


BMJ Open Conceptualising paediatric advance care planning: a qualitative phenomenological study of paediatricians caring for children with life-limiting conditions in Australia

Sidharth Vemuri ^{1,2,3}, Jenny Hynson,^{1,2} Katrina Williams,^{3,4} Lynn Gillam^{2,3,5}

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For numbered affiliations see end of article.

Correspondence to

Dr Sidharth Vemuri;
sid.vemuri2@rch.org.au

ABSTRACT

Objectives Advance care planning (ACP) helps families and paediatricians prepare and plan for end-of-life decision-making. However, there remains inconsistency in its practice with the limited literature describing what this preparation involves, and whether paediatricians recognise a difference between the process of ACP and its outcomes, such as resuscitation plans. This study aims to understand how paediatricians conceptualise ACP when caring for children with life-limiting conditions (LLC) who are unable to participate in decision-making for his/herself.

Design Individual, semistructured, vignette-based qualitative interviews.

Setting Acute inpatient and long-term outpatient paediatric care in three secondary and two tertiary centres in Victoria, Australia.

Participants 25 purposively sampled paediatricians who treat children with LLC, outside the neonatal period. Paediatricians were excluded if they worked within specialist palliative care teams or assisted in this study's design.

Results Four key themes were identified when approaching end-of-life decision-making discussions: (1) there is a process over time, (2) there are three elements, (3) the role of exploring parental values and (4) the emotional impact. The three elements of this process are: (1) communicating the child's risk of death, (2) moving from theoretical concepts to practice and (3) documenting decisions about resuscitation or intensive technologies. However, not all paediatricians recognised all elements as ACP, nor are all elements consistently or intentionally used. Some paediatricians considered ACP to be only documentation of decisions in advance.

Conclusion There is a preparatory process of discussions for end-of-life decision-making, with elements in this preparation practised within therapeutic relationships. Complexity in what constitutes ACP needs to be captured in guidance and training to include intentional exploration of parental values, and recognition and management of the emotional impact of ACP could increase its consistency and value.

INTRODUCTION

Advance care planning (ACP) is standard care for children with life-limiting conditions (LLC).¹⁻⁴ Often, these children are unable

STRENGTHS AND LIMITATIONS OF THIS STUDY

- ⇒ Our phenomenological approach takes data directly from individual paediatricians to describe their lived experience of advance care planning (ACP), an aspect of care where there is a mismatch between theory and practice.
- ⇒ Phenomenology focuses on richness of data rather than the sample size.
- ⇒ Using clinical vignettes captures how paediatricians view their communication approach in their understanding of ACP.
- ⇒ Paediatricians' self-report of practice may have been influenced by familiarity with the interviewer and does not allow for data triangulation nor for identification of how parental responses shape this communication.

to participate in decision-making due to their developmental capacity. In this context, ACP, theoretically, is a process of sharing concerns about a child's medical susceptibilities and eliciting parental values to facilitate shared decision-making, often at the end of life. These conversations may produce documented plans about resuscitation or intensive technologies.⁵⁻⁷ While there are existing tools to encourage ACP conversations,⁸⁻¹⁰ there remains inconsistency in this approach for children with LLC.¹¹ Decision-making often occurs when the child is critically unwell,^{12 13} a highly emotional time that is not conducive to making decisions. If parents¹⁴ and paediatricians have not contemplated end-of-life care in advance, they can feel underprepared.

It remains unclear what aspects of preparatory discussions paediatricians value when planning for end-of-life decision-making (EOLDM) in advance. There is a limited literature describing whether paediatricians recognise a difference between the ACP process (eg, discussions over time) and its

outcomes (eg, documented decisions). This may lead to diverse interpretations of what constitutes paediatric ACP and therefore its utility. This qualitative study explored how paediatricians conceptualise ACP when caring for children with LLC who are unable to participate in decision-making for themselves.

