

# Building capability in paediatric palliative care and enhancing education through the voice of parents: the Quality of Care Collaborative Australia

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## Abstract

**Background:** The greater proportion of children with a life-limiting condition (LLC) and their families want to remain at home as much as possible. Building capability in paediatric palliative care (PPC) for generalist health and social care professionals in nonmetropolitan regions through the Quality of Care Collaborative Australia (QuoCCA) has improved access to palliative care for families, regardless of where they live.

**Aim:** To understand the experience of families whose child has received specialist PPC, to ensure future service capability development is informed by lived experience.

**Design:** A retrospective, descriptive study in which parents participated in a semi-structured telephone interview guided by Discovery Interview methodology. Inductive thematic analysis identified the major learnings from participants.

**Participants:** Parents caring for a child referred to the specialist PPC service, who received a pop-up visit and whose child is stable or who are more than 6 months bereaved.

**Results:** Eleven parents ( $n=9$  mothers;  $n=2$  fathers) of children with an LLC ( $n=5$ ) or whose child had died ( $n=6$ ) participated in an interview. The overarching themes and subthemes were as follows: (1) burden of suffering, in which parents described grieving for the life once anticipated, confronting many life transitions and seeking quality of life for their child and (2) umbrella of support, in which parents built partnerships with professional support, activated a network of care around their family and sought responses to their whole family's needs.

**Conclusion:** Parents caring for a child with an LLC described significant personal, familial, social and existential adjustments. This study integrates a relational learning approach with QuoCCA education grounded in the relationships between children, families and professionals. Learning from lived experience in PPC education enhances the preparedness of generalist health and social care professionals to join a child and their family throughout their various life transitions and facilitates the goal to remain at home within their community for as long as possible. Education in PPC is an imperative component of service models, enabling regional services to gain confidence and capability in the context of a dying child and their family, empowered and informed through the voice of the family.

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## Plain Language Summary

### Enhancing palliative care for children through education informed by the experience of families

It is often the wish of many children/young people with a life-limiting condition to stay at home with their families as much as possible. It is important that specialist palliative care

services provide training and mentoring to the family's local care professionals to support the delivery of good care, particularly those in rural and remote areas.

This article aims to integrate the lived experience of families with palliative care education, so that the education reflects and addresses the needs that they express.

Parents were interviewed by telephone using a method called Discovery Interviews. This is an open interview process, guided by a spine that describes the main points of palliative care. Parents can openly talk about their experience, focusing on the areas that are important to them. Interviews were studied by four researchers, and emerging themes were discussed and summarised.

The study included parents whose child/young person was receiving support from specialist palliative care and bereaved parents whose child had died more than 6 months ago. In total, eleven parents (nine mothers and two fathers) were interviewed, five participants had children currently receiving palliative care and six were bereaved.

The overarching themes were as follows:

Burden of suffering, in which parents described grieving for the life they had expected, confronting transitions and seeking good quality of life for their child.

Umbrella of support, in which parents built partnerships with care teams and activated a network of care to address the needs of their whole family.

This study allowed the families' perspectives to be integrated into the palliative care education of care professionals in the family's local area. The lived experience of families prepared care professionals to support families with the care of their child/young person, allowing them to remain at home as long as possible.

**Keywords:** capability, education, parent, paediatric palliative care

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## Introduction

Paediatric palliative care (PPC) has emerged as a distinct medical specialty in response to the growing incidence in diagnosis of children with a life-limiting condition (LLC).<sup>1</sup> Within the paediatric setting, an LLC is referred to when there is no reasonable hope of cure and one where the child or young person will die. With over 300 conditions that can be classified as life-limiting, the health and social care needs of each child and their family are unique and complex.<sup>1</sup> The trajectory of life for an infant or child with an LLC may span from hours to years. In response to this variable trajectory, palliative care services for children and young people include specialist teams based in tertiary hospital settings, children's hospices and generalist health and social care professionals based in community and primary health settings.<sup>2</sup> A public health palliative care approach encourages partnerships between specialist and generalist palliative care services, who work with communities and neighbourhoods to enable access to care

wherever a child with an LLC and their family may live.<sup>3</sup>

With the breadth of nonspecialist services that integrate a palliative approach, education has become a service component within specialist PPC services.<sup>4</sup> Within the Australian context, in 2014, the Quality of Care Collaborative Australia (QuoCCA) was established as a mechanism for building confidence and capability of generalist and community-based health and social care professionals in the principles of PPC. A novel educational approach saw participants engage in a formal scheduled education session or 'pop-up' event, whereby education and mentoring were delivered by a multidisciplinary team of medical, nursing and allied health educators, and often parent educators, around the acute needs of a child and family in their home and community.<sup>5</sup> It has become evident that a large proportion of children with an LLC and their families find comfort in remaining at home and for many families this goal extends to

end of life and post death care.<sup>6</sup> Building capability in the local community serves to meet this goal and aligns with an optimal practice model encouraged by public health palliative care approaches.<sup>7</sup>

