Ekberg Stuart (Orcid ID: 0000-0001-8837-7440)

Enhancing paediatric palliative care: A rapid review to inform continued development of care for children with life-limiting conditions

Authors and affiliations: Stuart Ekberg[1], Alison Bowers[2], Natalie Bradford[3], Katie Ekberg[4], Melanie Rolfe[5], Norah Elvidge[6,7], Rebecca Cook[8,9], Sara-Jane Roberts[10,11], Christine Howard[12], Meera Agar[13], Renee Deleuil[14], Sara Fleming[15], Jenny Hynson[16,17], Ashka Jolly[18], Melissa Heywood[19], Simon Waring[20], Toni Rice[21], Annette Vickery[22]

[1] Queensland University of Technology, Victoria Park Road, Kelvin Grove, Queensland, 4059, Australia. stuart.ekberg@qut.edu.au

[2] Queensland University of Technology, L5, 62 Graham Street, South Brisbane, QLD 4101 Australia. ap.bowers@qut.edu.au

[3] Queensland University of Technology, Victoria Park Road, Kelvin Grove, Queensland, 4059, Australia. natalie.bradford@qut.edu.au

[4] Queensland University of Technology, Victoria Park Road, Kelvin Grove, Queensland, 4059, Australia. katie.ekberg@qut.edu.au

[5] Queensland University of Technology, Victoria Park Road, Kelvin Grove, Queensland, 4059, Australia. melanie.rolfe@qut.edu.au

[6] Queensland University of Technology, Victoria Park Road, Kelvin Grove, Queensland, 4059, Australia. norah.elvidge@gmail.com

[7] Greenslopes Private Hospital, Newdegate St, Greenslopes QLD 4120. Present Address. norah.elvidge@gmail.com

[8] Queensland University of Technology, Victoria Park Road, Kelvin Grove, Queensland, 4059, Australia. rkratch@gmail.com

[9] Queensland Paediatric Rehabilitation Service, Queensland Children's Hospital 501 Stanley Street, South Brisbane, Queensland, 4101, Australia. Present Address. rkratch@gmail.com

[10] Queensland University of Technology, Victoria Park Road, Kelvin Grove, Queensland, 4059, Australia. sara-jane.roberts@uts.edu.au

[11] University of Technology Sydney, Level 3, Building 10, 235 Jones St, Ultimo, New South Wales, 2007 Australia PO Box 123 Broadway NSW 2007 Australia. Present Address. sara-jane.roberts@uts.edu.au

[12] Queensland University of Technology, Victoria Park Road, Kelvin Grove, Queensland, 4059, Australia. christine@ch-consultancy.com.au

This is the author manuscript accepted for publication and has undergone full peer review but has not been through the copyediting, typesetting, pagination and proofreading process, which may lead to differences between this version and the Version of Record. Please cite this article as doi: 10.1111/jpc.15851

[13] University of Technology Sydney, 235 Jones Street, Ultimo, New South Wales, 2007, Australia. meera.agar@uts.edu.au

[14] Perth Children's Hospital, 15 Hospital Avenue, Nedlands, Western Australia, 6009, Australia. renee.deleuil@health.wa.gov.au

[15] Women's and Children's Health Network, 72 King William Road, North Adelaide, South Australia, 5006, Australia. sara.fleming@sa.gov.au

[16] The Royal Children's Hospital, 50 Flemington Road, Parkville, Victoria, 3052, Australia. jenny.hynson@rch.org.au

[17] University of Melbourne, Parkville, Victoria, 3052, Australia. jenny.hynson@rch.org.au

[18] Centenary Hospital for Women and Children, Gilmore Crescent, Garran, Australian Capital Territory, 2605, Australia. ashkaj17@hotmail.com

[19] Royal Children's Hospital Melbourne, Parkville, Victoria, 3052, Australia. melissa.heywood@rch.org.au

[20] Palliative Care Australia, PO Box 124, Fyshwick, Australian Capital Territory, 2609, Australia. simon@simonwaring.com

[21] Palliative Care Australia, PO Box 124, Fyshwick, Australian Capital Territory, 2609, Australia. Toni.Rice@palliativecare.org.au

[22] Palliative Care Australia, PO Box 124, Fyshwick, Australian Capital Territory, 2609, Australia. Annette.Vickery@palliativecare.org.au

Corresponding author: Stuart Ekberg, Queensland University of Technology, Victoria Park Road, Kelvin Grove, Queensland, 4059, Australia. stuart.ekberg@qut.edu.au +61 (7) 3138 6567

Acknowledgements: Susan Trethewie provided support in conceptualising and steering this project. Catherine Haden, a liaison librarian at the Queensland University of Technology library, provided assistance in developing the search strategy for this review. This project received grant funding from the Australian Government, as part of the Paediatric Palliative Care National Action Plan Project. This funding was administered by Palliative Care Australia. The views expressed in this article do not necessarily reflect the views of the Australian Government or Palliative Care Australia.

Conflict of interests: Meera Agar is Board Chair of Palliative Care Australia and Toni Rice and Annette Vickery are employed by Palliative Care Australia. The other authors declare that they do not have any financial or professional relationships which may pose a competing interest and inappropriately influence their work.

Ethics approval: This paper reports a literature review which did not require ethical approval to conduct.

Patient consent for publication: No patients were directly involved in the literature review reported in this paper.

Keywords: Palliative Care, Pediatrics, Policy Marking, Health Policy, Delivery of Health Care, Quality of Health Care, Health Services Accessibility, Teaching, Advance Care Planning, Patient-Centered Care.