METHODS

Study design

Informed by a phenomenological framework,¹⁵ this study explored how paediatricians understood their lived experience of ACP in clinical practice. Phenomenology was well-suited for this study, given the aim to elicit the lived experience of an aspect of care, which is inconsistently practised, as it focuses on the richness of data from a small number of participants.^{15 16} Paediatricians who treat children with LLC outside the neonatal period in Victoria, the second most populous state in Australia, were eligible to participate. Paediatricians who assisted in developing vignettes for this study were not eligible to participate. In addition, paediatricians working within specialist palliative care teams were excluded because the intention of the study was to investigate how ACP is understood by paediatricians outside the palliative care setting. Recruitment was via professional networks and snowballing. Purposive sampling obtained a spread of paediatricians treating children with curable versus non-curable conditions, in inpatient and outpatient settings. Paediatricians treating children with curable conditions were recruited from oncology and cardiology; those treating children with incurable conditions were recruited from general paediatrics. Inclusion of paediatric intensivists also allowed spread of participants across acute inpatient compared with long-term outpatient care for children with both curable and incurable conditions. Written consent was obtained prior to data collection.

Patient and public involvement

Given our objectives, it was not appropriate to involve patients or the public in this study.

Data collection

Individual semistructured interviews of 45–150 min duration were conducted between May 2019 and June 2020 by one researcher (SV). SV was trained in qualitative research methods and was known to all participants as a paediatric palliative care physician.

Vignette development

The interview was structured around the paediatrician's approach to a clinical vignette. Five vignettes were developed (online supplemental file 1), in consultation with subject-matter experts (paediatricians with more than 10 years experience in their relevant subspecialty) in accordance with published recommendations.¹⁷ Two vignettes involved a child with severe neurodisability, one in an outpatient clinic; the other in the intensive care unit. Two

vignettes involved a child with cancer, one with a solid tumour; the other with a haematological malignancy. The final vignette involved a child with complex heart disease. To improve plausibility, paediatricians were matched to one vignette based on their clinical experience.¹⁴ Each vignette described a scenario where concern about the child's medical susceptibility would be raised and the child was unable to participate in decision-making for his/herself. Face validity of each vignette was confirmed by at least two internationally based paediatricians.

Interviews

An interview guide (online supplemental file 1) was developed by SV, LG and JH and pilot-tested with KW. Prompts were consistent across vignettes, ensuring key areas of interest were explored, including;

- ▶ Approach to, and intention of, communication.
- ▶ Clinical concerns raised by the vignette.
- ▶ The extent to which the clinician recognised their communication as ACP.
- ▶ Experience and training in ACP.

Interviews were audio-recorded, transcribed verbatim and deidentified. SV transcribed the first 14 recordings; the subsequent 11 recordings were professionally transcribed, checked and deidentified by SV.

Data analysis

Data collection and inductive content analysis¹⁸ was an iterative process conducted by SV, JH and LG; six iterations occurred over the 13-month data collection period to allow for clarification of emerging themes and to follow new lines of inquiry. As described previously, SV was known to all participants in his clinical role as a paediatric palliative care physician and has been trained in qualitative research methods during his doctoral studies. JH is a paediatric palliative care physician and an experienced postdoctoral qualitative researcher, and LG is a clinical ethicist, experienced postdoctoral qualitative researcher, and supervisor of training in qualitative research methods. Given the structure of the interview, whereby participants' approach to communication was elicited prior to discussion about the extent to which they considered their approach ACP, transcripts were not returned to participants for member checking prior to analysis.

After the first interview, all three researchers individually read the transcript and organised data by opening coding. The researchers then met to discuss the similarities and differences between open codes within the transcript. SV then conducted the next four interviews. Each researcher read these new transcripts, and re-read the first transcript, generating open codes. All three researchers then met in a dedicated data analysis meeting to discuss their interpretations and initial coding sheets were created by consensus. Amendments to the interview guide and suggestions for lines of inquiry for subsequent interviews were discussed. This process was repeated after the 10th interview.