Providing education as a tool to build capability in the nonspecialist community to meet the needs of children and their families is imperative. Donovan *et al.* (2019) described the perspectives of health professionals who had received education through QuoCCA, finding enhanced workforce capability through education and mentoring, and improved quality and access to PPC for the families they serve. The next step was to conduct a similar study with parents whose child and family had participated in a 'pop-up' visit.<sup>5</sup> Parents caring for a child with an LLC describe a series of adjustments that take place on an individual, family, community and systems level. The inner world of the family becomes consumed by a health-care focus, challenging previous normalcy and creating a liminal space in which parents attempt to remain in the present, while holding fear for the future of their child.<sup>6</sup> Health and social care practitioners in nonmetropolitan locations may have little exposure to children with an LLC and their families. Browning and Solomon advocate for an educational approach 'grounded in the charged existential space of relationships among children, families and practitioners'.<sup>8,9</sup> Inviting parents caring for a child with an LLC to share their experiences enables a vicarious sense of relational learning for practitioners who otherwise may not be privy to this intimate experience and equips them with skills and knowledge to address their needs.

QuoCCA delivers an innovative approach to building the capacity and capability of a family and their community network to care for a seriously ill child, and in turn, meet the needs and goals of children and families to remain at home for as much time as possible. In the context of a dying child, the community may include parents, siblings and other assets such as extended family, friends, neighbours, schools, sporting clubs, churches and a parent's workplace, health and social care professionals and community services. The mission of QuoCCA aligns with a contemporary public health approach to palliative care (PHPC), whereby assets within the child, their family and their community network are activated.<sup>7</sup> The aim of this study was to understand the experience of families whose child had received specialist PPC in Australia, supported

through QuoCCA, to ensure future service development and capacity building of health and social care professionals is informed by their lived experience.

### Method

This study was approved by the Children's Health Queensland Hospital and Health Service Ethics Committee (HREC/16/QRCH/55). Participants were provided with an information pack, including a consent form, and provided written consent prior to interview. We adopted a three-phase recruitment approach that paralleled QuoCCA funding cycles throughout 2017 to 2020.

### Design

This retrospective, descriptive study explored the perceptions and experiences of parents whose child had been referred to the Children's Health Queensland specialist Paediatric Palliative Care Service (PPCS) and had participated in a pop-up education session. Discovery Interview (DI) methodology, originally developed as a service improvement tool by the National Health Service (NHS, UK), informed the study design.<sup>10</sup> This approach adopts a one-to-one interview technique, guided by a 'spine' (Table 1). The interviewer invites the interviewee to discuss their experience of each area displayed in the spine. The strength of this method sees participants leading the interview, describing what they feel was important at various stages of their experience.<sup>11</sup> There was an extensive education process for Discovery Interviewers to ensure that they were not driving the direction of the interview and only asking clarifying questions on content which the interviewee had provided already.

### Participants

Participants were recruited via a purposive sample with a postal invitation delivered to all parents whose family had received a 'pop-up' QuoCCA visit. Eligible parents were 18 years and over, whose child had been referred to the PPCS and was currently assessed as 'stable', or the bereaved parent of a referred child (more than 6 months bereaved). Parents were ineligible if they were unable to speak English, less than 18 years of age, had intellectual or mental impairment, were bereaved in the past 6 months and if their child was in the terminal or unstable preterminal phase of palliative care, ascertained through advice

**Table 1.** QuoCCA discovery interview spine: palliative and bereaved families.

## QuoCCA Discovery Interview Spine – Palliative Families

Meeting the people involved in caring for my child  
 Caring for my child at home  
 Caring for my family  
 Future care of my child  
 Ongoing support for my family

## QuoCCA Discovery Interview Spine – Bereaved Families

Meeting the people involved in caring for my child  
 Caring for my child at home  
 Caring for my family  
 Death of my child  
 Supporting my family after the death of my child

provided by the lead clinician of the PPCS/QuoCCA.

Invitations were distributed in three main waves in March and June 2017 (eight invitations, four consented and two interviewed), May 2019 (nine invitations, five consented and three interviewed) and November/December 2020 (eleven invitations, eight consented and six interviewed). Owing to low recruitment in the first phase of the study, ethical approval was gained to undertake a follow-up phone call 2 weeks post mail invitation. Of the total of 28 patients meeting eligibility criteria and invited to participate, 17 (60%) consented to participate. With the changing and challenging circumstances in the lives of families with a child with LLC, however, 11 were involved in interviews.