Abstract

Aim. Following the establishment of paediatric palliative care services over recent decades, this study sought to identify information to inform future policy and practice.

Methods. A rapid review using thematic synthesis was conducted to synthesise existing information about improving paediatric palliative care. Information was extracted in relation to key areas for investment and change: quality, access, advance care planning, skills, research, collaboration, and community awareness.

Results. A total of 2,228 literature sources were screened, with 369 included. Synthesised information identified clear ways to improve quality of care, access to care, advance care planning, and research and data collection. The synthesis identified knowledge gaps in understanding how to improve skills in paediatric palliative care, collaboration across Australian jurisdictions, and community awareness.

Conclusions. The findings of this review bring together information from a vast range of sources to provide action-oriented information to target investment and change in paediatric palliative care over coming decades.

Keywords: Palliative Care, Pediatrics, Policy Marking, Health Policy, Delivery of Health Care, Quality of Health Care, Health Services Accessibility, Teaching, Advance Care Planning, Patient-Centered Care.

Key Points:

- Rapid review methods were used to synthesise information to inform future improvements to paediatric palliative care in Australia.
- Detailed information is available to help improve quality and access to paediatric palliative care, advance care planning, and research and data

collection.
- Further information is needed to inform skills development, collaboration across Australian jurisdictions, and public awareness of paediatric palliative care.

1. Introduction

Paediatric palliative care aims to improve the quality of life of children with life-limiting conditions and their families, from diagnosis. This includes, but is not limited to, end of life care. In 2016, an estimated 24,386 children were living with life-limiting conditions in Australia.[1] The care of children with these conditions can be complex due to their physiological resilience, the uncertain trajectory of their illness, the role of parents or guardians as decision makers, and the ongoing development of a child – physically, emotionally, cognitively, socially, culturally, and spiritually.[2,3]

In response to the complex needs of children with life-limiting conditions, many countries have progressively developed specialist paediatric palliative care in recent decades.[2,3] Specialist services now exist in most states and territories of Australia,[4] although the pace of development has been slower than other Western countries such as the United Kingdom (UK).[5] Work undertaken over recent decades affords an opportunity to synthesise existing understandings of effective paediatric palliative care to inform future policy and practice. This article reports a review to inform the future development of paediatric palliative care in Australia.

2. Materials and Methods

This study used rapid review methods, which effectively synthesise large amounts and diverse sources of information to inform policymaking.[6] This review is the first phase of a broader project to develop a National Paediatric Palliative Care Action Plan. A steering committee comprised of staff, representatives, and nominees from Palliative Care Australia (PCA) and Paediatric Palliative Care Australia and New Zealand (PaPCANZ) oversaw the design and conduct of the review. Many steering committee members also contributed to this article as co-authors.

2.1. Search Strategy

Peer-reviewed literature was searched using Medline, CINAHL, and Embase. 'Grey' literature (i.e., literature that is unpublished and not peer-reviewed) was searched using Google Advanced Search. The search strategies are available in Supplementary File A. Additional literature was identified through sources such as reference lists of included literature sources.

2.2. Screening

The following inclusion criteria, developed in consultation with the steering committee, were adopted so the findings of the review would inform the National Paediatric Palliative Care Action Plan:

1. A specific focus on paediatric palliative care;
2. A focus on improvement in at least one of the following areas:
    a. Quality;
    b. Access;
    c. Advance care planning;
    d. Skills;
    e. Research and data collection;

    f. Collaboration across jurisdictions;
    g. Dissemination of information;
    h. Community awareness;
3. Including information relevant to the Australian context (e.g., information about developing paediatric palliative care in countries where this is currently non-existent was not eligible for inclusion).

Each source was screened using the online systematic review tool *Covidence* by a single reviewer, with a second reviewer consulted where necessary. Each source was screened by title and, where available, abstract. When necessary, the full literature source was read to determine eligibility.

2.3. Quality appraisal and information extraction

Consistent with other rapid reviews,[6] no established quality appraisal tool was used. An Information Extraction Tool was custom developed (see Supplementary File B). Quality appraisal and information extraction was undertaken by a single reviewer using *Covidence*, with a second reviewer consulted where necessary.

2.4. Information synthesis

Thematic synthesis was used to synthesise diverse forms of information across the literature sources.[7] A single reviewer synthesised information using the qualitative analysis software *NVivo*, with feedback from other reviewers. Four literature sources produced by key international and Australian policymaking organisations (the World Health Organization, the Australian Commission on Quality and Safety in Healthcare, Palliative Care Australia, and Paediatric Palliative Care Australia and New Zealand) were identified as providing policy recommendations that are particularly influential in Australia.[4,8-10] Each major finding from the synthesis was compared against these documents to determine compatibility with recommendations by key policymaking organisations.

3. Results

The peer-reviewed literature search was conducted on 30 October 2020, and the 'grey' literature search on 13 November 2020. Screening resulted in 369 sources being included in the review (see Figure 1). The majority of the included information sources were peer-reviewed empirical studies (n = 361). A small number of 'grey' literature sources were included (n = 8).

---------------INSERT FIGURE 1 AROUND HERE---------------

The synthesis identified many literature sources relevant to some key areas and relatively fewer sources relating to other areas (see Table 1). Many sources related to multiple key areas. No unique literature sources were identified in relation to improving dissemination of information that were not already addressed in another area. This area is therefore not specifically reported below.