Following this, in addition to individual researchers undertaking open coding, they also used the generated coding sheets for higher-order interpretation. New codes and differences in interpretation within and between transcripts were discussed in regular data analysis meetings. This process was repeated after the 14th, 19th and 24th interviews. Data analysis meetings were held every 2–3 months.

After the final interview, all three researchers met to discuss any new open codes that were generated within this transcript, and then revised the coding sheets by consensus and started grouping the list of headings. SV then re-read all transcripts with reference to the revised coding sheets and headings over a period of 4 months and raised any queries or differences at the final data analysis meeting. After further discussion and agreement among all three researchers, groups of headings were categorised and the final schema of themes derived from the data in relation to the research topic and objectives was formulated.

Reflexivity was practised throughout this process. Immediately following each interview, SV made field notes describing the environment in which the interview was conducted in, his self-reflection on the interview, his emotional state and response to the content raised, any observations of the participants' emotion or demeanour during the interview, and other general observations or thoughts which arose during the interview process. These notes were discussed during the regular data analysis meetings, and on two occasions, in more informal debriefing meetings with both JH and LG. Contemporaneous notes were also taken in each data analysis meeting. Data were managed using hardcopy files and electronically with NVivo.¹⁹

RESULTS

Participants

Of the 102 paediatricians approached, 25 participated. Most were male (n=17). Eleven paediatricians had more than 10 years' experience working at consultant level. Nineteen were employed in tertiary paediatric hospitals. No paediatrician received formal training in ACP. Demographics are detailed in table 1.

Key themes

Analysis identified four key themes in relation to EOLDM discussions for children with LLC; (1) there is a process over time; (2) there are three elements of this process, (3) the role of exploring parental values in the process and (4) the emotional impact of this process. Verbatim quotes supporting data interpretation are included in the text.

Theme 1: The process over time

All paediatricians indicated an evolving process of discussions for EOLDM. This involved 'different types of conversations' (ND-03) with differing intentions at different

stages (illustrated in figure 1). These 'conversations in advance [are] about patients who have a predicted course... (and) exploring perspectives around a predicted course' (PICU-04). Some paediatricians used ACP as the term for this process. That is, ACP helps paediatricians develop 'an understanding of where the family's at, in terms of how they think about their child's life' (ND-02). Developing this understanding is 'a good guide for [paediatricians] making management decisions' (ND-02). However, others viewed ACP as being just one part of these discussions, that is 'the document and formalising it [resuscitation and intensive technologies not to be used]' (ND-10). These paediatricians felt ACP needed to be 'explicit' (ND-04) involving 'tick-boxes, not for CPR' (ONC-02).

Theme 2: Elements of this process

Three elements of EOLDM discussions emerged: (1) communicating the child's risk of death, (2) moving from theoretical concepts to practice and (3) documenting decisions about resuscitation or use of intensive technologies.

Communicating the child's risk of death

Paediatricians described communicating the child's expected clinical course, including risk of death with parents. Ideally, this involved non-confrontational conversations 'informing families about your perception of risk [for the child]' (ND-01). The aim of this was 'preparing the family for a potential death' (ONC-04). By planting this seed 'you're actually coaching them [the parents] through what they need to think about' (ND-09). Furthermore, parental responses to concern being raised were thought to give 'a sense of if they're prepared to discuss it' (ND-09). The incorporation of this step in the conceptualisation of ACP varied; one paediatrician considered this 'preparing for ACP' (ND-03) while another described this as 'step one in ACP' (ND-05). Even if discussions did not progress beyond this point, paediatricians felt that there was value in setting 'expectations, as much as possible, of [the child's] future' (ND-03).

Moving from theoretical concepts to practice

Most paediatricians described moving from conceptual discussions around the child's risk of death to more practical elements: 'initial thoughts move from fantasy to reality... going from, 'yeah, he will die at some point' to 'ok, we've actually got to decide now whether we do treatment x vs treatment y'' (ND-05). The aim of this step was to clarify 'the nuts and bolts of if the child looks like they are going to die... what are we prepared to do at that time point' (ONC-04), 'talking about limitations to resuscitation is the key' (ND-06) and 'having an understanding of... a reasonable approach if this child comes in in extremis' (ND-02).