### Data collection

Audio-recorded telephone interviews with 11 parents were carried out between June 2017 and December 2020 and ranged in duration from 24 to 124 min. Interviews were conducted by three of the authors who were associated with the QuoCCA project with backgrounds in social work (L.A.D. – one interview), physiotherapy (S.J.B. – five interviews) and programme management (P.J.S. – five interviews) in the context of PPC. Each interviewer had undertaken training in DI methodology. Interviewers did not have a prior clinical relationship with participants in this study.

### Data analysis

All recorded interviews were outsourced for transcription, and an inductive thematic analysis was

conducted by three interviewers and an independent study investigator to identify themes. Reflexive thematic analysis is a deeply reflective qualitative method that organises and describes interview data in rich detail.<sup>12</sup> A thematic approach aligns well with the DI technique in allowing the data to guide the evolution of themes and concepts from a realist perspective.<sup>13</sup> This study sought to evoke the experiences, meanings and realities of participants to ensure the lived experience of participants influences future service development. A recursive and iterative approach to data analysis saw movement between the first five phases described by Braun and Clarke, followed by the production of the report.<sup>12</sup> Study investigators adopted a reflective process moving through phases I, II and III independently (becoming familiar with the interviews, generating initial codes and searching for themes) and reviewed and refined evolving themes collaboratively through a series of four workshops until a thematic map was developed that reflected the interviews. Investigators were then assigned a theme to investigate further and write up with representative quotes from parents. These were reviewed by all investigators and refined where necessary. Latent and semantic coding was undertaken manually and reported according to the Consolidated Criteria for Reporting Qualitative Research (COREQ) guidelines.<sup>14</sup>

### Results

The 11 participants were comprised of two fathers and nine mothers ( $n = 5$  palliative,  $n = 6$  bereaved). Seven participants (64%) resided in a regional or remote location,<sup>15</sup> and three children (27%) had been diagnosed with a malignant condition. Parent and child characteristics are described in Table 2. Presented topics and subthemes were relevant across all parents interviewed and example quotes provide additional context.

The thematic map that was developed from the analysis is shown in Figure 1. The interview themes will be described in detail with example quotes in this section and the outcomes from these findings for QuoCCA education will be explored in the discussion.

#### *Burden of suffering*

The researchers generated *Burden of Suffering* as one of the key overarching experiences described by parents of children with LLC receiving PPC.

**Table 2.** Participant characteristics.

Characteristic	Descriptor	Number (N)	Percentages (%)
Sex of parent	Male	2	18
	Female	9	82
ASGS Remoteness Areas	Major city	4	36
	Inner regional	4	36
	Outer regional	1	9
	Remote	0	0
	Very remote	2	18
Child's status at interview	Deceased	6	54
	Palliative	5	46
Sex of child	Male	4	36
	Female	7	64
Child diagnosis	Nonmalignant disease	8	73
	Congenital abnormalities	2	
	Neurological disease/cerebral palsy	5	
	Metabolic disease	1	
	Malignant disease	3	27
	Central nervous system tumour	2	
	Bone/soft tissue sarcoma	1	
	Neuroblastoma	0	
	Leukaemia	0	

ASGS, Australian Statistical Geographic Standard, 2016.

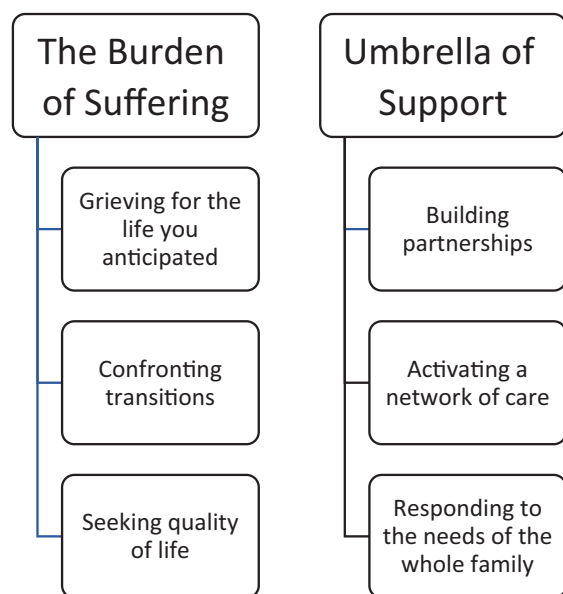
Three subthemes evolved that captured the experience of feeling burdened: (1) grieving for the life you anticipated, (2) confronting change and transition and (3) seeking quality of life.

