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Shepherding parents to prepare for end-of-life decision-making: a critical phenomenological study of the communication approach of paediatricians caring for children with life-limiting conditions in Australia

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ABSTRACT

Background/objectives Shared decision-making is widely accepted as the best approach for end-of-life decision-making for children with life-limiting conditions. Both paediatricians and parents find benefit in preparing for such decisions. However, little detail is known about this preparatory process. This study aims to explore how paediatricians prepare parents for end-of-life decision-making for a child with a life-limiting condition using clinical simulation.

Design Individual, semistructured, post-simulation qualitative interviews of paediatricians and parent-actors.

Setting Acute intensive and long-term outpatient paediatric care in Victoria, Australia.

Participants 18 purposively sampled paediatricians who treat children with life-limiting conditions and the two parent-actors involved in all simulations. Paediatricians were excluded if they assisted in the study design, worked within specialist palliative care teams or did not provide clinical care outside the neonatal period.

Results Three key themes in a preparatory process (termed 'shepherding') were identified: (1) paediatricians aim to lead parents along a pathway to future end-of-life decisions, (2) paediatricians prefer to control the pace of these discussions and (3) paediatricians recognise they need to have courage to face risk with this preparation. Paediatricians use a variety of shepherding strategies to influence the pace, content and framing of discussions, which may help prepare parents to make the best end-of-life treatment decisions when the time comes.

Conclusions Shepherding is a newly identified, subtle process intended to influence parents by guiding their understanding of their child's health and potential suffering in advance of decision-making. Shepherding does not fit within current descriptions of physicians' decision-making influence. Paced reflection, thinking and provision of information are shepherding strategies preferred by paediatricians, and these appear the same regardless of whether paediatricians intend to steer parents towards particular treatment decisions or simply prepare them for the process of decision-making. Further study about the intention of this influence and parental perception of this communication is needed.

STRENGTHS AND LIMITATIONS OF THIS STUDY

⇒ Our critical phenomenological approach moves beyond the paediatrician's description of the experience of preparing parents for end-of-life decision-making by allowing triangulation with the researchers' direct observation and the parent-actors' interview data set to provide a more robust exploration of this aspect of care.

⇒ Critical phenomenology treats first-person and third-person accounts of the experience as complementary and focuses on the richness of data from 'small' sample sizes.

⇒ Clinical simulation provides an ethically and logistically feasible approach to priming data collection through semistructured interviews focusing on communication-specific determinants of care.

⇒ Co-design strengthened this study by using: (1) bereaved parents to enhance the authenticity of the parent-actors' characters in the simulation thereby promoting the plausibility of the simulated encounter, and (2) international paediatricians to enhance the face validity of the scenarios in this study.

⇒ This translatability of the research findings outside the Australian context requires caution given the study was conducted in a single sociolegal jurisdiction.

INTRODUCTION

Paediatricians and parents are known to value thinking ahead to prepare for end-of-life decision-making (EOLDM) for children with life-limiting conditions (LLCs) before these decisions are clinically needed.[1–8] This is because end-of-life decisions commonly arise in clinical contexts when the child is acutely unwell.[5 9–14] At these acute times, there are often treatment options that could be offered in an effort to prolong life, but these treatments have uncertain efficacy and come with potential burdens for the child. Making decisions in the best interests of the child is made even more challenging when emotions are high and decisions are time critical, so preparation before time-critical decision-making is valuable. Empirical studies of this phenomenon have commonly relied on retrospective reports from paediatricians and bereaved parents,[3–5] as real-time exploration is ethically and logistically challenging.[15] These findings may be influenced by reframing of experiences that may occur over time.[5] Consensus guidelines recommend using shared decision-making (SDM).[16–20] However, while the tenets of SDM are well described,[9 21–23] there may be variability in how it is practised when caring for children with LLCs.[24] Our prior work provided evidence that paediatricians feel strongly about protecting children approaching the end of their life from the harm of invasive treatments, and about protecting parents from the perceived psychological burden of such decision-making.[24] Consequently, paediatricians voice a preference to lead EOLDM,[24–26] using their communication skills to involve and guide parents in the decision-making process.[23 26 27] However, little is known about the detail of this process or how paediatricians lay the groundwork for it. This study explores how paediatricians prepare parents for EOLDM for a child with an LLC.

