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Palliative Medicine

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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Keywords:	child, adolescent, palliative care, quality of death, quality of dying, terminal care, tools, review
Abstract:	<p>Background: The circumstances and care provided at the end of a child's life have a profound impact on family members. Although assessing experiences and outcomes during this time is challenging, healthcare professionals have a responsibility to ensure high quality of care is provided.</p> <p>Aim: To identify available tools which measure the quality of dying, death and end-of-life care for children and young people; describe the content, and data on validity and reliability of existing tools.</p> <p>Design: Scoping review was conducted following the Arksey and O'Malley methodological framework.</p> <p>Data sources: Four electronic databases (MEDLINE, EMBASE, CINAHL and PsycINFO) and grey literature were searched for studies published in</p>

	<p>English (January 2000 to June 2021). A review of reference lists and citation searching was also undertaken. Tools needed to include a focus on the 'dying' phase of illness (defined as the last month of life).</p> <p>Results: From 2078 articles, a total of 18 studies, reporting on 11 tools were identified. All tools were completed by primary caregivers or healthcare professionals as 'proxy' assessments; all except one was undertaken after death. Question items about quality of life and preparation for death were found in all tools; items relating to cultural aspects of care, grief and financial costs were less common. Only 6/11 had undergone psychometric testing within a paediatric palliative care setting.</p> <p>Conclusions: Future research should include ways to adapt, refine, and improve existing tools. Assessing their wider application in different clinical and cultural settings and conducting further psychometric assessment represent areas of focus.</p>



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Abstract (250)

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Conclusions: Future research should include ways to adapt, refine, and improve existing tools. Assessing their wider application in different clinical and cultural settings and conducting further psychometric assessment represent areas of focus.

Key words

child; adolescent; palliative care; quality of death; quality of dying; terminal care; tools; review

Key statements

What is already known about the topic?

- The circumstances and care received at the end of a child's life can have a profound effect on parents and siblings.
- Measuring experiences and outcomes during this time is challenging but extremely important to ensure high quality of care is provided.

What this paper adds

- This is the first scoping review to systematically identify tools assessing the quality of dying, death, and end-of-life care for children and young people.
- Gaps were identified in the assessment of salient domains relating to cultural aspects of care, economic costs and grief.
- Only six of the 11 tools had conducted specific psychometric testing within a paediatric palliative care setting.

Implications for practice, theory or policy

- Rather than developing new tools, future focus should include ways to adapt, refine, and improve existing ones.
- Further work is needed to determine whether the existing tools are suitable for use in a wider cultural context.

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- The direct views of the dying child and those of the sibling are not captured by existing measures.

For Peer Review

Introduction

Despite marked improvements in health services, medical treatments and public health, over 4600 babies, children and young people aged 0-19 years die each year in high-income countries, such as the United Kingdom (UK).¹ Globally, the Lancet Commission highlighted that 2.5 million children die each year with 'serious health related suffering,' with the majority of deaths occurring in low and middle income countries.² Therefore, a large number of parents and other family members worldwide suffer the consequences of a child bereavement. The effects of the death of a child on parental health and wellbeing are well known.³⁻⁶ However, the circumstances and care received at the end of a child's life can have a profound effect on parents and siblings in terms of their subsequent relationships, roles, friendships, and ability to carry on with their lives.⁷ The key elements of a 'good death'⁸ from the perspective of a dying child, the child's family and the healthcare providers, include: preserving quality of life; preparation for death; specific aspects of care such as continuity, addressing cultural and spiritual concerns; and considering the impact on survivors.⁹

The period of care up to and during the end of a child's life is extremely important and healthcare professionals have a responsibility to ensure high quality care, including dignity, respect and symptom control, is provided during this time. Defining high quality care at the very end of life is greatly dependent on the preferences and priorities of the patient and their family and their views are central to any efforts to measure quality. Measuring care, outcomes and experiences during end-of-life is challenging but patient reported outcome measures (PROMs) can be used.¹⁰ Although the patient's perspective on the quality of end-of-life care should be sought whenever possible, this is not easy, especially with children. Children receiving palliative care may be non-verbal, too young, or too unwell to complete self-report tools.¹¹ Debate also exists about who is best placed to complete outcome measures for children and young people.¹¹ Potential 'proxy' assessments can be undertaken by a parent, carer, or professional, but their degree of agreement with child self-report measures is variable. For example, child and parent scores tend to be better correlated for

more observable, physical aspects of care, and poorer for issues such as emotional problems.¹²

When evaluating outcomes, it is often the case that a range of PROMs are available that could be used for a given purpose (i.e. to assess quality of end-of-life care and death).

Reviews and evaluation work are therefore necessary for researchers and clinicians to help map what tools are available and their supporting psychometric evidence. In adults, a number of systematic reviews have identified, appraised and assessed tools used with ‘proxies’ e.g. bereaved family carers after the death to measure quality of end-of-life care.¹³⁻

¹⁶ None have specifically focused on tools used to assess quality of dying, death, and care at the very end of life for children and young people.

Scoping reviews represent a way of mapping broad areas; they provide breadth, as compared to depth, and help identify any research gaps in the literature.¹⁷ Within this scoping review, we aimed to address the following research question:

What existing tools are available to measure the quality of dying, death, and end-of-life care for children and young people?

An additional sub-question was:

What can we determine about the quality of these tools e.g., comprehensiveness of content, assessment for validity and reliability (as demonstrated by their development process and reported psychometric testing)?

Methods

Design

The scoping review was conducted in five stages following the Arksey and O’Malley framework¹⁷: identifying the research question; identifying relevant studies; study selection; charting the data; and collating, summarising and reporting the results. Additionally, we incorporated enhancements to this original framework using the Joanne Briggs Institute

guidance (<https://jbi.global/scoping-review-network/resources>). Reporting was informed by the PRISMA extension for Scoping Reviews (PRISMA-Scr).¹⁸

Search strategy

Working in collaboration with a subject librarian (MC), an initial limited search of EMBASE was undertaken to identify relevant target papers. Text words within titles and abstracts and the index terms of these articles were used to generate a full search strategy. The search strategy consisted of four main concepts: 'quality of death', 'tool', 'palliative care', and 'children and young people' (Textbox 1). We defined 'children and young people' as those less than 25 years of age, to include adolescents as well as younger children.¹⁹ We did not include studies which focused solely on neonatal deaths (within first 27 days of life)¹ as these tend to relate to perinatal factors,¹ infections and premature birth.²⁰ For the purposes of this review, the 'dying period of their illness' was regarded as the last month of life, reflecting that advanced, incurable illnesses have different disease trajectories. Where a specific time period was not stated, tools which had specific questions about the quality of dying or death were also included.

The National Institute for Health and Care Excellence (NICE) guidance for end-of-life care for children²¹ was used to inform the chosen search terms under each search concept. Modifications were made, for example, to ensure the search strategy focused on the 'dying period' rather than the broader remit of palliative care. An electronic literature search was conducted on 15th June 2021 with four electronic databases (MEDLINE, CINAHL, EMBASE and PsycINFO) covering the years from January 2000 to June 2021 (Supplementary file 1). This time period reflects more recent changes within paediatric palliative care (e.g., formation of the Association of Paediatric Palliative Medicine within the UK (<https://www.appm.org.uk/>)). Specified inclusion and exclusion criteria (Textbox 1) were used to identify studies.

Textbox 1. Inclusion and Exclusion Criteria

Inclusion Criteria

- Focus on tools used to assess quality of death, dying or quality of care at the end of life
- Participants are children or young people identified as dying OR parents/family members/ carers/healthcare professionals caring for dying children or young people OR recently bereaved parents /family members
- Published studies of any research design

Exclusion Criteria

- Focus only on neonates or individuals > 25 years old
- Focus on tools, used with children /young people with a life-limiting illness, BUT have not been used to assess the dying period of their illness (defined for the purpose of this review as 'last month of life')
- Articles such as case studies, case series, books, editorials, commentary or opinion pieces, or conference abstracts
- In language other than English

Titles and abstracts were initially screened by teams of two independent reviewers. A full text review of all potentially eligible studies was conducted independently the same teams; any areas of uncertainty were resolved by discussion with the lead author. Review articles were not included, but reference lists were screened to identify any additional papers. A citation search of all selected articles was completed, and reference lists of all included papers were screened for potentially relevant studies. Grey literature was also searched using the search terms "*palliative care*" AND (*child* OR *children*) AND (*questionnaire* OR *survey*) AND "*quality of death*". These included Internet searches of Google, World Health Organisation Europe, NICE, and Royal College of Nursing. Specific organisation websites were reviewed for information on potential tools.

Data extraction

Data was extracted using a specially designed proforma (piloted prior to use) by one member of the research team and verified by the lead author. Data was mapped out, using selected principles developed by the Scientific Advisory Committee of the Medical Outcomes Trust to assess quality-of-life instruments,²² namely: conceptual model, and reported psychometric testing (validity and reliability). The content of each tool was mapped to the seven key dimensions of a 'good death' (from research which incorporated the perspectives of the dying child, the child's family and healthcare providers).⁹ These considerations were supplemented by information on the study objective, tool purpose and description, assessment period, setting, population, participants, and key study findings.