*Grieving for the life you anticipated.* All parents reported multiple layers of grief, amid uncertainty. Parents communicated an overarching sense of loss for many aspects of their lives including for their child, the expectations of family and friends and a sense of isolation and loneliness. All parents highlighted the fragility of their child's life and the looming presence or reality of death, describing the world as their family once knew, no longer being the same or feeling a safe place:

Nobody knew how long she was meant to live for. So we were just happy to do our bit and go along for the ride and take each day at a time and just try and make it somewhat meaningful. (FAM7M)

Some families talked about friends and family members who did not have the capacity of ability to empathise with their family's experience. Several parents described how previously close relationships had drifted away:

And when you've been in it as long as we have, we don't have other friendships anymore because they all petered away, we couldn't go to events . . . and after a while they stop inviting you, and your point of view on life becomes different and . . . it's not



**Figure 1.** Thematic map: family caregiver discovery interviews.

that you don't love them anymore, you just grow on different paths. (FAM10F)

Most parents described feelings of loneliness, a sense of physical and social isolation from their family, friends and workplace, in contrast to life prior to caring for a child with an LLC. Life revolved around the routine of caring for their sick child with little room for life beyond their child's care needs:

Our life, it's a blur, because you're full-time care givers between the two of you and she needed full hourly care. Every four hours, she had to be turned so she didn't get pressure sores which meant that we had a rotating sleep roster sort of thing . . . And there was nights where we'd just be battling the saturations monitor, and making sure she was pretty much staying alive. (FAM7M)

*Confronting transitions.* All parents referenced the significant impact of transitions and timelines highlighting the fragility of life for a child living with an LLC. Feelings of vulnerability and heteronomy were present in all parents' narratives about the health of their children and life:

He's having his big third birthday soon, I mean we never thought we would get to this stage but, yeah, we had a really big first birthday and it was done by Starlight, it was amazing. And then his second

birthday we did an even bigger version of it at our house . . . like I never thought we would get to this one, and we still haven't made it but I'm hoping that we'll get there. (FAM3F)

Parents explained the liminal space they learned to hold as they held onto days, weeks, months and often years of their child's life. The capacity of families to sustain this 'holding' space on the threshold between life as they knew it and a new life potentially without their child appeared to be influenced by the language of health professionals and the nuances of rare diagnoses:

So when we were referred – what happened back then was just one night like we were told that day basically that she was going to pass away very shortly because her lungs had collapsed and there was no hope. She was only five, and now she's 14. (FAM4F)

Parents described living in a constant state of uncertainty. Some examples included their child having periods of being 'well' then ill, living at home then travelling away for treatments to city hospitals often without a perceived timeline, from diagnosis to end of life and the roller coaster in between:

. . . after that emergency surgery we went off to Brisbane where we had our first year of treatment, which actually turned into 14 months, she went through chemo, radiation, several surgeries, and then was in remission for about six months (went home). We returned to Brisbane again, had another treatment scheduled that was eight months long with surgery, chemo, . . . then she went into remission again. But then after that time, for the next six years since her diagnosis, we were in and out of hospital. . . . (FAM8F)

All parents described the world that their family once knew, no longer being the same or feeling a safe place. Some parents questioned their life foundations, such as their life philosophy, beliefs, meaning and values. Parents articulated loss of a longed-for future, hopes and plans they once held for their child, themselves and family. Parents expressed a sense of disablement in fulfilling their parental role as they expected. They partnered this with a sense of changing personal identity and for some the loss of careers. Parents described a new role as the expert in their sick child's life, yet a sense of confusion when their expertise was not valued or respected by health professionals:

When he got diagnosed, it was almost like an unsaid thing, my husband had to stop his work and come and be with us because . . . that's where he needed to be . . . it was a big change, it was a huge change but it wasn't even something that we needed to discuss . . . (FAM3F)

*Seeking quality of life.* All parents communicated attempting to seek quality of life, for their child and their family, and the challenges of enabling this. Most parents affirmed that their child's referral to the PPCS supported quality of life:

Once we got in (to PPCS) it was awesome. It's like, oh my God. We can talk about death and quality of life. We can talk about what life expectancy or what treatments or stuff like that, whereas before it was just we're treating a disabled child, but she wasn't just disabled; she was disabled and critically ill and in extreme pain and suffering. (FAM2M)

In most cases, parents in this study were able to describe a sense of gratitude, a new capacity to see what was important in life. They described an inner resilience as they navigated ongoing adversity:

It's not all negative, do you know, there are a lot of positives that have come out of all of this situation and if you sit yourself in the negative, it's only going to create darkness. So you actually need to be able to get into that positive stuff and look at it with light. (FAM3F)

