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Exploring 'values, goals and preferences' in paediatric care:

A content analysis of ACP conversations

ZonMw

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Impact

Introduction

Advance care planning (ACP)

aims to align future care with the **values, goals and preferences** of children and their families

A challenge for healthcare professionals

to **recognize, clarify, and translate** these values into concrete plans for future care

Translation from values to action

is important to achieve the purpose of ACP

Why this research?

Little is known about **how this process unfolds** in actual ACP conversations and which communicative actions and factors may support

Aim

To explore during ACP conversations:

- How families **express their values, goals and preferences**
- How HCPs **explore these elements**
- What HCPs **do with the outcomes** of this exploration

Methods



Audio-recorded paediatric ACP conversations*

(n = 20)

- HCPs ***(n = 16)***
- Parents ***(n = 28)***

- Hospital ***(n = 13)***
- Pediatric home care ***(n = 4)***
- Children's hospice ***(n = 3)***



Qualitative content analysis

using the QUAGOL framework

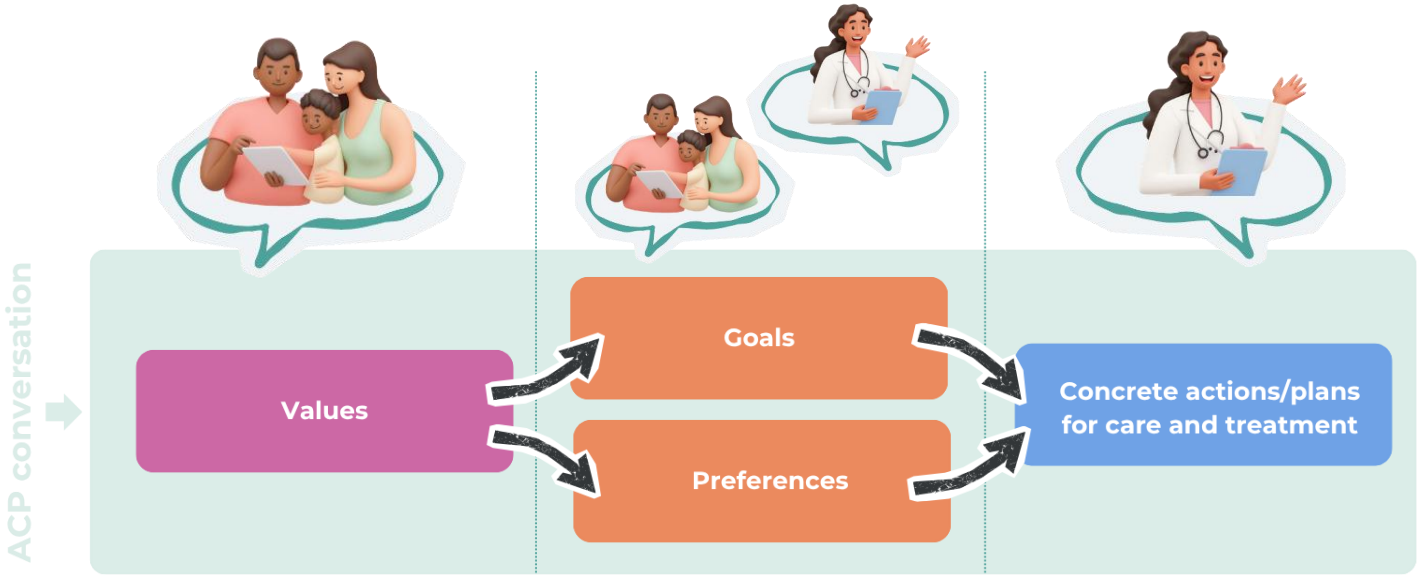
combined deductive-inductive coding approach:

- Predefined concepts
- Identifying additional communicative actions and patterns

