

Draw me a ladder, so I can climb to heaven.

Young children's understanding of their own end of life;
a qualitative study in the Netherlands.

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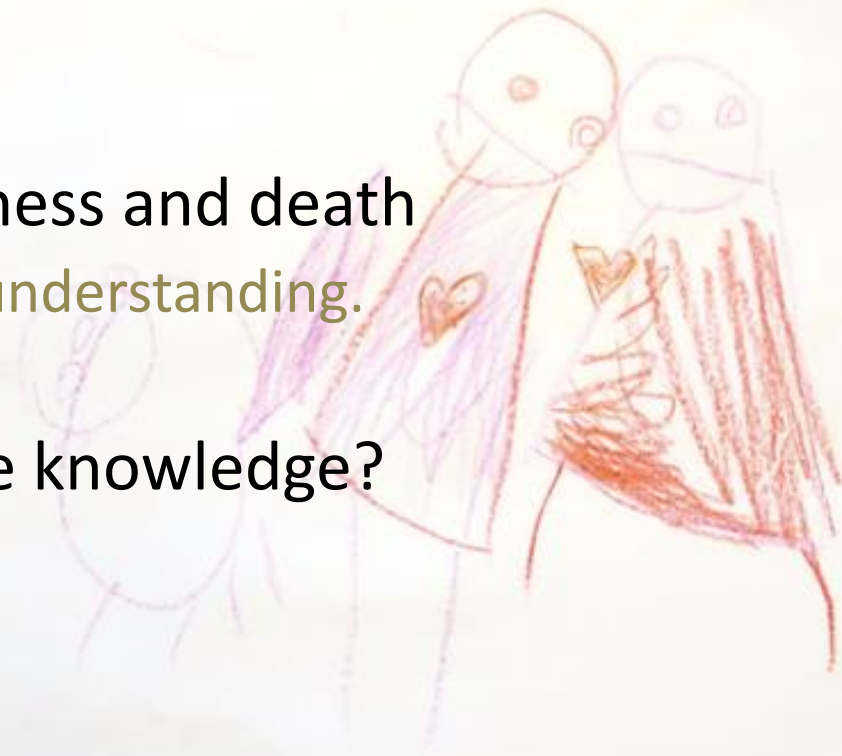


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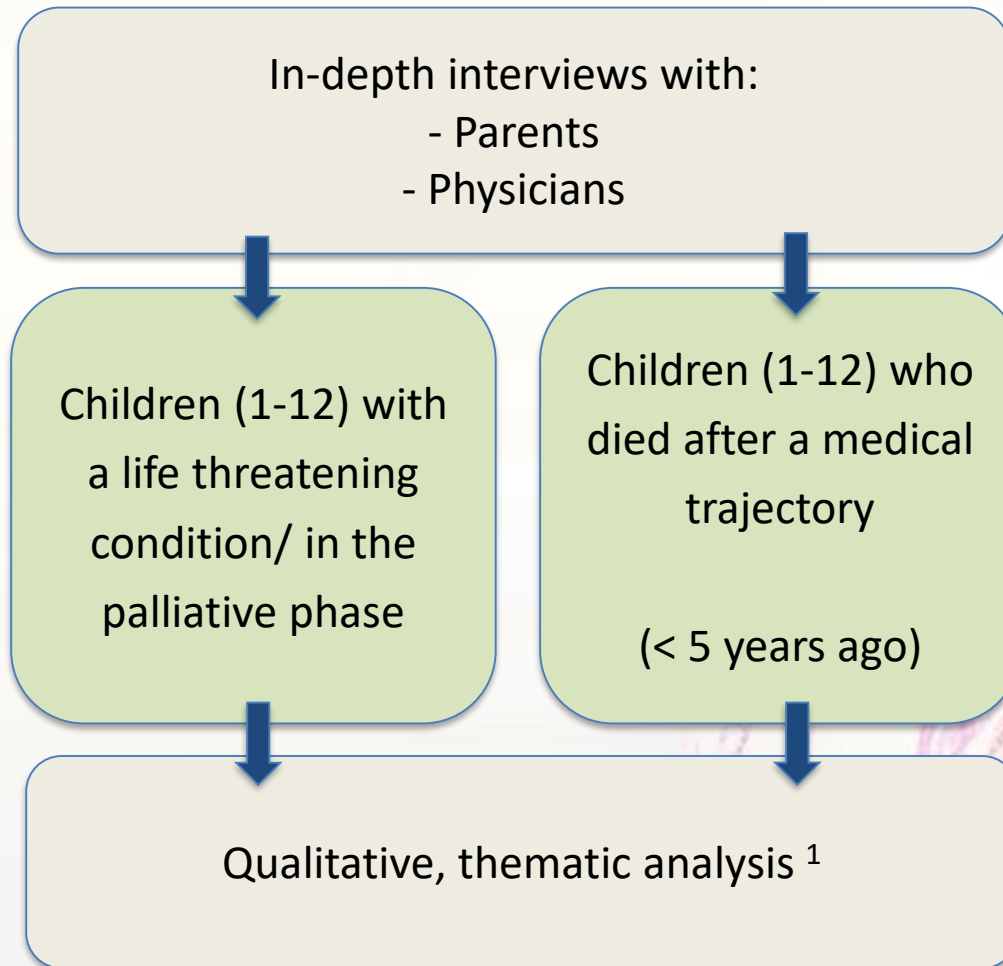