Parents described the challenges and ambiguities of navigating various health services and complex symptom management. The level of health care required by their children appeared multifaceted and often a trial-and-error process. Parents expressed concern that the symptoms became the focus rather than their child as a whole. Parents felt validated and empowered once receiving PPC:

They (PPCS) really understood. For the first time . . . a doctor who sat and just talked about quality of life. No doctor ever talks about quality of life or the impacts and it's always about extending life and doing everything possible to further it. But for the first time actually somebody going, 'You've had a really hard time'. Doctors don't talk about that generally. (FAM2M)

Being able to create memories in addition to upholding their child and families wishes allowed

parents to create a sense of meaning and sustained an intimate connection with their child in bereavement. Many parents focused on the present given the uncertainty of what the future held. Parents also referred to transitioning between the reality of creating 'happy' memories, while holding the heaviness of their child's future:

Look the things that are important are actually spending time, having that quality of life rather than trying to buy them something to make them happy or, you know, those types of things. . . . having something like this happen to your family where you've got to go, well what's actually really important to us? (FAM3F)

### *Umbrella of support*

The second key theme was the parent's description of the activation of an *Umbrella of Support* in response to the burden of suffering previously described. Three subthemes were generated: (1) building partnerships, (2) activating a circle of support and (3) responding to the needs of the whole family.

*Building partnerships.* The term palliative care initially elicited a negative response from many parents as they associated this with end of life, rather than improving their child's quality of life. Transitioning into palliative care and meeting the team was met with initial reluctance, seen by most parents as giving up and losing hope. One parent shared her perception 'You're agreeing . . . that your baby is going to die' (FAM4F). Parents became more accepting of this service transition through clarification of the broader remit of PPC:

[PPC staff member] said it's not so much end of life care, it's managing pain care, and I sort of wish I could've had that mindset earlier . . . that was through no fault of the hospitals; that was just my aversion to that word . . . (FAM5F)

Conversely, some parents felt their referral to palliative care was delayed by others in the health system including general practitioners and paediatricians:

. . . how do people get into the palliative team in the first place. There are some people just not getting the right information at the right time. . . . you will get some paediatricians who just don't get it. (FAM2M)

Some families described a sense that the transition to palliative care meant their child's existing medical team had abandoned them or had given up hope. This transition was enabled when the primary care team maintained a partnership with the specialist PPC team:

. . . in that time when you're feeling like you need the team that you know. We got . . . passed off to this other team that we didn't know which obviously now we know was the best thing ever for us. But at that time . . . You're with a team and then all of a sudden your child is dying, here you go – we don't want you anymore. (FAM4F)

As the family's partnership with PPC became established, parents described their appreciation for symptom management, access to specialist advice, practical assistance, and facilitating care of the child in the family's home. Parents saw the specialist PPC service as the central point of contact who radiated advice to generalist medical teams, hospital and community services:

. . . I could just ring pall care and say, hey, I'm running short on this. And it was quite cool because they made the connection themselves, with the hospital and with . . . [community nursing service], so a nurse could start coming out just for an hour every day. (FAM5F)

Parents found comfort in the PPCS proactively planning ahead for a range of potential health scenarios for their child, with community-based care facilitated through QuoCCA pop-up visits. The increased understanding of their child's condition, what to expect, how to manage symptoms and where to access the right support, improved the parents' state of mind:

Whereas now you can sort of probably manage it all from home a little bit better because you've got those doctors there. And they have a plan in place. Like if she goes into status again with her seizures, they have a step-by-step plan and you know that if you need to go to a hospital, then you're confident with the doctors at the hospital because they're going to notify the palliative care team, and they're going to work together. (FAM9F)

*Activating a network of care.* Parents described the PPCS as pivotal in activating support systems to enable their child to remain at home, an environment in which they felt comfortable and safe, surrounded by family and friends. Home visits,

phone support and telehealth reduced additional stress for parents and enabled partnerships with health providers in the family's community. These partnerships were strengthened through home visits from PPC team members with education and support provided through QuoCCA:

Some of the team actually flew down . . . I'm so grateful because they really made a very clear and easy track for us to access the hospital, the pharmacy . . . they organised an account there . . . with the hospital and with [community care], so a nurse could start coming out just for an hour every day. (FAM5F)

Parents heavily utilised the PPCS 24-h 1800 phone number for help with medication, symptom management or equipment. Familiarity with the staff member on the phone who knew their child and the context of their family's life enabled trust and comfort. Parents described this service providing reassurance, advice, options and reduced stress by having access day and night to a specialist sounding board:

We had to ring up all the time . . . the guys were just amazing . . . you just feel like there's so many things happening, you ring and then something else would happen or that doesn't work . . . 'This medicine, see how that works, in half an hour give us a call back if it doesn't work'. So then you will ring again and you just keep going through the whole night and we had . . . weeks, months where there was just constant interactions. (FAM2M)