Discussions about 'future care before you get to that clinical state' (ND-03) were considered by some paediatricians as being 'part of ACP' (ND-07). These conversations were easier if families 'ask you, 'so how are they going to die?'' indicating 'they are ready to start that conversation' (ONC-04). However, challenges in these discussions were

**Table 1** Clinician demographics

Paediatrician	Gender	Specialty	Location of work*	Experience†	Interview mode
Vignette 1: Child with a severe neurodisability in an outpatient clinic					
ND-01	Male	General paediatrician	Tertiary/metropolitan‡	>20 years	In-person
ND-02	Female	General paediatrician	Tertiary/metropolitan‡	>20 years	In-person
ND-03	Female	General paediatrician	Tertiary/metropolitan§	5–10 years	In-person
ND-04	Female	General paediatrician	Tertiary/metropolitan§	<5 years	In-person
ND-05	Male	General paediatrician	Secondary/metropolitan§	16–20 years	In-person
ND-06	Female	General paediatrician	Tertiary/metropolitan§	5–10 years	In-person
ND-07	Male	General paediatrician	Secondary/rural§	16–20 years	In-person
ND-08	Male	General paediatrician	Secondary/rural§	11–15 years	In-person
ND-09	Male	General paediatrician	Secondary/rural§	16–20 years	In-person
ND-10	Male	General paediatrician	Secondary/rural§	>20 years	In-person
Vignette 2: Child with a severe neurodisability in an intensive care admission					
PICU-01	Male	Paediatric intensivist	Tertiary/metropolitan‡	5–10 years	In-person
PICU-02	Male	Paediatric intensivist	Tertiary/metropolitan‡	16–20 years	In-person
PICU-03	Male	Paediatric intensivist	Tertiary/metropolitan‡	5–10 years	In-person
PICU-04	Female	Paediatric intensivist	Tertiary/metropolitan‡	<5 years	In-person
PICU-05	Female	Paediatric intensivist	Tertiary/metropolitan‡	>20 years	Videoconference
Vignette 3: Child with a haematological malignancy					
ONC-01	Female	Paediatric oncologist	Tertiary/metropolitan‡	<5 years	In-person
Vignette 4: Child with a solid tumour					
ONC-02	Male	Paediatric oncologist	Tertiary/metropolitan‡	5–10 years	In-person
ONC-03	Female	Paediatric oncologist	Tertiary/metropolitan‡	11–15 years	In-person
ONC-04	Male	Paediatric oncologist	Tertiary/metropolitan‡	5–10 years	In-person
Vignette 5: Child with complex congenital heart disease					
CAR-01	Male	Paediatric cardiologist	Tertiary/metropolitan§	5–10 years	Videoconference
CAR-02	Male	Paediatric cardiologist	Tertiary/metropolitan‡	11–15 years	In-person
CAR-03	Male	Paediatric cardiologist	Tertiary/metropolitan‡	16–20 years	Telephone
CAR-04	Male	Paediatric cardiologist	Tertiary/metropolitan‡	5–10 years	In-person
CAR-05	Male	Paediatric intensivist	Tertiary/metropolitan‡	11–15 years	In-person
CAR-06	Male	Paediatric intensivist	Tertiary/metropolitan‡	5–10 years	In-person

*Location of work classified by the Department of Health and Human Services, Victorian Government.⁴⁶ Tertiary paediatric centres are children's hospitals with subspecialty departments. Secondary centres are general paediatric departments within an adult hospital.

†Years' experience working at consultant level.

‡Public clinical practice only.

§Combination of both public and private clinical practice.

foreshadowed if 'your perception and the family's perception [of the child's prognosis and quality of life] are different' (ND-01).