Outline

- Research & Methods
- Children's understanding of their end-of-life.
 - Different forms of knowledge
- Children's understanding of illness and death
'being different' as a catalyst of understanding.
- When does awareness become knowledge?

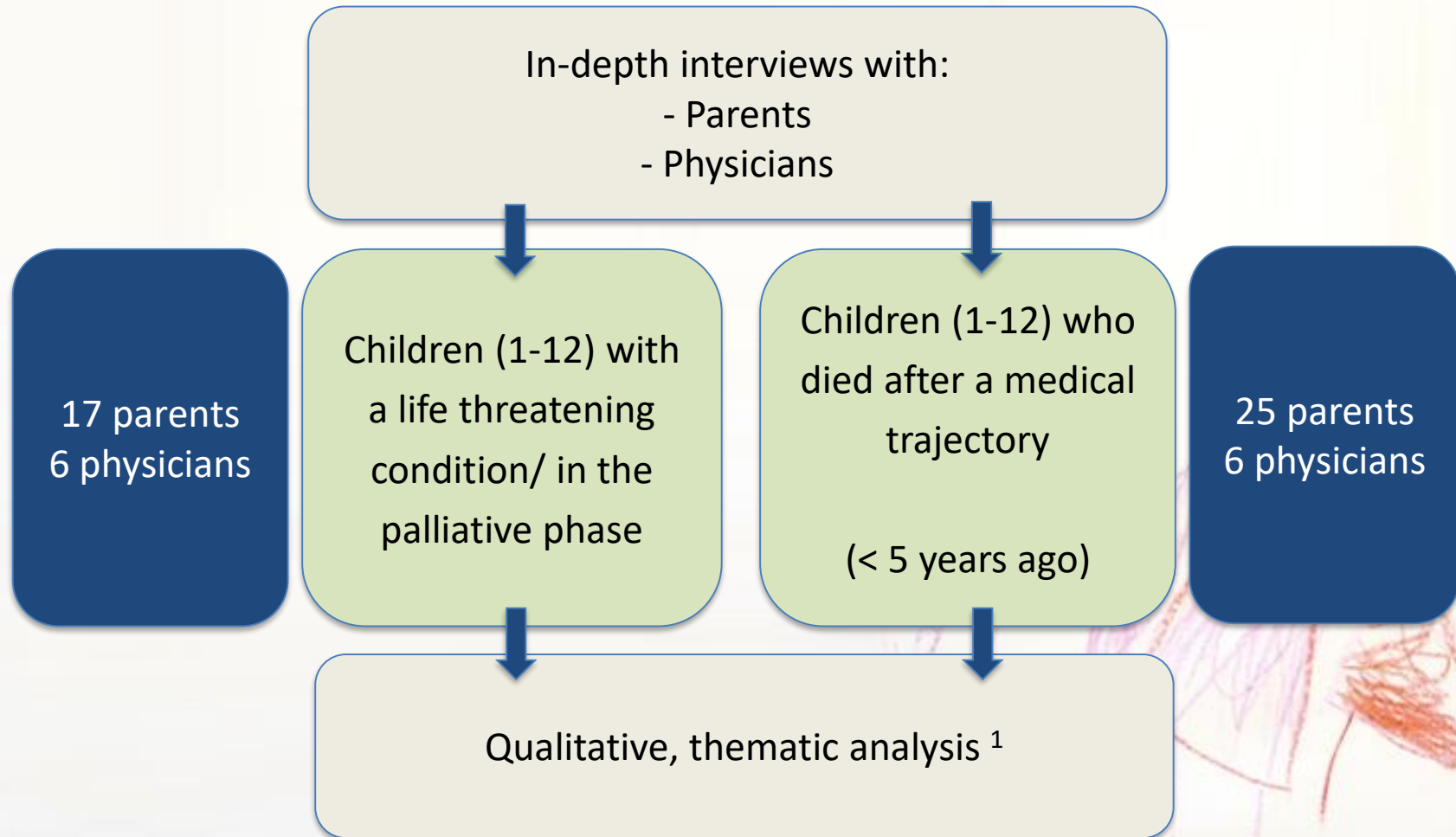


Research & Methods



