

Do we evaluate the outcomes of our interventions in paediatric palliative care? A systematic review.

Friedel M. RN, PNP, DPCP, MPH, PhD student^{1,2}, **Degryse J.-M.** MD, PhD^{1,3}, **Dubois A.-C.** RN, PNP⁴, **Aujoulat I.** PhD¹

¹ Université catholique de Louvain, Institute for Health and Society, Brussels, Belgium; ² Haute Ecole VINCI, Institut Parnasse-ISEI, Brussels, Belgium; ³ Katholieke Universiteit Leuven, Belgium; ⁴ Master student, Université catholique de Louvain, Faculty of Public Health, Brussels, Belgium.

Background and objective

The main outcome of paediatric palliative care is to promote children's quality of life in a family-centred approach.¹ However, direct measurement of this multidimensional, subjective outcome is challenging and no ideal instrument was found yet.^{2,3}

Measuring outcomes in PPC is a priority for global research in PPC⁴. It is considered **essential to improve clinical care, to evaluate the quality of services and to secure funding**.⁵

This systematic review aims to identify all the outcomes of PPC interventions which had been measured by an instrument.

Methods

Following **PRISMA** checklist.⁶

Databases : Embase, Scopus, Cochrane Library, Psycinfo, Medline
Inclusion criteria: published 2006-2016; available in English, French, German, Italian or Dutch; Definition of PPC; children's age 0-18 years; disease listed in the Directory of life-limiting conditions⁷; empirical data; description of a PPC intervention, its outcomes and a measurement instrument.

Assessment and extraction of data by 3 independent researchers, and each discrepancy was resolved through consensus.

Quality assessment of the studies by a checklist, the Standard Quality Assessment Criteria or Evaluating Primary Research papers from a Variety of Fields.⁸ Calculation of standard error of measurement (SEM) for each instrument of the included studies.

Results

19 articles met inclusion criteria (of 2150)
Most of studies used **quantitative methods (n=15)**, qualitative (n=1), mixed-methods (n=3)

Timeframe: from 1990 to 2014

Multidimensional outcomes included Health-related QoL, spiritual well-being, satisfaction with care/communication, perceived social support and family involvement in treatment or place of care preferences.

PPC interventions ranged from home-based (n=6), to hospital (n=5) respite care (n=3), or a combination (n=3).

23 instruments were found in 14 studies.

Only 3 instruments referred to self (child) reported outcomes measures: PedsQL 4.0⁹, NEST¹⁰, Pedquest¹¹

Quality assessment of studies⁸

High quality	>8/10 (n=5)
Good quality	6-8/10 (n=5)
Moderate quality	4-6/10 (n=9)
Poor quality	< 4/10 (n=0)



Discussion

Outcome measures are predominantly exploring parental perspectives **retrospectively** (after child's death), whereas children are rarely involved in reporting outcomes.

Nine studies indicated improving QoL as the main objective of PPC, but **none of the instruments used**

- **were based on individual QoL measures**
- **combined children's (self) and parental (proxy) report**
- **described an underlying theoretical model**

Although half of the studies were found of high or good quality, the psychometric properties of many instruments used to assess the impact of PPC interventions were found scarce.

Conclusion

To evaluate and improve the quality of PPC interventions, new tools focusing patient-reported outcomes should be developed, involving children in a sensitive and age-appropriate way. The use of instruments combining self and proxy-reports for children lacking verbal capacity (due to age or cognitive impairment) needs further investigation.

References

- ¹ WHO. Definition of palliative care for children, 1998
- ² Huang I, Shenkman E, Madden V, Vadaparampil S, Quinn G, Knapp C. Measuring quality of life in pediatric palliative care: challenges and potential solutions. *Palliative Medicine*. 2010; 24(2): 175-182.
- ³ Coombes LH, Wiseman T, Lucas G, Sangha A, Murtagh F. Health-related quality-of-life outcome measures in paediatric palliative care: a systematic review of psychometric properties and feasibility of use. *Palliat Med*. 2016 Dec;30(10):935-949.
- ⁴ Downing J, Knapp C, Muckaden MA, Fowler-Kerry S, Marston J; ICPCN Scientific Committee. Priorities for global research into children's palliative care: results of an International Delphi Study. *BMC Palliat Care*. 2015; 4;14:36.
- ⁵ Harding R, Wolfe J, Baker JN. Outcomes measurement for Children and Young People. *Journal of Palliative Medicine* 2017, 20(4):313.
- ⁶ Moher D, Liberati A, Tetzlaff J, Altman DG, PRISMA Group. Preferred reporting items for systematic reviews and meta-analyses: The PRISMA statement. *PLoS Med* 2009 21;6(7):e1000097.
- ⁷ Hain R, Devins M, Hastings R, Noyes J. Paediatric Palliative Care: development and pilot study of a "Directory" of life-limiting conditions. *BMC Palliat Care*. 2013; 12:43.
- ⁸ Kmet LM, Lee RC, Cook LS. STANDARD QUALITY ASSESSMENT CRITERIA FOR EVALUATING PRIMARY RESEARCH PAPERS FROM A VARIETY OF FIELDS. HTA initiative #13, Feb 2004.
- ⁹ Varni JW, Burwinkle TM, Seid M. The PedsQL as a pediatric patient-reported outcome: reliability and validity of the PedsQL Measurement Model in 25,000 children. *Expert Rev Pharmacoecon Outcomes Res*. 2005 Dec;5(6):705-19. doi: 10.1586/14737167.5.6.705.
- ¹⁰ Emanuel LL, Alpert HR, Emanuel EE Concise screening questions for clinical assessments of terminal care: the needs near the end-of-life care screening tool. *J Palliat Med*. 2001 Winter;4(4):465-74.
- ¹¹ Wolfe J, Orellana L, Cook EF, Ullrich C, Kang T, Geyer JR, Feudtner C, Weeks JC, Dussel V. Improving the care of children with advanced cancer by using an electronic patient-reported feedback intervention: results from the PediQUEST randomized controlled trial. *J Clin Oncol*. 2014.10;32(11):1119-26

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Contact: marie.friedel@uclouvain.be