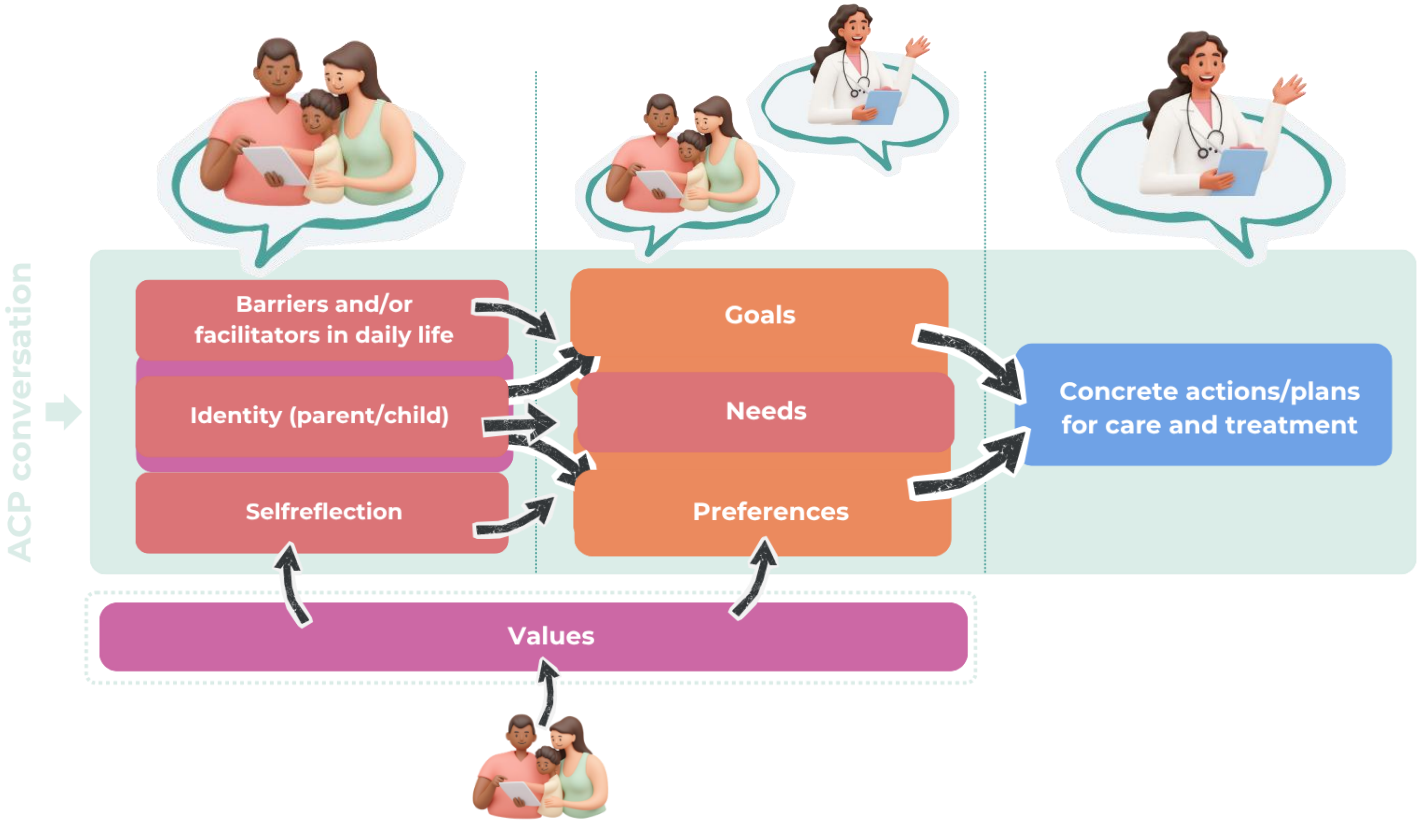
*Conducted according to the IMPACT method (*IMplementing Pediatric Advance Care planning Toolkit*)

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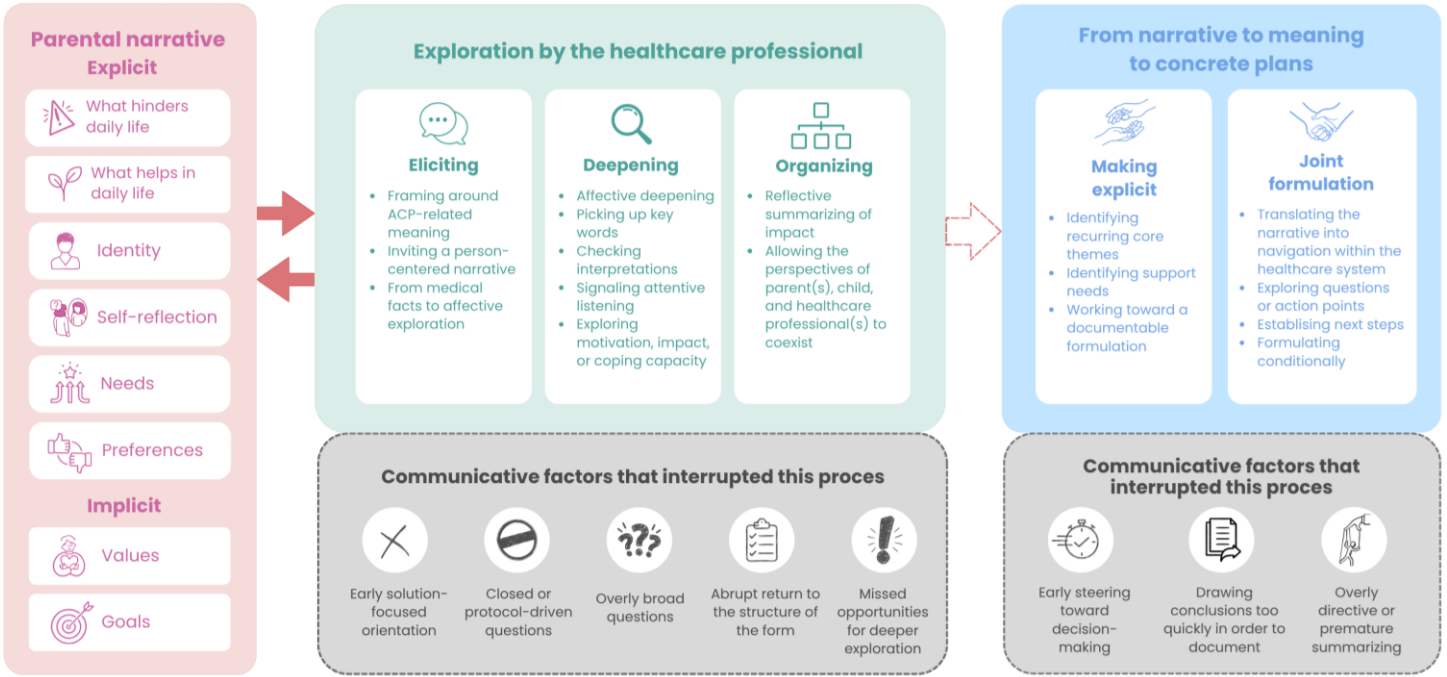
Results


