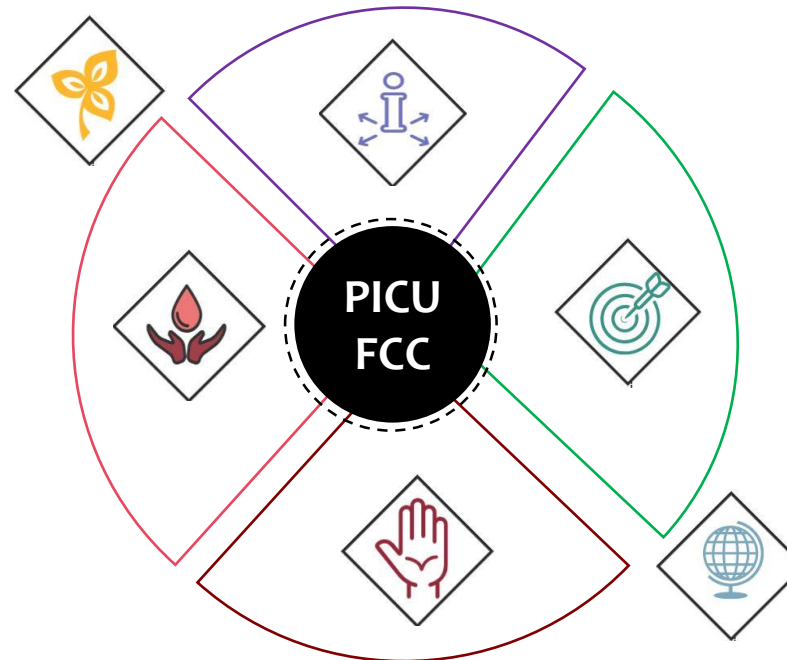
- Proactive palliative care consultation
- Ethics consultation
- Spiritual support
- Psychologist's intervention
- Social workers
- Family navigators

## SUPPORT

- Education in care participation
- Written informations about the ICU environment
- ICU diaries
- Tools to support decision-making
- Peer-to-peer support

## PARTICIPATION

- Open flexible family presence at the bedside
- Family visitations policy
- Family presence: invasive procedures & CPR
- Participation in interdisciplinary team rounds





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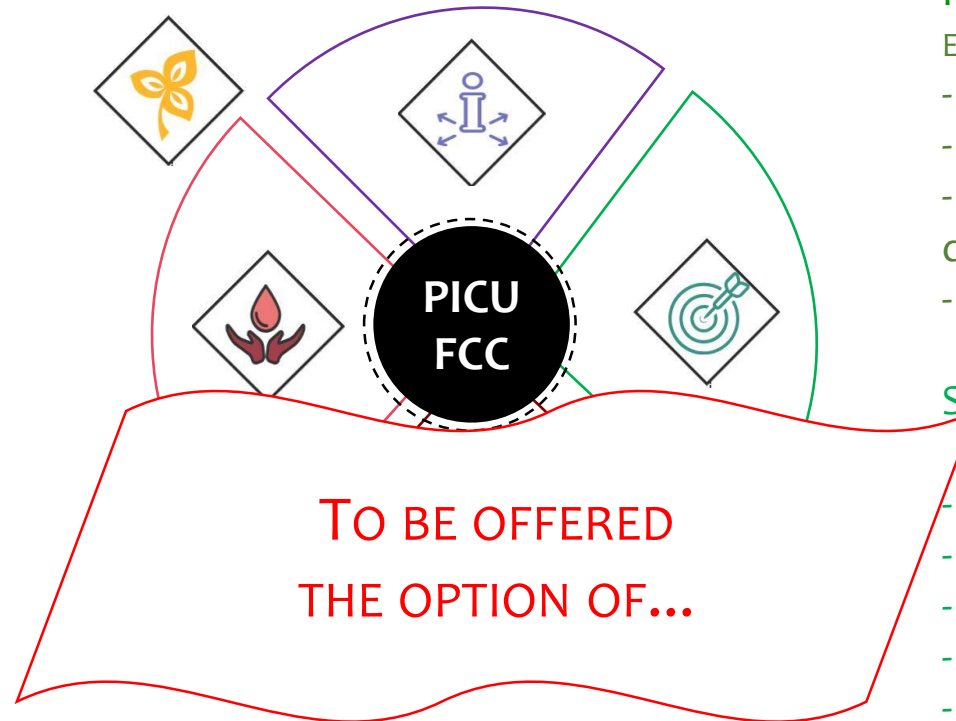
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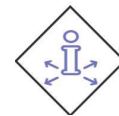
# Family-centered care in PICU: Outcomes