Collating and summarising data

Charted data were then tabulated into the following categories, reflecting the predominant use of the tools:

1. Healthcare professional: tool used solely with healthcare professionals
2. Cancer: tool used solely within a cancer population
3. Cancer and non-cancer: tool used in populations with more than one disease groups (both malignant and non-malignant illnesses)
4. Life-limiting cardiac disease: tool used solely within an advanced cardiac disease population.

Comparisons were made between the extracted results focusing on development and use, content, participants and psychometric testing. This method highlighted dominant areas and allowed gaps to be identified. In keeping with the accepted remit of scoping review guidance, specific quality appraisal (e.g., of the methodology or psychometric properties), was not conducted. Rather, where documented within the manuscripts, these details were directly extracted. Where specific details were missing about tool content, the corresponding author of the relevant study was contacted and invited to provide further information.

Results

Range of studies

The initial search identified 2078 articles across all databases. Removal of duplicates resulted in 1663 papers, 65 of which were retrieved for full text review. A further 49 papers were excluded on reviewing full papers (Figure 1). Two additional articles were identified through reference lists and citation searches. A total of 18 papers²³⁻⁴⁰ were included in the review, reporting on 11 tools. One study reported on the use of two different tools,²⁷ whereas all other studies used a single tool.

The 18 studies were conducted in 7 countries: USA (n=9);^{25, 27-29, 35, 36, 38-40} Japan (n=2);^{23, 24} Switzerland (n=2);^{32, 33} Germany (n=2);^{30, 31} Canada (n=1);³⁷ South Korea (n=1);²⁶ and Spain

(n=1).³⁴ Twelve of the studies involved children's hospitals: paediatric oncology +/- haematology departments (n=5);^{23, 24, 26, 28, 31} paediatric cardiology centres (n=2);^{39, 40} paediatric intensive care units (n=2);^{25, 38} medical centres/hospitals (n=2);^{27, 30} or mixed hospital environments (n=1).³⁴ The remaining 6 studies involved hospital and community settings (e.g., home care).^{29, 32, 33, 35-37} The primary objective of the studies varied, with the two main aims being to develop and test a tool^{24, 25, 32, 35, 37} or to explore perspectives of parents and/or healthcare professionals about the quality of dying and end-of-life care experiences.^{23, 26-31, 33, 34, 36, 38, 39} Study participants comprised parents only (n=10);^{26, 28-34, 39, 40} healthcare professionals only (n=3);²³⁻²⁵ parents and partners (n=1);²⁷ parents and guardians (n=1);³⁸ and parents and healthcare professionals (n=3).^{35-37, 40} In total, there were 1859 participants involved in the development, validation or use of tools, representing 1048 children and young people. For studies involving family caregivers, participants tended to be female (range 56-100%) and, when specified, from a white ethnic background (range 72.9-100%).

Range of tools

The 11 tools were sub-categorised into the defined groups: sole use by healthcare professional tools (n=2) (Table 1); tools used within a cancer population (n=4) (Table 2); tools used with both cancer and non-cancer populations (n=4) (Table 3); and tools used solely within a life-limiting cardiac disease population (n=1) (Table 4). The content of each tool was mapped to the key dimensions of a 'good death' (Table 5).

With the exception of one tool,³⁵ all the other tools were developed for use after death. The time period in which the child's death had occurred ranged from within a previous 12-month period²⁵ up to the previous seven years.²⁸ No tool had been developed or used directly with patients (child or young person) during the dying phase of their illness nor specifically with siblings. The definitions of the specified assessment period varied and could include the last three days (n=2);^{24, 25} last 4 weeks (n=1)³³ or last month prior to death (n=1).²⁸ Additionally, the phrase 'the time before death when the physician estimated that the child had no realistic

chance for cure' was used (n=2).^{30, 40} For the remaining tools, the assessment period wasn't defined within the study, but question items specifically asked about dying or death. Most (n=10) tools were used within the context of a survey; the other, had also been used within an interview setting (face-to-face or via telephone).²⁸ One of the surveys was undertaken alongside a concurrent qualitative interview.³⁸

All the tools assessed aspects of quality of life (e.g., pain and symptom control) and preparation for death (e.g., communication, decision-making). Items relating to 'legacy' (e.g., establishing meaning, importance of ritual / funeral), were assessed within five tools (Table 5). Question items less frequently asked about cultural aspects of care (n=2), economic costs (n=2) and grief and bereavement (n=4).

Tools used predominately with Healthcare Professionals

The two tools used with healthcare professionals were the Good Death Inventory - Paediatrics (GDI-P)^{23, 24} and the Paediatric Intensive Care Unit – Quality of Dying and Death 20 (PICU-QODD)²⁵ (Table 1).

Quality of tool

Both tools underwent a robust process of development and have been tested for validity and reliability.^{23, 24} PICU-QODD-20 has question items mapping across all 7 dimensions of a 'good death'.²⁵

Clinical implications

Whereas the GDI-P purpose is focused on nursing perspectives of paediatric cancer deaths across several care settings (including hospital, PICU and home),²³ the PICU-QODD-20 seeks to obtain a variety of healthcare professional perspectives about deaths due to different illnesses but only for those occurring in PICU.²⁵

Tool used solely within a cancer population

The four tools used solely within a cancer population were: Good Death Inventory (GDI),²⁶ Family Satisfaction with the End-of-Life Care (FAMCARE),²⁷ the Toolkit After-Death Bereaved Family Member Interview (subsequently referred to as the ‘Toolkit’)²⁷ and a questionnaire, initially developed by Wolfe et al, which was later called Survey about Caring for Children with Cancer (SCCC)²⁸⁻³¹(Table 2).

Quality of tool

The SCCC is the most extensive tool (211 items)²⁸⁻³¹ with question items spanning across many different aspects of cancer care as well those relating to care at the very end of life. It has undergone a careful process of question item development and selection. FAMCARE and the ‘Toolkit’²⁷ are established, validated tools previously used with bereaved families for adult deaths. Only the GDI,²⁶ however, has undergone initial psychometric testing of validity and reliability specifically within a palliative paediatric population. None of the tools incorporated all aspects of multi-dimensionality in terms of a ‘good death’.

Clinical findings

Findings from the study using the GDI indicated that aspects of advance care planning (e.g., establishing a ‘living will’) were associated with more positive parental perspectives about a ‘good death’.²⁶ Both FAMCARE and the ‘Toolkit’ were used within the same study, assessing the quality of end-of-life care for adolescents and young people (aged 15-39 years) from the caregiver perspective.²⁷ The study showed most caregivers were satisfied with care, but there were unmet information and religious/spiritual care needs.²⁷ SCCC has been used within four studies conducted in two different countries. Within the first study, 92 (89%) bereaved parents reported their child experienced ‘a lot’ or ‘a great deal’ of suffering’, although 70% said the actual death was ‘very peaceful’.²⁸ A further study found that those receiving home care services were more likely to die at home.²⁹ An additional two studies,

conducted within a single state in Germany, enabled a comparison of quality of end-of-life care over two time periods.^{30, 31} Although symptom reporting was similar, preferences about place of death were more concurrent with actual place of death in the second study.³¹

Tool used with both cancer and non-cancer populations

The four tools used within both cancer and non-cancer populations were: the PELICAN questionnaire (PaPEQu);^{32, 33} the Experience @HOME Measure;^{35, 36} the Quality of Children's End-of-life Care Instrument;³⁷ and the PICU-QODD³⁸(Table 3).

Quality of tool

The first three tools have all undergone a robust process of development;^{32, 35, 37} the PICU-QODD was modified from an existing, validated tool used with bereaved families for adult deaths.³⁸ All tools except the Experience @HOME Measure have reported on their psychometric properties with the PaPEQu being the most extensively reported.³² Only the PICU-QODD covers all seven dimensions of a 'good death'.³⁸

Clinical findings

The Experience @HOME Measure focuses purely on the home care setting. It is the only tool intended to be used before death and retrospectively assesses care provided in the previous week.^{35, 36} The Quality of Children's End-of-life Care Instrument focuses on the bereaved mothers' perspective of the quality of end-of-life care.³⁷ Both the PaPEQu and the PICU-QODD have been used within clinical studies. PaPEQu has been used to assess quality of end-of-life care for children who died from a variety of illnesses (cardiac, neurological or oncological illness or during the first four weeks of life).³² Studies show that bereaved parents' perceptions about overall care were highest for children dying with cancer, those who had engaged with Paediatric Palliative Care teams, and lowest for children dying with neurological conditions or in the neonatal period.^{32, 33} The PICU-QODD was used alongside a qualitative interview and explored both bereaved parents and

grandparents’ views about end-of-life care. The majority of aspects of care within the PICU-QODD were rated highly, whereas the qualitative findings highlighted the need for more direct communication with healthcare professionals.³⁸

Tool used solely within a life-limiting cardiac population

The one tool used within a life-limiting cardiac population is the Survey for Caring for Children with Advanced Heart Disease (SCCHD)^{39, 40} (Table 4).

