

“You should ask if I am happy!”

Children’s Palliative Outcomes Scale (POS) developments in Belgium.

Assessing quality of care or quality of life?

Results from the **MOSAİK** study

MOVE to OPEN SHARED ADVANCED INTERVENTIONS for KIDS with life-limiting conditions

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BACKGROUND/AIMS

Paediatric palliative care (PPC) aims to promote quality of life (QoL) but measures to assess QoL in PPC settings are lacking. The **MOSAİK** study had the objective to further develop the APCA children’s palliative outcome scale (Downing et al. 2018), to conduct a cross-cultural validation study of the APCA-CPOS to French and Dutch, to assess the face/content validity, the feasibility and the acceptability of the CPOS-2.

METHODS

A mixed methods design within a collaborative approach with the main stakeholders (Children, Parents, Health care professionals) was applied into 4 substudies:

- i) Secondary data analysis of all national PPC teams 2010-2014
- ii) PRISMA systematic review on instruments used to measure outcomes in PPC;
- iii) Pilot-test of the CPOS-2
- iv) Field-study of the CPOS-2.

RESULTS

- >700 children/year followed by PPC teams in Belgium (Friedel et al. 2018)
- Only 1,7% of children with complex chronic conditions in Brussels region referred to a PPC team (Friedel et al. 2019).
- Scarcity of outcomes measures for PPC, and do not include self-report for children (Friedel et al. 2019).
- 20 items-Children’s palliative outcome scale/CPOS-2 (parent proxy and child self-report) in French and Dutch presents satisfactory reliability and concurrent validity (Friedel et al. 2021).
- CPOS-2 is perceived by PPC teams as a compass to deepen the relation with families, to address unmet needs, to engage in difficult conversations and to confirm their intuition on the level of suffering and care needs.

CONCLUSION

Children and parent’s QoL scores (n=73 families) do not seem to be linked to the severity of a child’s disease. The CPOS-2 might assess QoL more than quality of care.

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