Beyond illness

A qualitative exploration of talking about the future in pediatrics with IMPACT

J. Brunetta, L.L. Rondelle, S.C.C.M. Teunissen, I.M.L. Ahout, J.L. Aris-Meijer, M. Engel, M.C. Kars, J.C. Fahner

University Medical Center Utrecht, Julius Center for Health Sciences and Primary Care, Center of Expertise Palliative Care Utrecht

- No conflict of interest

I♡pact

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IMPACT: IMplementing Advance Care planning Tool

Aim

To identify the **experiences, perspectives and needs** of **children with life-limiting conditions, their parents and health care providers** (HCPs) when conducting **advance care planning conversations** with IMPACT on:

1. Content

2. Structure

3. Lay-out

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Method

- **Qualitative interview study** using thematic analysis
- **Focus groups**: reading the IMPACT content

Children with life-limiting or life-threatening illnesses
- Different developmental fases/ages (4-6;7-11;12-18 years old)

Health care providers
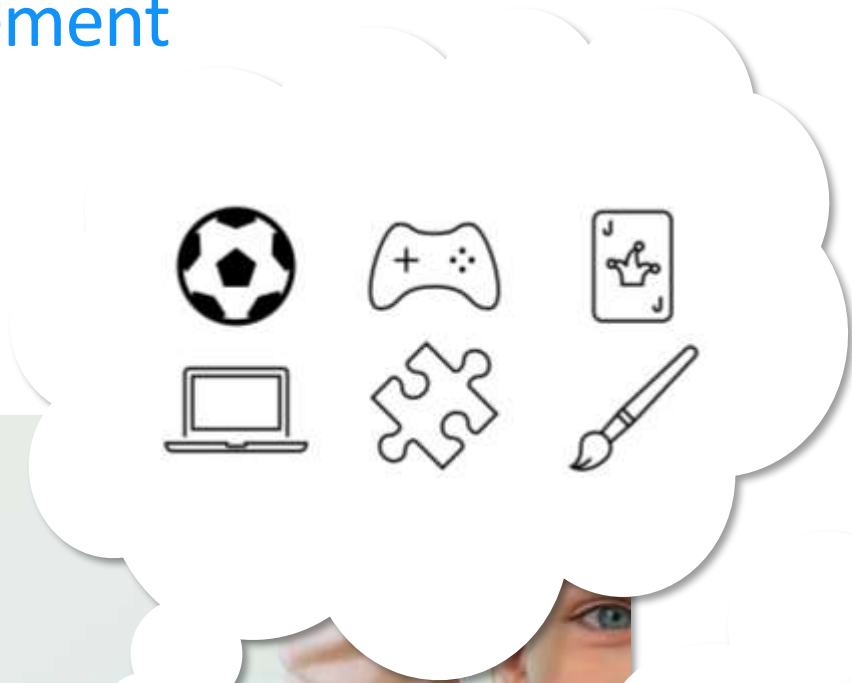- Academic/local hospitals
- Home care/hospice care

Parents
- Different disease(s)/ trajectories
- With different cultural and religious backgrounds

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Interviewing children

Age-appropriate involvement

Background characteristics

	Children (n=8)	Parents (n=18)	HCPs (n=16)
Sex			
• Female	5	10	15
• Male	3	8	1
• Intersex	0	0	0
Age (in years)			
• 4-6	0	0	0
• 7-11	3	0	0
• 12-18	5	0	0
• 30—50+	0	18	16
Religion			
• Roman catholic	1	0	0
• Protestantisme	1	2	6
• Humanism	0	0	1
• Hindoeism	0	0	1
• Islam	1	0	8
• None	5	15	0
• Other	0	1	0
Cultural background			
• Dutch	7	16	16
• Indonesian	0	0	0
• Turkish	0	0	0
• Marrocan	1	0	0
• Surinamese	0	0	1
• Antillean	0	1	0
• Other	1	1	0

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• Other	1	1	0

Baseline characteristics

|	Children	Parents	HCPs
Disease (HCP: speciality)			
• Cancer	0	5	6
• Other	8	13	10
Disease staging			
• After diagnosis	1	0	
• Stable disease	6	3	
• Detoriation	1	3	
• Preparing for end of life	0	9	
• Deceased	0	3	
• Other (recovered)	0	3	
Function			
• Nurse (specialist)			11
• Doctor			5
Working experience (in years)			
• 0-5			3
• 5-10			4
• 10+			9
Setting			
• Academic hospital			4
• Local hospital			9
• Home/hospice care			3
IMPACT experience			
- Yes	1	2	15
- No	7	16	1

