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Title: Measuring quality of dying, death and end-of-life care for children and young people: a scoping review of available tools

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Aims: The care provided up to and during end-of-life for children and young people is extremely important and there is a responsibility on healthcare professionals to ensure it is of a high quality. Patient (or proxy) reported outcomes (PROs) are central to the evaluation of care quality, yet the field of PROs in paediatric end-of-life care is poorly understood. This scoping review aimed to: i) identify tools designed to assess the quality of dying, death and end-of-life care for children and young people; and ii) describe data on the validity and reliability of these tools.

Methods: Systematic searches were conducted on four databases (MEDLINE, EMBASE, CINAHL and PsycINFO) and grey literature for studies published between 01/2000 and 06/2021. Results were reviewed by independent teams of reviewers to identify primary research studies featuring tools assessing quality of death, dying or quality of care at end-of-life (defined as the last month of life). Data from included studies on the study, tool, findings, and psychometrics was extracted using an a priori extraction sheet and qualitatively synthesised. The tools' content was conceptually mapped on to a seven-dimension framework designed to characterise the 'good death of a child'.

Results: From 2078 search results, 18 studies, reporting on 11 tools, were included. All tools were 'proxy' reported by either the primary caregiver or healthcare professional and all, bar one, was designed for use after the child's death. All tools assessed aspects of quality of life during the dying phase (e.g., pain, emotional wellbeing) and preparation for death (e.g., communication). The majority assessed aspects of care (e.g., religion/spirituality; n = 10), participation (e.g., being present at death; n = 9), and personal style (e.g., dignity, individuality; n = 8). Less coverage was given to impact on survivors (e.g., grief/bereavement; n = 5) and legacy (e.g., memories, ritual; n = 4). Only 6 tools had supporting psychometric evidence.

Conclusions: Eleven tools were identified assessing dying, death and end-of-life care for children and young people. Their limitations included not including the patients' perspective; limited coverage of some aspects of a 'good death', and insufficient psychometric evidence.