METHODS

Study design

A critical phenomenological study design,[28] involving individual semistructured, post-simulation interviews, was chosen to elicit richly detailed data. Interviews were conducted following a simulation with both paediatricians and the two medically trained actors who participated in the simulation. Critical phenomenology was particularly well suited for this study, because how we communicate with others about death is influenced by our cultural attitudes and the meanings we assign to their reactions.[29] Critical phenomenology maps out how first-person and third-person accounts of experiences are possible, analyses their function and identifies new possibilities that can influence development of meaning of an experience.[28] Further detail of the rationale underpinning the research question with the choice of methodology and research design has been published elsewhere.[30] Paediatricians who care for children with life-limiting neurodisability in Victoria (Australia) were eligible to participate. Purposive sampling recruited paediatricians across acute intensive care and long-term care outpatient settings.

Clinical simulation

The simulation prior to the interview was matched to the clinical context of the participating paediatrician. The simulated scenario was either: (1) meeting with anxious parents of a child with life-limiting neurodisability currently admitted to the intensive care unit (ICU) with their first respiratory deterioration requiring non-invasive ventilatory support, or (2) the first outpatient clinic review two weeks following discharge from the ICU admission. Two internationally based paediatricians confirmed that each scenario portrayed a child sufficiently vulnerable to a shortened life that any paediatrician would consider initiating discussions to share clinical concern with the child's parents but not feel compelled to reorientate the goals of care for the child to only comfort at this time. Each simulation was pilot tested by a relevant subject matter expert (neurodevelopmental paediatrician and paediatric intensivist). The same two highly experienced medically trained actors were involved in all simulations across the study to allow for comparison of different communication approaches: they played the role of parents in each simulation and were interviewed together after each simulation drawing on their expertise in communication.

Patient and public involvement

The characters played by the medically trained actors were developed during a full-day workshop, in which five bereaved parents of children with severe neurodisability shared their experiences with the actors. Further details of this workshop, including the attention to ethical considerations when involving bereaved parents in research design, have been published elsewhere.[31]

Data collection

The study was conducted between April and May 2021. Data were collected from semistructured post-simulation interviews with paediatricians and the parent-actors. Each 30-minute simulation was directly observed by the research team (SV, JO, JH, LG). Interview guides were developed by the research team (online supplemental file 1), and further refined and particularised based on the research team's observation of each simulation. Paediatrician interviews, conducted by SV (a paediatric palliative care physician and trained qualitative researcher, who was known to all participants), were of 30 to 60 minutes in duration. Actor interviews, ranging from 25 to 45 minutes in duration, were conducted following each simulation by JO (a bereaved mother, clinical nurse consultant involved in the care of children with neurodisability and trained postdoctoral qualitative researcher). The interviews were undertaken approximately 15 to 20 minutes after each simulation. All interviews were audio-recorded, professionally transcribed verbatim and checked.

Data analysis

After completion of all data collection, thematic analysis was undertaken. Figure 1 illustrates the process of data analysis conducted by SV, JO, JH (paediatric palliative care physician and postdoctoral qualitative researcher) and LG (clinical ethicist and postdoctoral qualitative researcher). Transcripts from the paediatrician interviews were analysed first to identify the paediatricians'