The availability of equipment was an important aspect of support at home, with parents sharing that sometimes the QuoCCA team visited the local services to train the staff and the family around the equipment needs:

We had to have a specific ventilator . . . when it got shipped home, they made sure that they let us know that they've been to the hospital, locally trained in the equipment area so, if you ever had to get to the hospital for any reason . . . they could take care of us. (FAM7M)

Parents described a network of care that developed over time in their community, including community nursing, general practitioner and the regional hospital. These strong connections, while clinical in nature, often shared a dual role of social support for families isolated in their homes due to the fragility and care needs of their child:



So we felt like we . . . weren't abandoned or anything like that, we always felt that we had contact, if there was someone that we needed we could get hold of them relatively easily . . . even the [community nurses] who came in are local people that we knew so we always felt like we were with friends looking after her. (FAM8F)

Families relied on access to in home or hospice respite care to reduce the burden of 24-h care of their child, but also described barriers to accessing respite due to the National Disability Insurance Scheme (NDIS) protocols or the fluctuating health of their child:

The whole idea of the place [children's hospice] is not only used for respite from your child, to go and have time without being a carer, a diagnostician, a chemist, . . . a therapist, everything, but also to be a family unit in the house . . . you can come as a family and you can have quality time together as a family, without having to do the night cares or the medicines and all of that kind of thing. (FAM10F)

While parents praised the support from the network of health-care professionals throughout their child's life, many described immense loss following the withdrawal of these connections after the death of their child:

And then I came home and we had silence, there was no blue care nurses, there was no hospital in the home, there was no palliative care, there was no [children's hospice], there was no carers coming three times a week who became our family . . . because you can't help it . . . they say that you shouldn't be bonding with these people, and they're told that they shouldn't be bonding with you . . . It's impossible not to have these people in your home, dealing with your son on a personal level, dealing with you and seeing your loss and grief, and every day heartbreak and your foibles and your stupidity, and your laughter, and not build up a rapport and a friendship, and then to have them ripped away from you. It's like you've done something wrong, but you haven't, your child just died. (FAM10F)

Parents expressed a mixed experience of extended family and friends remaining connected throughout their child's life. Some friendships petered away and invitations to social events stopped with the formation of different life paths. Others described strengthened networks that included

new friends and peers also caring for a child with an LLC:

I always wanted to do treatments here, and not be in Brisbane all the time . . . and that really helped us a lot, to be with our family and friends . . . (FAM1F).

*Responding to the needs of the whole family.* Caring for a child with an LLC placed significant pressure on parents' relationships. Parents reported it was supportive for their relationship to agree philosophically how to balance care of their child, while finding time to have occasional breaks to spend time with each other. Parents advocated for counselling and support groups in the hospital to provide tools for coping as a partnership and family unit:

There needs to be some marriage tools, there needs to be family tools because they're either too exhausted, too heart broken, or too full of grief to even know how to live sometimes . . . it will hopefully save a lot of marriages, it will save a lot of families, it will save lives, it will give us the tools that we can to be able to cope with it, because it's devastating, that diagnosis from the beginning is devastating. (FAM10F)

Parents described a change in identity from a past occupation to full-time carer. Intense care needs of a sick child often meant one or both parents withdrew from employment and career, leading to financial distress. Long-term caring responsibilities then meant difficulties in re-entering the workforce following the death of their child. Services could guide families in the access of support:

We were on a pension for so long and [parent/carer] was working a couple of days because that's all she could do and . . . after five years your career just either disappears, you go to the back of the line or worse because they look at your resume and being a carer for a disabled child doesn't rank highly . . . it takes so long for you to claw your life back financially . . . (FAM2M)

Parents spoke of the juggle of caring for a child with an LLC and raising other siblings. Some parents described working hard to ensure individualised time with their other children. Parents shared awareness around the role siblings played in the lives of their sick brother or sister and the associated loss in their lives in bereavement.