¹Ziebland S, McPherson A. Making sense of qualitative data analysis: an introduction with illustrations from DIPEX (personal experiences of health and illness). Medical education. 2006 May 1;40(5):405-14.

Research & Methods



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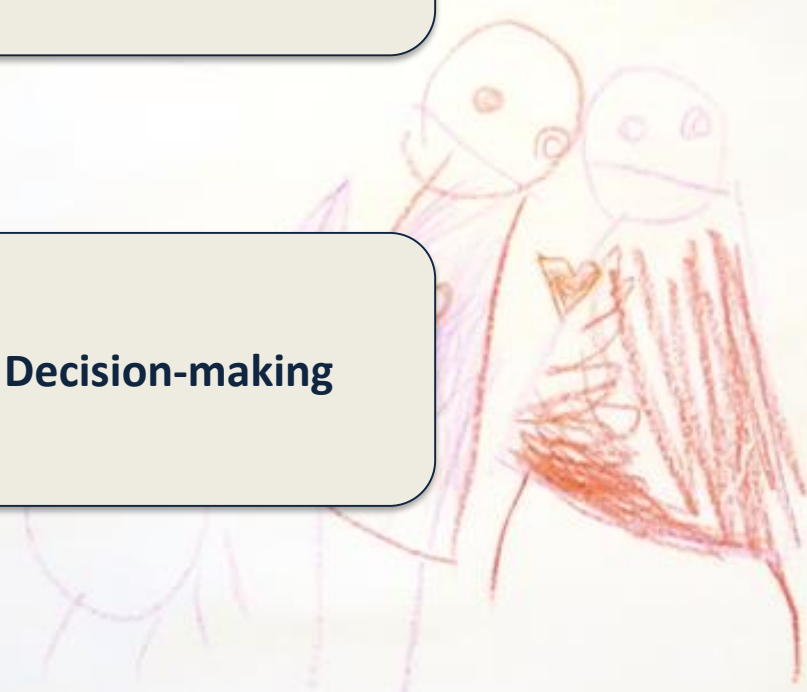
Children's understanding

