Familienzentrierte Pflege bei Langzeitkindern auf der Intensivstation

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

23.10.2018

Chantal Grandjean, PhD candidate
Scientific collaborator, PICU cert. Nurse

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

adapted from Smith, 2018
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 == ↓ childs’ 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

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

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

Davidson et al., 2017
Family-centered care in PICU: Evidence-based recommendations

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

**COMMUNICATION**
- Routine interdisciplinary family conferences
- Standardized communication techniques
- Caregivers’ training

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

**TO BE OFFERED**
**THE OPTION OF...**

**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

Davidson et al., 2017
Family-centered care in PICU: Outcomes

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

Family-Professionals
Quality of clinician-family communication
Partnership

Professionals
Support for staff

Child & Family
Psychological outcomes
Family decisional conflict
Length of PICU & hospital stay

Family-Professionals
Conflict between clinicians and family members

Professionals
Moral distress & burnout

Davidson et al., 2017; Curtis et al., 2016
Objectives of the presentation

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

   The OCToPuS study
**PICU long-stay => Chronic Critical Illness (CCI)**

Long stay PICU hospitalization (≥ 14 days)  
**OR** Repeated acute hospitalization (≥2x /year)  
**AND** Ongoing dependence on technology

Shapiro et al., 2017

- **Prevalence**: 8-10%
- **PICU bed occupancy**: 19-63%
- **Mortality rate**: 15-18%
- **Impaired QoL**: 43-68%

Initial acute illness

Acute decline of chronic conditions

Marcin et al., 2001; Colon et al., 2009; Naghib et al., 2010; Namachivayam et al, 2012; Namachivayam et al., 2015; Chan et al., 2016
**CCI IMPACT ON FAMILIES & TEAMS**

**PICU FAMILIES**
- Family intensive care unit syndrome (FICUS)
- Post-intensive care syndrome (PICS-F)

- Lack of care continuity & coordination
- Individualized care not respected
- Critical period of PICU discharge

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

**Families with CCI children**

- Lack of sense of accomplishment & achievement
- Feel unprepared to care for this population
- Experience families-team & intrateam conflicts

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
THROUGHOUT PICU LONG STAY HOSPITALIZATION

PARENTS PROCESS

ACUTE

Increasing knowledge of the child in medical context

ADJUSTEMENT

Increasing time spent in the environment

NORMALISATION «INSTITUTIONALISATION»

Increasing time spent observing staff and care

PARENT/STAFF INTERFACE

Parents seek greater involvement with care

STAFF

Parents want individualised care

STAFF-LED MECHANISMS FOR PROVIDING SUPPORT

Disagreement/conflict with care providers

Difficult transitioning out of ICU

adapted from Geoghegan et al., 2016
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

<table>
<thead>
<tr>
<th>Design</th>
<th>Care characteristics</th>
<th>Barriers &amp; facilitators</th>
<th>PICU stressors</th>
</tr>
</thead>
<tbody>
<tr>
<td>Retrospective</td>
<td>Resource utilization</td>
<td></td>
<td>Family functioning</td>
</tr>
<tr>
<td></td>
<td>Long term outcomes</td>
<td></td>
<td>Unmet needs</td>
</tr>
<tr>
<td>Cross-sectional</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

POPULATION

- All Swiss PICU patients 2014 to 2017
- Nurses
- Nurse assistants
- Physicians
- Physiotherapists
- Family members of CCI patients

SETTINGS

- 8 PICUs
- Monthly until discharge
Family-centered care with CCI patients & families

**OCToPuS STUDY - EXPECTED OUTCOMES**

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

Chantal.grandjean@chuv.ch