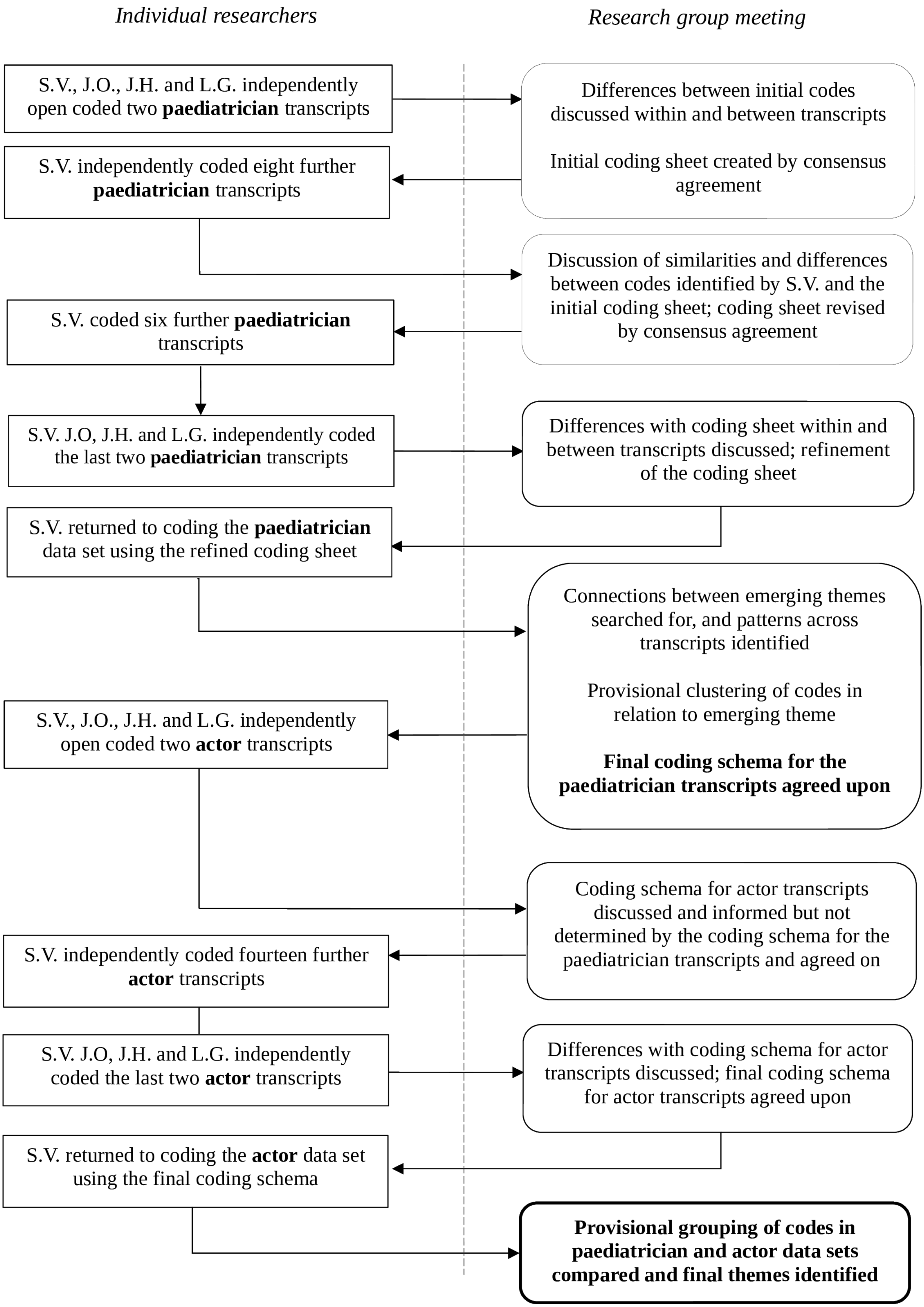

Figure 1 Process of thematic analysis.

experiences. The final agreed coding schema for the paediatrician data set informed but did not determine coding of the actor transcripts. The actor data set was analysed independently. Once the coding of the two data sets was finalised, codes were grouped together across the data sets, and common themes in relation to the research objectives were identified.

Rigour was maintained in several ways: triangulation of coding between paediatrician and actor transcripts; prolonged engagement[32] with the data over 11 months; contemporaneous notes on the robust, critical discussions in the interdisciplinary research team meetings; and attention paid to reflexivity (using field notes and regular debriefing during the analytical process). Data were managed using both hardcopy and electronic NVivo files.[33]

RESULTS

Participants

Eighteen paediatricians participated in this study: 13 were female, 5 were male, 10 had received formal communication skills training and 13 had prior experience with simulation. Eleven participants were general paediatricians who worked in both inpatient and outpatient care settings, and the remaining seven participants worked solely in one of the two paediatric ICUs in Victoria. There was spread of experience working at consultant level: six had <10 years, five had 10–20 years and seven >20 years. Both parent-actors had formal training and more than 10 years' experience in simulation-based communication skills training in healthcare contexts.

Key themes

Analysis identified three key themes in relation to how paediatricians perceive preparing parents for EOLDM for a child with an LLC: paediatricians (1) aim to lead parents along a pathway to future end-of-life decisions, (2) prefer to control the pace of discussions and (3) recognise the need for courage to face risk. Verbatim quotes supporting data interpretation are included in the text and tables below with source indicated as paediatrician (P) with numerical identifier (1–18), actor-mother (AM) or actor-father (AF).

Theme 1: Paediatricians aim to lead parents along a pathway to future end-of-life decisions

Paediatrician responses highlighted a variety of strategies used in the simulation to help prepare parents for decisions to be made at some time in the future. These strategies are listed in table 1 and included behaviours such as encouraging parents to think about the child's quality of life; asking open-ended questions; using 'fishing lines'; encouraging parents to articulate their worries about their child's discomfort and suffering; and introducing the concept of risks versus benefits of therapies. These strategies may influence the content and direction of these discussions and EOLDM. As one paediatrician described, guiding parents to consider quality of life, in