Assessing information

Reasoning

Valuing

Decision-making



Children's understanding

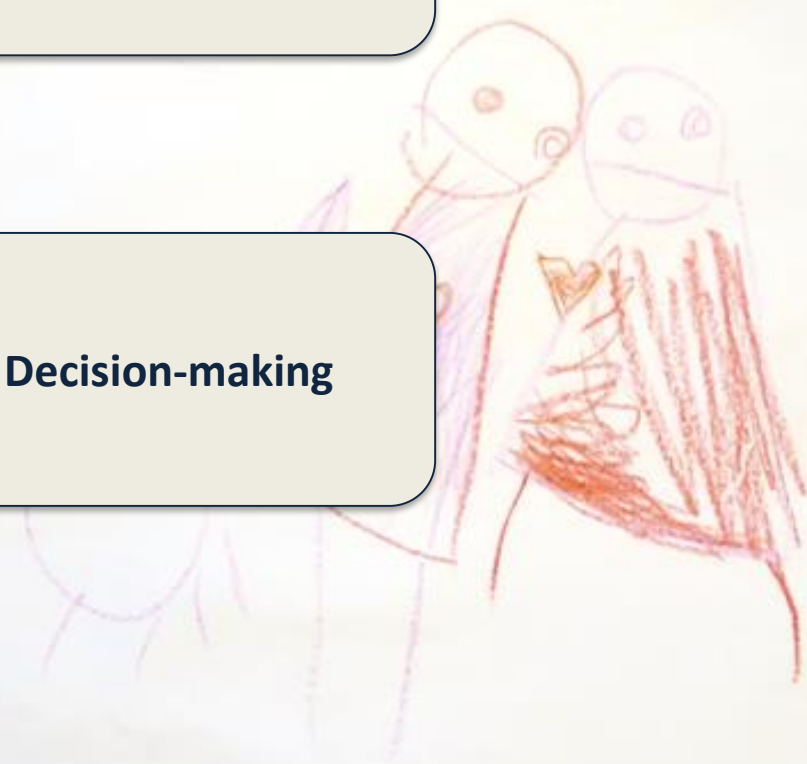
3 y.o.
→

Assessing information

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Children's understanding

Assessing information

Reasoning

Mother of boy (8)

“He asked me: ‘Can I hold on for 18 more years, mum?’”

And I answered, ‘No, if you have such a lump as yours inside your head, you can’t.’

Then he asked: ‘6 years?’ And I said: ‘No...’

‘Two years?’ And then he saw my face, and asked: ‘Will I still see Santa Claus?’

And I cried ‘no’, and that’s how he realized that he would die soon.”

Children's understanding

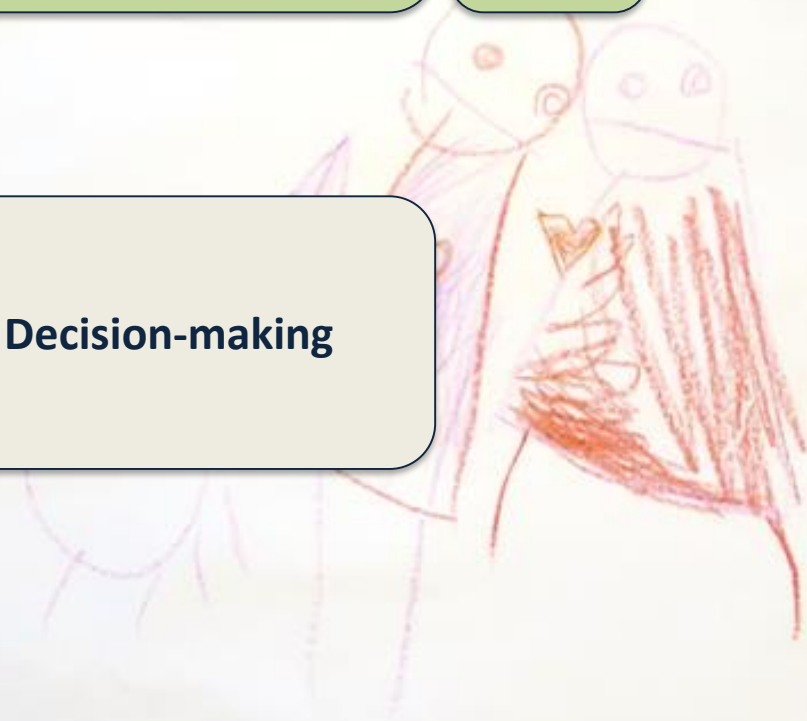
Assessing information

Reasoning

4 y.o.
→

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Children's understanding

Assessing information

Reasoning

Father of boy: (4 y.o.)

