









Copyright is held by the authors with the first publication rights granted to the journal. Conditions of sharing are defined by the Creative Commons License [Attribution-ShareAlike-NonCommercial 4.0 International](https://creativecommons.org/licenses/by-nc-sa/4.0/)

Citation: Delaney, AM, Duffield, JA, Iten, R, Heywood, M, McLarty, AM & Bowers, AP 2024, 'An education model for paediatric palliative care', *Health Education in Practice: Journal of Research for Professional Learning*, vol. 7, no. 1 <https://doi.org/10.33966/hepj.7.1.17855>

An education model for paediatric palliative care

Angela M Delaney ^{1,6}, Julie A Duffield ², Rebecca Iten ³, Melissa G Heywood ⁴, Alison M McLarty ^{1,6}, Alison P Bowers ^{5,6}

Abstract

Introduction: Meeting the palliative care needs of children and their families is complex and challenging. For countries such as Australia, whose relatively small paediatric palliative care population is dispersed across a very large geographical area, one challenge is maintaining a skilled workforce in regional, rural, and remote areas, where, when compared to major cities, there are fewer resources, and the workforce is often transient.

Methods: The Quality of Care Collaborative Australia (QuoCCA) Pop-up Model of Education was used to provide palliative care education to health professionals across three geographical locations and facilities, to facilitate a 2,500-km transfer of a child with complex palliative care needs from a tertiary hospital to the remote family home on Country.

Results: Each Pop-Up provided effective education to facilitate the successful transfer of the child to the next hospital location. Over 18 months, three Pop-Ups occurred. Relational learning and real-time problem solving enabled health professionals to build confidence and capacity to successfully transfer the child from the regional hospital to the remote family home.

Implications: The QuoCCA Education Pop-up Model is a feasible method to deliver timely access to speciality education. The model can be successfully applied in multiple settings.

Keywords: paediatric, palliative care, integrated health care delivery, learning, rural, education models.

¹ Paediatric Palliative Care Service, Children's Health Queensland Hospital and Health Service, Brisbane, Australia

² Paediatric Palliative Care Service, Women's and Children's Health Network, Adelaide, Australia

³ Paediatric Palliative Care Service, Perth Children's Hospital, Perth, Australia

⁴ Victorian Paediatric Palliative Care Program, Royal Children's Hospital, Melbourne, Australia

⁵ Cancer and Palliative Care Outcomes Centre, Centre for Healthcare Transformation, Queensland University of Technology, Brisbane, Australia

⁶ Centre for Children's Health Research, Queensland University of Technology, South Brisbane, Australia

Corresponding author: Angela M Delaney, Queensland Children's Hospital, 501 Stanley Street, South Brisbane, Queensland, 4101, Australia, angela.delaney@health.qld.gov.au

INTRODUCTION

Over the past two decades, specialist paediatric palliative care (SPPC) services have grown globally (Ekberg, Bowers & Bradford 2021). As the need and demand for SPPC continues to grow faster than the specialist workforce, it is imperative that alternative models of SPPC education are explored to ensure that high quality, well-coordinated family-centred care is delivered in the right place at the right time (Mherekumombe 2018).

