

## A national quality of care collaboration to improve paediatric palliative care outcomes

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### Background

It is estimated that there are 32 per 10,000 children aged 0-19 years in Australia living with a life limiting condition (LLC). All of these patients would benefit from a "palliative approach to care".<sup>1,2</sup> There are less children dying compared to adults with one child death for every sixty adult deaths in Australia.<sup>1</sup> The unique challenges of caring for a dying child, and the relative rarity, present challenges with how to provide the best care to these children and their families. The complexity of providing "wrap around" care for young patients and families impacts service delivery, health professionals' confidence and capability. In Australia, many families reside in regional and rural locations. In Queensland alone, 58% of the children supported by the State-wide Paediatric Palliative Care Service (PPCS) live in regional and rural areas.<sup>1</sup> Australia's geography and dispersed population distribution requires innovative methods of delivering palliative care to a child within the context of their family, community and health services.

This paper presents a pop-up methodology of delivering education to health professionals as one solution to expanding the capacity of the small specialist paediatric palliative care workforce within Australia, particularly in regional, rural and remote locations.<sup>3</sup>

### *The experience of families*

Child and family centred care is espoused as a best practice philosophy in paediatric health care services.<sup>4</sup> Parents and the health care professional (HCP) are encouraged to work collaboratively. In the context of paediatric palliative care (PPC), parents often become experts in their child's medical care and are actively encouraged to be involved in care decisions.<sup>5</sup> Care of a child with a life limiting condition is often emotionally, physically, spiritually and financially demanding, with stressors that are individualised and complex.<sup>6,7</sup> Families require emotional and practical support (e.g. respite, financial) to minimise the significant stress and burden in the short and long term, and after the death of their child.<sup>7,8</sup>

Aboriginal and Torres Strait Islander families experience additional stressors in relation to health care generally citing poor access to culturally appropriate health services, dislocation from cultural support systems, exposure to racism, poor communication with health care professionals and economic hardship.<sup>9</sup> From 2013-2015, infant mortality rates for Aboriginal and Torres Strait Islander people was close to twice the rate for non-Indigenous Australians with many causes due to complex and chronic conditions. In 2010-2012, 75% of infant deaths were because of perinatal and congenital conditions.<sup>10</sup>

Place and family is core to wellbeing for Aboriginal and Torres Strait Islander families.<sup>11</sup> However supporting a child with a LLC in a remote community demands a service response that can deliver complex medical care, equipment, and culturally appropriate conversations around end of life and death and dying. Innovative solutions described in the literature include providing outreach education

to both health professionals and patients within remote Aboriginal and Torres Strait Islander communities.<sup>12</sup>

### *The experience of service providers*

Almost half the services providing PPC in the Asia-Pacific region are in adult settings.<sup>13</sup> Within Australia, most specialist PPCs are based in capital cities and have developed with little co-ordination from a national perspective.<sup>14</sup> Outreach has been provided to regional, rural and remote centres by telehealth.<sup>15</sup> Small numbers and geographical diversity means most generalist health professionals are not exposed to or experienced with either the diagnostic conditions or the palliative care needs of such children.<sup>1</sup> An additional challenge for health practitioners in these non-metropolitan locations is building self-efficacy around optimising scope of practice.

Improved provision of care by health professionals may mean better outcomes for the child (less pain, distress and anxiety) and reduced risks of poor mental health, marriage quality and social function for parents.<sup>16</sup> Parents whose child experiences pain and suffering at their end of life demonstrate significant levels of grief for up to nine years following the death of their child.<sup>17</sup>

From a social and ecological perspective the role of communities in PPC is also pivotal. A contemporary response encourages 'collaborative care in dying' whereby facilitating a 'good death' should be complemented by facilitation of 'good grief'.<sup>18</sup> The role of community organisations or groups in supporting children and families at such a difficult time is critical, no matter where the child lives (metropolitan, regional, rural). Support and collaboration between government services (education, health, emergency and social services), non-government organisations, extended family, neighbours and volunteers can be particularly beneficial to families.<sup>19</sup> Where this does not occur naturally, efforts can be made to facilitate such collaborative support with the family's permission.<sup>20</sup>

### *Building capacity through a 'pop up' model of paediatric palliative care*

The mismatch between the incremental growth of children requiring palliative care and health professionals skilled in this speciality indicates a need for high quality, compassionate, consistent, coordinated care and management via education modules driven by learner needs. Acknowledging the limitations of centralising care in geographically dispersed populations such as Australia, a public health perspective has been adopted as a framework for influencing provision of palliative and bereavement care throughout the state. A central tenet to this model is a community capacity building approach, which encourages palliative care services to collaborate and empower local communities through the mobilisation of formal and informal social networks.<sup>21</sup>

In 2014, the Quality of Care Collaborative Australia (QuoCCA) project was formed with funding from the Commonwealth Department of Health, National Palliative Care Projects. A 'pop up' model of care previously trialled in adult settings (n=11) and in paediatrics NSW was adopted.<sup>3</sup> This model consists of 'just in time' learning via face to face case consultations between the tertiary specialist team and local/community inter professional services.