He figured it out all by himself.

We had explained the tumor as crocodile-eggs that stole energy of him, and how the eggs would grow.

And in the summer he got quiet, and asked: but if they steal my energy, then I won't be able to do anything. And then I can't stay with you anymore, so where do I go then? That's how he figured it out: that he could die.

The doctor said young children don't make that connection, but he did. “

Children's understanding

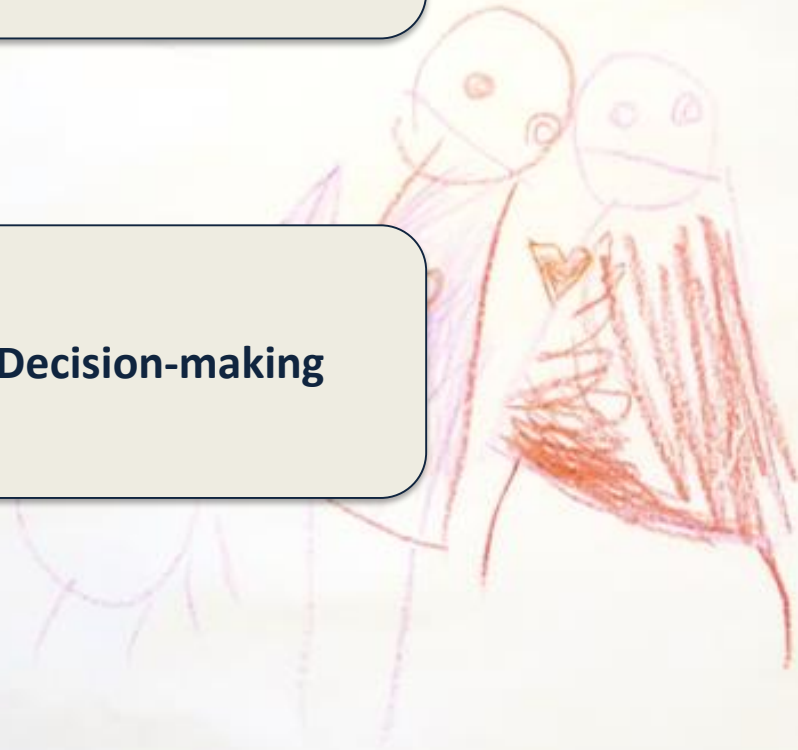
Assessing information

Reasoning

4 y.o.
→

Valuing

Decision-making



Children's understanding

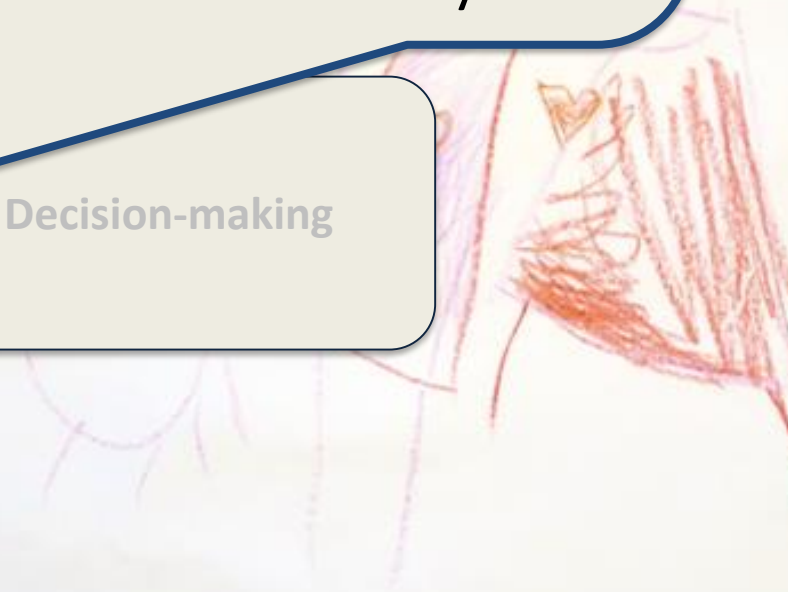
Mother of girl: (5 y.o.)