Table 1 Strategies to help prepare parents for EOLDM

Strategy	Paediatrician's intention
Encouraging parents to think about the child's quality of life	'Because I think that might be a phrase that I can pick up on in the future, quality of life, and that could then lead to discussions. So, my next consultation I might pick up and say we discussed quality of life last time and you mentioned that [the child]'s not in that much pain and that he loves school, and then talk about the ICU admission and say quality of life is something that I see as really important, and I'm thinking you do too, and then sort of lead into [further discussions].' (P5) 'The discussion about quality of life and what [the child] enjoys and what the family enjoys, and the fact that that might be limited needs to start at some point. If it was not started before his admission to ICU, I think that the first admission to ICU definitely is the point where it must begin.' (P7)
Asking open-ended questions	'Asking more open-ended questions than I often do in the hope that they would spill the beans about what they wanted to talk about.…I'm hugely relieved if and when the time comes that I can say 'is it just getting too hard for you to care for [the child]?' There are other avenues, that's a hard conversation but perhaps we should have that.' (P9)
Using fishing lines	'I threw a few fishing lines out about 'is he distressed, and we don't know?' [to see if we are] getting a presentation of parents in distress because they knew in their heart of hearts that their child was deteriorating.' (P9)
Encouraging parents to articulate their worries about the child's discomfort and suffering	'Are they able to actually vocalise how much discomfort?…I'll be encouraging them to tell me, 'how do you think he's coping with this? Do you think he likes it?' And I'm just going to probe that so that they vocalise all this because then you can't retract it.…they've already vocalised that this is causing a lot of distress and we can work on that…it allows them to vocalise and they will hear themselves say that, so that when it gets to the point that this is happening too much and they feel, 'this is the limit for my [child]', that we can encourage them to say the words and it's okay to say the words.' (P13) 'Give space to the possibility of one of those parents saying 'my priority is that [the child] doesn't suffer'…to explore that more as a concept.' (P11) 'Trying to get [parents] to describe the elephant in the room [concern for the child's risk of death]…[because] that would make it easier for me.' (P9)
Introducing concept of risks vs benefits of treatments	'Giving them the opportunity to reflect but to also try to encourage them to think about what their wishes might be and trying to introduce this concept in terms of the risks and benefits of the therapies and that sometimes, we have to make hard decisions around that.' (P2)

EOLDM, end-of-life decision-making; ICU, intensive care unit.

advance of decision-making times, helped frame future discussions about treatment decisions:

> At some point, we're going to start doing, to treat for the sake of treatment…but that's not quality of life, so part of what I want to start with the family as a discussion is what's the quality of life for the child? What does this child enjoy? What does the family enjoy with the child? What is your family's line in the sand regarding the quality of life and the treatment? I think it is important to say that when the treatment is worse than the quality of life it might bring, then why are we doing that? (P7)

Parent-actors were aware of these strategies. For example, they confirmed instances of being encouraged to think about the child's quality of life, saying that the paediatrician in some simulations 'provok[ed] us to think about [our child's comfort and coping]' (AM), or used:

> lots of little warning shots…rather than labouring it…[some doctors were able to raise concerns and develop parental understanding] without [parent-actors] panicking…it was subtle, and it was there, but it wasn't handled heavily or prolonged. (AF)

This reflection was often considered by parent-actors as 'really helpful…to see a bigger picture [about the child]' (AM). Direct questions about the child's suffering met with a more equivocal response: sometimes, it 'felt great to be asked…liberating…gives you permission to say 'yes'' (AM) but at other times, '[it was] confronting' (AF). When one paediatrician subtly led this discussion, the actor-mother described:

> There was a lot of joint reflection…it didn't feel like [the paediatrician] was imposing something on us or was asking for us to come up with all the answers…it felt very shared and equal collaboration. (AM)

However, parent-actors confirmed that different approaches existed and that most paediatricians 'had a very clear agenda' (AM), which was sometimes to convey the message that the treatment decisions would be 'made by the medical team' (AM), and at other times, that is was ultimately up to the parents: 'like it was ours' (AM). This variation in perception occurred with paediatricians in both the outpatient clinic and ICU simulations.

Theme 2: Paediatricians prefer to control the pace of these discussions

All paediatricians reflected that the pace of discussion is generally informed by their clinical assessment of the child's risk of death: 'you identify the risk for [the child], and then it shifts your pace of discussions' (P14). Pace related to the rate of progress towards explicit discussions about the child's inevitable death in the future and specific treatment decisions needing to be made. As one paediatrician described:

> I think through those difficult conversations, that dance of too far, not far enough, parents over time get permission to say how bloody awful, difficult or increasingly less joyous life is for them and their children…then I would….that conversation around 'how do you feel it is for [the child] at the moment' or 'what were the last three admissions like' or 'it seems to me this is getting harder, what are we doing here?'… Because I think, the more clinical experience I get, the more I realise that yes, some parents will say 'you just make the decision', but the vast majority, by the time you get to that pointy end, there's no decision to make anymore because you've already taken so much movement in that direction. (P9)