Paediatricians worried these discussions were confronting for families. This sometimes led to delay: 'most of the time it is too late if anything. Because it is a pretty usually horrific discussion to have...it is one thing saying, 'ultimately the prognosis is poor and your child will probably die' but then to say, 'just in case your child stops breathing, I don't want to do anything about that'' (ONC-04).

One paediatrician challenged this negative focus, suggesting families could instead be engaged in conversations about what care will be provided when their child

is critically ill: 'there is often a focus in healthcare on things we won't do...that's there for the clinicians to worry about...they (parents) do not (need to know) we will not do CPR...they need detailed things of what we will do' (PICU-02).

Documenting decisions about resuscitation or use of intensive technologies

Documentation was considered by most paediatricians to be the crux, if not the sole basis, of ACP. It involved documenting the outcome of discussions 'what not to do, really' (ND-02) if the child acutely deteriorated. A few paediatricians suggested documentation protected parents so 'they

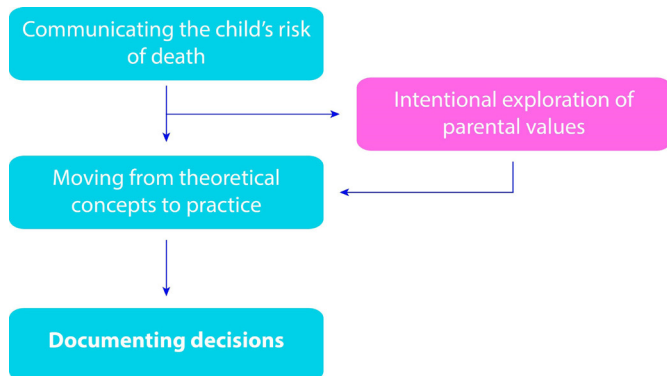


Figure 1 Process of preparatory discussions for end-of-life decision-making.

are not asked...how far do you want us to go?’ (ND-02) when their child presents unwell to hospital. Others described ‘having something in writing provides comfort...[to] the system in which I work’ (ND-07), ‘other clinicians that won’t have been there for the conversations that you’ve had’ (ND-04).

Paediatricians looked for ‘a tick-box guide...in the acute situation...rather than nuance’ (PICU-04) with respect to resuscitation and intensive technologies, and found it difficult documenting treatment decisions in advance for all potential clinical scenarios. As one paediatrician described: ‘most of us are black-and-white...and like to have things concrete...a tick-box is concrete...it can be hard for some people to know how to document...where a family’s at...when it’s about things which are not clear...[and] you can’t provide for every situation’ (ND-10). Documentation was ‘important so that stupid stuff doesn’t happen in the hospital’ (ND-08). While this documentation ‘is not a decision and then that’s it’ (ONC-03), ‘a lot of families don’t like...having to revisit it’ (ND-07).

Completing this documentation was also challenging when the child was receiving disease-directed therapies as ‘it is hard to go to ACP when you are still giving active therapy, you’re saying ‘hey I’m giving you chemotherapy but, you know, we’re not really wanting to resuscitate’’ (ONC-04).

The threshold for documenting decisions about resuscitation and use of intensive technologies varied for paediatricians. Some opted to document only when there was an ‘escalation of risk [of death] for the child’ (ND-01), usually in an acute setting when a ‘situation is totally irreversible’ (ONC-03) and ‘we can’t avoid those discussions anymore’ (ONC-04). Sometimes, paediatricians opted to ‘just let it [documentation] go and things just happen’ (ONC-03). However, one paediatrician highlighted that even if the ideal is ‘a conversation that can be had with their regular paediatrician and documented...before time...space can still be made [when acutely unwell in hospital] to do that in a very sensitive way’ (ND-04).

