

Identification of age-appropriate communication about advance care planning topics in children with complex medical conditions

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This study is integral part of the follow-up research of the IMPACT project (Implementing Pediatric Advance Care Planning Toolkit) which focuses on enhancing children's involvement in their care

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Introduction

Pediatric advance care planning (pACP)

Commitment to care that aligns patient values and goals of care

Underrepresented child's perspective

- Doctor-parent-child interaction dominated by adults
- Yet, children are eager and able to engage in pACP
- Lack of tools to incorporate age-appropriate pACP elements into pACP interventions

Aim of this study

To identify the communicative developmental characteristics of children of different ages, regarding pACP topics to create strategies for age-appropriate communication

Research question:

How do children of different ages with complex medical conditions communicate about and value pediatric advance care planning (pACP) topics?

Methods

Study design

Semistructured qualitative picture-aided interview study

Population

14 children between 4-18 years old with a complex medical condition.

Preoperational stage (4-6 years old): n = 6

Concrete operational stage (7-11 years old): n = 4

Formal operational stage (12-18 years old): n = 4

Study procedure

- Development interviewguide with multidisciplinary team
- Individual face-to-face interview at the hospital, outpatient department or at patient's home

Study analysis

Interviews were recorded and transcribed verbatim

Qualitative thematic analysis:

- Following the steps of the Qualitative Analysis Guide of Leuven (QUAGOL)
- Using analysis software Nvivo 12

Methods

Data collection

How do children of varying ages communicate about pACP topics?

- “What comes to mind when you see this picture?”
- “What is that like in your life?”

How do children of varying ages value pACP topics?

- “Can you point out the three most important pictures for you and explain why you chose them?”
- “How would you like to talk to your doctor about this?”