---------------INSERT TABLE 1 AROUND HERE---------------

Due to space constraints, key findings and references are reported below. A comprehensive report is available at: https://eprints.qut.edu.au/211016/

3.1. Improving quality

Patient- and family-centred care as a way of improving the quality of paediatric palliative care is promoted across literature sources,[11,12] including by key policymaking organisations.[4,8-10] Although there is some uncertainty about the extent to which patient- and family-centred care is currently achieved,[13] ensuring continuity of care by a trusted clinician is known to promote such care.[12]

A multidisciplinary approach (sometimes referred to using related terms such as 'interdisciplinary') is also known to improve quality,[14,15] and is advocated for by key policymaking organisations.[4,8-10] This should extend beyond specialist paediatric palliative care to include other acute care specialities where children receive palliative care, such as neonatal intensive care.[14,15] Multidisciplinarity should also encompass community healthcare services, including but not limited to community palliative care. One strategy for facilitating this is the 'pop up' model, where specialist paediatric palliative care services support local acute- and community-based services to care for individual children at times when they need this.[16] Integrating care across disciplines and settings can be managed through care coordination.[3,15]

Setting benchmarks through documents such as guidelines, frameworks, and policies is one way to improve quality.[17] Key documents in Australia include *A Practical Guide to Palliative Care in Paediatrics*, published in 2014,[18] and service development guidelines published in 2018.[4] Future iterations could be informed by methodologies (e.g., systematic reviews) that have been used in other countries, such as the UK.[19]

3.2. Improving access

Early integration of paediatric palliative care so that it is delivered alongside care with curative intent, is known to improve access[17,20] and is recommended by key policymaking organisations.[4,8-10] The most common strategy for early integration is through the adoption of one or more 'triggers', such as those in the Paediatric Palliative Screening Scale (PaPaS).[21]

Many literature sources highlight the importance of improving access by providing paediatric palliative care in various settings,[22] and key policymaking organisations recommend this.[4,8-10] This includes providing access to respite care, to ensure families have opportunities to manage the needs of their child with a life-threatening or life-limiting condition alongside the needs of other family members.[19,23] In Australia, a population dispersed across vast geographical space creates challenges for ensuring equitable access to paediatric palliative care. Support for families living in regional, rural and remote parts of Australia can be improved through strategies such as the 'pop-up' model described above[16] and through telehealth.[24]

A small number of literature sources emphasise the specific needs of culturally and linguistically diverse populations,[25,26] and key policymaking organisations recommend addressing these.[4,8,10] In Australia, policymaking organisations place particular emphasis on Aboriginal and Torres Strait Islander people.[4,10]

3.3. Improving advance care planning

Advance care planning (ACP) is "…a process of discussions between families and health care providers about preferences for care, treatments and goals in the context of the patient's current and anticipated future health".[27] ACP is recommended by key policymaking organisations.[4,8-10] Nevertheless, many children who are likely to benefit from ACP either do not receive this at all or receive it close to the end of their life, when its usefulness may be limited.[28]

At the level of healthcare systems, ACP can be improved by early integration of specialist paediatric palliative care,[29,30] a finding consistent with the literature about improving access. There is some evidence that uptake of ACP can be improved at a population level by developing policies and procedures that support proactive planning.[31] An Australian framework is available that includes triggers to commence advance care planning.[32]

The synthesis of literature sources highlighted that ACP could be improved through patient- or family-focused interventions.[33,34] Interventions should be targeted or adaptable to the needs of particular groups, such as adolescents and young adults and culturally and linguistically diverse populations.[34] In addition to patient- or family-focused interventions, clinician training is important for improving ACP.[35] This is addressed further in the next section.

3.4. Improving skills

There are important limitations in the literature about improving skills, knowledge, and confidence in providing paediatric palliative care. First, most literature focuses on clinicians with far less consideration given to improving the skills and knowledge of patients or families. Second, although many sources recommended training in specific areas, very few determined priorities. Those sources that did determine priorities have limited transferability to contemporary Australia,[36,37] although Palliative Care Australia has suggested priority areas.[4] Third, there is an absence of robust evidence about optimal education approaches.[38]

There are calls for a foundational level of competence in palliative care across a range of specialties in paediatrics, in recognition that these clinicians are likely to encounter instances where a palliative approach to care will be appropriate.[39] Developing foundational competencies are recommended by several key policymaking organisations.[4,8,10] A hierarchy of skill levels may guide investment in training.[39] For instance, foundational competencies in a palliative approach could be required for undergraduates and qualified paediatric clinicians. Beyond this, general palliative care training could be provided to those more frequently involved or with an interest in caring for children with life-limiting conditions. At the highest level, specialist paediatric palliative care training could be provided to those whose core activity is caring for children with life-limiting conditions.

A recent call was made for developing central repositories of educational resources and curricula that suit the different contexts in which paediatric palliative care is provided.[40] To achieve this, there may be scope to expand existing international initiatives, such as Education in Palliative and End-of-Life Care (EPEC) Pediatrics.[41] There are also resources available in Australia through the Quality of Care Collaborative Australia in Paediatric Palliative Care (QuoCCA), which facilitates scheduled, ‘pop-up,’ or incidental training.[42]

3.5. Improving research and data collection

A common theme identified across the literature was the need to enhance routine data collection by developing and implementing quality indicators relevant to the specific needs and characteristics of paediatric palliative care.[43,44] Although some key policymaking organisations have specifically recommended this,[4,8] and a checklist of clinical indicators for paediatric palliative care is available,[18] no quality indicators specifically developed or adapted for use in Australia were identified.