The QuoCCA team includes representatives from Australia's tertiary Children's Hospitals, including:

- Lady Cilento Children's Hospital, Brisbane, Qld (Project Lead site)
- John Hunter Children's Hospital, Newcastle, New South Wales
- Sydney Children's Hospital, Randwick, New South Wales

- Royal Children's Hospital, Melbourne, Victoria
- Women's and Children's Hospital, Adelaide, South Australia
- Princess Margaret Hospital for Children, Western Australia

The Children's Hospital at Westmead, Sydney also provided mentorship and support.

Modelled on the existing PPCs, the QuoCCA project utilises a 'hub and spoke' model. Lady Cilento Children's Hospital is the main hub for project management, national ethics application processes, educator networking, including workshop development and collation of resources. The other tertiary children's hospitals listed form similar hubs.

Pop-ups may occur for different reasons at the time of diagnosis, deterioration, difficult to manage symptoms or for end of life care.<sup>3</sup> The inter-professional team assess for when a pop-up consultation is required, guided by: the patient's clinical need; psychosocial care of the family, education needs of local clinicians, bereavement follow-up and geographical location (rural/remote).<sup>22</sup>

## Project aims

The overarching aim of the national collaborative is to promote high quality palliative care provided to children in close proximity to their home through education initiatives, evaluation and research, specifically:

1. To build capacity for local health services, including regional, rural and remote settings, to provide care for patients and their families at home or as close to home as possible, and
2. To enhance the scope of generalist HCP's in regional, rural and remote settings by enhancing confidence in paediatric palliative care.

## Methods

This study adopted a mixed method design to determine:

- the learning needs and impact of PPC educational modules on health clinicians' knowledge and confidence
- the consumers' perspective working in regional, rural and remote Australia. Quantitative data was gathered from an online learning needs analysis, pre and post surveys and FAMCare2. Qualitative data was derived from interview transcripts and free text comments collected in above surveys.

### *Educational initiatives (data collection)*

#### **Learning needs analysis**

An on-line learning needs analysis (LNA) was developed based on a survey by Chong and colleagues<sup>13</sup> with author permission and guidance from the QuoCCA collaborators and working groups. The LNA incorporated closed questions including demographics, levels of experience and paediatric palliative care topic ratings, and optional free text comments in relation to most closed questions and specifically for service delivery and perceived challenges. Participants rated 17 topics with a five point Likert scale. HREC approved a low negotiable risk (LNR) application for this

evaluation within the project lead's state. Ethics applications for South Australia, Western Australia, and Victoria are pending. Hence presented data is primarily from Queensland. The online survey was disseminated by email to a broad cross section of health professionals and organisations.

### Outcomes from targeted education initiatives

A self-report pre and post education survey was developed to assess confidence levels relating to paediatric palliative care knowledge and skills through attendance at targeted education events. The 17 item pre-survey included demographic details and confidence levels as measured by a 5 point Likert scale 'not at all' to 'extremely confident'. Anticipated learnings and preferred topics were encouraged as free text responses. The 8 item post-education survey included demographic details, confidence questions relating to PPC knowledge/skills and two free comments about learnings and future topic preferences.

### Consumer engagement perspectives

The Discovery Interview (DI), a semi structured interview technique was adopted to assess family and health professional perspectives of pop up visits.<sup>23</sup> Interview participants are invited to share their experience through prompts from a pre-determined spine.<sup>24</sup>