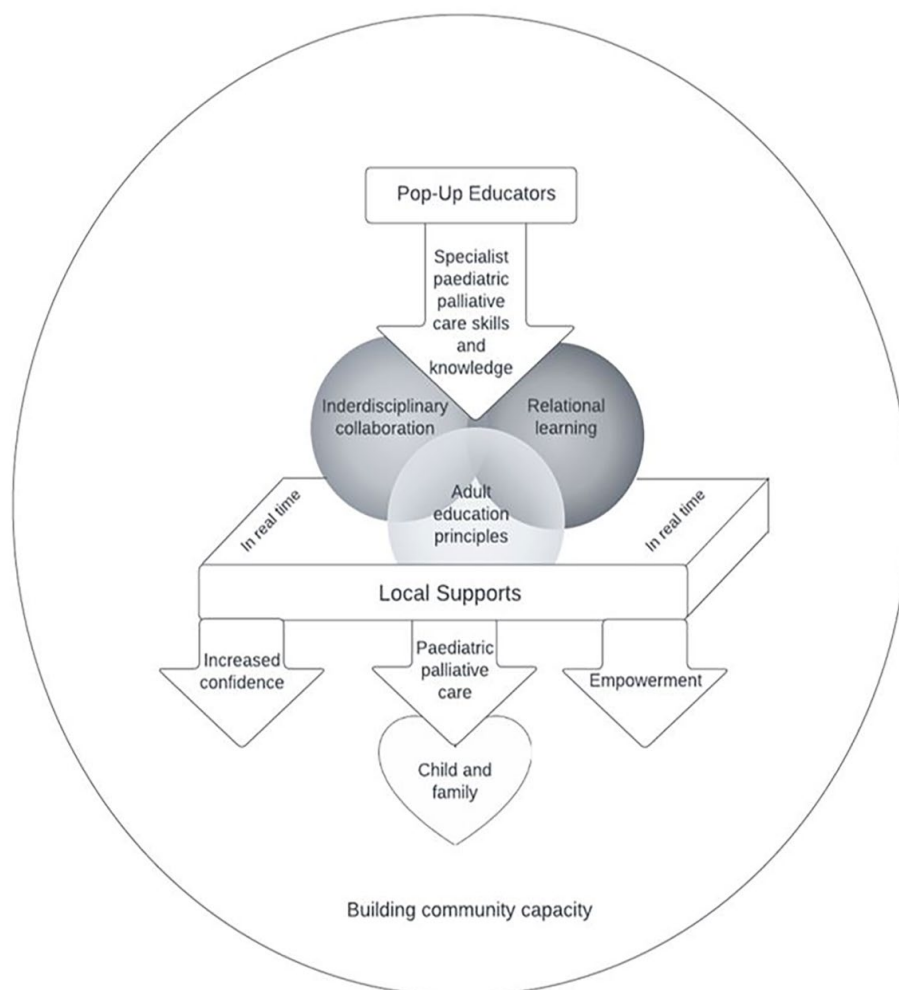
Compared to the adult population, the paediatric palliative care population is relatively small and often geographically dispersed. The combination of the complexity of the child's condition and intricacies of health systems makes delivery of paediatric palliative care challenging (Bowers et al. 2020). Delivery of such care in areas where there are less resources and fewer service providers can add further complexity (Queensland Health 2019). In Australia, the distance and diverse terrain between major cities, where SPPC services are based, and regional, rural and remote areas where families live is an additional challenge to timely palliative care (Dassah et al. 2018). Children receiving palliative care present with varying considerations including rarity of diagnoses, developmental considerations, complex symptom management and the psychosocial implications of family-centred care (Bowers et al. 2020).

In 2015, the Quality of Care Collaborative Australia (QuoCCA) project, a nationally funded collaboration of interdisciplinary services, was established to deliver paediatric palliative care education to health professionals across Australia who may care for children with palliative and end-of-life care needs. The aim of this national collaborative is to 'improve the quality of palliative care provided to children in close proximity to their home, throughout Australia through innovative education.' (CareSearch & QuoCCA 2018). The Commonwealth Department of Health and Aged Care National Palliative Care Projects has continued to fund the QuoCCA project through to June 2026.

METHOD

The QuoCCA project was conducted in collaboration with the five state-wide SPPC services. The aim was to ensure education was delivered to health professionals caring for children with life-limiting conditions across Australia and the families of the children. Ethical approval was obtained from the Children's Health Human Research Ethics Committee. Informed consent was obtained verbally and in written form from the participant in this report. This paper uses Jo's (pseudonym) 18-month journey to describe the QuoCCA Education Pop-Up Model for Paediatric Palliative Care (QE-PMOC) (Figure 1) in practice. The QE-POMC aligns with central tenets of the public health approach to palliative care, as it encourages collaboration between acute and community services, supports the creation of supportive environments and helps strengthen community action (Rosenberg, Mills & Rumbold 2016).