Quality of tool

This was developed from the Wolfe et al questionnaire,^{28, 39} although no psychometric testing has been reported.

Clinical findings

A subsequent study used the SCCHD to assess both bereaved parents and cardiologist views reflecting different perspectives about the degree of preparation for death and overall quality of care.⁴⁰

Discussion

Main findings

This scoping review identified 11 tools, developed and used across seven countries, which assess the quality of dying, death and end-of-life care for children and young people. The majority of tools have been used after the child’s death with bereaved parents, predominantly mothers, in a hospital setting. In terms of content, all tools asked about quality of life and preparation for death whereas aspects relating to cultural concerns, financial costs, grief and bereavement were more variable. The PICU-QODD-20 and PICU-QODD had the most comprehensive content across the dimensions of a ‘good death’.

Only six tools have undergone some degree of psychometric testing for validity and reliability specifically within a paediatric palliative care population. Those which have reported the most extensive testing for validity and reliability are GDI-P, PICU-QODD-20 and PaPEQu, whereas initial findings were more limited for the GDI, the Quality of Children's End-of-Life Care Instrument and PICU-QODD. Although the SCCC has not undergone formal psychometric validation, it represents an extensive 'question bank' which has been developed and used across two different countries to assess quality of end-of-life care. No tool has addressed the challenges of assessing the views of children or young people themselves or specifically been used to assess the perspective of siblings.

What this study adds

Whilst previous systematic reviews, have focused on health-related quality of life outcome measures,¹¹ none have been directed towards identifying tools used to assess quality of care provided at the end of a child's life. This scoping review allows comparison of tools and helps identify gaps for which future research is needed.

Establishing whether the identified tools are suitable for use in a wider cultural context is required. Existing studies have predominately been undertaken within the USA, which has a specific type of healthcare system, reliant on health coverage and economic resources. No tools have been developed or revised to be used within the UK, Ireland, Canada nor Australia, which are all regarded as having a high level of palliative care integration into mainstream children's healthcare services.⁴¹ The majority of studies were conducted, at least in part, within hospital settings. This may reflect specific cultures such as that within the UK, where most children and young people's deaths occur in hospital.⁴² International partnerships have previously been recommended to enhance learning and inform tool validation.⁴³ Hence, there is a need to establish whether existing tools are relevant and meaningful across much more diverse countries and cultures. This is especially pertinent when terms such as 'grief' and 'distress' can be specific to the English language.^{44, 45}

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Rather than developing new tools, future focus should be on further improving and validating existing tools. It is also important to consider whether the identified tools have utility within different clinical settings. For example, the content of PICU-QODD-20 covered all seven dimensions of a ‘good death’ and has been assessed for some aspects of validity and reliability.²⁵ The remit of the tool, however, is within a very specific intensive care environment. It would be important to establish whether this tool could be adapted and have wider application. The SCCHD offered comparative views about care from both the bereaved parents and the cardiologists’ perspective.⁴⁰ As there are two different versions of the GDI and the PICU-QODD (one for healthcare professionals; one for bereaved parents),^{24-26, 38} these tools also offer that possibility. Establishing whether tools such as these could be adapted to incorporate the views of siblings would also be of value. The Experience @HOME Measure is the only tool used before death.³⁵ Hence, exploring the possibility of the dying child’s ability to participate in completion would be a further area of exploration.

Only one study combined the use of a tool with an individual qualitative interview.³⁸ The opportunity for bereaved relatives to be able to ‘tell their story’, to share narrative accounts, is recognised to have potential therapeutic benefit.⁴⁶ Hence, it would seem important for existing tools to include free-text space to enable opportunities for sharing experiences not captured within the specific question domains. Additionally, it has been recognised that there is strength in combining both qualitative and quantitative approaches for paediatric palliative care research⁴⁷ - evaluation of quality of dying, death and end-of-life care would be an area where both rigorously developed outcomes and qualitative approaches would enrich the detail of reported experiences.

Strengths and limitations of the study

The search strategy conducted followed a robust, systematic methodology and included grey literature, reverse citation searching and screening of reference lists. We were not able to contact every individual author to enquire about additional work/unpublished studies, hence some relevant studies may have been overlooked. Additionally, our main focus was on the

identification and development of available tools so subsequent studies focusing only on their use, may have been omitted. In keeping with the aims of a scoping review, we did not undertake a formal assessment of study quality nor psychometric properties. As the reporting of these details within each study was not always consistent, there may be some ambiguity when directly comparing different tools. Additionally, we did not consider all the principles which can be used to assess quality-of-life instruments e.g. respondent and administrative burden. The choice of our dimensions for a 'good death' came from a study which, although involved multiple stakeholders, was focused on children dying from cancer.⁹ Experiences about what constitutes a 'good death', however, is complex and multi-faceted, potentially varying for different types of life-limiting illnesses.^{48, 49}

Conclusion

This review has identified 11 available tools for assessing quality of dying, death and end-of-life care in paediatrics, yet there is variability in terms of instrument content and evidenced quality (i.e., degree of assessment of validity and reliability). Improvement of existing tools should involve the inclusion of additional items representing salient domains of a 'good death' and further psychometric testing to ensure more valid, reliable and comprehensive assessment. International partnerships are key to determining suitability for wider use, informing tool validation and application across different countries and cultures. Despite the recognised challenges, sensitive and timely ways to identify data about the last weeks of life, can help facilitate learning about experiences, leading to further improvements in quality of care both before and after the death.

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Declarations

Authorship

CRM conceived the initial idea and designed the study along with MC, PT, PAP, LZ, KF and LKF. MC undertook the searches. CRM, KAS, PT, PAP, LZ, VC, CG, and NT conducted initial screening and full manuscript reviews. CRM and KAS analysed and interpreted the data. CRM and KAS drafted the initial manuscript. All authors have reviewed the article critically for clarity and intellectual content, provided revisions and have approved this version for submission.

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Conflicts of interest

The authors declare that there is no conflict of interest.

Research ethics and consent

As this study represents a scoping literature review, not formal ethics approval was required.

Data management and sharing

Further information about the search strategies are available from the corresponding author on reasonable request.

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For Peer Review

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Figure 1. PRISMA flow diagram for the scoping review process

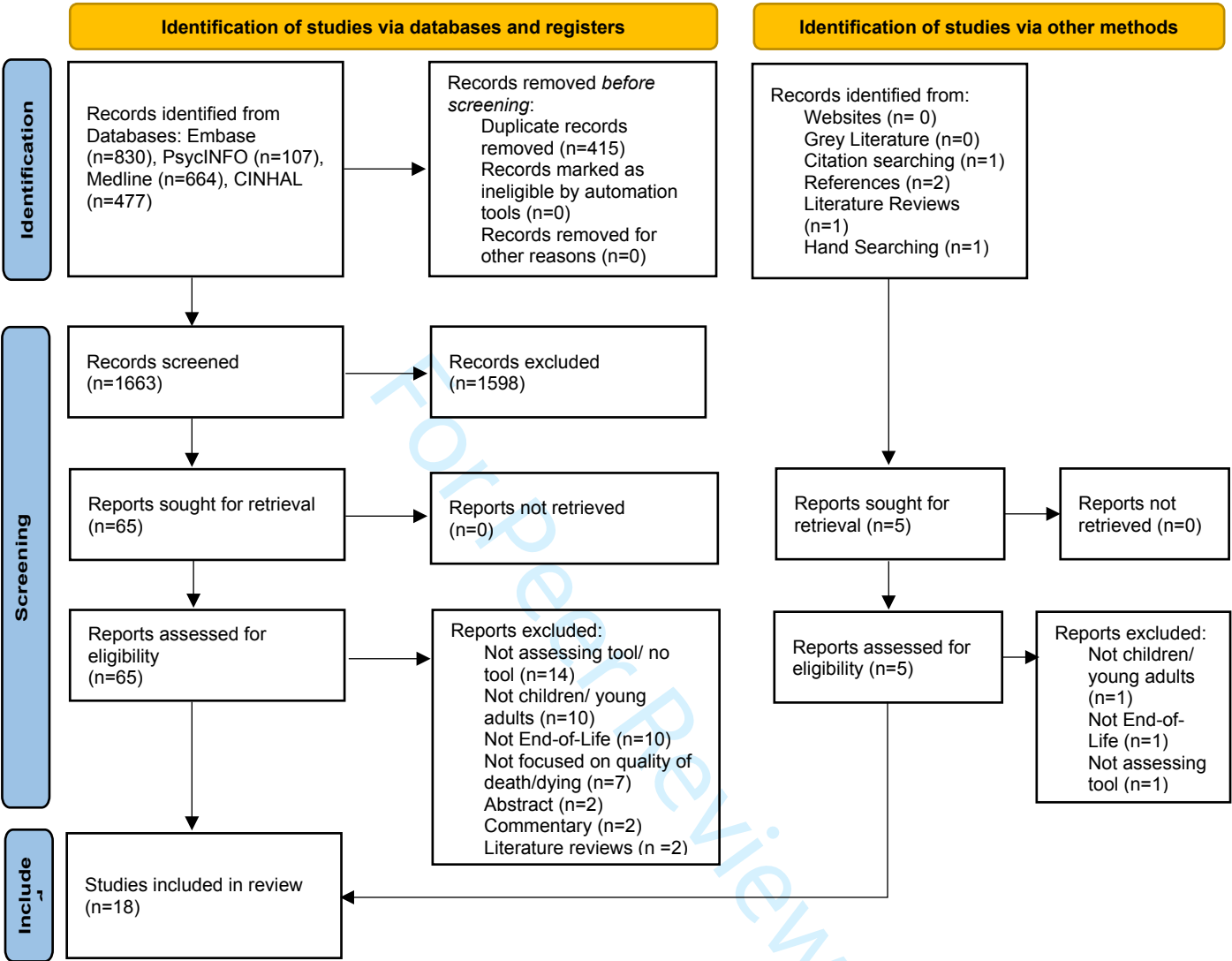


Table 1: Studies detailing the development, validation and initial use of healthcare professional tools assessing quality of dying, death, and end-of-life care for children / young adults