Many projects have been undertaken that identify priorities for research in paediatric palliative care,[45,46] although no sources could be identified that specifically considered research priorities in Australia. There are calls to include key stakeholders across the research process, including child patients, their well siblings, and other family members.[43,45] This would help ensure research meets any needs specific to paediatric palliative care in Australia. Investment in research is recommended by key Australian policymaking organisations.[4,9]

3.6. Improving collaboration across jurisdictions

Both federal and state or territory governments have a role in developing, funding, and providing paediatric palliative care in Australia.[47] Service development guidelines produced by Palliative Care Australia advocate planning across jurisdictions to ensure all children with life-limiting conditions and their families have access to at least one specialist paediatric palliative care service, even if a child lives in a state or territory that does not have a specialist service.[4] Very little information was identified to inform improved collaboration across jurisdictions.

Following a recommendation to ensure state-based services are developed and delivered in line with best-practice guidelines (including those developed at the national level)[47] additional guidelines have been developed by key policymaking organisations.[4,10] Beyond policy, the QuoCCA initiative described earlier provides a clear example of national collaboration to improve paediatric palliative care across Australia.[42] These existing policies and programs provide a foundation for future initiatives to improve collaboration across Australian jurisdictions.

3.7. Improving community awareness

Improving awareness of palliative care within the community is likely to contribute to enhanced quality of care. For example, families are more likely to approve of and access paediatric palliative care once they understand that it focuses on alleviating symptoms and enhancing quality of life.[48] Although improving community awareness is critical, very little information addressing this topic was identified through the review. There is some evidence to support the promotion of death literacy within schools,[49] and to work with communications specialists to promote community understanding of paediatric palliative care.[50] There is scope for further work in this area.

4. Discussion

Paediatric palliative care has rapidly developed over recent decades, both in Australia and internationally.[2,3] Alongside policy and service development, research evidence has grown in a way that will enable further developments in policy and practice. The major findings of this rapid review (see Table 2) could facilitate the future development of policy and practice by systematically identifying and synthesising information with relevance to paediatric palliative care in Australia.

--------------INSERT TABLE 2 AROUND HERE--------------

This review has identified many literature sources that provide information about improving quality and access to paediatric palliative care. Priorities in this area should be to promote: 1) patient- and family-centred care; 2) a multidisciplinary approach to care; 3) early integration of specialist paediatric palliative care; 4) the use of advance care planning; 5) the provision of care in a variety of settings; and 6) considering the specific needs of the culturally and linguistically diverse people that comprise contemporary Australia. Australian guidelines are currently available to inform initiatives across each of these areas[4,10] but future development could be enhanced by methodologies that have been utilised in other countries.[19] For example, UK guidelines are based on systematic reviews, supplemented by expert opinions from clinicians and lived experience from children.[19]

Many literature sources consider ways to improve skills in paediatric palliative care. Although hierarchies of competency in palliative care have been identified for different areas of paediatrics, there is ongoing need to identify priorities for skills development, and optimal ways of delivering education.[38] Furthermore, although enhancing the skills and knowledge of the clinical workforce are essential, this should not be at the expense of considering the skills and knowledge of patients and families. Enhancing the knowledge and skills of patients and families will increase the likelihood that the child can be cared for in a location of their choice, including their own home.

A subset of the literature sources included in the review highlight the importance of routine data collection to inform continuous quality improvement and research to underpin evidence-based practice. Considerable work has been undertaken internationally to identify research priorities,[45,46] as well as to develop quality indicators that can be used for routine data collection.[21,43,44] The extent to which these are applicable in the Australian setting remains unclear.

Effective collaboration across jurisdictions is critical to the delivery of paediatric palliative care in a federated nation state such as Australia.[47] Improving community awareness of paediatric palliative care will also be essential.[48] The paucity of information available about both these areas is indicative of the need for further research and investment to underpin future improvement.

There are strengths and limitations associated with the broad focus of this rapid review. A key limitation is a lack of detailed analysis of how to accomplish specific initiatives that will improve paediatric palliative care. However, often the synthesised literature sources included review articles that consider these initiatives in greater detail. Although the review was broad, an absence of literature in certain areas, such as about Aboriginal and Torres Strait Islander children, means significant gaps in knowledge remain. A key strength of the broad focus of this rapid review is bringing together information from a vast range of literature sources, with a specific aim of considering this information in relation to Australia. In comparison to other Western countries, there is scope to accelerate the development of paediatric palliative care in Australia.[5] The results of this review thereby provide action-oriented information to target future investment.

5. References

1. Bowers AP. Planning for paediatric palliative care services in Queensland: Characteristics, demographics and health needs of children and young people with life-limiting conditions [unpublished PhD thesis]. Brisbane: Queensland University of Technology; 2020.
2. Behrman RE, Field MJ. When children die: Improving palliative and end-of-life care for children and their families: The National Academies; 2003.
3. Hynson JL, Gillis J, Collins JJ, Irving H, Trethewie SJ. The dying child: How is care different? Medical Journal of Australia 2003;179:S20-S2.
4. Palliative Care Australia. Paediatric addendum: Palliative care service development guidelines. Canberra: PCA; 2018.