## Child & Family

Child-parents relationship  
Family experiences  
Medical comprehension  
Confidence and competence  
Satisfaction with care

## Child & Family

Psychological outcomes  
Family decisional conflict  
Length of PICU & hospital stay



## Family-Professionals

Quality of clinician-family communication  
Partnership

## Family-Professionals

Conflict between clinicians and family members

## Professionals


Support for staff

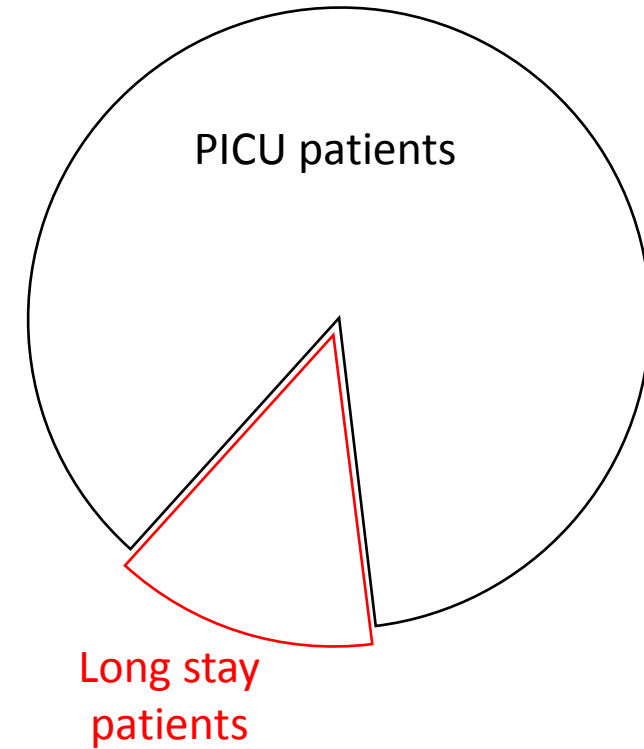
## Professionals

Moral distress & burnout

# Objectives of the presentation

- What should be Family-centered care in PICU long stay patients and families ?

The OCToPuS study 





# DEFINITION

## PICU LONG-STAY => CHRONIC CRITICAL ILLNESS (CCI)

Long stay PICU hospitalization ( $\geq 14$  days)  
**OR** Repeated acute hospitalization ( $\geq 2x$  /year)

**AND** Ongoing dependence on technology

Shapiro et al., 2017



Initial acute illness



Acute decline of chronic conditions

8-10%

Prevalence



19-63%

PICU bed  
occupancy



15-18%

Mortality rate



43-68%

Impaired QoL



# CCI IMPACT ON FAMILIES & TEAMS



## PICU FAMILIES

Family intensive care unit syndrome (FICUS)

Post-intensive care syndrome (PICS-F)