In relation to the explicitness of EOLDM discussions, a slower tempo helped some paediatricians identify 'what's going to be the best language and the most helpful approach' (P3) in conveying messages to parents. Paediatrician responses illustrated strategies they used in the simulation when discussions did not progress at the pace they intended, going either too slowly or too quickly for the paediatrician (table 2). One paediatrician described their intention of controlling pace:

> Pacing my recommendation…laying the groundwork for future, yeah, so little bite-sized pieces, meanwhile, working on rapport so that if and when the time came for that, 'I've got bad news for you, he's not getting better, in fact he's getting worse', that groundwork has already been laid and they've already heard the beginnings of how appropriate intubation is or ECMO [extracorporeal membrane oxygenation] or whatever. We've already given a lot of that information in previous conversations, and it is several conversations….[the aim of which is to help parents]…to be informed…my responsibility was actually to give them all that information before I am asking them to **not** make a decision….so that when the time came, we would both, in partnership, make that decision together, so that I know that by the time I say 'this is not going to be beneficial for him', they would already understand why…it's informed consent without actually asking them to make a decision…I don't want to impose it on them and I don't what them to feel like they have to make a decision. (P13)

Pacing of information was also noted by the parent-actors: 'the challenge for the clinician is to pitch how much information is deemed safe' (AM), and to provide 'steps where you can [digest the information] and then function and cope' (AF). Within the simulation, these discussions required a 'set-up prior…to really land' (AF) and a degree of 'nuance…holding [parents] down this path, [otherwise] it felt like a sledgehammer' (AF).

Theme 3: Paediatricians recognise the need for courage to face risk

Many paediatricians recognised the need to have 'courage to [initiate explicit EOLDM discussions]' (P1). They worried about being seen as 'too pessimistic…being

Table 2 Strategies if discussions are not progressing as per paediatrician's preference

Strategy	Paediatrician's intention
Progressing **too slowly** for paediatricians	
Cautiously throw out ideas and probe for a chink in their defences	'I was just being cautious, I think, you know, I was throwing a few ideas out there just to see whether they, how they responded.' (P1) 'Just sort of probing for a chink in their defenses to see whether….there was a discrepancy between the two of [the parents]…just to [open them] up a little bit.' (P1)
Intentionally push too far and then apologise	'I am very aware that people won't give you an answer if you don't give them a space or a question to say it and I do feel, not uncommonly in my work, that I perhaps do what I did there, which is kind of dob myself in and then have to apologise, go too far and say 'look, you looked really shocked by that, I just wanted to give you some clarification about the world that I work in'. It's a bit like I'm going to peel a bit of the denial scales off you.' (P9)
Go with the flow if the conversation indicates parental coping style	'I find it difficult to lie to people… if someone's way of self-preservation is saying, 'I can beat the odds, I can do that', I'm not going to argue with them, but if they phrase it as a question, I find it very difficult to just go with the flow.' (P7) 'As a junior doctor, I would have jumped on that and really like tried to beat it out of [the parents]…that that's a silly thing to think and [they] need to have realistic expectations….anyway, I evolved beyond that….what does it really matter if in other aspects of their care we're talking in a fairly honest way….just the difference between whether it's their method of coping versus complete misinformation…which is [not letting them] engage in a therapeutic relationship which is realistic.' (P11)
Progressing **too quickly** for paediatricians	
Acknowledge, park and defer discussion	'I definitely would've had a choice to park it.' (P4) 'And so, it's a conversation that's like way too premature…I didn't want to dismiss [the father] but I just kind of wanted to like acknowledge it and then move on.' (P11) 'I'm happy to discuss that, but I need to understand a bit more, just kept me in control and meant that I could actually get the information that I needed to be able to do a better job of that discussion, particularly if they'd had a negative discussion before.' (P16)
Navigate away from discussion	'I find we're too early to think that, so I tried to navigate my boat from the whole talk about where we… yeah, about limiting, even though I had whatever in my mind, I did not want to reach there before I knew the family.' (P17)
Being vague in response	'The first time I was vague [when questioned by parents about EOLDM], second time I was a bit less vague, third time they kind of demanded to get more so I gave it to them.' (P7)
Delve deeper into discussion	'I decided not to ignore that but to delve into that which, so we kind of went deeper than I think I intended to, but that's fine.' (P7) 'I don't think there was any harm because they brought it up and that's what they're scared of. If you run away from it then you're not going to have a lot of respect from them, they're worried about is [the child] going to go to ICU again, is this going to happen again, and if you brush that under the table, that's not helpful.' (P18)

