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

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Background and objective
The main outcome of paediatric palliative care is to promote children’s quality of life in a family-centred approach. However, direct measurement of this multidimensional, subjective outcome is challenging and no ideal instrument was found yet.

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

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

Methods
Following PRISMA checklist. 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 conditions; 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. This systematic review used the quality assessment tool to evaluate the quality of the studies included.

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 hospital-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 4.0, NEST, Pediquest.

Quality assessment of studies

- 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

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