	Study objective	Purpose of tool & underlying concepts	Description of tool & specified assessment period	Details of tool development	Setting	Population	Participants	Reported psychometric testing	Key findings including any quality of dying, death, EOL evaluations
Good death Inventory – Paediatrics (GDI-P)									
Nagoya Y et al, 2017 ²²	To identify & describe important items & concepts related to QoL for paediatric cancer patients' EOL in Japan	To evaluate QoL of paediatric cancer patient's EOL Care Four dimensions- physical, psychological, social & spiritual	Used after-death Questionnaire – survey Initial 55 items reduced to 35 items Response options on a 5-point Likert-type scale from 'very important' to 'not important' Time phase='time before death when the physician estimated that the child had no realistic chance for cure'; items include ' <i>dying in presence of family</i> '	Items developed from previous qualitative research (7 bereaved families, 7 paediatric oncologists & 13 nurses - published in Japanese)	Japan Nationwide survey of 75 paediatric oncology treatment facilities	Directors of 46 paediatric oncology institutes & 49 nursing institutes who had at least 1x EOL care experience	157/253 oncology directors (RR 62.1%); 48 (31%) female; mean age 40.53 years (SD 8.75); ethnicity N/S 270/646 nursing directors (RR 41.8%); 254 (94.8%) female; mean age 34.35 years (SD 8.79); ethnicity N/S	Face validity assessed by 4 nurses; 35 items rated 'very important/ important' by >80% respondents EFA identified 12 QoL domains: Playing & learning; Fulfilling wishes; Spending time with family; Receiving relief from physical & psychological suffering; Making wonderful memories; Having a good relationship with the staff; Having a peaceful death in the presence of family; Spending time with a minimum of medical treatment; Living one's life as usual; Spending time in a calm hospital environment; Being oneself; Having a close family	Identified 35 common, important QoL items for assessing EOL care in paediatric cancer patients
Nagoya Y et al 2020 ²³	To develop & test a proxy rating scale assessing QoL of paediatric	To assess QoL of paediatric patients receiving EOL care, as perceived by nursing staff	Used after-death Questionnaire – survey	Developed from previous qualitative & quantitative	Japan 60 paediatric facilities	Paediatric nurses working in EOL care	85/112 completed QA (RR 76%)	Good internal consistency (Cronbach's α 0.71-0.87 for each factor; overall scale 0.88)	GDI-P usable as a proxy outcome measure

	cancer patients receiving EOL Care To develop a shortened version of GDI-P	8 main factors: A peaceful death in the presence of family; Relief from physical & psychological suffering; Playing & learning; Making wonderful memories & fulfilling wishes; Living a normal life; Good relationships with medical staff; Spending time with the family; Minimum medical treatment	GDI-P: 8 factors with 22 items Response options on a 5-point Likert-type scale from 'strongly agree' to 'strongly disagree' Higher scores = greater degree of achievement for that item Time phase='time before death when physicians estimated the child had no realistic chance of being cured'	work (see above) Tested for face validity (4 nurses) & pilot study (n=7, 6 nurses & 1 physician) at single study centre Short version GDI-P: 8 items (one from each factor)	including hospitals for childhood cancer	Cared for child (<=20 years) who died from cancer (Oct 2012–Oct 2015) Child's family been told child was in EOL phase Asked for 2 nurses' perceptions per child	32 pairs (64 QA) where 2 nurses evaluated single child; 21 single assessments Mean age 31.9 years (SD 7.5); 81 (95%) female; ethnicity N/S Representing 53 children; mean age 8.5 years (SD 4.9); most died in general hospital ward (84%); also deaths in ICU, home & 'unknown' 47 retest QA returned	Construct validity assessed by convergent & discriminant validity testing Low GFI<0.90 - potentially due to small sample size ICCs for test-retest moderate-good (0.61-0.94) Short version GDI-P: correlations between item-overall scores ranged from 0.82-0.91; Cronbach's α =0.67 for all 8 items	assessing EOL phase of illness for paediatric cancer patients
Pediatric Intensive Care Unit - Quality of Dying and Death 20 (PICU-QODD-20)									
Seller DE et al, 2015 ²⁴	To develop & assess reliability & validity of a clinician measure of the quality of dying & death in the paediatric intensive care setting	To assess 'the degree to which the hopes & priorities of the patient &/or the family for the process of dying & the moment of death are respected & met'	Used after-death Questionnaire - survey Final version has 20 items; each has 11-point scale (0='as terrible' to 10='as good as it could be, under the circumstances') Standardised score out of 100; higher scores = more positive experience	Adapted from adult version of QODD Developed using focus groups with PICU clinicians; qualitative interviews with parents of children who died in a PICU	USA PICU's from 2 large children's hospitals	5 types of HCP for each child's death: 'bedside' nurse; child's primary nurse; child's intensivist; most involved critical care fellow & other clinician	300/551 completed QA (RR 54%) Percentage of distributed QA completed by: 'bedside' nurse 55%, primary nurse 50%,	Good internal consistency (Cronbach α =0.891-0.959) Construct validity assessed by comparison with other measures: total PICU-QODD-20 score significantly related to single-item 'quality of EOL care' and 'Meeting Family	Findings provide initial support that PICU-QODD-20 is valid & reliable outcome of the quality of dying & death in the PICU setting

		Key themes within final items: Communication issues; Privacy & PICU environment issues; Decisions to withdraw life support; Pain & symptom management; Emotional needs/support of family; Physical and instrumental needs of family; Spirituality & religion/cultural issues; Continuity/coordination of care; Fulfilling the parental role; Grief & bereavement	Time phase=last 3 days of life	& cognitive interviews; systematic literature review		(psychosocial staff) To children who died in a PICU over 12-month period from 2008 (multiple different causes of death)	intensivist 57%, fellow 47%, other clinician 61% 33-95% female; 5-27% non Caucasian; age N/S Representing 94 children; mean age 7.3 years (SD 7.2); range 0-24 years; <i>'just under half were female'</i> ; ethnicity not consistently recorded	Needs' scale (r=0.333-0.797) Hypothesized that 'family barriers' (e.g. anger, unrealistic expectations) associated with poorer experiences of dying & death; PICU-QODD-20 negatively associated with >= 2/8 potential barriers for all clinicians except bedside nurses	
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EFA=exploratory factor analysis; EOL=end-of-life; GFI=goodness of fit index; HCP=healthcare professional; ICC=intraclass correlation; N/S=not stated; PICU=paediatric intensive care unit; QA=questionnaire; QODD=Quality Of Dying and Death; QoL=quality of life; RR=response rate; SD=standard deviation; USA=United States of America

Table 2: Studies detailing the development, validation and initial use of tools assessing quality of dying, death, and end-of-life care for children / young adults within a cancer population

	Study objective	Purpose of tool & underlying concepts	Description of tool & specified assessment period	Details of tool development	Setting	Population	Participants	Reported psychometric testing	Key findings including any quality of dying, death, EOL evaluations
Good Death Inventory (GDI)									
Kim JY et al, 2021 ²⁵	<p>To assess essential domains for a 'good death,' using the GDI, as perceived by parents whose children have cancer</p> <p>To examine characteristics associated with perceptions of a good death</p>	<p>To evaluate perceptions regarding EOL care from the perspective of bereaved family members</p> <p>10 core domains: Physical & psychological comfort; Dying in a favourite place; Maintaining hope & pleasure; Good relationships with medical staff; Not being a burden to others; Good relationships with family; Independence; Environmental comfort; Being respected as an individual; Life completion</p>	<p>Used after-death (although this developmental work was conducted prospectively before death)</p> <p>Questionnaire – survey</p> <p>18 domains (10 core, 8 optional); each domain has 3 items</p> <p>Revised original GDI tool so each participant rated the importance of each item using 7-point Likert scale (1=absolutely unnecessary to 7=absolutely necessary)</p> <p>Total GDI score=18-126 (higher scores=good death)</p> <p>Time phase=not specified but domains include focus on death/dying</p>	Previous translation into Korean & validated within adult population	South Korea	Parents to children (aged 7-18 years) who had undergone any stage of cancer treatment	<p>109/120 data analysed (11 had incomplete data)</p> <p>93 (85.3%) female (85.3%); age & ethnicity N/S</p> <p>Representing 109 children; mean age 9.65 years (SD 5.88); 60 (55%) male; ethnicity N/S</p>	<p>Face validity of revised GDI evaluated by 3 parents; parents within current study also 'evaluated the validity of revised GDI'</p> <p>Good internal consistency (Cronbach's α - 0.87)</p>	<p>Mean total GDI score was 107.47 (SD 6.02)</p> <p>Most important domains (had highest scores) were "maintaining hope & pleasure" & "being respected as an individual"</p> <p>Perception of good death (highest GDI scores) associated with following factors: children had discussed EOL plans with parents; agreement between children & parents to establish a living will</p>