Health professionals played an important role in providing education for siblings around treatment, medication and equipment, and a safe place to talk:

And we've been quite open and honest with [sibling] with how things are going to be with them because my husband and I both feel like it's the way to go, you know, we can't leave them in false hope and then all of a sudden [sick child] goes . . . they need to be a part of this journey too and it's working for our family so far. (FAM3F)

Creating and accomplishing goals with and for the sick child was a priority for parents. Goals took the form of adjusting medications to enable quality of life, place of care, place of death, creating a will and memory making. The little control patients had over their life due to their regime of care was offset in some way by being able to achieve important goals:

[She] didn't want to go to hospital, she absolutely hated it . . . So we were trying to keep her home and not having to take her in as much as we possibly could. . . . don't get me wrong, there definitely were times where self-doubts came in . . . it would be easier in a hospital, but then it wouldn't, because that would be against her wishes. (FAM5F)

A number of parents described the PPCS as a source of encouragement to create family memories and fulfil hopes and dreams to support their long-term grieving:

And they were the ones that actually encouraged us to go and find memories and take photos and do all of those things to give us the confidence. So two weeks after being diagnosed with all of his new medicines and he had a nasal gastric tube, and we had all of these pumps and all of these instructions, and all of this stuff that we had to take with us but we got into a campervan, two weeks on the South island and then two weeks on the North and we did it. (FAM3F)

## Discussion

Caring for a child with an LLC is a whole of community experience, with the impact of the child's illness and associated care extending to parents, siblings, extended family, friends and the broader community. The geographical context of Australia, and for the purposes of this study, Queensland, also means reliance on generalist

health-care teams to partner with families, within their community, throughout the life of their sick child and a family's transition into bereavement. Enabling opportunities for parents and carers to share their experience guides the approach of specialist paediatric palliative care (SPPC) teams, particularly in the context of bolstering capability and confidence of a family's formal and informal network of care. Education that aligns with the concept of relational learning, in which learners engage vicariously in a lived experience, serves to meet this goal.<sup>9,16</sup> In this study, parents described a 'burden of suffering' in their care role and the associated 'umbrella of support' that formed following a connection with the PPCS. Educators could use these quotes and stories of parent's lived experience to relay insights to the health professionals that would equip them to better meet the families' needs. Such use of DIs with health professionals has been shown to raise their awareness of the perspectives of families and impact on the way they delivered care and interact with families.<sup>10</sup> In this study, parents described capacity building within their formal and informal community networks, which the authors suggest was enabled through the provision of QuoCCA pop-up education.

At the outset, parents described the emotional hurdle that preceded referral to a service that in their minds represented the reality of their child's death. Each family is unique in how they consider their child's present and future. For some parents in this study, the referral to palliative care felt delayed, while others resisted this transition from their child's primary care team. Parents confirmed the need for education with generalist health-care providers to ensure compassionate and accurate delivery of information regarding PPC, and timely referral to a service that could enhance their child and family's quality of life. Integrating dedicated educator roles in SPPC services, as demonstrated through QuoCCA, builds capability for health and social care professionals, enables the development of inter-professional partnerships and encourages guidance from children and families.<sup>4,5,17</sup>

Throughout the trajectory of care, parents experienced a chronic sorrow for the myriad of unanticipated life changes as a result of their child's health fragility and care needs.<sup>18</sup> Within this liminal space, parents attempted to remain in the present for fear of thinking ahead to life milestones their child may never achieve.<sup>19</sup> Honouring their

child's shortened lifespan through small yet significant milestones and capturing precious memories appeared to enable a source of meaning and a form of legacy building.<sup>20</sup> Skilled and compassionate communication from health professionals invites parents to explore ways to balance their child 'living well' in the present, while tolerating the possibility of dying. Jacobsen and colleagues share, in the context of a dying adult, a dual framework that supports movement between the developmental process of living as fully as possible, while also preparing for the possibility of dying.<sup>21</sup> This concept of 'hoping for the best, preparing for the worst' is embedded in SPPC, often in the context of Advanced Care Planning.<sup>22</sup> Health-care providers, particularly those who rarely care for a dying child, often fear navigating these conversations.<sup>22</sup> Embedding QuoCCA education as a core feature of SPPC service delivery meets the dual goal of building capability in health and social care professionals, while ensuring parents experience a compassionate response at a time of immense suffering.<sup>17</sup>

While the dominant narrative for parents in this study focused on quality of life for their child, an underlying theme addressed the physical and emotional toll of caregiving, the duration of which often extended to years. In seeking quality of life for their child, parents experienced a reduction in quality of life for themselves as a result of high carer burden, psychological and emotional distress. Numerous studies affirm an association between carer strain, elevated stress, anxiety and depression,<sup>23,24</sup> and impact on a parent's capacity to engage in work and associated financial issues.<sup>25,26</sup> A study of 28 parents caring for a child with an LLC in Australia, described their highest social support needs, included having time for yourself, practical help in the home, and financial, legal or work issues.<sup>25</sup> For parents in this study, an intense child focus and associated strain also meant a gradual distancing from pre-existing networks, social isolation and loneliness, consistent with previous research in PPC.<sup>23,24</sup> QuoCCA education will raise the awareness of this carer burden to health and human professionals who were caring for families and give them the opportunity to proactively discuss and apply avenues of support as appropriate and available in their area.