### Data analysis

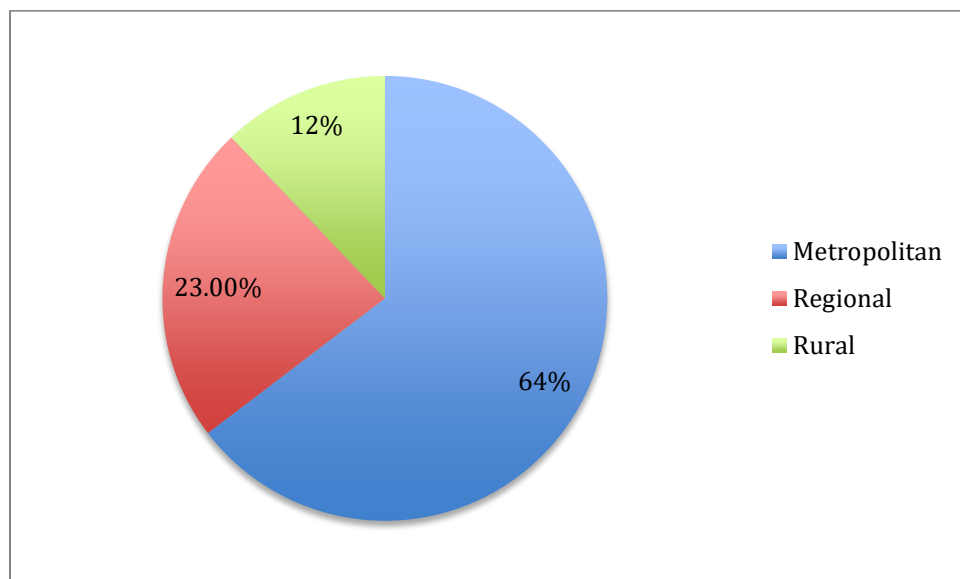
Analysis for the QuoCCA project is on-going. This paper will present preliminary outcomes from the Learning Needs Analysis. LNA results were calculated using descriptive statistics and weighted average of the rated 17 topics. Preliminary thematic analysis for the open questions has been undertaken.

## Results

### Participants

The online survey was completed by 151 participants from Queensland with the largest proportion of respondents from a metropolitan area (Figure 1)

Figure 1 Geographical location of LNA respondents



More than half respondents identified as nursing staff with the remainder allied health or medical (Table 1).

Table 1 Professional background

Profession Type	Responses (%)
Nursing	54%
Allied Health	24.5%
Medical	19%

Almost three per cent of participants identified as Aboriginal or Torres Strait Islander descent. One (0.66%) responded 'yes' to being an Aboriginal and Torres Strait Islander Health Practitioner and 1.3% reported as being 'other' (chaplain and administration assistant). One participant was from a remote primary health centre.

#### *Professional experience*

Twenty-six per cent of respondents stated they had 11-20 years of experience in their current HCP role. The majority of respondents (44%) described minimal to no experience working in PPC.

#### *Education and training*

The majority of respondents (44 %) had not undertaken any university based education specific to palliative care. A small number (12%) completed a short course specific to palliative care, and 6% completed a post-graduate course. Thirty-one per cent of respondents indicated nil to minimal on the job training,

Self-initiated reading in the previous two years was reported as the highest learning methodology by respondents (34%), followed by workshop attendance (31%), and in-service attendance (26%), and case consultation (21%). Fourteen per cent reported not participating in any paediatric palliative care education.

Table 2 Twelve most highly rated learning needs of healthcare professionals according to weighted average

Paediatric Palliative Care Topic	Weighted Average
1. Preparing families for the death of their child	4.28
2. Palliative care resources	4.25
3. Management of the dying child	4.16
4. Communication skills	4.14
5. Pain Management	4.14
6. Other symptom management	4.12
7 Bereavement Care	4.02
8 Emotional Supports	4.02
9 Practical support	4
10. Grief and loss	3.95
11. Self Care	3.87
12 Management of Non-Oncology cases	3.86

## Challenges

Fifty-eight per cent provided additional feedback via a free text response 'challenges from most recent clinical interactions with children requiring palliative care support'. Two preliminary themes were identified.

## Communication

Respondents described vulnerability in knowing how to converse sensitively with families caring for a child referred for PPC.

Knowing the language to speak—being able to ask the questions required without being insensitive I guess. As this area is very new to me I am finding it difficult to know exactly how much to say/what to say/what not to say! (Clinical Nurse, less than two years' experience of PPC)

Coordination and communication between multiple teams. Access to documentation regarding end of life planning. Different interpretation by staff as to the meaning of 'palliative'. (Senior Medical Officer, 10-20 years' experience of PPC)

## Uniqueness of each child and family

Participants described the unique social presentation of each child and family and the challenges for HCP in meeting their specific needs.

I would like to think every child and their families are unique in every way. There lies the challenge. Every child and their families are in a position of our own worst nightmare. Challenges include emotions of the child and his family which change daily. The challenge for me would be to try to tune in as much as possible to better understand what is happening on that day at that time. (Clinical Nurse Team Leader, 6-10 years of PPC)

## Discussion

Paediatric Palliative Care is an emerging specialty that enhances quality of life for children and young people for their family in bereavement. However the specialised nature of PPC demands a diversity of HCP skills that can meet the needs of children and families wherever they live in Australia. This study reviewed outcomes from a learning needs analysis to determine the demographic profile and learning needs of generalist HCPs.