Family Satisfaction with End-of-life Care (FAMCARE)									
Currie ER et al, 2021 ²⁶	To understand bereaved caregiver perspectives' (to adolescents/young adults (AYA)) about EOL care & quality of EOL communication	To measure family satisfaction with advanced cancer care 4 domains: Family satisfaction with cancer care; Satisfaction with communication with HCP; Availability of clinicians; Pain & symptom management	Used after-death Questionnaire – survey 20 items; 5-point nominal scale from 'very dissatisfied' to 'very satisfied' Time phase=not specified (but used concurrently with tool below)	Established tool previously used & validated with bereaved families for adult deaths	USA 3 academic medical centres with Palliative Care Research Cooperative sites within 3 different states	Bereaved primary caregivers To deceased oncology AYA (aged 15-39); died 2013-2016	35/260 bereaved caregivers completed QA(13.5% RR) 25 (71%) female; 30 (86%) white; age N/S; 15 (44%) spouse/partner; 17 (50%) parent Representing 35 AYA; 11 (31%) <25 years; 15 (43%) female; 28 (80%) white	Not specifically undertaken within this study	Most caregivers satisfied with EOL care; 6 (17%) caregivers dissatisfied with information about prognosis, answers from HCP & availability of doctors
The Toolkit After-Death Bereaved Family Member Interview (TIME)									
Currie ER et al, 2021 ²⁶ Same study as above	As above	To measure quality of EOL care Conceptual model of patient-focused, family centred medical care Toolkit After-Death Bereaved Family Member Interview, previously used with bereaved families for adult deaths	Used after-death Questionnaire - survey 64 items; mix of dichotomous and scaled responses (further details not provided in study) Time phase=not specified but question items include focus on death/ dying e.g. 'was information given about what to expect about dying?'	Established tool previously used & validated with bereaved families for adult deaths	As above	As above	As above	Not specifically undertaken within this study	Unmet needs about what to expect at time of death (n=17, 50%), the dying process (n=15, 45%) & spiritual/religious needs (n=13, 38%) Lowest quality of EOL care scores related to communication & emotional support
Questionnaire initially developed by Wolfe et al; subsequently called 'Survey about Caring for Children with Cancer' (SCCC)									
Wolfe J et al, 2000 ²⁷	To determine patterns of care, symptoms in last	Purpose of tool linked to study objectives:	Used after death	Question items developed from literature,	USA	Bereaved parents	103/165 bereaved parents	Not specifically undertaken	89% reported their child experienced 'a

	month of life, effectiveness of their treatment & factors associated with suffering from pain at EOL for children who die of cancer	To determine patterns of care, symptoms in last month of life, effectiveness of their treatment & factors associated with suffering from pain at EOL for children who die of cancer	Questionnaire - face-to-face or telephone interview 211 items assessing symptoms; degree to which child 'appeared to suffer' (5-point Likert scale); effectiveness of treatment; anxiety, fear, mood; quality of life (determined by 'degree to which he/she had fun'); degree of physician involvement in EOL care; quality of care & communication; involvement of home care staff; decisions & 'peacefulness of the child's death' Time phase=last month of life	parent & HCP focus groups, & existing validated surveys	Single institution (children's hospital & cancer institute)	To children who had died from cancer (1990 – 1997)	completed interviews (62% RR) Mean 43 years (SD=7.7); 86% female; 91% white Representing 103 children; mean age 10.8 (SD 6.7); 46 (45%) female; ethnicity N/S	within this study Instrument was assessed for content, wording, burden on respondents, cognitive validity, & willingness to participate; found to be 'satisfactory'	lot' or 'a great deal of suffering' from >=1 symptom (most common were fatigue, pain, dyspnoea, poor appetite) 70% described their child's death as 'very peaceful' 'Suffering' from pain more likely reported when physician not actively involved in providing EOL care (OR 2.6)
Friedrichsdorf SJ, 2015 ²⁸	To compare EOL pain & symptom management in children with advanced cancer who received care from a paediatric oncology service (Oncology) with those who also received concurrent PPC home care services (PPC/Oncology)	As above – to evaluate EOL care domains Specific domains assessed in this study: Symptoms & their treatment; Quality of life	Used after-death Questionnaire – survey Contains 211 items; prevalence of symptoms, 'suffering' from these, management; decision-making at the EOL; quality of life Time phase=parents recalled aspects of their child's QoL during the last month of their life	As above	USA 2 children's hospitals within single state (including those who had in-patient, out-patient or home care/home hospice services)	Bereaved parents To children (aged 0-17 years) who died of cancer (2002-2008)	60/166 surveys obtained (RR 37%); 50% PPC/Oncology Mean age 43.6 years (SD 7.7); 48 female (81%); 56 white (93%) Representing 60 children; mean age 10.1 years (SD 6.3); 27 (45%) female; ethnicity N/S	Not specifically undertaken within this study	PPC/Oncology group more likely to have constipation (p=0.01) & perceived to 'suffer' from energy loss/fatigue (p=0.007) PPC/Oncology group more likely to have 'fun' (70% vs 45%, p=0.03), to experience 'an event that added meaning' to life (89% vs 63%, p=0.02), & to die at home (93% vs 20%, p<0.0001)

Hechler T et al, 2008 ²⁹	To investigate bereaved parents' perspectives on: symptoms & QoL; characteristics of child's death; anticipation of child's death & care delivery; EOL decisions; impact of death on parents	Used German version of questionnaire developed by Wolfe (see above)	As above Assessing symptoms, QoL, quality of care, burdens after child's death Time phase=time span when parents aware there was 'no realistic chance of their child being cured of cancer' (parents assessed EOL period as average 9 weeks prior to death)	Translated into German; minor modifications; pilot with children's oncologists, nurses, psychologists & interviews with 10 bereaved parents	Germany 6/19 children's hospitals within single state	Bereaved parents To children who had died from cancer (1999-2000)	48/136 bereaved families participated (35% RR); 40 interviews with single parent, 8 with both parents; demographics N/S Representing 48 children; 17 (35%) female; mean age 8 years (SD 4.9), range 1-20; ethnicity N/S	Not specifically undertaken within this study	Fatigue (n=40, 91%) & pain (n=35, 83%) most common symptoms; dyspnoea & anxiety caused most 'suffering' & were less adequately treated 48% children died at home; in hindsight, 88% participants would have chosen home as most appropriate place; 88% rated quality of care for home care team as 'good'/'very good' 7 (15%) weren't contacted by team following death
von Lutzau P, 2012 ³⁰	To investigate bereaved parents' perspectives on: symptoms & QoL at EOL; perspectives about impending death; palliative home care; quality of care EOL decision-making; characteristics of death	Used German version of questionnaire developed by Wolfe (see above)	As above Assessing symptoms, QoL, quality of care, burdens after child's death Time phase=time span when parents aware there was 'no realistic chance of their child being cured of cancer' (parents assessed EOL period as average 8.5 weeks prior to death)	As above	Germany 16 specialised paediatric oncology departments (hospital setting) within single state	Bereaved parents To children who died from cancer (2005-2006)	48/128 bereaved families participated (RR 38.3%); 37 interviews with single parent, 11 with both parents; 35 female (72.9%); age & ethnicity N/S Representing 48 children; 11	Not specifically undertaken within this study	Results suggested some improvement in EOL care c.f. above study Fatigue (n=44, 91.7%) & pain (n=40, 83.3%) most common symptoms; 65% symptoms adequately

							(22.9%) female; mean 9.93 years (SD 7.3); ethnicity N/S		treated; 84% with 'severe' pain treated successfully' 43.8% children had psychological support 24 (50%) died at home; in hindsight, majority (72.9%) of parents would not have changed preference for place of death
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AYA=adolescents and young adults; EOL=end-of-life; HCP=healthcare professional; N/S=not stated; OR=odds ratio; PPC=paediatric palliative care; QA=questionnaire; QoL=quality of life;
RR=response rate; SD=standard deviation; USA=United States of America

Table 3: Studies detailing the development, validation and use of tools assessing quality of dying, death, and end-of-life care for children / young adults within a mixed cancer and non-cancer population