Figure 1. QE-PMOC. This model is designed to deliver paediatric palliative care education that facilitates collaboration and capacity building.



THE POP-UP MODEL

A Pop-Up is described as ‘a specific intervention over and above care that is provided to a child and family, with identified goals, objectives and interventions leading towards improving the confidence of local health care providers to deliver paediatric palliative care’ (Mherekumombe et al. 2016; Mherekumombe 2018). The QuoCCA project has developed the QE-PMOC with other key enablers using the principles of Pop-Up education (Table 1) to deliver education to individuals involved in the care of the child and their family. These key enablers are central to the development of the education while allowing for flexibility of delivery.

Jo’s case is used to illustrate how the QE-PMOC is implemented to deliver effective palliative care education, resulting in the collaboration and capacity building of health professionals.

Table 1: Key enablers for Pop-Up education

Key Enablers	Definition
Adult learning principles	Enhance the transfer of knowledge and understanding for health professionals providing patient care. 1. Need to know 2. Self-concept 3. Prior experience 4. Readiness 5. Learning orientation 6. Motivation to learn
Relational learning	Learning via vicarious lived experience enhances a deeper understanding of the child and family's lived experience.
Real time	At the time of care delivery, tailoring topics to learners' needs in relation to the specific care issues of the patient and family.
Local champion	Local champions are the point of contact health professionals who take responsibility for the facilitation and coordination of care, and education sessions to other health professionals, conveying the family's goals of care.

(Browning & Solomon 2006; Slater, Osborne & Herbert 2021; Adult Learning Australia 2024)

THE CASE OF JO

Jo, an Aboriginal Australian, was born prematurely. Jo had multiple health complications and co-morbidities that would shorten life expectancy. Jo's family live in a remote community over 2,500 km from the tertiary health service where Jo was an admitted patient. It was of cultural importance that Jo and family lived on Country¹. Although Jo's life expectancy remained shortened, several months later, Jo's condition was stable enough to consider a transfer to a hospital on Country closer to the family's community.

¹ Country is the term often used by Aboriginal peoples to describe the lands, waterways, and seas to which they are connected. The term contains complex ideas about law, place, custom, language, spiritual belief, cultural practice, material sustenance, family, and identity (Australian Institute of Aboriginal and Torres Strait Islander Studies, 2022).

RESULTS

Due to the vast distance and remote terrain between the tertiary hospital and Jo's community, Jo's transfer home required three Pop-Up education sessions over a period of two years. The first transfer was from the tertiary hospital to a small remote hospital >1,000 km from the family home.

THE FIRST POP-UP

The SPPC Nurse Educator (NE) and the Regional Adult Palliative Care Service (RAPCS) visited the child and family in the remote hospital within a month of the first transfer. The first Pop-Up occurred during this initial visit.

EDUCATION TOPICS

Many staff in rural or remote hospitals have never cared for a child with palliative care needs; therefore, it is important that the professionals involved identify the topics relevant to their learning needs in caring for the patient and family. The health professionals caring for Jo experienced moral and ethical challenges, and identified general care, complex symptom management and how to navigate moral and ethical challenges when delivering best-practice palliative care as relevant topics.

THE LOCAL CHAMPION

Identifying a 'local champion' is an important element of facilitating a Pop-Up. The SPPC NE engaged the RAPCS Aboriginal Health Worker (AHW), who already had an established relationship with the family, and understood their need for culturally safe care, to help coordinate and facilitate group and one-to-one education sessions at the rural hospital.

RELATIONAL LEARNING IN REAL TIME

The collaboration between the AHW and the SPPC NE facilitated the delivery of education sessions that met the needs of the health professionals and the culturally safe holistic care of the family in real time. This enabled health professionals and the family to be supported as they navigated decision-making and care interventions.