EOLDM, end-of-life decision-making; ICU, intensive care unit.

proven wrong' (P1) and setting up 'conflict' (P2) with parents more generally, compromising the therapeutic alliance. One paediatrician described being without courage:

> The risk I'm aware of is you start off being this friendly person that's just letting them, you know, stay in their comfort zone and you risk setting a pattern where that just perpetuates and, you know, five years' later you're still in the same position. So at some point things need to start shifting and always the path of least resistance is just, you know it's another consultation, okay we'll all, we'll stay on the surface and not delve any deeper… it's like this conspiracy between the doctor and the patients where everyone's, you know they're all agreeing that we'll just keep on the surface and pretend that everything's going to be fine and we'll avoid those more difficult conversations. (P1)

The parent-actors also identified the need for paediatricians' 'courage for those discussions…candidness and honesty' (AF). The parent-actors noted that in the simulations, their preference about explicitness of the child's inevitable decline towards death varied both individually and between parent-actors. In one simulation, the actor-mother found it helpful: 'explicitness and that language around what's happening in steps is actually very anxiety-allaying because it's not a mystery, it's not smoke and mirrors…it's out there on the table', while it was less palatable for the actor-father, who noted that it can 'scare people'. During most simulations, the actor-father found a subtle approach helpful 'without having to actually be hit over the head', whereas at times, he 'wanted for [the doctor] to be direct'. This variation in preference of parent-actors connects with the paediatrician's need for courage when parents' responses are not fully predictable.

On one occasion, the actor-mother described the difficulties for a parent in receiving non-explicit communication:

> Trying to talk about these really difficult topics in a very soft and ambiguous way to soften it, to make it more palatable…just makes it more ambiguous, puts the onus more on the parents to draw the connections, and then you're still left with the ambiguity because you then are questioning whether you've drawn those connections properly. (AM)

In contrast to this, some paediatricians felt that a less explicit approach would be easier for the parent:

> Being vague…people have understood what happens…without being explicit about it and without naming it…usually you don't have to tell people, people know what you're actually talking about. (P6)

Also, 'most families in their hearts know when nature is trying to close and end a life' (P15).

DISCUSSION

A number of important findings were identified in this study, including variation in the approaches and perceptions of paediatricians, and their feelings of not always being in control. This discussion, however, will focus on articulating the construct that draws together the common themes we have identified in paediatricians' description of their practices. We propose the term 'shepherding' to characterise this. The construct of shepherding explains how paediatricians enact their aim to lead parents and their preference to control discussions without being overtly directive. Shepherding involves finding a balance between being too subtle and too explicit in the words carrying guidance or direction. Finding the balance between too subtle and too explicit is a general communication challenge, but is brought into sharp relief in this setting. Our results suggest that paediatricians aim to gently lead parents on a pathway of reflective discussions to help coach them in how to think about their child's situation before EOLDM occurs. Although not overt about it, they do this to help parents develop an understanding of their child's quality of life, suffering, risk of death, and the concept of risks and benefits of treatments. In so doing, paediatricians can advance parental thinking about emergent decisions concerning life-prolonging treatments while normalising decisions not to pursue such treatments. This reflective process may enable parents, over time, to cognitively reach a place where they can make the treatment decisions that paediatricians anticipate will need to be made. Later in this process, paediatricians provide parents with their rationale for treatment recommendations, hoping this might assist decision-making when circumstances become more time pressured and emotionally charged. To our knowledge, shepherding has not previously been described in the literature, although its strategies are akin to motivational interviewing. However, unlike motivational interviewing, which is a communication intervention targeted towards behavioural lifestyle change,[34 35] shepherding is a construct of what occurs in the practice of the paediatricians who participated in this study. Shepherding is significant as it intends to influence parents by framing information and guiding parental understanding in advance of decision-making. In what follows, we will consider how this newly identified preparatory approach differs from previously recognised forms of physician influence in decision-making and discuss its ethical status and implications.

Paediatrician influence in therapeutic alliances is well described.[36 37] This influence is essential to avoid a purely transactional therapeutic relationship.[38] Beauchamp and Childress[39] recognised three primary categories of influence existing along a spectrum of increasing ethical permissibility, running from clearly unethical coercion (using threats), through manipulation (managing information to influence decisions covertly) and then to ethically appropriate persuasion (giving explicit reasons for a particular treatment decision). Where does shepherding fit on this spectrum? Shepherding is not coercive as it does not involve paediatricians threatening parents to control decision-making.[39] It also differs from persuasion, as it is more subtle than explicit and starts well before the discussion and reasoning that occurs when paediatricians provide specific treatment recommendations.[27 39–41] Notably, shepherding is more delicate and less specific than the persuasive communication strategies identified by Popejoy *et al*,[27] which include overt discussion of treatment choices preferred by paediatricians, early and repeated emphasis on how such choices would be in the child's best interests, and, at times, explicit discussion of the limits of parental decisional responsibility.[27] In contrast, shepherding strategies identified in this study include pacing of reflection, encouragement of thinking about quality of life and discussions over time. No specific treatment decision is referred to.

