How can we evaluate quality of life of children with life-limiting conditions?

Pilot-test at one PPC centre in Belgium.

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INTRODUCTION
PhD research: the MOSAIK study
for Move to Open Shared Advanced Interventions for Kids with life-limiting conditions

1. Facts and Figures
Paediatric Palliative Care provision in Belgium?
Friedel et al Building Bridges. BMC Palliative care 2018

2. Systematic literature review:
Instruments used to assess outcomes in PPC. Do we measure what matters?

3. Pilot-study
What is the relevance, acceptability and feasibility of the APCA CPOS french version?

4. Cross-sectional study
What are the psychometric properties of the CPOS french version?
A constant paradox...

Explore and measure quality of **LIFE**, in the shadow of **DEATH**.

«I want to live, but I will die.»


https://fotografiapriniciantes.wordpress.com/category/contraste/
What is quality of life?

all that makes the spice of life ...

https://www.writeraccess.com/blog/variety-is-the-spice-of-life-6-social-media-marketing-types/
What is palliative care for children?

It is an active, holistic, family-centred, interdisciplinary care, starting at diagnosis of a life limiting disease, sometimes in parallel of curative care, including end-of-life care, bereavement care, and respite care aiming to promote QUALITY OF LIFE.

Abu Saad Huijer et al. IMPaCCT 2007; WHO 1998
PPC is provided in Belgium

Through 5 paediatric liaison teams (PLT) providing curative and palliative care for children with life-limiting conditions throughout the disease course.

PLT’s are defined by a Royal Decree issued in December 2010

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STATE OF THE ART
• Children’s QoL with life-limiting conditions  
  Heath 2010, Hechler 2008, Wolfe 2000 is linked to parent’s QoL  
  Smith 2017, Van der Geest 2014, Rallison 2013 and to siblings QoL  
  Olivier d’Avignon 2014

• Paediatric Palliative Care  aims to - and sometimes does - improve QoL  

• Main aim of PPC is to promote QoL, but no validated measure tool for PPC outcomes found  
  Coombes 2016

• Current standardized measures of QoL are criticized  
  Huang 2010, Dussel 2010, Knapp 2010
Challenges

The « ideal » instrument to measure children’s QoL in a family centred approach, should be:

• short and easy to use
• combine child (self) and parental (proxy) perspectives
• capture dimensions of QoL that matter
• flexible for all ages and diseases
• acceptable to children, parents, carers

=> APCA c-POS

Downing, 2012, Huang 2010, Dussel 2010
OBJECTIVES
To analyse from the perspective of children, parents and health care professionals, the relevance, acceptability and feasibility of the new French version of the APCA-Children’s Palliative Outcome Scale (CPOS)
METHODS
Starting with exploratory interviews with each paediatric liaison team

1. What are your objectives?
   « Pain control, family comfort, information, ... »

2. How do you evaluate your objectives?
   « by feel, by intuition, also with pain scales »

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Steps of the pilot-study

- Selection instruments
  - To evaluate QoL through PROM

Cross-cultural validation
  - To translate CPOS and PaPAs in french

Interviews with children and parents
  - To assess relevance, accessibility of c-POS fr. version

Meetings with PLT
  - To assess relevance and feasibility of c-POS fr. version

Within a collaborative and iterative approach with children, parents and paediatric liaison teams (PLT)

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## 1. Selection of instruments

<table>
<thead>
<tr>
<th>Name</th>
<th>Measure</th>
<th>Form</th>
<th>Context</th>
<th>Validation</th>
<th>Lang</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Children’s palliative outcome scale</strong></td>
<td><strong>CPOS</strong></td>
<td><strong>Scale Self +proxy-report 12 questions</strong></td>
<td>Uganda, Kenya, South Africa 302 children, 299 family carers</td>
<td>Content- Validity Downing 2014, 2016, APCA 2012</td>
<td>Engl</td>
</tr>
<tr>
<td><strong>Scheduled evaluation of individual QoL</strong></td>
<td><strong>SEI QoL</strong></td>
<td><strong>Semi-structured interview</strong></td>
<td>Adult oncology (Rodary 2005) Children with Diabetes (Wagner 2004) with Cerebral Palsy (Vinson 2010)</td>
<td>Validation complete (Hickey 1996)</td>
<td>Fr.</td>
</tr>
<tr>
<td><strong>Quality of life family carers</strong></td>
<td><strong>QOLLTI-F</strong></td>
<td><strong>Scale 7 domains 16 questions</strong></td>
<td>Used in PPC context: Groh 2013, Vollenbroich 2012</td>
<td>Validation complete version 2 french Cohen R. 2015</td>
<td>Fr.</td>
</tr>
<tr>
<td><strong>Paediatric Palliative Screening Scale</strong></td>
<td><strong>PaPas</strong></td>
<td><strong>Scale 5 domains 11 questions</strong></td>
<td>Not yet tested</td>
<td>Validation stage 3 Bergstraesser 2013, 2014</td>
<td>Engl</td>
</tr>
</tbody>
</table>
2. Cross cultural validation of CPOS and PaPAs