Theme 3: Role of exploring parental values in the process

Some paediatricians, particularly those caring for children with severe neurodisability, described exploring parental values rather than making treatment decisions in advance. According to these paediatricians, exploring

parental values helped them gain greater understanding of the parents’ perception of their child’s life in a way that ‘would actually influence decisions’ (ND-09). Discussions focusing on exploring parental values as part of ACP ‘[wouldn’t] do any harm’ (ND-09) and may address concerns raised by some paediatricians about documenting treatment decisions in advance. This focus ‘has actually been a positive thing for my practice in terms of de-emphasising the form filling...parents are very responsive to that...that’s the sort of terminology they like’ (ND-09).

Of those who spoke about exploring values, one paediatrician felt it was unrelated to the process of preparing for EOLDM but rather a ‘part of a general process of looking at quality of life’ (ND-03), while another explored parental values as part of ACP (the process of discussions over time): ‘[while] I’m getting a bit of values-based stuff in our [therapeutic] relationship...it [ACP] gets me more’ (ND-09). Those who did not describe an exploration of parental values in their approach to care did not consider it to be part of paediatric ACP even when specifically asked: ‘so that’s not ACP’ (ONC-03). However, paediatricians often reflected that interprofessional communication of parental values would ‘be much more useful [compared to tick-boxes]’ (PICU-04) in clinical care. Documentation of parental values was considered possible but ‘a bit full on’ (ND-09) and does not meet the tick-box preference described earlier. Nevertheless, these details could be helpful when considering ‘decisions where people aren’t on the same page’ (CAR-05).

Theme 4: The emotional impact of the process

All paediatricians reflected that EOLDM discussions are ‘emotionally laden’ (ND-01). This mostly related to the family’s emotional responses, although one paediatrician described projection of their ‘own awkwardness [around grief] rather than the [parent’s] that’s stopping you from talking about it [ACP]’ (ND-04). All paediatricians felt pressure to be confident with the timing of its commencement as it ‘forces them [parents] to think about something that is terribly traumatic’ (PICU-02). Because of ‘grief that occurs with families just in starting the ball-rolling [with ACP]’ (ND-01), two oncologists expressed ACP (the documentation) was a ‘specialist area...not something we should all be trying to play with’ (ONC-03). Recognising the need to manage emotions arising from ACP, some framed it as ‘more a psychosocial exercise’ (ONC-01), not part of medical care.

DISCUSSION

Paediatricians in this study described a process for EOLDM discussions in line with theoretical definitions of ACP¹⁻⁴ but predominantly focused on documenting decisions around resuscitation and use of intensive technologies. Specifically, they seemed most concerned with communicating which treatments should not be used when a child with an LLC deteriorates. Hein *et al*²⁰ identified a similar focus, and a majority of the published literature uses the presence of a ‘do-not-resuscitate order’ to indicate successful paediatric ACP.^{5 21-29}

Given paediatricians in this study described a process for EOLDM discussions, does it matter whether they conceptualise this as ACP? One view could be that regardless of whether this process is called ACP or not, there is need for improvement as parents prefer earlier preparation¹⁴ so that they feel empowered to make decisions^{5,30} and can come to terms with their child's prognosis.⁵ However, it is hard to evaluate ACP when there are differing concepts of what it involves, and what the outcomes of interest are. Concern has been raised in the literature about the failure to demonstrate significant improvements in care despite multiple ACP initiatives.³¹ Focusing solely on documenting decisions in advance risks alienating parents³² thereby undermining the value paediatricians afford to ACP, which may, in turn, influence their practice of it. To improve consistency of practice around EOLDM discussions, and to facilitate evaluation, we propose that this entire process, including exploration of parental values and recognition and management of emotions be regarded as ACP.