5. Arias-Casais N, Garralda E, Pons JJ, et al. Mapping pediatric palliative care development in the WHO-European region: Children living in low-to-middle-Income countries are less likely to access it. Journal of Pain and Symptom Management 2020;60:746-53.
6. Tricco AC, Antony J, Zarin W, et al. A scoping review of rapid review methods. BMC Medicine 2015;13:224.
7. Thomas J, Harden A. Methods for the thematic synthesis of qualitative research in systematic reviews. BMC Medical Research Methodology 2008;8:45.
8. World Health Organization. Integrating palliative care and symptom relief into paediatrics. A WHO guide for health care planners, implementers and managers. WHO; 2018.
9. Palliative Care Australia, Paediatric Palliative Care Australia & New Zealand. Policy statement: Paediatric palliative care. Canberra: PCA; 2019.
10. Australian Commission on Safety and Quality in Healthcare. National consensus statement: Essential elements for safe and high-quality paediatric end-of-life care; 2016.
11. Gilmer MJ. Pediatric palliative care: A family-centered model for critical care. Critical Care Nursing Clinics of North America 2002;14:207-14.
12. Mastro KA, Johnson JE, McElvery N, Preuster C. The benefits of a nurse-driven, patient- and family-centered pediatric palliative care program. The Journal of Nursing Administration 2015;45:423-8.
13. Stevenson M, Achille M, Lugasi T. Pediatric palliative care in Canada and the United States: A qualitative metasummary of the needs of patients and families. Journal of Palliative Medicine 2013;16:566-77.
14. Cooper H, Clutbertson L, Fleming S. Neonatal palliative care nursing: Working with infants on the cusp of life: A thematic review. Neonatal, Paediatric & Child Health Nursing 2013;16en:2-10.
15. Nilsson S, Ohlen J, Hessman E, Brännström M. Paediatric palliative care: A systematic review. BMJ Supportive & Palliative Care 2020;10:157-63.
16. Mherekumombe MF, Frost J, Hanson S, Shepherd E, Collins J. Pop Up: A new model of paediatric palliative care. Journal of Paediatrics and Child Health 2016;52:979-82.
17. Balaguer A, Martin-Ancel A, Ortigoza-Escobar D, Escribano J, Argemi J. The model of palliative care in the perinatal setting: A review of the literature. BMC Pediatrics 2012;12:25.
18. Bradford NK, Herbert AR, Pedersen L-A, et al. A practical guide to palliative care in paediatrics. South Brisbane: Queensland Health; 2014.
19. National Institute for Health and Care Excellence. End of life care for infants, children and young people: Planning and management: Full guideline. 2017.
20. Snaman JM, Kaye EC, Baker JN, Wolfe J. Pediatric palliative oncology: The state of the science and art of caring for children with cancer. Current Opinion in Pediatrics 2018;30:40-8.
21. Chong PH, Soo J, Yeo ZZ, Ang RQ, Ting C. Who needs and continues to need paediatric palliative care? An evaluation of utility and feasibility of the Paediatric Palliative Screening scale (PaPaS). BMC Palliative Care 2020;19:18.
22. Friedrichsdorf SJ, Postier A, Dreyfus J, Osenga K, Sencer S, Wolfe J. Improved quality of life at end of life related to home-based palliative care in children with cancer. Journal of Palliative Medicine 2015;18:143-50.
23. Kaye EC, Rubenstein J, Levine D, Baker JN, Dabbs D, Friebert SE. Pediatric palliative care in the community. CA: A Cancer Journal for Clinicians 2015;65:315-33.
24. Bradford N, Armfield NR, Young J, Smith AC. The case for home based telehealth in pediatric palliative care: A systematic review. BMC Palliative Care 2013;12:4-.
25. Kaye EC, Gushue CA, DeMarsh S, et al. Impact of race and ethnicity on end-of-life experiences for children with cancer. American Journal of Hospice & Palliative Medicine 2019;36:767-74.
26. Contro N, Davies B, Larson J, Sourkes B. Away from home: Experiences of Mexican American families in pediatric palliative care. Journal of Social Work in End-of-Life & Palliative Care 2010;6:185-204.
27. Spicer S, Macdonald ME, Davies D, Vadeboncoeur C, Siden H. Introducing a lexicon of terms for paediatric palliative care. Paediatrics & Child Health 2015;20:155-6.
28. Durall A, Zurakowski D, Wolfe J. Barriers to conducting advance care discussions for children with life-threatening conditions. Pediatrics 2012;129:e975-e82.

