“Will you still visit my family when I am gone?”

Participation of a young boy with hypoplastic left heart syndrome in Advance Care Planning: A qualitative case study

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Background Ensuring appropriate participation is essential in order to respect the child's autonomy and to reduce emotional distress for parents and professionals.

Methods qualitative longitudinal case study

Aims

- ✓ to clarify individual steps of participation in pediatric advance care planning (pACP) in accordance with growing decisional capacity and
- ✓ to present child- and age-appropriate participation.

Results

- ✓ **Summary of ACP process** along the timeline from starting integration of palliative care in december 2012 up to time talking about imminent end of life in january 2018
- ✓ **Summary of psychological care (right side) 2016 - 2018**

2014-2017 Advance Care Planning for Joshua

11/2014 Trigger for advance care planning

- Self-reported anxiety during a critical pulmonary bleeding and
- disease progression

Joshua's thoughts about medical treatment:

„Things not working you wouldn't do, would you?“

08/2016 Parental request for support

how could Joshua participate in decisions e.g. about treatment at hospital?

One-hour-talk with Joshua about UN-Convention on Rights of the Child (CRC)

12/2017 - 08/2018 Advance Care Planning discussions with parents and Joshua

Joshua participated together with his parents, his psychologist and the palliative care physician

Joshua's key message to his care team:

Diagnostics and/or treatment is only meaningful to me when it can improve my situation.
If not I want to stay at home with my family and take the time for enjoying my life including all things I was not allowed to do due to my illness. I believe in live after death. Please, visit my family when I am gone.

12/2012
Start PPC

11/2014
Progression

12/2014
1st ACP
Discussion parents

2015

07/2016

08/2016

09/2016

10/2016

01/2017

04/2017

06/2017

11/2017

12/2017

Joshua participates in ACP discussions

01/2018

Talking about the imminent end of life

08/2018

Joshua died.

Joshua diagnosed with Fontane failure in hypoplastic left heart syndrome, palliative care from age 9 to 15 years.

Psychological Care 2016 – 2018

Support for Joshua to become more and more involved in ACP discussions and decision-making

STOP- sign

to quit conversation when questions become too intimate or difficult to practice asking each other things the other might or might not want to answer yet
„Hey, did you ever kiss a girl?“
to prevent fear of too difficult questions

„That's me“ book 09/16

to introduce each other to practice describing emotions

Head - and heart- conversation 09/16

to understand, that the head tells information whereas the heart speaks emotionally.

„So, this was, what your head recognised, but what did your heart tell you, when the doctor looked so seriously?“

Creating a memory game of emotions 01/17

to become familiar with the variety of emotions e.g. anxiety, courage, disgust, love, trust

Fridolin-tale

07/17 – 4/18 – 12/18

is a representative story of a flying frog becoming weaker and weaker. Fridolin made experiences that Joshua made himself. It was discussed what would be the best for Fridolin to adapt to his situation. Joshua learned becoming aware of his own condition and finding ways to cope. In addition Fridolin wrote down all he was observing and learning about Joshua and his family-life. Updating the story every meeting it became a book of more than 30 pages.

Family Game 03/17

with parents and brothers questions had to be answered to win points with funny questions
„Who of all players has the funniest nose?“

and self-relevant, emotional questions about strength and anxiety, life and death:
„Do you think there will be life after death?“

Power-watch 04/17

created with fingerprint-fantasy-figures who might help in difficult situations
„This is Leo the wizard. He helps me being tough when it's difficult to find veins to take a blood sample!“
with the aim to talk about time: past, presence and future:
„What would you like to experience once again? Are there incidents you fear in future?“