	Study objective	Purpose of tool & underlying concepts	Description of tool & specified assessment period	Details of tool development	Setting	Population	Participants	Reported psychometric testing	Key findings including any quality of dying, death, EOL evaluations
Parental PELICAN Questionnaire (PaPEQu)									
Zimmermann K et al 2015 ³¹	To develop & test the Parental PELICAN Questionnaire (PaPEQu)	<p>To assess parental experiences & needs during EOL care of their child</p> <p>Items generated from 6 quality domains grounded in framework of the 'Initiative for Pediatric Palliative Care'</p> <p>Holistic care of the child; Support of the family unit; Involvement of child & family in communication, decision-making & care planning; Relief of pain & other symptoms; Continuity of care; Grief and bereavement support</p>	<p>Used after-death Questionnaire - survey</p> <p>Separate questionnaires for 4 different diagnostic groups; items organised into scales about parental experiences & indexes for parental needs</p> <p>Experience-related items, 7-point adjective response options or 5-point Likert scale response options with varying end-point anchors e.g., 'never-always', 'not clear at all-very clear'</p> <p>Needs-related items, 7-point adjectival response options with end-point anchors 'not important at all-very important'</p> <p>Overall satisfaction with each of the 6 domains (7-point scale)</p> <p>Additional: to list 3 positive & negative EOL experiences; indicate</p>	<p>Development (4 phases):</p> <ol style="list-style-type: none"> 1. Item generation 2. Validity testing with HCP expert panel (including I-CVI calculations) & cognitive interviews with bereaved mothers (n=4) 3. Translation (from German into French/Italian) 4. Pilot survey 	<p>Switzerland</p> <p>Pilot: children's hospitals (n=3) /paediatric hospital dept (n=1)/ paediatric medical centre (n=1)</p> <p>Main study: children's hospitals/ paediatric units (n=17), long-term institutions (n=2) & community care services/ practices (n=6)</p>	<p>Pilot: bereaved parents (n=36)</p> <p>To children who had died due to cardiac, neurological or oncological illness or during first 4 weeks of life</p> <p>Main study: bereaved parents</p> <p>To child who died (same conditions as above) during 2011-2012</p>	<p>Pilot: 36 families invited; 31 QA sent (mother & father versions) to 20 families; 24 completed QA (77% RR)</p> <p>Main study: 200/224 completed QA (89% RR) representing 124 families; 112 (56%) mothers; 88 (44%) fathers; age N/S</p> <p>No ethnicity data reported, but language = 162 German (81%), 29 French (14.5%), 9 Italian (4.5%)</p> <p>Representing 124 children; median age 3.3 years (range</p>	<p>Development phase: average CVI >0.78; feedback used to reduce/revise items</p> <p>Main study: EFA showed one factor for each scale supporting uni-dimensionality</p> <p>Correlations between scale mean & satisfaction score statistically significant (0.37-0.63)</p>	<p>Psychometric testing of 6 quality domains showed uni-dimensionality & internal consistency of each domain</p>

			areas of life negatively influence by child's death; rate current QoL (10-point VAS)				0.1–17.4); gender & ethnicity N/S		
			Time phase = not specified but used for care within last 4 weeks of life in study below						
Zimmermann K et al 2016 ³²	To describe parental experiences & explore differences in perspectives in relation to underlying medical condition causing death (cardiac, neurological or oncological condition or during the neonatal period)	As above	As above Experience related items range 44–48 items (depending on diagnostic group version); 34 needs-related items; & 13 socio-demographic items Total item count of the PaPEQu range 91–95 items. Time phase=last 4 weeks of life	As above	Switzerland As above (main study): Paediatric hospital (n=17) & community care settings (n=8)	As above (main study): Bereaved parents To children who died due to cardiac, neurological or oncological condition or during the neonatal period (2011 or 2012)	As above (main study) 200/224 completed QA (89% RR); 112 (56%) mothers; 88 (44%) fathers; mean age 40 years (SD=6.48); Swiss residents 87%, migrant families 13%; representing deaths due to cardiac (26, 13%), neurological (48, 24%), oncological (45, 22%) illness or during neonatal period (81, 42%) Representing 124 children median age 3.3 years (range 0.1 - 17.4); gender/ethnicity N/S	As above	Experience scores highest for 'relief of pain & other symptoms' (mean 4.99, SD - 1.05); lowest for 'continuity & coordination of care' (mean 4.29, SD=1.37) Highest perceptions for cancer EOL care (mean 4.80, SD=0.51); lowest for neurological conditions (mean 4.51, SD=0.44)
Plaza Fornieles M et al 2020 ³³	To assess effectiveness of the PPC team	As above	As above	Translated Italian version of the PaPEQu into	Spain	Bereaved parents	2 copies of QA sent to 55 families (1 for	As above	PPC group had highest scores (experiences &

	To assess whether involvement of the PPC team improved EOL care based on experiences & parents' level of satisfaction with care			Spanish using international guidelines	Department of Paediatrics in single university hospital	To children who died (June 2014-June 2017) from life-threatening/ life-limiting disease	<p>father; 1 for mother)</p> <p>46/108 completed QA (42.6% RR) (2 single parent households)</p> <p>26 (56.5%) mothers, mean age 32.96 years (SD 8.7); 18 (36.7%) fathers, mean age 36.71 years (SD 5.7); 41 Spanish (89.1%); 5 'immigrants' (10.9%) – Moroccan, Honduran, Ecuadorian, Ukrainian</p> <p>Representing 28 children mean age 42.21 months, 16 female (57.1%); deaths due to cardiac (1, 3.6%), neurological (6, 21.4%), oncological (9, 32.1%) illness or during neonatal period (12, 42.9%); ethnicity N/S</p>	<p>satisfaction) for family support, communication, shared decision-making, bereavement support (p<0.05)</p> <p>Neonatal group had least positive experiences</p> <p>Greater proportion of PPC group involved in decisions about CPR, withdrawal of treatment</p>
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EXPERIENCE @Home Measure									
Boyden JY et al 2021 ³⁴	To develop & conduct preliminary evaluation of a family-reported measure of experiences with paediatric palliative & hospice care at home - PPHC@Home	<p>To assess family-reported experiences of palliative and hospice care for children & caregivers at home</p> <p>National Consensus Project's Clinical Guidelines for Quality Palliative Care used as framework</p> <p>Initial 20 domains reduced to 16 final domains: Access to care; Caregiver support at EOL; Communication at EOL; Communication between family & care team; Coordination of care; Continuity of care; Cultural aspects of care; Ethical and legal aspects of care; Knowledge and skills of care team providers; Physical aspects of care; Practical aspects of care; Psychological & emotional aspects of care; Extended social network; Relationship between family & care team; Social aspects of care; Spiritual & religious aspects of care</p>	<p>Used before death - retrospectively assess care provided during previous week (although in this development work also assessed with bereaved parents)</p> <p>Questionnaire - survey</p> <p>Initial pool of 70 items – final measure had 22 items; 5-point Likert scale from 'strongly disagree' to 'strongly agree'</p> <p>Time phase=not specified but question items include 'what my child's last weeks of life' may be like</p>	<p>Phase 1: Item identification & development (using guidelines, peer-reviewed literature, existing instruments, key stakeholder feedback)</p> <p>Phase 2: Initial prioritisation & reduction of items by HCP using discrete choice experiments (DCE)</p> <p>Phase 3: Final prioritisation & reduction of items by parents using DCE</p> <p>Phase 4: Cognitive interviewing with parents</p>	<p>USA</p> <p>Home-care setting</p> <p>Phase 2: Hospital, community, academic institutions (USA & Canada)</p> <p>Phase 3 & 4: Children's hospital & virtual community of parents</p>	<p>Phase 2: HCP/parent advocates</p> <p>Phase 3 & 4: Parents & bereaved parents</p> <p>To children (<25 years) with/died from 'serious illness' – either receiving/ previously received PPHC@ Home</p>	<p>Phase 2: 37 HCP/parent advocates; 31 (91.2% female & white); mean age 48.4 years (SD 9.7)</p> <p>Phase 3: 47 parents; mean age 42.6 years (SD 8.5); 44 (93.6%) mothers; 42 (89.4%) white (further details in study below)</p> <p>Phase 4: 11 parents (subgroup of phase 3); mean age 43.8 years, (SD 6.5); 10 (90.9%) mothers; 11 (100%) white</p> <p>Representing children mean age 9 years (SD 6.4); 3 (27.3%) female; 8 (72.7%) white; range of diagnoses (neurological, cardiac, oncological, genetic)</p>	<p>Not specifically undertaken within this study – identified as next step</p> <p>As above</p>	<p>Multi-method, multi-stakeholder approach used for instrument development</p> <p>First tool specifically measuring family-reported experiences of palliative & hospice care at home</p> <p>Overall, highest-rated domains were: Physical</p>
Boyden JY et al 2021b ³⁵	To explore how parents' rate & prioritise	<p>As above</p> <p>20 specific domains</p>	As above	As above - Phase 3 (DCE with	As above	As above	As above – Phase 3	As above	Overall, highest-rated domains were: Physical