THE SECOND AND THIRD POP-UP

In Jo's case there were two more Pop-Ups to facilitate subsequent transfers. Local champions were identified from each hospital and worked in partnership with each other, other health professionals, and the community services that provided care to Jo and Jo's family.

For the second and third Pop-Up, topics and support provided by the SPPC NE to health professionals were directed by each participating group, proving similar to the learning needs of the previous group. At each transfer point the SPPC NE provided Pop-Up face-to-face education, while the interdisciplinary specialist paediatric palliative care service provided support and guidance via telephone, email, and telehealth throughout all stages of Jo's journey back to Country. During a Pop-Up visit, the SPPC NE will often visit the patient in the family home. In Jo's case the SPPC NE visited the family home and provided education to the support workers. The

number of stakeholders and interagency collaborations grew with each transfer, building the capacity of clinicians across the geographical expanse.

Throughout Jo's 18-month journey, the SPPC NE was supported, via the QuoCCA project, to facilitate three in-person Pop-Ups which delivered education and support to over 60 health professionals, from three acute service providers (hospitals) and three community health services. Table 2 illustrates specific information related to each of the Pop-Up education sessions.

Table 2: QE-PMOC Education Data

	Pop-Up 1	Pop-Up 2	Pop-Up 3
Timeline	Oct 2018 & Feb 2019	June 2019 & Oct 2019	Nov 2020
Jo's age	4–6 months	12–14 months	2.5 years
Location	Hospital & adult palliative care service	Hospital	Health centre & family home
Facilitators	SPPC NE & clinical nurse consultant	SPPC NE	SPPC NE & medical fellow
No. of sessions	3	4	3
Mode of delivery	Face-to-face	One video conference & three face-to-face	Face-to-face
Total Pop-Up hours	6.25	6	6.5
Family session hours	3	3	1.5
Professionals:			
Medical	3	3	3
Nursing	12	15	3
Allied Health	11	9	0
Support worker	–	–	6
Other	13	8	–
Total participants	36	35	12

Evaluation of Pop-Up education at the time included open-ended responses from educators.

Across the three Pop-Ups, the NE reported consistent themes and suggested successful outcomes which included increased inter-professional collaboration, improved confidence and capacity building of local professionals, and families trusting local teams following the tertiary team working collaboratively with local services.

“Building this relationship has been vital. We were able support the team in their decision making and symptom management of the patient.” Nurse educator (2019).

DISCUSSION

Through in-time professional education, interprofessional collaboration and acknowledgment of the expertise of the family, the QE-PMOC successfully built the capability, skills, knowledge and confidence of an inter-professional care network, and increased the capacity of the local community (Slater et al. 2018).

As demonstrated by Jo’s case, the success of the QE-PMOC is reliant on effective education via methods appropriate to the situation and learners’ needs (Browning & Solomon 2006; Curran & Sharpe 2007). The Pop-Up education delivered at the time of care provision promoted in-time interprofessional collaboration, and enabled questions to be addressed and challenges to be overcome as they occurred.

STRENGTHS

QE-PMOC education is learner-driven, with the child and family at the centre, resulting in the right care in the right place at the right time (Palliative Care Australia 2018). Furthermore, the QE-PMOC can help overcome the challenge of location by taking specialist skills, knowledge, resources and support from the tertiary centre to the family’s local service providers and community. The QE-PMOC supports the real-time sharing of evidence-based best-practice paediatric palliative care in the family and patient’s choice of location and at the time of need, which mitigates local health costs of travel for professional development.

Challenges and questions can be addressed in real time, enabling professionals to confidently provide coordinated care (Mherekumombe 2018; Slater et al. 2018). This facilitates effective communication between local professionals and family members. Effective communication helps professionals to build trust with families, and helps families build confidence in the professional’s ability to provide effective care, where the family’s knowledge and experience are valued and decision making is shared (Stein et al. 2019).