29. Miller EG, Levy C, Linebarger JS, Klick JC, Carter BS. Pediatric palliative care: Current evidence and evidence gaps. The Journal of Pediatrics 2015;166:1536-40.e1.
30. Sieg SE, Bradshaw WT, Blake S. The best interests of infants and families during palliative care at the end of life: A review of the literature. Advances in Neonatal Care 2019;19:E9-E14.
31. Kaempf JW, Tomlinson MW, Campbell B, Ferguson L, Stewart VT. Counseling pregnant women who may deliver extremely premature infants: Medical care guidelines, family choices, and neonatal outcomes. Pediatrics 2009;123:1509-15.
32. Royal Children’s Hospital Melbourne. Thinking ahead framework: Planning care for children with life-limiting conditions. 2017. Available at: https://www.rch.org.au/thinkingahead/framework/.
33. Edwards D, Carrier J, Gillen E, Hawker C, Sutton J, Kelly D. Factors influencing the provision of end-of-life care for adolescents and young adults with advanced cancer: A scoping review. JBI Database of Systematic Reviews & Implementation Reports 2014;12:405-47.
34. Sansom-Daly UM, Wakefield CE, Patterson P, et al. End-of-life communication needs for adolescents and young adults with cancer: Recommendations for research and practice. Journal of Adolescent & Young Adult Oncology 2020;9:157-65.
35. Basu S, Swil K. Paediatric advance care planning: Physician experience and education in initiating difficult discussions: Advance care planning in paediatrics. Journal of Paediatrics and Child Health 2018;54:510-4.
36. Hilden JM, Emanuel EJ, Fairclough DL, et al. Attitudes and practices among pediatric oncologists regarding end-of-life care: Results of the 1998 American Society of Clinical Oncology survey. Journal of Clinical Oncology 2001;19:205-12.
37. Chong PH, Hamsah E, Goh C. Paediatric palliative care in the Asia Pacific region: Where are we now? BMJ Supportive & Palliative Care 2017;7:17-22.
38. Quinn M, Gephart S. Evidence for implementation strategies to provide palliative care in the neonatal intensive care unit. Advances in Neonatal Care 2016;16:430-8.
39. Downing J, Ling J, Benini F, Payne S, Papadatou D. A summary of the EAPC White Paper on core competencies for education in paediatric palliative care. European Journal of Palliative Care 2014;21:245-9.
40. Kaye EC, Applegarth J, Gattas M, et al. Hospice nurses request paediatric-specific educational resources and training programs to improve care for children and families in the community: Qualitative data analysis from a population-level survey. Palliative Medicine 2020;34:403-12.
41. Friedrichsdorf SJ, Remke S, Hauser J, et al. Development of a pediatric palliative care curriculum and dissemination model: Education in Palliative and End-of-Life Care (EPEC) Pediatrics. Journal of Pain and Symptom Management 2019;58:707-20.e3.
42. Slater PJ, Herbert AR, Baggio SJ, et al. Evaluating the impact of national education in pediatric palliative care: The Quality of Care Collaborative Australia. Advances in Medical Education and Practice 2018;2018:927-41.
43. Feudtner C, Rosenberg AR, Boss RD, et al. Challenges and priorities for pediatric palliative care research in the U.S. and similar practice settings: Report from a pediatric palliative care Research network workshop. Journal of Pain & Symptom Management 2019;58:909-.
44. Friedel M, Aujoulat I, Dubois A-C, Degryse J-M. Instruments to measure outcomes in pediatric palliative care: A systematic review. Pediatrics 2019;143:1-22.
45. Booth A, Maddison J, Wright K, Fraser L, Beresford B. Research prioritisation exercises related to the care of children and young people with life-limiting conditions, their parents and all those who care for them: A systematic scoping review. Palliative Medicine 2018;32:1552-66.
46. Downing J, Knapp C, Muckaden MA, Fowler-Kerry S, Marston J. Priorities for global research into children's palliative care: Results of an International Delphi Study. BMC Palliative Care 2015;14:1-10.
47. Herbert A, Bradford N, Donovan L, Pedersen L-A, Irving H. Development of a state-wide pediatric palliative care service in Australia: Referral and outcomes over two years. Journal of Palliative Medicine 2014;17:288-95.
48. Rosenberg AR, Wolfe J. Approaching the third decade of paediatric palliative oncology investigation: Historical progress and future directions. The Lancet Child & Adolescent Health 2017;1:56.

49. Beccaro M, Gollo G, Ceccon S, et al. Students, severe illness, and palliative care: Results from a pilot study on a school-based intervention. The American journal of hospice & palliative care 2015;32:715-24.
50. Toce S, Collins MA. The FOOTPRINTS^{SM} model of pediatric palliative care. Journal of Palliative Medicine 2003;6:989-1000.

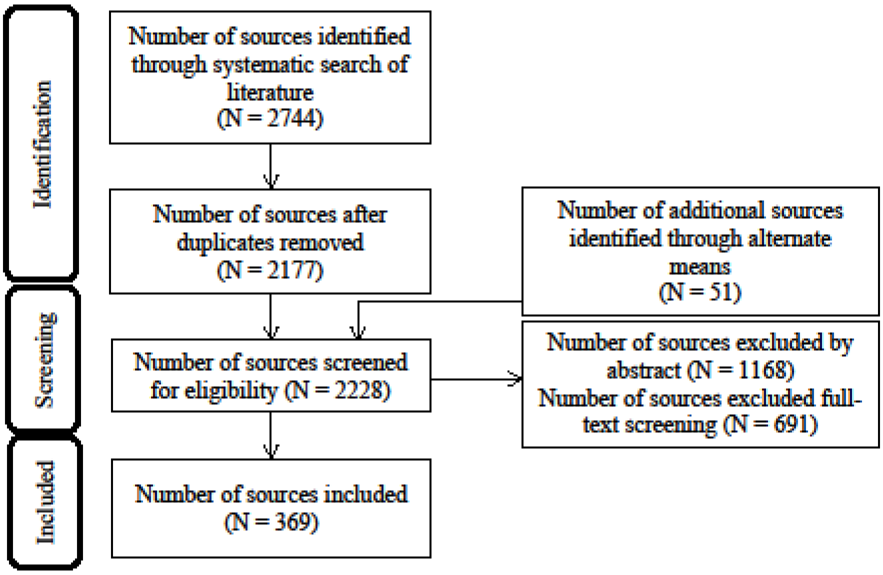
Figure 1: Screening results
Please refer to separate file submission