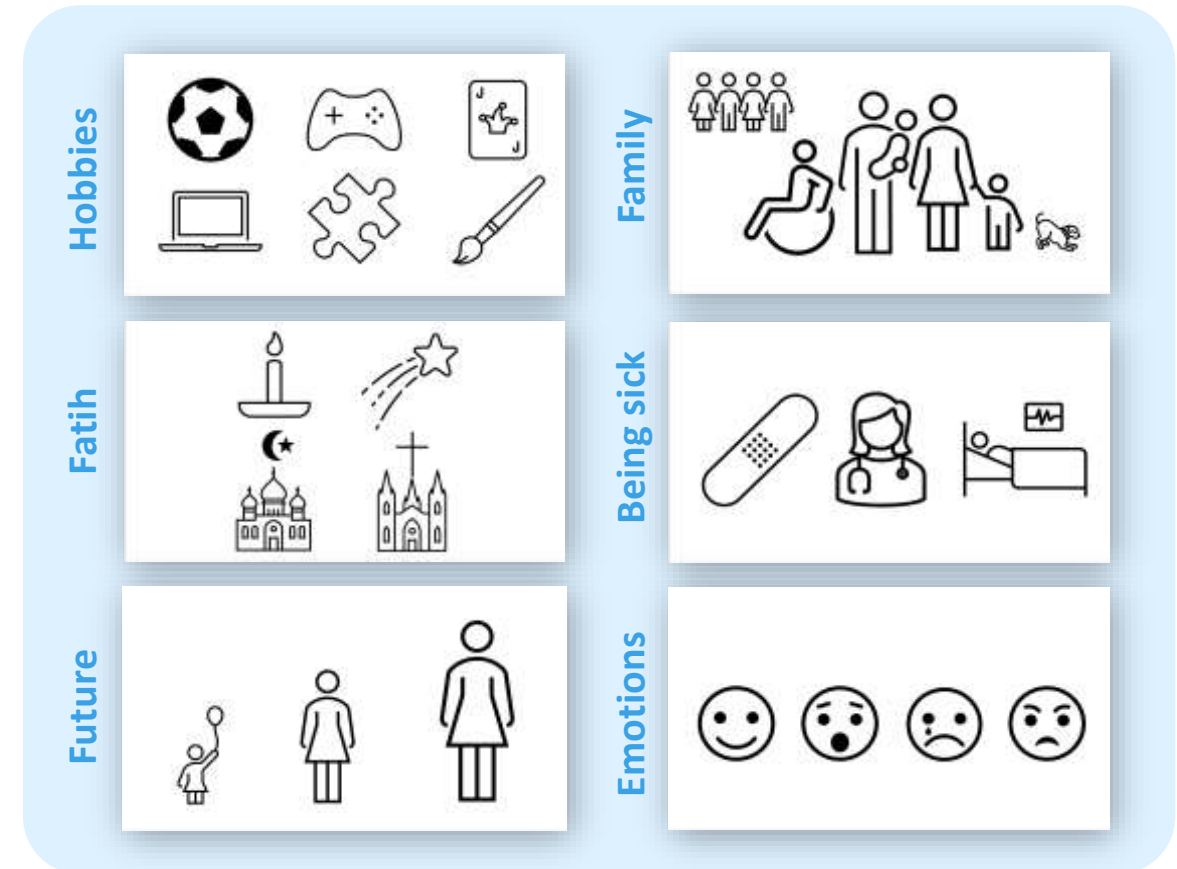
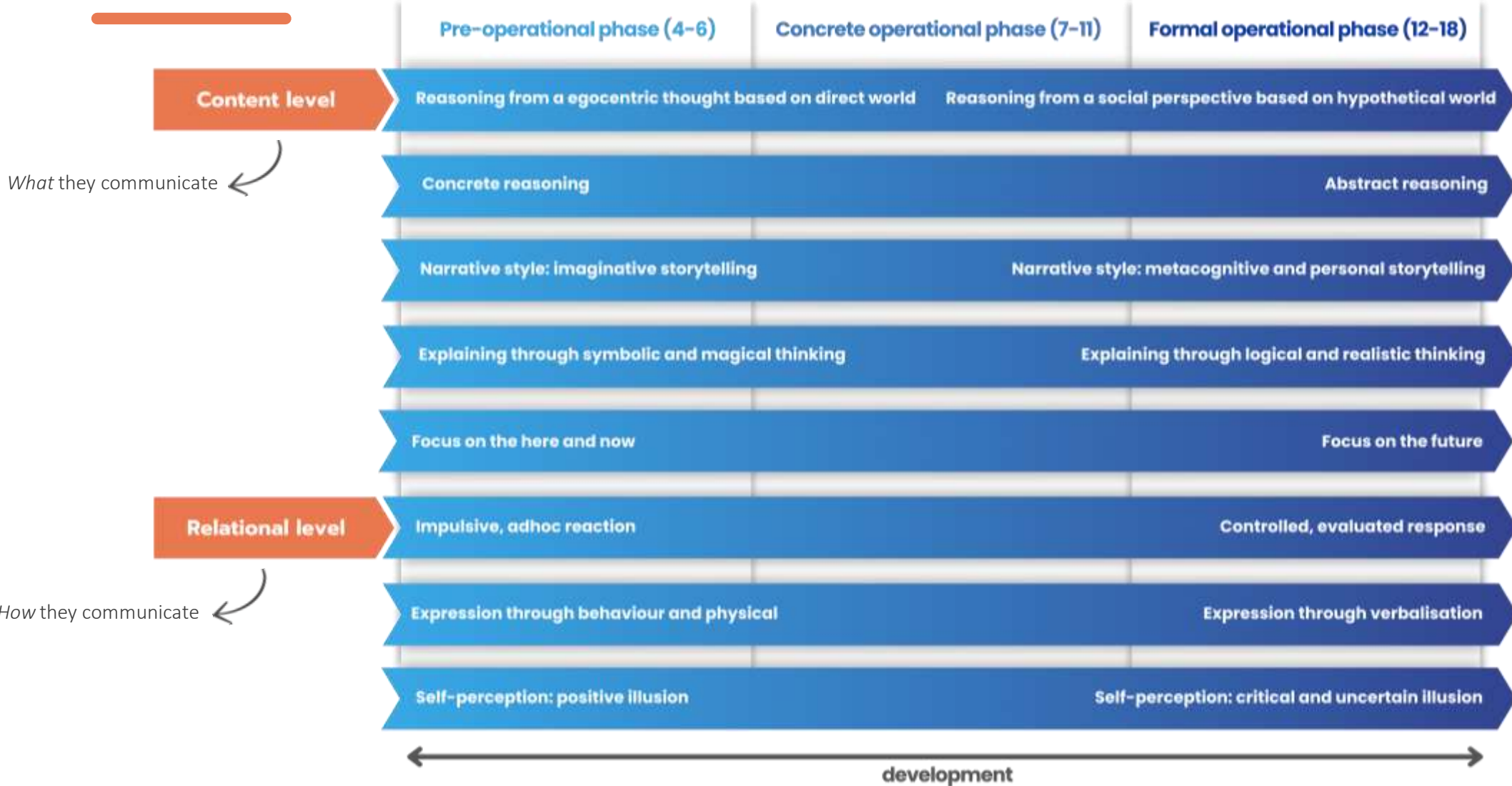