Graphic representation of the recommended stages of cross-cultural adaptation of an instrument.
3. **Pilot-test**

at 1 single center in Brussels

* 6 semi-structured interviews with children and parents

* 6 discussions with paed liaison nurse after interview with families

* 3 meetings with paed liaison teams

* 1 meeting with 2 physicians

**Iterative process!**
RESULTS
Characteristics of the sample  (n=6 children)

<table>
<thead>
<tr>
<th>Age</th>
<th>Gender</th>
<th>Pathology</th>
<th>Verbal capacity</th>
<th>Instruments</th>
</tr>
</thead>
<tbody>
<tr>
<td>8 years</td>
<td>M</td>
<td>neuro</td>
<td>none</td>
<td>CPOS, PaPas</td>
</tr>
<tr>
<td>9,5 years</td>
<td>M</td>
<td>neuro</td>
<td>none</td>
<td>CPOS, QOOLTI, PaPas</td>
</tr>
<tr>
<td>15 years</td>
<td>F</td>
<td>onco</td>
<td>good</td>
<td>CPOS, SEIQoL, QOOLTI, PaPas</td>
</tr>
<tr>
<td>18 years</td>
<td>F</td>
<td>onco</td>
<td>good</td>
<td>CPOS, SEIQoL, QOOLTI, PaPas</td>
</tr>
<tr>
<td>10 years</td>
<td>F</td>
<td>onco</td>
<td>limited</td>
<td>CPOS, SEIQoL, QOOLTI, PaPas</td>
</tr>
<tr>
<td>18 years</td>
<td>M</td>
<td>neuro</td>
<td>limited</td>
<td>CPOS, SEIQoL, QOOLTI, PaPas</td>
</tr>
</tbody>
</table>
Relevance of the CPOS fr. version

• Children/adolescents facing LLC want to: dance, play, learn, move, listen to music, have pets, have friends, be with their family as any other children
• CPOS and SEIQoL don’t seem to measure the same dimensions. SEIQoL revealed the importance of social interactions
• Parental QoL is affected by financial and administrative procedures
• Recall period « since yesterday » was changed into « the last few days » (and even further in the past)
• Difficulty for parents to plan the future: « day by day »
• Children’s scores (CPOS/SEIQoL) seem not to be linked to parental QoL scores (QOLLTI-F).
Acceptability

• All families contacted accepted being interviewed
• Children and parents appreciated being interviewed
• Interview was a trigger leading to expression of important aspects never told before
• Questions easily understood by children and parents
Feasibility

- Completion time (mean of 20 min)
- PLT perceive the instrument as a guide for making clinical decisions and improving individualized care
- PLT are eager to use it routinely in their practice
TAKE HOME MESSAGES
Measuring what matters...

- **Collaborative approach** with the principal stakeholders (child, parents, health care professionals) is the key-element for developing meaningful outcome measures!

- Development and implementation of instruments into clinical care **needs time**!

- Be ready for **surprises** and therefore be **flexible**!
The process of developing outcomes measures in PPC should be such as those dynamic sculptures...

Created by Theo Jansen
https://www.youtube.com/watch?v=pCtA5kX-Ktg
Acknowledgements

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• To Fonds Marguerite-Marie Delacroix and Institut Parnasse-ISEI for funding this PhD
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Thank you!

https://hcldr.wordpress.com/2015/01/11/the-art-and-skill-of-listening/

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