	different domains of paediatric palliative & hospice care at home - PPHC@Home (detailing Phase 3 of above study)			parents/bereaved parents)			47 parents; 14 (29.8%) were bereaved; 33 (70.2%) were currently caring for their child at home; mean age 42.6 years (SD 8.5); 44 (93.6%) mothers; 42 (89.4%) white Representing 45 children; 21 (46.7%) female; > 50% aged 10-25 years; 37 (82.2%) white; most common diagnoses (could have >1): neuromuscular, neurologic, or mitochondrial (51.1%), genetic/ congenital (48.9%), cardiovascular (22.2%), metabolic (22.2%)		aspects of care: Symptom management; Psychological/ emotional aspects of care for the child; Care coordination Lowest-rated domains were: Spiritual & religious aspects of care; Cultural aspects of care (but participants were mainly white, non-Hispanic, & Christian)
Quality of Children's End-of-Life Care Instrument									
Widger K et al 2015 ³⁶	To develop & test an instrument measuring quality of EOL care, from the perspective of bereaved mothers	To assess quality of children's EOL care Instrument designed to measure structure, process, or outcome (in keeping with Donabedian's model of quality health care)	Used after death Questionnaire - survey Revised instrument had 95 items on structures, processes, outcomes; 6 subscales	Phase 1: Literature review – identified indicators of high-quality EOL care Phase 2: Focus groups – bereaved parents	Canada Phase 2 & 3: death occurred in hospital or home setting Phase 4: 10 children's	Phase 2: Bereaved parents Phase 3: HCP with expertise in paediatric EOL care &	Phase 2: 10 bereaved parents; mean age 44.5 years; 90% Caucasian Representing 10 children (mean age 5 years); 7	Phases 1, 2 & 3 supported face & content validity Phase 3: CVI scores for individual items (0.67-1.0) & overall = 0.84 (items scoring	Initial evidence for reliability & validity of 6 subscales & content validity for 4 additional subscales

		<p>10 final domains: Connect with families; Involve parents; Share information with parents; Share information among HCP; Support the child; Support siblings; Support Parents; Structures of care; Provide care at death; Provide bereavement follow-up</p>	<p>Most items have 5 adjectival response options (‘never’ to ‘always’) or are satisfaction ratings; some dichotomous response options</p> <p>Time phase=not specified but includes domains focusing on care provided at death (whether ‘<i>peaceful death</i>’)</p>	<p>asked about important domains for EOL care</p> <p>Phase 3: Item development & refinement – HCP to assess content validity & cognitive interviews with bereaved parents</p> <p>Phase 4: Psychometric testing</p>	<p>hospitals & hospices</p>	<p>bereaved parents</p> <p>Phase 4: Bereaved mothers</p> <p>To children (<19 years old) who died in a hospice/ hospital (2006- 2009)</p>	<p>female; 4=cancer, 5=congenital illness, 1= neuromuscular condition</p> <p>Phase 3: 7 HCP were physicians (n=2), advanced practice nurses (n=4), & social worker (n=1); 6 bereaved parents from phase 2</p> <p>Phase 4: 128/657 bereaved mothers completed instrument (18% RR); further 31 for test-retest assessment; mean age 36.5 years (SD 8.3); ethnicity N/S</p> <p>Representing 128 children, mean age 4.1 years; 66 (51.6% female; ethnicity N/S; most common 1^o diagnosis= congenital malformations (23.4 %) & neoplasms (16.4%)</p>	<p><0.8 were revised)</p> <p>Phase 4: EFA only possible for 6/10 subscales (due to missing data, ‘not applicable’ responses); good test-retest reliability (ICC 0.81-0.9) & good internal consistency (Cronbach’s alpha 0.76-0.96)</p> <p>Remaining 4/10 subscales had good content validity</p>	
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PICU-QODD									
Yorke D, 2011 ³⁷	To explore parents' experiences of a child's death in PICU To explore ideas about how to improve experiences	To allow parents to evaluate their & their child's experience Published 'Framework for a Good Death' guided overall research	Used after death Questionnaire – completed PICU-QODD & conducted face-to-face qualitative interview 25 items - each has a initial question with response options on a 5-point scale ('none of the time' to 'all of the time'); then item asking to 'rate this aspect of your child's dying experience' on an 11-point scale (0='terrible' to 10='almost perfect') Time phase=not specified but focus on care up to & including death	Established tool, QODD, previously used & validated with bereaved families for adult deaths Modified original version to form PICU-QODD - reviewed by PICU nurses (n=3), bereaved parent (n=1) & compared with aspects of care from 'Framework for a Good Death'	USA Single PICU in an academic children's hospital	Bereaved parents/ guardians To children who died in PICU (2004-2005)	23/80 parents/ grandparents participated (28.8% RR); age range 27-63 years; gender/ethnicity N/S Representing 14 children; age range newborn to 20 years; cancer n=4, congenital heart disease n=5; other causes n=5; gender/ethnicity N/S	Internal reliability assessed with Cronbach's α 0.929 (but small sample size & missing values)	Majority of aspects of care rated highly in PICU-QODD; range of scores 4-10/10; mean score 7.25 (SD 2.11) Item with lowest rating was whether child was able to be fed or feed him/herself Qualitative interview findings suggest parents want more direct communication, to remain present & involved in care & support after the death

CVI=content validation index; DCE=discrete choice experiment; EFA=exploratory factor analysis; EOL=end-of-life; HCP=healthcare professional; ICC=intraclass correlation; N/S=not stated; PPC=paediatric palliative care; PICU=paediatric intensive care unit; PPHC@HOME=paediatric palliative and hospice care at home; QA=questionnaire; QODD=Quality Of Dying and Death; QoL=quality of life; RR=response rate; SD=standard deviation; VAS=visual analogue scale; USA=United States of America

Table 4. Studies detailing the development, validation and use of tools to assess quality of dying, death, and end-of-life care for children / young adults within a life-limiting cardiac population

	Study objective	Purpose of tool & underlying concepts	Description of tool & specified assessment period	Details of tool development	Setting	Population	Participants	Reported psychometric testing	Key findings including any quality of dying, death, EOL evaluations
Survey for Caring for Children with Advanced Heart Disease (SCCHD)									
Blume ED et al 2014 ³⁸	To describe bereaved parents' perspectives whose children died from Advanced Heart Disease (AHD)	Describe parental perspectives of EOL care 10 different domains; 4 main domains reported within this study: Symptom control; Quality of life; Communication with care team; Use of treatment-directed technologies at EOL	Used after death Questionnaire - survey 110 questions across 10 different domains; items have Likert-style & nominal response options Time phase=not specified but survey includes items focusing on last month of life	Adapted from another questionnaire (developed by Wolfe J et al, 2000 – see Table 2) Items selected based on literature review & adapted to cardiac ICU setting; used items from previously validated questionnaires, where possible Pilot: feedback from 4 x parents of deceased children (2x AHD, 2x cancer)	USA Two large paediatric cardiology centres (hospitals) in single city	Bereaved parents To children (<21 years) who died from any type of heart disease (Jan 2007-Dec 2009)	50/128 bereaved parents completed QA (39% RR); 47 (95%) female; median age 37.6 years; 47 non-Hispanic white (94%) Representing 50 children; median age 6 months (range 3.6 days-20.4 years); gender & ethnicity N/S	Not specifically undertaken within this study	47% perceived child 'suffered' 'a great deal/a lot/somewhat' during EOL Parents to children <2years perceived breathing & feeding difficulties & fatigue to cause most 'suffering' c.f. fatigue & sleeping difficulties in older children 71% reported QoL in last month of life as 'poor' or 'fair'; 84% reported quality of care 'good' or 'excellent' 14 (40%) realised <=1 day prior to death that death was imminent; 9 (18%) never realised until time of death 31 (70%) agreed that their child had

									experienced a 'good death'
Balkin EM et al 2015 ³⁹	To describe & compare primary cardiologists & bereaved parents' perspectives about care for children who died of AHD	Sub study of original cohort study (see above) Describe parental & physician perspectives of EOL care	Used after death Questionnaire - survey SCCHD: 110 questions across 10 different domains SCCHD-physician: 11 questions, 7 which correspond with SCCHD Shared domains between 2 questionnaires: Treatment goals at diagnosis; Quality of life; EOL decision making; Quality of communication & caregiver-family relationship Time phase='time after which you realized your child had no realistic chance of survival' & includes items focusing on last month of life	SCCHD: as above SCCHD-physician survey developed from SCCHD (further details not provided)	USA Single large paediatric cardiology centre (hospital)	Bereaved parents & primary cardiologists To children (<21 years) who died from any type of heart disease (Jan 2007-Dec 2009)	33/78 bereaved parents completed QA (42% RR); 30 (97%) female; mean age 47.4 years; 29 non-Hispanic white (94%) 31/33 cardiologists completed QA (94% RR); demographics N/S Total = 31 parent/physician pairs Representing 31 children; median age 6 months (range 4 days - 20.4 years); gender & ethnicity N/S	No specific psychometric testing conducted	15% bereaved parents thought their child had suffered 'a great deal' while no cardiologist did 17 (55%) bereaved parents perceived they were unprepared for the way their child died c.f. 29% cardiologists; little agreement between 12/28 (43%) parent/physician pairs 29 (93%) bereaved parents perceived quality of care in last month was 'excellent/very good' compared with 24 (78%) cardiologists