This leaves the possibility that shepherding could be considered manipulation. Manipulation is the deliberate management of information to alter patients' understanding of a situation with the intent to influence decision-making.[39] One major way in which manipulation is distinguished from persuasion is that it operates under the surface, rather than in the open. The intention of shepherding, as preparation for more overt EOLDM discussions in the child's future, is under the surface, in that it is not necessarily made clear to parents when commenced. A second feature of manipulation is that it is achieved by imposing physicians' values paternalistically, leaving patients ignorant of other values or options. Manipulation therefore undermines patient autonomy.[38] We believe shepherding is different because its strategies leave space for parents' own thinking. Shepherding does not guarantee parents will think in the way that paediatricians hope they will or make treatment decisions that paediatricians prefer. Furthermore, parents maintain influence around the pace and content of the conversation, and may react to information differently than expected and have their own agenda.[42] Shepherding, we suggest, is not ethically problematic because parents retain control in assigning meaning and weight to the concepts and concerns that paediatricians raise.

We argue in fact that shepherding is an important and ethically legitimate part of the paediatrician's role, if done well. It involves assessing the child's situation, raising parental awareness of important considerations and then listening to the value parents place on these considerations. This is a way of enhancing SDM and is analogous to the underlying premise of the deliberative physician–patient decision-making model described by Emanuel and Emanuel.[38] In this model, physicians assume responsibility for explicitly raising the patient's awareness of the weight that the physician places on the specific values that ultimately contribute to what they see as the preferred course of action. This tends to occur at the time of decision-making. Shepherding has the same ethos but is more subtle and commences well before a decision-making point is reached. Regardless of what parents choose, the practice of shepherding can enhance parental autonomy by preparing them to make the best possible decisions for their child and family, through a process of carefully paced reflection, thinking and provision of information.[43 44]

The lack of explicitness in shepherding may raise ethical concerns, which need to be addressed. Parental preferences for communication at this time are well-known; they prefer active collaboration,[9 21 22 45] and contextualisation to their child and family circumstance.[46 47] Even though shepherding is not out in the open, we suggest that it can still satisfy these preferences by facilitating shared responsibility for decisions made. If paediatricians were more explicit in the practice of shepherding, this may risk emphasising the hierarchy within the therapeutic alliance and create an impression that they are telling parents what to do. The opposite risk in shepherding is that paediatricians may be too subtle, such that parents do not hear what they are obliquely trying to convey. This may hinder a parent's ability to make decisions aligned with their own values. This complexity is reflected in the variations in parent-actor reactions to explicit or non-explicit communication approaches.

There is a further tension between candour and subtlety, with the latter potentially being misconceived by paediatricians as a method to preserve parental hope. This may, in part, explain the delicacy of shepherding and worries about taking parents 'too far'. Paediatricians may use vague language when discussing death,[48] citing concerns about taking away hope.[48–50] A hopeful approach is valued by many parents and is perceived as an essential part of a paediatrician's ability to relate to, and support, parents' feelings.[50] However, hope and clarity of information are not mutually exclusive. It has been found that clear prognostic disclosure may not compromise parental hope[51]; it may actually enhance it.[52]

Dealing with the risks of subtlety is where courage comes in: paediatricians need courage to face parents' and their own emotions, their own fears about being incorrect in their prognostication and their concerns about potential conflict with parents. Some paediatricians in this study worried that without courage, they would remain in a superficial therapeutic alliance with parents by avoiding meaningful substantive discussions around EOLDM. Janvier *et al*[53] earlier identified this need for courage in communication: to discuss death and to provide treatment recommendations at times of clinical uncertainty.

The key clinical implication of recognising shepherding related to how clinicians think about their practice is it provides a shared language for clinicians to critically reflect, both individually and with colleagues, on the challenges and subtleties of preparing parents for EOLDM. It also provides a frame of reference for further research to look at variations in practice and practical and ethical challenges. One important ethical question requiring further attention is whether there is any material or ethical difference between shepherding parents with the intention of optimising their process of decision-making (wherever it leads), and shepherding with the intention of steering them towards a particular decision. The latter would bring shepherding closer to being a form of ethically questionable manipulation. The shepherding strategies described in this study could be used for either intention. Other important questions here are: *what do paediatricians think is their goal?* and *how do parents perceive this process?* Our results do not provide clarity on these issues, so further study is needed to facilitate ethical debate about this aspect of shepherding.

