ENDURING AMBIVALENCE

PREPARE – DEVELOPMENT OF AN ADVANCE CARE PLANNING INTERVENTION IN PEDIATRIC PALLIATIVE CARE

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I DO NOT HAVE ANY CONFLICTS OF INTEREST TO DECLARE
PACP – TRANSFER OF AN ADULT CONCEPT (1)

Why is ACP relevant in pediatrics:

- Parents are not always available in a medical crisis
- Difficulty to raise EOL issues in acute crisis situations
- Discussions on EOL care often held after acute deterioration

ACP facilitates informed decision-making

Potentialy avoidable hospital and intensive care admissions
PACP – TRANSFER OF AN ADULT CONCEPT (2)

Particularities in pediatrics:
- Prognostic uncertainty, unknown diagnoses
- Long and variable disease courses
- Parents as surrogate decision-makers
- Importance of the family
- Numerous medical and non-medical care providers
- Child-specific needs

➢ Adjustments required
➢ Assessment of needs and challenges, involving patients, parents and (health) care professionals (HCPs)
PREPARE

PLANNING RESPONSES AT THE END OF LIFE IN PEDIATRICS: ACTION RESEARCH AND EVALUATION

- Start July 2017
Objectives

- Developing a pediatric advance care planning (pACP) intervention for children with life-limiting diseases
- Testing its feasibility and acceptability
- Identifying stakeholder-generated outcome variables and piloting their assessment
Review evidence base
Review and analyse literature, own results and expertise

Workshop I
3 focus groups: Professionals and parents; Identification of needs, barriers and key components of the intervention

Development of draft
Development of a draft for the pACP program based on workshop I

Workshop II
Presentation of the draft, discussion and revision of the material

Training of facilitators

Pilot phase
PARTICIPANTS

**Professional caregivers** (n=15)
Settings: inpatient, outpatient, emergency care, hospice, care home, school

**Medical caregivers** (n=8)
pediatricians (4), nurses (4)

**Non-medical caregivers**
social worker (2), psychologist (1), chaplain (1), pedagogue (3)

**Bereaved parents** (n=6, 4f)
Diff. diagnoses (2 cancer)
Age at death: 5-18 yrs
Death at home: 5/6
Palliative care: 6/6
FIRST WORKSHOP (WS I)

Objectives of the 3 focus groups:

- to highlight different perspectives on the process and the implementation of pACP
- to identify and discuss needs, barriers and helpful aspects regarding each perspective
- to develop a common understanding of pACP
- to develop a framework for pACP based on the perspectives and experiences of all participants
RESULTS OF WS I

TOPICS:

Timing

Communication

Decision making and Documentation
TIMING: THEMES

Parents not ready
- Fear of „giving up“
- Wish to keep up normality and focus on the presence
- Wish to maintain hope

The wrong time point
- Immediately after the diagnosis is communicated
- Close to an acute crisis
- Under time pressure

Parents ready
- Awareness of the child’s severe condition
- Recognition of the futility of medical interventions
- Perception of decline of the child’s quality of life

The “missed” time point
- Parents not prepared for a “sudden” death
COMMUNICATION

NEEDS:

Parents

- Early discussions
- Proactive offers
- Open & honest information
- Preparation for what may come
- Time for reflection & coping
- Involve the child in an age-appropriate way
- Scheduled follow-up discussions

HCPs

“The reality cannot be as bad as the imagination”

“We knew what will happen at the end – that we will not kill him with the medication, but ease his way. And the discussions have assured me.”
COMMUNICATION

NEEDS:

Parents
- Being *listened* to & taken seriously
- **Maintain hope**
- Stepwise process, take time
- Open offers, written material
- Exchange with other parents
- Involve family members

Non-medical issues

Non-medical & outpatient caregivers

„And the question: How can we help him, what can we do?“

„There is hope – the hope to have a good time together. This was important.“
COMMUNICATION

CHALLENGES:

Parents
- High ambivalence
- Refusal of ACP discussions

HCPs
- Tendency to close eyes to facts
- Uncertainty & discomfort with EOL discussions
- Cultural taboos
- Fear of destroying relationship with parents

"I was not ready for this."

"You want to push away these thoughts."
DECISION MAKING

- Parents need time to “digest” the information and to allow the decision to evolve
- The decision making process does not only take place during the pACP discussions. Parents discuss their decisions with family, friends, support groups etc.
- Parents need to discuss important decisions as a couple
- Parents requested that the pACP discussion should be open to all outcomes and non-judgmental
- Parents do not want to be urged by HCPs to decide
WHAT IS PERCEIVED AS SUPPORTIVE IN THE DECISION MAKING PROCESS?

- Parents want to focus on their child’s personality, needs and abilities, and what supports the child’s QoL
- Parents want to discuss their fears
- Parents want to prepare for crisis situations, but not to be confronted with details of every possible scenario
NEEDS:

**Parents**
- Little importance of ADs
- Only for crisis situations when absent

**HCPs**
- ADs important for HCPs for assurance
- Emergency plans with specific requirements
CHALLENGES:

**Parents**
- Reluctance to make decisions in advance
- Prefer to decide in the situation
- Feeling bound by AD

**HCPs**
- Legal uncertainties & discomfort with ADs for children
- Burden for parents
- Revocability of ADs
- Too standardized or too long

"I did not want to commit myself."

"I want to make an individual decision, depending on what the actual situation is."
“...These conversations are also very difficult. But in the end, I have realized that this has been effective. Not to avoid this. [...] But to repeatedly work a little in this direction. But then, you need really sensitive people.”

Mother
CONCLUSIONS

1. pACP: a stepwise communication process aimed at supporting children and/or parents in their decision-making and to plan ahead for medical crises

2. pACP should start as soon as possible (parents ready?) and respects families’ hopes & resources

3. Need for written information on medical & psychosocial EOL issues for parents and HCPs

4. Round tables with service providers to facilitate coordination

5. ADs (recommended by HCPs) should be clear, validated & accessible. Parents should never be urged to sign an AD.

6. Need for systematical implementation in health care systems

7. Need for guidelines & professional education on pACP for HCPs
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