Netzer and Sullivan, 2014; Colville et al., 2012



## Families with CCI children

Lack of care continuity & coordination

Individualized care not respected

Critical period of PICU discharge

Geoghegan et al., 2016a; Henderson et al., 2017



## PICU TEAMS

Moral distress: 48-58%

Burnout: 22%

Larson et al., 2017; Fumis et al., 2017



## PICU teams when caring CCI patients & families

Lack of sense of accomplishment & achievement

Feel unprepared to care for this population

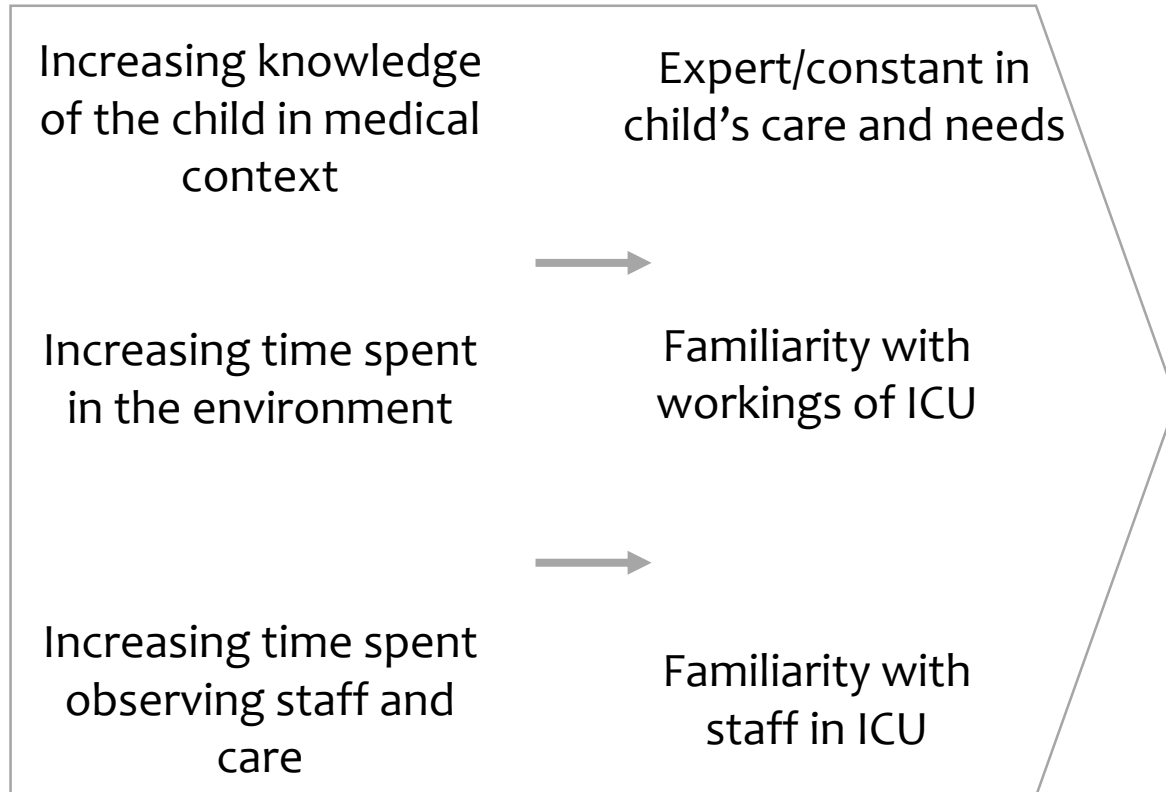
Experience families-team & intrateam conflicts

Geoghegan et al., 2016b; Donohue et al., 2018

# CCI FAMILIES PROCESS TROUGHTOUT PICU LONG STAY HOSPITALIZATION



## PARENTS PROCESS



## PARENT/STAFF INTERFACE

Parents seek greater involvement with care

Parents want individualised care

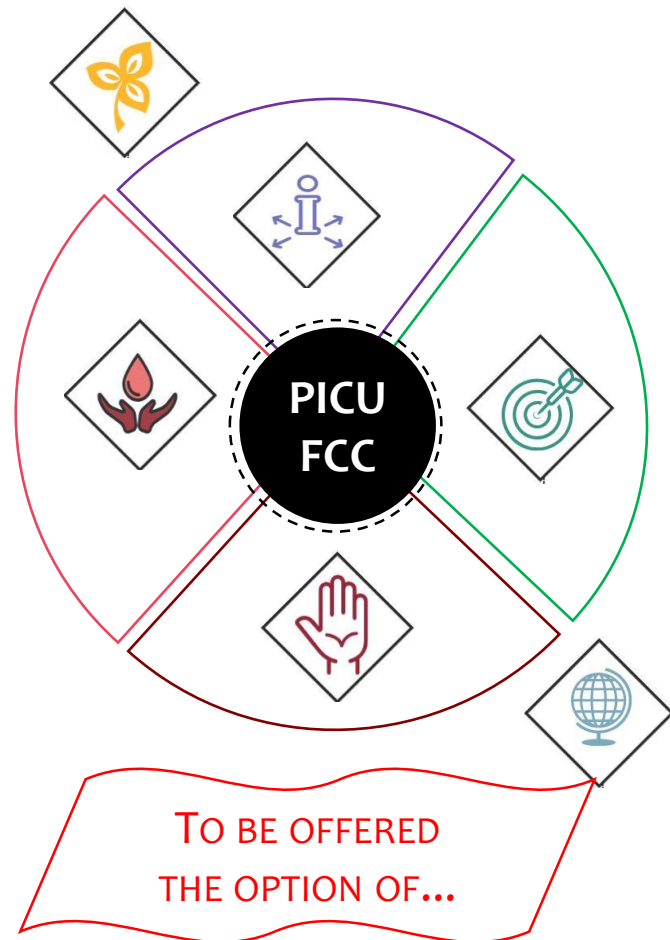
Disagreement/conflict with care providers