Results
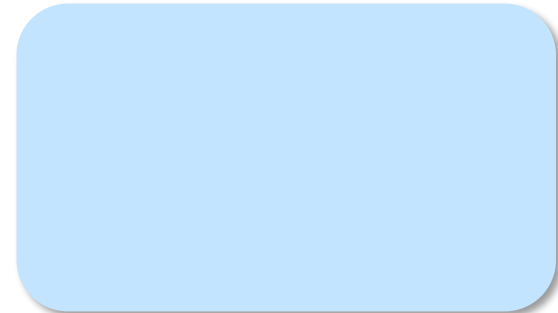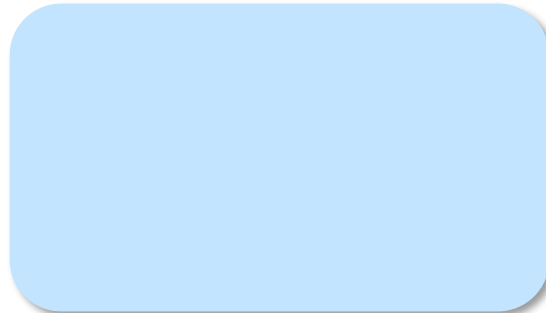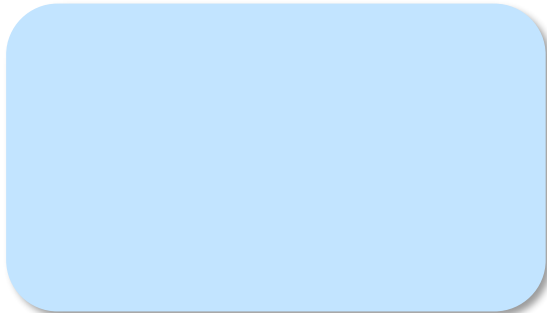
	Content	Structure	Lay-out
N=8			
N=18			
N=16			

Results

	Content	Structure	Lay-out

N=8

N=18

N=16

All participants value the content of IMPACT.

Results

	Content	Structure	Lay-out
N=8	• Need to tell about who they are, what they like		
N=18	• Need to clarify the goal of IMPACT, "hidden agenda"		
N=16	• Repetition in themes, summaries		

Results

Content

Structure

Lay-out

N=8

N=18

N=16

Talking about the future is experienced as:

1. Difficult
2. Important, to prepare them on future worst-case scenario's

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Results

Content

Structure

Lay-out

N=8

N=18

N=16

Talking about the future is experienced as:
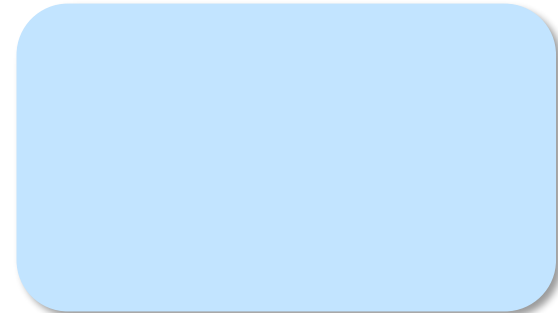1. Difficult
2. Important, to prepare them on future worst-case scenario's

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All participants feel a need to a reorganise IMPACT themes:
1) Who we are
2) What we go through
3) What we wish for
4) Where we go to

Trusting the HCP's

Results

	Content	Structure	Lay-out
N=8			• "Boring" • Need for more age-appropriate lay-out
N=18			
N=16			Appreciate the current lay-out of IMPACT, need for more age-appropriate lay-out

Implementation

Discussion

- **Selection/population bias**
  - Lack of children with cancer, 4-6 years old, preparing for EOL
  - Lack of multiple religious and cultural backgrounds
  - HCP with experience in IMPACT

- **Future research: CO-IMPACT**
  - Qualitative and quantitative evaluation of advance care planning conversations with the new developed IMPACT materials

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Key message

Children

HCP

Parents

All participants value:
- Content of **IMPACT**
- Talking about **future care and treatment**

All participants:
- Feel a **need in reorganising the IMPACT themes**
- Express an uncertainty in the goal of the conversation

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Thank you!