The impact of the caring role and the associated impact on siblings and the broader family network require a holistic child and family-centred response.<sup>27</sup> Parents in this study described the

health services, including PPCS, general practitioners and community nurses as partners in the care of their child, enabling children and families to remain in the comfort and familiarity of home, close to friends, school, employment and other important community members. These concepts of relationships and partnerships between families and health-care professionals are reinforced in previous studies.<sup>27-29</sup> Remaining at home or as close to home as possible throughout their child's life and facilitating a choice for their child to die at home is a theme affirmed in PPC literature, in which the normalcy of life can be held for all family members.<sup>6,30,31</sup>

Enabling this goal requires a community that is aware, skilled and committed to responding to the health-care needs of the sick child and the social support needs of the family. PHPC approaches have emerged as a contemporary response to reorienting and returning death and dying to the family and community setting.<sup>32,33</sup> Education such as that provided through QuoCCA is a cornerstone of public health that addresses anxieties for families and communities, about death, dying, loss and end of life care.<sup>34,35</sup> The Report of the Lancet Commission on the Value of Death argues that rebalancing death and dying can only be achieved by changes on a systemic level.<sup>32</sup> A solely clinical model of palliative care will not address the issues of carer burden and social isolation as described by parents in this and other studies.<sup>24,36</sup> We argue that SPPC services have a role to play in partnering with families caring for a child with an LLC, generalist palliative care and compassionate communities to activate and educate networks of care equipped with knowledge and skills of death, dying and bereavement in a child and family's community.

### Strengths and limitations

Learning from the lived experience brings authenticity to the practice of health and social care professionals. This study shares experiences of parents caring for a child with an LLC and those who have suffered the devastation of the death of their child. The richness of these voices informs future service approaches within the PPCS and QuoCCA.

A limitation of this study saw recruitment limited to one Australian state. Greater diversity of experiences would be captured through inclusion of families that represent the particular nuances of

each Australian state. Eligibility criteria meant the experiences of parents from non-English speaking backgrounds are not represented.

Recruitment to the interview process was low, which reflected low numbers of PPC families generally. Completed interviews was also affected by funding and researcher capacity as QuoCCA funding mostly covered education activities rather than protected time for research. The methodology used involved specific training for interviewers which also impacted their capacity. Recruitment was interrupted by the ending of the 3-year phases of funding, for example, one phase finishing after the 2017 recruitment, which was followed by a gap in funding. There were practical challenges with changing variables involved with parents of children receiving palliative care. The DI methodology is not one that requires a specific sampling regime, as each interview is a rich source of information as the parent tells their unique story.

### What this study adds

QuoCCA in partnership with the specialist PPC is an innovative response to building the capability and confidence of generalist health and social care providers when caring for a child with an LLC and their family. This partnership approach focuses attention on the experience and needs of the formal and informal network of care that families draw on within their local community. This study, which shares the stories and perspectives of parents, complements the previous evaluation of the impact of QuoCCA for professionals who participated in scheduled or pop-up education sessions<sup>4,5,17</sup> and demonstrates how the family voice can be included in QuoCCA education.

### Conclusion

QuoCCA has delivered education to health and social care professionals in metropolitan, regional, rural and remote communities throughout Australia.<sup>4,5,17</sup> This innovative approach to education aligns with the expressed needs of children diagnosed with an LLC and their parents, who hold a strong desire to find a sense of normalcy in life that can only be found in the routines and rituals of being at home, for the majority of time.<sup>6</sup> Education in PPC is an imperative component of service models, aligning with a public health approach to enabling those beyond SPPC services

to gain confidence and capability in the context of a dying child and their family, empowered and informed through the voice of the family.

### Declarations

#### *Ethics approval and consent to participate*

This study was approved by the Children's Health Queensland Hospital and Health Service Ethics Committee (HREC/16/QRCH/55). Participants were provided with an information pack including a consent form and provided written consent prior to interview.

#### *Consent for publication*

The participant information pack and the consent form discussed approval for the publication of the de-identified research.

#### *Author contributions*

**Leigh A. Donovan:** Conceptualisation; Data curation; Formal analysis; Methodology; Validation; Writing – original draft; Writing – review & editing.

**Penelope J. Slater:** Conceptualisation; Data curation; Formal analysis; Funding acquisition; Methodology; Project administration; Writing – original draft; Writing – review & editing.

**Angela M. Delaney:** Conceptualisation; Data curation; Formal analysis; Project administration; Writing – original draft; Writing – review & editing.

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### Competing interests


The authors declared no potential conflicts of interest with respect to the research, authorship and/or publication of this article.

### Availability of data and materials

The interviews that form the basis of this paper have not been consented to be released outside of the research team, apart from de-identified quotes as displayed.

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