Table 1: Number of literature sources addressing each topic

Improvement Area	**Number of Sources**
Quality	137
Access	128
Advance care planning	62
Skills and knowledge	133
Research and data collection	69
Collaboration across jurisdictions	9
Community awareness	7

Table 2: Summary of key areas for investment

Investment Area	**Key Initiatives**
Quality	• Ensure patient- and family-centred care • Facilitate multidisciplinary care • Set quality benchmarks
Access	• Ensure early integration • Deliver care across different settings • Accommodate diversity
Advance care planning	• Ensure early integration of specialist paediatric palliative care • Develop and implement patient- or family-focused interventions • Provide clinician training
Skills and knowledge	• Ensure foundational competence in palliative care across the paediatric workforce • Develop educational resources and curricula • Identify priorities for skills development • Understand optimal ways to deliver education
Research and data collection	• Develop and implement quality indicators • Identify research priorities in Australia
Collaboration across jurisdictions	• Invest in better understanding how to enhance collaboration
Community awareness	• Invest in better understanding how to improve awareness


Identification
Screening
Included
Number of sources identified through systematic search of literature (N = 2744)
Number of sources after duplicates removed (N = 2177)
Number of additional sources identified through alternate means (N = 51)
Number of sources screened for eligibility (N = 2228)
Number of sources excluded by abstract (N = 1168)
Number of sources excluded full-text screening (N = 691)
Number of sources included (N = 369)

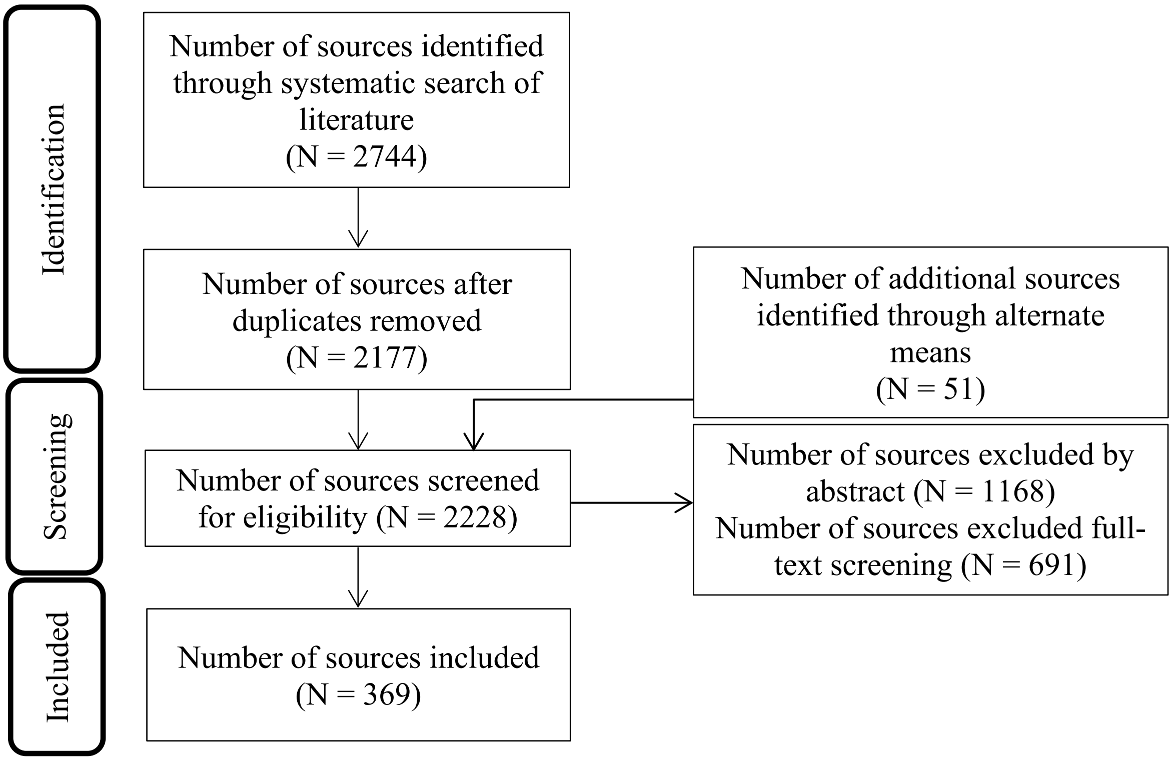

Identification
Screening
Included
Number of sources identified through systematic search of literature (N = 2744)
Number of sources after duplicates removed (N = 2177)
Number of additional sources identified through alternate means (N = 51)
Number of sources screened for eligibility (N = 2228)
Number of sources excluded by abstract (N = 1168)
Number of sources excluded full-text screening (N = 691)
Number of sources included (N = 369)

Table 1: Number of literature sources addressing each topic

Improvement Area	**Number of Sources**
Quality	137
Access	128
Advance care planning	62
Skills and knowledge	133
Research and data collection	69
Collaboration across jurisdictions	9
Community awareness	7

Table 2: Summary of key areas for investment

Investment Area	**Key Initiatives**
Quality	• Ensure patient- and family-centred care • Facilitate multidisciplinary care • Set quality benchmarks
Access	• Ensure early integration • Deliver care across different settings • Accommodate diversity
Advance care planning	• Ensure early integration of specialist paediatric palliative care • Develop and implement patient- or family-focused interventions • Provide clinician training
Skills and knowledge	• Ensure foundational competence in palliative care across the paediatric workforce • Develop educational resources and curricula • Identify priorities for skills development • Understand optimal ways to deliver education
Research and data collection	• Develop and implement quality indicators • Identify research priorities in Australia
Collaboration across jurisdictions	• Invest in better understanding how to enhance collaboration
Community awareness	• Invest in better understanding how to improve awareness