In the experience of QuoCCA educators, the local champion is a role based on the local team’s understanding and value of an individual’s experience, skills, and any existing rapport with the family. The local champion is the key link between the SPPC NE and local health professionals and has a key role in advocating the views and wishes of the family and in coordinating care (Department of Health and Aged Care 2022).

Drawing on a strengths-based approach (Miller 1990), the QE-PMOC facilitates reframing what individuals feel they do not know and cannot provide, to what they do know and can provide. Reflections of QuoCCA educators suggest that once a QE-PMOC has been provided, local health care professionals delivering care will confidently seek to contact the SPPC service, for reassurance, guidance, and knowledge-sharing. This is supported by Sansone, Ekberg and Danby (2022), who report that an SPPC provided reassurance to individuals who called a SPPC help-line.

The model can be successfully applied in multiple settings, including in areas with limited resources or service infrastructure. The model has the potential to be used in specialities other than paediatric palliative care.

LIMITATIONS

Further research is needed to explore the impact of the QE-PMOC on health professionals receiving education and on the families at the centre of the intervention. The preparation time leading into a Pop-Up education event, including topic preparation and coordination, has not been documented. However, as activities associated with Pop-Up education are multi-layered and cannot be viewed in isolation, quantifying the effects and impact of a Pop-Up may be challenging. Despite these challenges, work is currently underway to quantify such impacts and effects.

CONCLUSION

The QE-PMOC ensured that all professionals, services, and community members received the education and support needed to plan and transition Jo's care back to the family home and community. Australian SPPC educators consider the QE-PMOC as the gold standard for improving equitable, accessible, and quality paediatric palliative care. The QE-PMOC is a feasible method of delivery of timely speciality education that meets the learning needs of health professionals and the culturally safe holistic palliative care needs of children and their families.

Acknowledgements

We would like to acknowledge and thank the family who agreed for this case to be shared, and pay respects to their Elders, lores, customs and creation spirits. We acknowledge the traditional owners of the lands where the family live and where the Pop-Ups occurred. We recognise that these lands have always been places of teaching, learning and research. We acknowledge the important role Aboriginal and Torres Strait Islander people play within our communities.

We would also like to acknowledge the contribution of Ashka Jolly, QuoCCA NE for the Australian Capital Territory, and Sarah Baggio, Allied Health Educator, and the contributions of the rest of the National QuoCCA project team.

Conflicts of Interest and Source of Funding

No conflicts to declare. The QuoCCA project is funded by the Commonwealth Department of Health and Aged Care through the National Palliative Care Projects.

Ethics

This project received multi-centre ethics from the Children’s Health Queensland Human Research Ethics Committee reference HREC/16/QRCH/55. Both verbal and written parental consent was obtained, as advised by HREC for the use of this case.

Contributorship Statement

AD, JD and RI drafted the initial manuscript.

AB, AM, MH, AD, JD and RI made substantial contributions to interpretation of the work, developed the model of care figure, and reviewed and critically revised drafts of the manuscript for important intellectual content. AD, JD, RI, MH, AM, and AB approved the final version for publication.

REFERENCES

Adult Learning Australia 2024, *The principles of adult learning*, viewed March 2024, <https://ala.asn.au/adult-learning/the-principles-of-adult-learning/>

Australian Institute of Aboriginal and Torres Strait Islander Studies 2022, *Welcome to country*, viewed 19 October 2022, <https://aiatsis.gov.au/explore/welcome-country#>

Bowers AP, Chan RJ, Herbert A, Yates P 2020, 'Estimating the prevalence of life-limiting conditions in Queensland for children and young people aged 0-21 years using health administration data', *Australian Health Review*, vol. 44, pp. 630–6. DOI: 10.1071/AH19170.

Browning DM & Solomon MZ 2006, 'Relational learning in pediatric palliative care: Transformative education and the culture of medicine', *Child and Adolescent Psychiatric Clinics of North America*, vol. 15, pp. 795–815, DOI: 10.1016/j.chc.2006.03.002.