Medical presentations of children with a LLC are complex as are the psycho-social needs of families caring for a child with a LLC. This complexity demands a multi-disciplinary approach from HCPs. Previous studies refer to the range of care providers who make up a palliative care team, however in our study more than half the participants were nursing staff.<sup>13</sup> This could be attributed to the higher number of nurses employed in Queensland (61, 039), compared to the combined allied health (14, 922) and medical professionals (4, 313).<sup>25</sup> Given the small population of children receiving PPC, teams are generally comprised of part-time staff whereby only a portion of their role is allocated to PPC.<sup>13</sup>

Forty-four per cent of participants had not undertaken any university education specific to palliative care and 31% reported limited on the job PPC training and exposure. Lack of university education could be due to access and opportunities for generalist HCPs. In addition generalist HCPs may perceive PPC specialist knowledge as a lower priority given the rare exposure to children with a LLC in comparison to the adult sector.

This limited education and training is somewhat surprising given the majority of participants are from metropolitan areas; but it does align with current evidence for health professionals in more isolated

settings.<sup>1,26</sup> In light of this, it is encouraging that the highest reported learning strategy was self-initiated reading as a way to keep up to date with paediatric palliative care.

The twelve most reported learning needs identified in this study provide the basis for a QuoCCA curriculum in paediatric palliative care. The difference of the weighted average between the first (Preparing families for the death of their child—4.3) and twelfth (Management of non-oncology cases—3.8) ranked topic was only 0.5. Education provision should be flexible, multi-disciplinary and interactive professional development programs, including with inter-professional case based learning and discussion and opportunities to validate new knowledge.<sup>27-29</sup> Applying these principles to the delivery of these identified topics is paramount. Workplace (e.g. having time professional development leave), financial (e.g. provision of finances for registration, travel and accommodation at workshops and placements) and promotion of educational initiatives are all important components of program delivery and workforce sustainability.<sup>30</sup>

### **Barriers**

Participants described challenges around communication as a barrier to providing good palliative care for children. Sensitive and empathic communication is core to best practice palliative care.<sup>31-33</sup> Critical time points such as transition to palliative care and facilitating conversations around end of life and advanced care planning require skill and confidence most often gained through teaching opportunities and exposure to PPC. This topic also required innovative teaching methodology (e.g. role play, small group discussion, and video case studies).<sup>33-35</sup>

Responding to the unique and often complex social and emotional dynamics of families caring for a child with a LLC was a barrier to effective PPC for respondents. While specialist PPC teams are generally comprised of a multi-disciplinary team, HCP's in non-metropolitan locations are often required to demonstrate knowledge of multi-disciplines within their role.

An associated barrier described by respondents in this study was the emotional burden of caring for children with a LLC and for families in bereavement. Self Care is a critical feature of PPC and identified as Standard 13 in the Palliative Care Australia Standards.<sup>36</sup> Lack of confidence, fear of being inadequate and making mistakes are common barriers for HCP's which may vicariously impact staff wellbeing.<sup>37</sup>

### **Limitations**

Due to delays in obtaining ethics approval in each state this formal evaluation of the National collaboration is largely confined to Queensland which limits the generalisability of these results to other states in Australia.

Dissemination of the LNA as an on-line survey to rural and remote settings was difficult due to internet band-width and inability of HCP's in these regions to access email or the survey monkey link in a timely manner. This may have influenced the low response rates in rural/remote settings.

Conversations around death and dying with Aboriginal and Torres Strait Islander people require cultural sensitivity. This study had poor representation from these groups which we recognise as a significant limitation in terms of enhancing our understanding of the PPC specific learning needs of Aboriginal and Torres Strait Islander Health practitioners in regional, rural and remote settings.

## Conclusion

There are many challenges to providing palliative care to children in Australia due to the relative rarity and exposure to children with a LLC and the geographical diversity of the Australian population and health care system.

This study has identified a number of learning needs that healthcare professionals describe as important in facilitating the provision of paediatric palliative care. Topics range from “Preparing a family for the death of their child” to “Management of Non-oncology Cases”. All health professionals have a role in the provision of children’s palliative care, and in this context, an inter-professional approach to the delivery of education is critical. The pop-up methodology of PPC education offers promise in delivering education to health professionals based in regional, rural and remote settings. This ‘just in time’ responsive model provides meaningful education to HCPs caring for the child and their family. Further evaluation of this model is required to better understand the impacts on HCPs confidence and capacity and transferability into clinical practice. Further, the pop up methodology seems a particularly effective way to support Aboriginal and Torres Strait Islander patients living in rural and remote locations.<sup>38</sup> Further engagement with Aboriginal and Torres Strait Islander community leaders, healthcare workers and consumers is required to better understand their learning needs around PPC. It is hoped that more insights are to be gained from the continued evaluation of the QuoCCA Project, particularly regarding the impacts of the educational initiatives and the consumer perspectives. Further evaluation is required from a national perspective to understand the broad needs of generalist HCP’s who are increasingly exposed to the complex needs of children with a LLC.

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