Enhancing paediatric palliative care: A rapid review to inform continued development of care for children with life-limiting conditions

Authors and affiliations: Stuart Ekberg[1], Alison Bowers[,2], Natalie Bradford[3], Katie Ekberg[4], Melanie Rolfe[5], Norah Elvidge[6,7], Rebecca Cook[8,9], Sara-Jane Roberts[10,11], Christine Howard[12], Meera Agar[13], Renee Deleuil[14], Sara Fleming[15], Jenny Hynson[16,17], Ashka Jolly[18], Melissa Heywood[19], Simon Waring[20], Toni Rice[21], Annette Vickery[22]

[1] Queensland University of Technology, Victoria Park Road, Kelvin Grove, Queensland, 4059, Australia. stuart.ekberg@qut.edu.au

[2] Queensland University of Technology, L5, 62 Graham Street, South Brisbane, QLD 4101 Australia. ap.bowers@qut.edu.au

[3] Queensland University of Technology, Victoria Park Road, Kelvin Grove, Queensland, 4059, Australia. natalie.bradford@qut.edu.au

[4] Queensland University of Technology, Victoria Park Road, Kelvin Grove, Queensland, 4059, Australia. katie.ekberg@qut.edu.au

[5] Queensland University of Technology, Victoria Park Road, Kelvin Grove, Queensland, 4059, Australia. melanie.rolfe@qut.edu.au

[6] Queensland University of Technology, Victoria Park Road, Kelvin Grove, Queensland, 4059, Australia. norah.elvidge@gmail.com

[7] Greenslopes Private Hospital, Newdegate St, Greenslopes QLD 4120. Present Address. norah.elvidge@gmail.com

[8] Queensland University of Technology, Victoria Park Road, Kelvin Grove, Queensland, 4059, Australia. rkratch@gmail.com

[9] Queensland Paediatric Rehabilitation Service, Queensland Children's Hospital 501 Stanley Street, South Brisbane, Queensland, 4101, Australia. Present Address. rkratch@gmail.com

[10] Queensland University of Technology, Victoria Park Road, Kelvin Grove, Queensland, 4059, Australia. sara-jane.roberts@uts.edu.au

[11] University of Technology Sydney, Level 3, Building 10, 235 Jones St, Ultimo, New South Wales, 2007 Australia PO Box 123 Broadway NSW 2007 Australia. Present Address. sara-jane.roberts@uts.edu.au

[12] Queensland University of Technology, Victoria Park Road, Kelvin Grove, Queensland, 4059, Australia. christine@ch-consultancy.com.au

[13] University of Technology Sydney, 235 Jones Street, Ultimo, New South Wales, 2007, Australia. meera.agar@uts.edu.au

[14] Perth Children's Hospital, 15 Hospital Avenue, Nedlands, Western Australia, 6009, Australia. renee.deleuil@health.wa.gov.au

[15] Women's and Children's Health Network, 72 King William Road, North Adelaide, South Australia, 5006, Australia. sara.fleming@sa.gov.au

[16] The Royal Children's Hospital, 50 Flemington Road, Parkville, Victoria, 3052, Australia. jenny.hynson@rch.org.au

[17] University of Melbourne, Parkville, Victoria, 3052, Australia. jenny.hynson@rch.org.au

[18] Centenary Hospital for Women and Children, Gilmore Crescent, Garran, Australian Capital Territory, 2605, Australia. ashkaj17@hotmail.com

[19] Royal Children's Hospital Melbourne, Parkville, Victoria, 3052, Australia. melissa.heywood@rch.org.au

[20] Palliative Care Australia, PO Box 124, Fyshwick, Australian Capital Territory, 2609, Australia. simon@simonwaring.com

[21] Palliative Care Australia, PO Box 124, Fyshwick, Australian Capital Territory, 2609, Australia. Toni.Rice@palliativecare.org.au

[22] Palliative Care Australia, PO Box 124, Fyshwick, Australian Capital Territory, 2609, Australia. Annette.Vickery@palliativecare.org.au

Corresponding author: Stuart Ekberg, Queensland University of Technology, Victoria Park Road, Kelvin Grove, Queensland, 4059, Australia. stuart.ekberg@qut.edu.au +61 (7) 3138 6567

Acknowledgements: Susan Trethewie provided support in conceptualising and steering this project. Catherine Haden, a liaison librarian at the Queensland University of Technology library, provided assistance in developing the search strategy for this review. This project received grant funding from the Australian Government, as part of the Paediatric Palliative Care National Action Plan Project. This funding was administered by Palliative Care Australia. The views expressed in this article do not necessarily reflect the views of the Australian Government or Palliative Care Australia.

Conflict of interests: Meera Agar is Board Chair of Palliative Care Australia and Toni Rice and Annette Vickery are employed by Palliative Care Australia. The other authors declare that they do not have any financial or professional relationships which may pose a competing interest and inappropriately influence their work.

Ethics approval: This paper reports a literature review which did not require ethical approval to conduct.

Patient consent for publication: No patients were directly involved in the literature review reported in this paper.

Keywords: Palliative Care, Pediatrics, Policy Marking, Health Policy, Delivery of Health Care, Quality of Health Care, Health Services Accessibility, Teaching, Advance Care Planning, Patient-Centered Care.