CareSearch & the QuoCCA project 2018, *Quality of Care Collaborative Australia* (QuoCCA), viewed 19 October 2022, <https://www.quocca.com.au/default.aspx>

Curran VR & Sharpe D 2007, 'A framework for integrating interprofessional education curriculum in the health sciences', *Education for Health* (Abingdon, England), vol. 20, pp. 93.

Dassah E, Aldersey H, McColl MA & Davison C 2018, 'Factors affecting access to primary health care services for persons with disabilities in rural areas: A “best-fit” framework synthesis', *Global Health Research and Policy*, vol. 3, pp. 36. DOI: 10.1186/s41256-018-0091-x.

Department of Health and Aged Care 2018, *The national palliative care strategy*, viewed 19 October 2022, <https://www.health.gov.au/resources/publications/the-national-palliative-care-strategy-2018>

Ekberg S, Bowers A, Bradford N, Ekberg K, Rolfe M, Elvidge N, Cook R, Roberts SJ, et al. 2021, 'Enhancing paediatric palliative care: A rapid review to inform continued development of care for children with life-limiting conditions', *Journal of Paediatrics and Child Health*, vol. 58, pp. 232–7. DOI: 10.1111/jpc.15851.

Mherekumombe MF 2018, 'From inpatient to clinic to home to hospice and back: Using the "pop up" pediatric palliative model of care', *Children (Basel)*, vol. 55, no. 5, pp. 55. DOI: 10.3390/children5050055.

Mherekumombe M, Frost J, Hanson S, Shepherd E & Collins J 2016, 'Pop Up: a new model of paediatric palliative care', *Journal of Paediatrics and Child Health*, vol. 52, pp. 979–82. doi.org/10.1111/jpc.13276

Miller GE 1990, 'The assessment of clinical skills/competence/performance', *Academic Medicine*, vol. 65, S63–7, DOI: 10.1097/00001888-199009000-00045.

Palliative Care Australia 2018, *Palliative care service development guidelines*, viewed 19 October 2022, http://palliativecare.org.au/wp-content/uploads/dlm_uploads/2018/02/PalliativeCare-Service-Delivery-2018_web2.pdf

Queensland Health 2019, *Queensland health palliative care services review: Key findings*, viewed 19 October 2022, https://www.health.qld.gov.au/___data/assets/pdf_file/0025/852622/palliative-care-services-review-key-findings.pdf

Rosenberg JP, Mills J & Rumbold B 2016, 'Putting the 'public' into public health: Community engagement in palliative and end of life care', *Progress in Palliative Care*, vol. 24, pp. 1-3. DOI: 10.1080/09699260.2015.1103500.

Sansone HM, Ekberg S & Danby S 2022, 'Uncertainty, responsibility, and reassurance in paediatric palliative care: A conversation analytic study of telephone conversations between parents and clinicians', *Qualitative Health Communication*, vol. 1, pp. 26–43, DOI: 10.7146/qhc.v1i1.125538.

Slater PJ, Herbert AR, Baggio S, Donovan LA, McLarty AM, Duffield JA, Pedersen LC, Duc JK, et al. 2018, 'Evaluating the impact of national education in paediatric palliative care - The Quality of Care Collaborative Australia', *Advances in Medical Education and Practice*, vol. 9, pp. 927–41. DOI: 10.2147/AMEP.S180526.

Slater PJ, Osborne CJ & Herbert AR 2021, 'Ongoing value and practice improvement outcomes from pediatric palliative care education: The Quality of Care Collaborative Australia', *Advances in Medical Education and Practice*, vol. 12, pp. 1189–98. DOI: 10.2147/AMEP.S334872.

Stein A, Dalton L, Rapa E, Bluebond-Langner M, Hanington L, Stein KF, Ziebland S, RoCHAT T, et al. 2019, 'Communication with children and adolescents about the diagnosis of their own life-threatening condition', *The Lancet*, vol. 393, pp. 1150–63, DOI: 10.1016/S0140-6736(18)33201-X.