FIGURE 1. GUIDING INTERVIEW MATERIAL: SYMBOLIC PLATES REPRESENTING pACP THEMES

Results

FIGURE 2. DEVELOPMENTAL COMMUNICATION CHARACTERISTICS BY AGE GROUP ON GRADUATED SCALE



Results

Chronical age ≠ mental age

- Age limits are not always strictly normative

Pre-operational → formal operational stage

- Clear distinction

Concrete operational stage

- No fixed markers
- Transitional period of refine patterns of preoperational stage or develop patterns of formal operational stage

Variability

Timing of transitions and patterns varies by:

- Child
- pACP topic

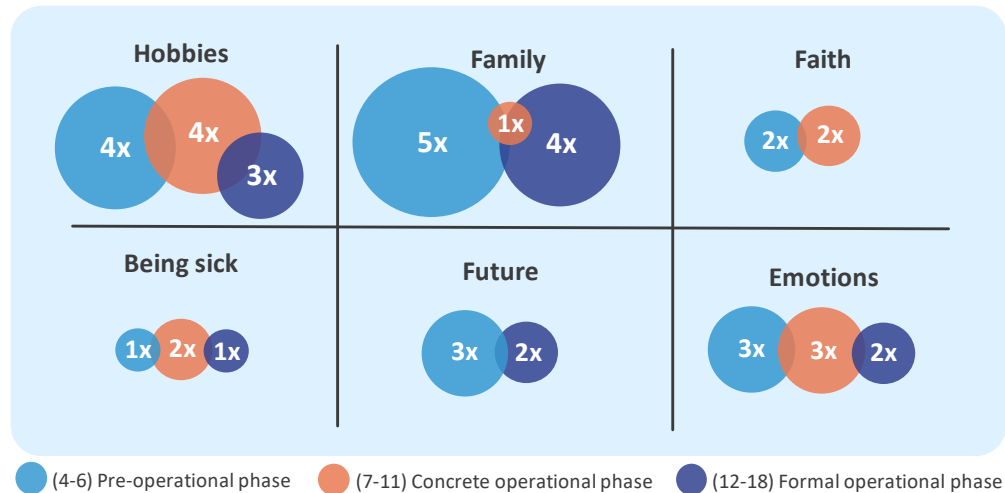
Interested in this variability?

Oral presentation on 'Factors affecting the child development in the context of serious illness: a scoping review' @ Maruzza Congres – Friday 18th 13.30-14.30h

Results

What themes do children identify as important in pACP?

Difference between age groups in preference for pACP themes:



How do children prefer discussing pACP topics with their doctor?

Focus on 'fun' topics

- Children mainly want to talk about things that reflect themselves as a human being

Children prefer a direct approach from the doctor

- Ask straightforward questions to understand their perspective: "Just ask"

Conclusion and discussion

- Participation competence in children is not an on-or-off phenomenon
- Envolves and varies per child and pACP-topic
- Flexible application to a pedagogical model, tailoring it to each child's unique characteristics

- Future research: strategies to asses the individual child's desires and developmental stage across different pACP-topics
- Limitation: the same results in the context of a real pACP conversation?



Thank you!



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