Differing parental and clinician expectations when initiating ACP discussions leads to misunderstandings and dissatisfaction in the process.³³ Paediatricians often focus on documenting care decisions,²⁰ whereas parents want time to understand the expectations of their child's future.^{10 32 34} While documenting decisions in advance enables the best care to be provided when a child becomes seriously unwell (and their primary paediatrician is unavailable), problems can arise when the focus is exclusively on documentation. Orkin *et al*³⁵ emphasise the core of ACP discussions is the partnership between parents and paediatricians; outcomes of these discussions are secondary. Often, despite extensive discussions, parents and paediatricians cannot settle on decisions that can be documented in advance.^{6 34} This does not mean they will be unable to make decisions when the child acutely deteriorates.⁶ Indeed, information related to parental understanding of the child's future, their hopes, goals, values and belief systems can inform management decisions in real time, or in advance at parental discretion.³⁵ This information is often held within therapeutic relationships and is rarely documented. It remains unclear how such information is elicited, understood and used by paediatricians. Furthermore, given that differences between paediatricians' and parents' understanding of prognosis is often cited as a challenge to ACP,^{5 24 26 29 36} it remains unclear how paediatricians facilitate concordance between parental and paediatrician understanding and expectations. While some paediatricians may not believe it is their role to explore such concepts, a structured ACP programme facilitated by a trained interventionist may be one way to meet this gap in service and provide a level of support to paediatricians and families.¹⁰

As indicated in the literature,³⁵ and supported by this study, shifting the focus of ACP from making hypothetical instructional management decisions to an intentional exploration of the child's quality of life, and parental understanding and values, helps paediatricians approach

EOLDM discussions for children without feeling like they are causing harm. In so doing, paediatricians can help ready parents to make in-the-moment decisions at times of crisis.³⁷ This preparation can even occur in parallel with discussions about treatments to extend the child's life and could potentially help improve quality of life.^{37 38}

Limitations

Paediatricians' self-reported communication approaches may have been influenced by familiarity with SV and could reflect perceived best practice rather than reality. However, unlike Orkin *et al*,³⁵ explicit reference to ACP only occurred in the interview after discussion about the paediatrician's approach to the vignette. In so doing, it was possible to explore their overall practice before raising ACP specifically, thereby identifying that elements of the ACP process are widely practised but are not necessarily described in such terms. While there is a relatively 'small' sample size, this is not considered to be a true limitation, as it is consistent with the phenomenological methodological approach.¹⁶ Data triangulation would improve reliability of these results,³⁹ but direct observation of these discussions is challenging ethically and feasibly. Clinical simulation is an alternative, offering an opportunity to triangulate data related to clinician-specific determinants in communication,^{40–45} and should be considered in future research.

CONCLUSION

Paediatricians caring for children with LLC recognise a preparatory process for EOLDM; however, there is variability in practice and extent to which they view this as ACP. There appeared to be greater focus on outputs such as documented treatment decisions than on the process of sharing information and understanding parental values. This variability is likely to be reflected in practice, clinical outcomes and research.

While sometimes practised within therapeutic relationships, intentionally exploring parental values and acknowledging it as a key part of ACP has potential to prepare parents and paediatricians to make decisions should the child become critically unwell. This may be helpful even if decisions have not been made in advance. The emotional responses of both paediatricians and parents to these difficult discussions may challenge effective ACP. Specific training in recognition and management of emotions in this setting and navigating values-based decision-making warrants further exploration to improve the quality and consistency of communication in this essential aspect of care. Studies to date have generally relied on clinician self-report, and further research is needed as to how paediatricians actually practise ACP and the extent to which parents influence and shape this communication.

Author affiliations

¹Victorian Paediatric Palliative Care Program, The Royal Children's Hospital Melbourne, Parkville, Victoria, Australia

²Department of Paediatrics, The University of Melbourne, Melbourne, Victoria, Australia

³Neurodisability and Rehabilitation, Murdoch Children's Research Institute, Parkville, Victoria, Australia

⁴Department of Paediatrics, Monash University, Clayton, Victoria, Australia

⁵Children's Bioethics Centre, The Royal Children's Hospital Melbourne, Parkville, Victoria, Australia

Twitter Sidharth Vemuri @SidVemuri

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ORCID iD

Sidharth Vemuri <http://orcid.org/0000-0003-1900-4557>

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