EOL=end-of-life; ICU=Intensive Care Unit; N/S=not stated; OR=odds ratio; QA=questionnaire; QoL=quality of life; RR=response rate; USA=United States of America

Table 5. Content of the tools mapped to the ‘good death of a child’ dimensions⁸

Dimension	Participation	Personal style	Quality of life	Preparation for death	Aspects of care	Legacy	Impact on survivors	Other domains within tools
<i>Examples of attributes of dimensions</i>	<i>Awareness of dying/acceptance; autonomy/timing/location (of death); expectations & personal ideal</i>	<i>Dignity; affirmation of whole person; individuality/personal/privacy</i>	<i>Pain & symptom management; social relations; survival goals</i>	<i>Advance care planning; honesty/communication; hope; completion</i>	<i>Aspects of staff; Continuity; Cultural & spiritual concerns</i>	<i>Having someone present; contributing to others; establishing meaning; importance of ritual/funeral</i>	<i>Grief resources; economic resources</i>	
Tool								
GDI-P	Y	Y	Y	Y	Y	Y	N	N
<i>Domains mapped to dimensions</i>	A peaceful death in the presence of family	Living a normal life	Relief from physical & psychological suffering; Spending time with the family	Minimum medical treatment	Good relationships with medical staff	Making wonderful memories & fulfilling wishes; Playing & learning		
PICU-QODD-20	Y	Y	Y	Y	Y	Y	Y	Y
<i>Domains (& specific question items where needed) mapped to dimensions</i>	Privacy & PICU environment issues (item about parental privacy to be with child at end-of-life)	Emotional needs/support of family (item about clinical staff cared about ‘the child as an individual’)	Pain & symptom management; Emotional needs/support of family	Communication issues; Decisions to withdraw life support	Spirituality & religion/cultural issues; Continuity/coordination of care;	Fulfilling the parental role	Grief & bereavement	Physical & instrumental needs of family (items about bathroom/carpark facilities)
GDI	Y	Y	Y	Y	Y	Y	N	Y
<i>Domains mapped to dimensions (including 8 optional domains)</i>	Dying in a favourite place; Natural death; Unawareness of death	Being respected as an individual; Maintaining hope & pleasure; Independence; Pride and beauty	Physical & psychological comfort; Good relationships with family	Receiving enough treatment; Control over the future; Preparation for death	Good relationships with medical staff; Religious and spiritual comfort	Life completion; Not being a burden to others; Feeling that one’s life is worth living		Environmental comfort

FAMCARE*	N	N	Y	Y	Y	N	N	Y
<i>Domains mapped to dimensions</i>			Pain & symptom management	Satisfaction with communication with HCP	Availability of clinicians			Family satisfaction with cancer care
Toolkit**	Y	Y	Y	Y	Y	N/S	N/S	N/S
<i>Question items mapped to dimensions (study only highlighted specific question items)</i>	<i>Item about 'knew what to do at the time of death'</i>	<i>Item about how well 'the patient died with dignity'</i>	<i>Items about how well 'the patient's symptoms were controlled' & 'providing emotional support'</i>	<i>Items about 'was information given about what to expect about dying' & 'did doctors listen to concerns?'</i>	<i>Item about 'spiritual/religion addressed?'</i>			
SCCC	Y	N	Y	Y	Y	N	Y	N
<i>Question items mapped to dimensions</i>	<i>Items about location & peacefulness of the child's death</i>		<i>Items about symptoms & their treatment; quality of life & emotional well-being</i>	<i>Items about decision-making at the EOL (e.g., DNACPR); quality of care & communication</i>	<i>Items about degree of physician/home care team involvement in EOL care; teamwork; religious/spiritual mentor</i>		<i>Items about burdens after child's death; contact after death; economic impact of child's terminal illness</i>	
SCCCH (study focus only on specific areas; so unable to state whether more dimensions covered)	<i>N/S</i>	<i>N/S</i>	<i>Items about symptom control & quality of life</i>	<i>Items about communication with care team & use of treatment-directed technologies at EOL</i>	<i>N/S</i>	<i>N/S</i>	<i>N/S</i>	<i>N/S</i>
PaPEQu **	Y	Y	Y	Y	Y	N/S	Y	N/S
<i>Domains (& specific question items where needed) mapped to dimensions</i>	Grief and bereavement support (item about 'choosing the place of death')	Holistic care of the child	Relief of pain & other symptoms; Support of the family unit	Involvement of child & family in communication, decision-making & care planning	Continuity of care; Support of the family unit (item about access to 'spiritual counselling')		Grief and bereavement support	
EXPERIENCE @Home Measure (final 22 items)	Y	Y	Y	Y	Y	N	N	Y
<i>Question items mapped to dimensions</i>	<i>Item about 'last weeks of life and what they may be like'</i>	<i>Item about 'care team considers all of my child's needs'</i>	<i>Items about child's physical symptoms & emotional support; support of parent; sibling support</i>	<i>Items about decision-making, information provision, trust, hope</i>	<i>Items about coordination of care, knowledge & skills of healthcare team</i>			<i>Items about on-call services & adaptation of home</i>

Quality of Children's End-of-life Care Instrument	Y	Y	Y	Y	Y	N	Y	Y
Domains (& specific question items where needed) mapped to dimensions	Provide care at death	Connect with families (item included being treated 'as a unique person')	Support parents; Support the child (items about physical, emotional, social & spiritual needs); Support siblings	Share information with parents; Involve parents	Share information among HCP; Connect with families; (items about spiritual needs & cultural/spiritual/religious practices asked within 3 separate domains)		Provide bereavement follow-up	Structures of care (items include food and car parking)
PICU-QODD	Y	Y	Y	Y	Y	Y	Y	N
Question items mapped to dimensions	Items about feeling at peace with dying, saying goodbye, being present at moment of death	Items about keeping dignity & self-respect	Items about pain, breathing, spending time with family/friends	Items about receiving support from ventilator, discussing wishes for end-of-life care	Items about visits from religious/spiritual leader, having spiritual service/ceremony & care received from healthcare team	Items about making end-of-life plans or funeral arrangements	Items about healthcare costs	

Y=yes; N=No; N/S=not stated (detail not provided within study); DNACPR=do not attempt cardio-pulmonary resuscitations; EOL=end-of-life; HCP=healthcare professional; PICU=paediatric intensive care unit; * only communication items were reported within study; further information about FAMCARE items obtained from http://www.npcrc.org/files/news/famcare_scale.pdf; ** full details of question items used not provided within study and did not receive response from corresponding author

Supplementary file 1. Search Strategy for CINAHL Database

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1. ("Quality of dying").ti,ab
 2. ("Quality of death").ti,ab
 3. ("good death").ti,ab
 4. ("bad death").ti,ab
 5. (quality).ti,ab
 6. ("end of life").ti,ab
 7. "ATTITUDE TO DEATH"/
 8. (tool).ti,ab
 9. (measur*).ti,ab
 10. (scale).ti,ab
 11. (instru*).ti,ab
 12. (assess*).ti,ab
 13. (question*).ti,ab
 14. (survey).ti,ab
 15. (questionnaire).ti,ab
 16. (test).ti,ab
 17. (outcome*).ti,ab
 18. exp QUESTIONNAIRES/ OR exp "OPEN-ENDED QUESTIONNAIRES"/
 19. exp "TERMINALLY ILL PATIENTS"/
 20. exp RESUSCITATION
 21. exp "LIVING WILLS"/
 22. "TERMINAL CARE"/ OR "HOSPICE CARE"/ OR "PALLIATIVE CARE"/ OR "RESUSCITATION ORDERS"/
 23. "HOSPICE AND PALLIATIVE NURSING"/
 24. ((terminal* OR advanced OR incurable OR life-limit* OR life-threaten*) ADJ2 (ill* OR disease* OR condition* OR stage*)).ti,ab
 25. (terminal* ADJ2 (care OR caring)).ti,ab
 26. (end ADJ2 life).ti,ab
 27. (palliat*).ti,ab
 28. (hospice*).ti,ab
 29. (dying).ti,ab
 30. ADOLESCENCE/ OR "ADOLESCENT, HOSPITALIZED"/ OR CHILD/ OR "MINORS (LEGAL)"/
 31. INFANT/ OR "INFANT, DRUG-EXPOSED"/ OR "INFANT, HIGH RISK"/ OR "INFANT, HOSPITALIZED"/
 32. PEDIATRICS/
 33. (adolescen* OR teen* OR youth* OR juvenile* OR minors OR child* OR schoolchild* OR preschool* OR toddler* OR boy* OR girl* OR paediatric* OR pediatric* OR infant* OR infancy).ti,ab
 34. (5 AND 6)
 35. (1 OR 2 OR 3 OR 4 OR 7 OR 34)
 36. (8 OR 9 OR 10 OR 11 OR 12 OR 13 OR 14 OR 15 OR 16 OR 17 OR 18)
 37. (19 OR 20 OR 21 OR 22 OR 23 OR 24 OR 25 OR 26 OR 27 OR 28 OR 29)
 38. (30 OR 31 OR 32 OR 33)
 39. (35 AND 36 AND 37 AND 38)
 40. 39[DT 2000-2021][Languages eng]
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