“ She asked me: ‘Mum, when you die, that’s worse for other people, than it is for yourself, isn’t it?’

Because I will not know it, because I’m not there anymore.’

Valuing

Decision-making



Children's understanding

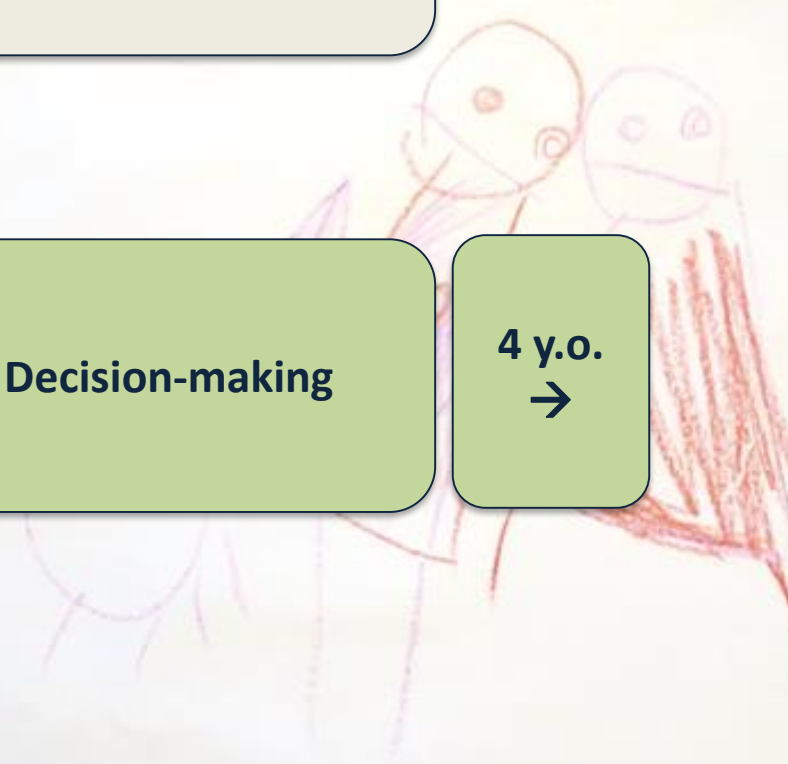
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**4 y.o.
→**



Children's understanding

Mother of boy: (4 y.o.)

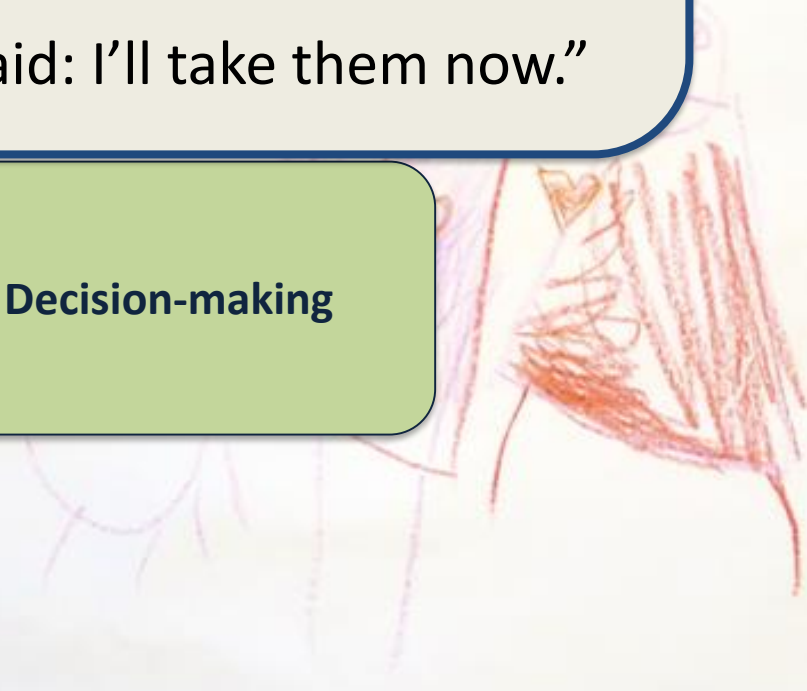
“We had planned to sedate him at night.