ACP conversation
Values
Goals
Preferences
Concrete actions/plans for care and treatment

Results


ACP conversation
Barriers and/or facilitators in daily life
Identity (parent/child)
Selfreflection
Goals
Needs
Preferences
Concrete actions/plans for care and treatment
Values

Results


Parental narrative
Explicit
What hinders daily life
What helps in daily life
Identity
Self-reflection
Needs
Preferences
Implicit
Values
Goals
Exploration by the healthcare professional
Eliciting
Framing around ACP-related meaning
Inviting a person-centered narrative
From medical facts to affective exploration
Deepening
Affective deepening
Picking up key words
Checking interpretations
Signaling attentive listening
Exploring motivation, impact, or coping capacity
Organizing
Reflective summarizing of impact
Allowing the perspectives of parent(s), child, and healthcare professional(s) to coexist
From narrative to meaning to concrete plans
Making explicit
Identifying recurring core themes
Identifying support needs
Working toward a documentable formulation
Joint formulation
Translating the narrative into navigation within the healthcare system
Exploring questions or action points
Establising next steps
Formulating conditionally
Communicative factors that interrupted this proces
Early solution-focused orientation
Closed or protocol-driven questions
Overly broad questions
Abrupt return to the structure of the form
Missed opportunities for deeper exploration
Communicative factors that interrupted this proces
Early steering toward decision-making
Drawing conclusions too quickly in order to document
Overly directive or premature summarizing

Conclusion

Advance care planning (ACP)