Difficult transitioning out of ICU

## STAFF

STAFF-LED MECHANISMS FOR PROVIDING SUPPORT

# Family-centered care with CCI patients & families



- Lack of knowledge on Swiss CCI patients, families and PICU teams
- Low level of evidence

# ChrOnic CriTical illness in Pediatric intenSive care - the OCToPuS study



## RESEARCH TEAM

Chantal **Grandjean**, PICU cert. nurse, PhD candidate  
Dr Maria-Helena **Perez**, MD, Head of PICU, co-investigator  
Marie-Christine **Fazan**, Head nurse of PICU, co-investigator  
Prof Anne-Sylvie **Ramelet**, Full professor and Thesis main supervisor

## MAIN AIMS

- 1) To have a comprehensive understanding of the **care of CCI children** hospitalized in Swiss PICUs
- 2) To measure the **impact of CCI hospitalization** on families over time

# METHODS



Care characteristics  
Resource utilization  
Long term outcomes



Barriers & facilitators



PICU stressors  
Family functioning  
Unmet needs

## DESIGN

Retrospective

Cross-sectional

Longitudinal

D4 D14 D30 Monthly until discharge



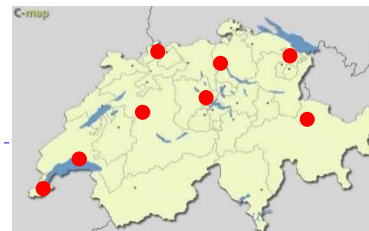
## POPULATION

All Swiss PICU patients  
2014 to 2017

Nurses  
Nurse assistants  
Physicians  
Physiotherapists

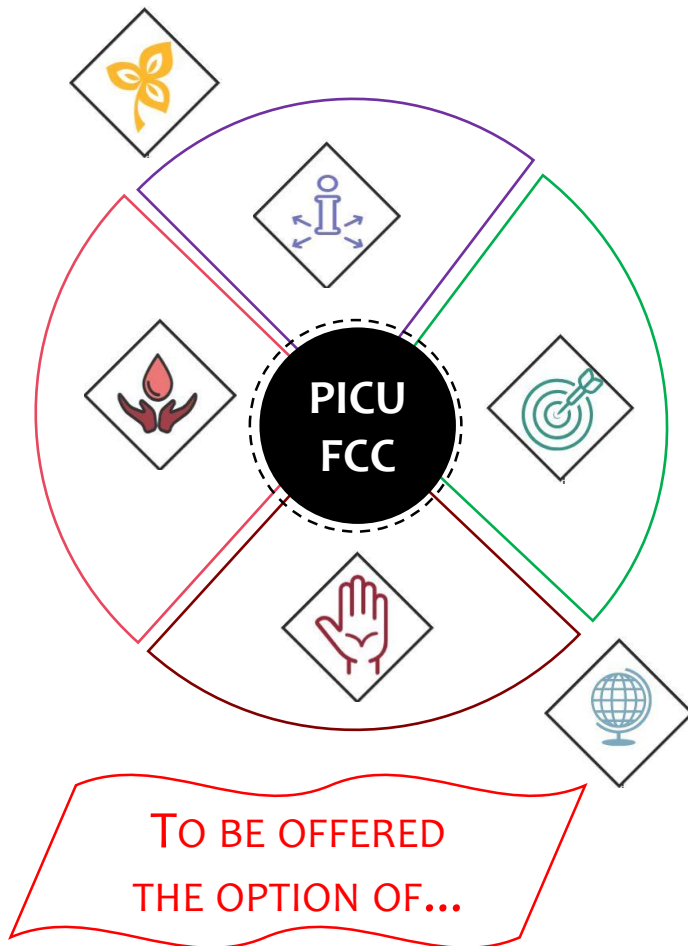
Family members of CCI patients

## SETTINGS



8 PICUs





## OCToPUS STUDY - EXPECTED OUTCOMES

Inform on the need to develop a family-centered care intervention to support CCI patients and their families