But he said: ‘ I don’t want that medicine. I want the other medicines, but not that one, because then I can’t tell you if I’m in pain.’

But two days before he died, he said: I’ll take them now.”

Valuing

Decision-making



Children's understanding

Take Home Message 1:

Up from a very early age, children are seen making mature and complex reasonings regarding their own end-of-life.



Children's understanding of illness and Death

- There is some development with age, but not as clear as expected.
- “Catalysts of understanding” :

“being different”



Children's understanding of illness and Death

"Even when she was two years old, she did realize that it was odd... being bald." (2 y.o.)

"I don't think she realized, that it was strange. The hospital was all she knew." (6 y.o.)

"She always told she had a 'little stripe' on her belly that made her tired (5 y.o.)

"Once he did realize that it wasn't normal, to be in the hospital all the time. He started to ask questions about his illness" (4 y.o.)

"being different"

Children's understanding of Death

Take Home Message 2:

Instead of merely looking at age, maybe we should take 'catalysts of understanding' into account, such as a child's realization that being ill is 'different'

Finally: embodied awareness?

mother of girl, 3

“One morning, she- with all her spasms- was drawing stars, and she asked me: will you draw a ladder for me?

And I asked her: why do you want me to draw a ladder?

Ans she answered: So I can climb to heaven, I’m going to the stars soon.”



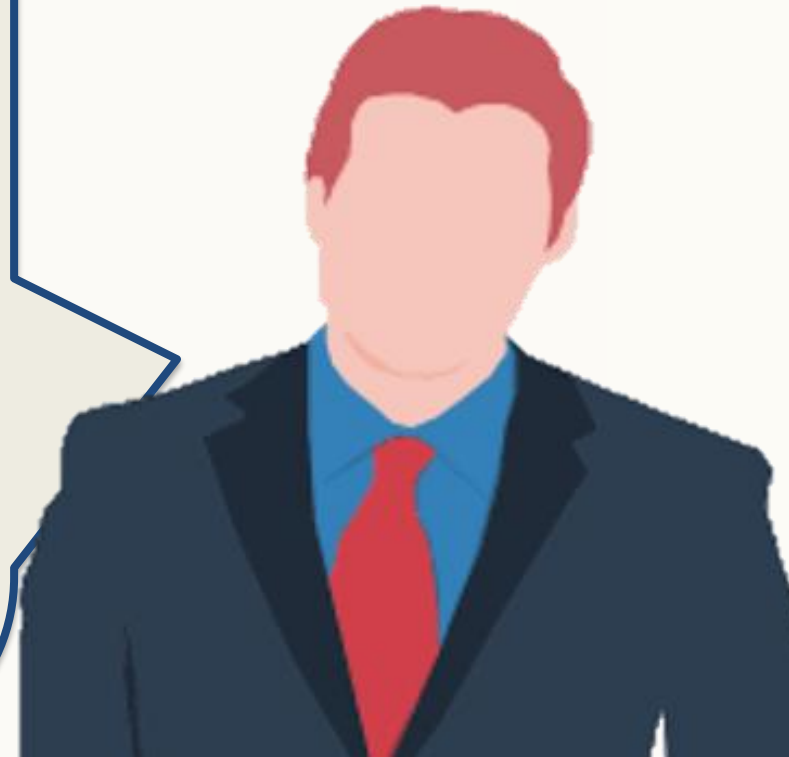
Finally: embodied awareness?

father of boy, 2

“The day the bad news came, I asked him: ‘you already knew this, didn’t you?’

And he just nodded.

And even before that: when you’d ask him: are you gonna get better? He’d always say ‘no’.. He’s never answered yes.



Discussion

something to think about:

It seems that children display awareness about their end of life in way that doesn't fit within our traditional understanding of knowledge...

But should *and* can we let that play a role in paediatric palliative care?



Let's keep the discussion going



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