Creates valuable space to explore what matters to families

Meaningful exploration

Does not automatically become a concrete care plan

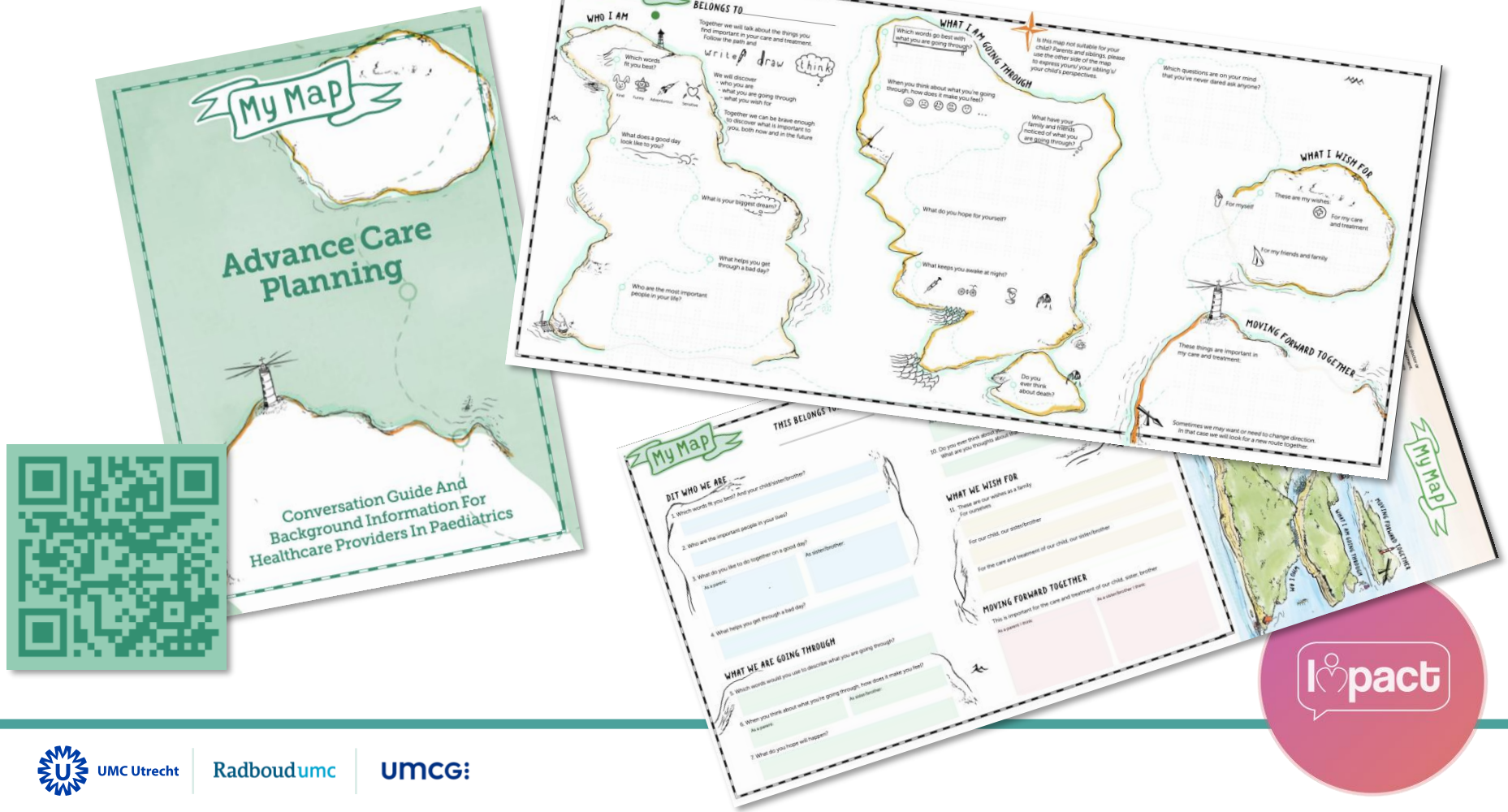
Insights into communication practices

- Highlight the importance of active, responsive HCP guidance
- May help improve HCP training and support

What helps bridge the gap from values to action?

For example:

- Conversation structure
- Clearly introducing the goal of ACP
- Open-ended questions
- Mutual understanding of perspectives
- Summary at the end of the ACP conversation


My Map
Advance Care Planning
Conversation Guide And Background Information For Healthcare Providers In Paediatrics
My Map
THIS BELONGS TO
WHO I AM
Together we will talk about the things you find important in your care and treatment. Follow the path and
write draw think
We will discover
- who you are
- what you are going through
- what you wish for
Together we can be brave enough to discover what is important to you both now and in the future
Which words fit you best?
What does a good day look like to you?
What is your biggest dream?
What helps you get through a bad day?
Who are the most important people in your life?
WHAT I AM GOING THROUGH
Which words go best with what you are going through?
When you think about what you're going through, how does it make you feel?
What have your family and friends noticed of what you are going through?
What do you hope for yourself?
What keeps you awake at night?
Do you ever think about death?
Is this map not suitable for your child? Parents and siblings, please use the other side of the map to express yours/ your sibling's/ your child's perspectives.
Which questions are on your mind that you've never dared ask anyone?
WHAT I WISH FOR
For myself
These are my wishes
For my care and treatment
For my friends and family
MOVING FORWARD TOGETHER
These things are important in my care and treatment.
Sometimes we may want or need to change direction. In that case we will look for a new route together.
My Map
THIS BELONGS TO
DIT WHO WE ARE
1. Which words fit you best? And your child/sister/brother?
2. Who are the important people in your lives?
3. What do you like to do together on a good day?
As a parent
As sister/brother
4. What helps you get through a bad day?
WHAT WE ARE GOING THROUGH
5. Which words would you use to describe what you are going through?
6. When you think about what you're going through, how does it make you feel?
As a parent
As sister/brother
7. What do you hope will happen?
10. Do you ever think about what are you thoughts about
WHAT WE WISH FOR
11. These are our wishes as a family
For ourselves
For our child, our sister/brother
For the care and treatment of our child, our sister/brother
MOVING FORWARD TOGETHER
This is important for the care and treatment of our child, sister, brother
As a parent / mom
As a sister/brother / mom
My Map
WHAT I AM GOING THROUGH
MOVING FORWARD TOGETHER
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Thank you!

Questions?

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