Limitations

We used simulation to prime interviews to study this communication because of our assessment of the ethical and logistical challenges of observing this communication in real life. Over the course of many years of medical care, it is difficult to predict when these communication events will occur, and it would be a significant intrusion into the privacy of the doctor–parent relationship to audio record a large number of consultations. Feasibility was an additional concern. While there are inherent differences between reality and simulation, we believe our approach has yielded meaningful and trustworthy data. Simulation has been successfully used previously in studies of communication practices[11 54–56] and research involving qualitative inquiry.[57–60] There is good evidence that clinicians find simulations believable enough to elicit realistic communication from them.[54 61] It might appear that the actors' lack of personal experience of EOLDM is a limitation. However, we did not interview them as proxy parents, but rather as experts in communication. The actors were able to provide observations and reflections based on their many years of experience in clinical communication skills training.

We acknowledge that paediatricians' responses in the interviews may have been influenced by their familiarity with SV. While this may have prompted them to frame their responses to suit perceived expectations of the researchers, it most likely also promoted trust, enabling clinicians to be franker than with an interviewer not known to them. Finally, caution must be exercised when considering the generalisability of these findings. Given this study was conducted in a single sociolegal jurisdiction, we are uncertain of the extent of influence the sociolegal context of clinical practice has on these research findings. Applicability to other settings needs to be assessed rather than assumed.

CONCLUSIONS

Paediatricians in this study described undertaking a process of 'shepherding' parents, in anticipation of and, preparation for, EOLDM for a child with an LLC. This process has not previously been documented in the literature. Paced reflection, thinking and provision of information are shepherding strategies used by paediatricians in this context to influence how parents think about their child's health and potential suffering, well before they are in the position of making decisions about life-prolonging treatments. The ethics of shepherding are nuanced, with some ethical risks involved but we suggest that when done carefully, this is an ethically appropriate approach. Shepherding strategies would appear to be the same regardless of whether the intent is to facilitate a well-considered decision-making process with parents or to steer parents towards a particular treatment decision. However, future studies focusing on paediatricians' intentions in shepherding are needed, as are studies of parents' experiences of and perspectives on communication with paediatricians in the extended time before acute deterioration at the end of their child's life.

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Contributors SV conceptualised and designed the study and interview guide, collected data, carried out the data analysis, drafted the initial manuscript and reviewed and revised the manuscript. JH and LG conceptualised and designed the study and interview guide, supervised the data collection, carried out the data analysis, and reviewed and revised the manuscript. JO collected the data, carried out the data analysis, and reviewed and revised the manuscript. KW conceptualised the study, and reviewed and revised the manuscript. SV, JH, KW, JO and LG approve the final version of the manuscript to be published and agree to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved. SV, as the guarantor, accepts full responsibility for the work and/or conduct of the study, had access to the data, and controlled the decision to publish.

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Patient and public involvement Patients and/or the public were involved in the design, or conduct, or reporting, or dissemination plans of this research. Refer to the Methods section for further details.

Patient consent for publication Not required.

Ethics approval This study involves human participants and ethical approval was obtained from the Royal Children's Hospital Melbourne Human Research Ethics Committee (HREC/50340/RCHM-2019). Written consent was provided prior to data collection. Paediatricians consented to participate in the simulation and post-simulation interview. Parent-actors were employed for the simulation and post-simulation interviews.

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Interview guide: PARTICIPANTS

******Focus on intention behind behaviour/communication and messages trying to be sent by doctor*

Reminder that this is a research study and NOT an evaluation/communication skills training exercise. We're trying to find out how consultants undertake advance care planning and raise their concern about the future of a child with a life-limiting condition.

Demographics

- Details about clinical practice and career experience
- Involvement in clinical skills and communication skills training

Questions related to performance in simulation

- How did you try to explore the parents' understanding of their child's condition and prognosis?
- Why did you use that approach? What were you hoping to achieve?
- How did you share information about your assessment of the child's condition and prognosis?
- Why did you use that approach?
- To what extent would you regard your approach as advance care planning?

Questions related to potential differences with parents' opinion in future care and expectations

- Did you suspect that there might be a divergence in opinions between yourself and the parents?
- How did you identify this?
- How did you approach this divergence?
- Why did you adopt this approach? What were you hoping to achieve with this approach?

Question related to roles in decision-making

- What role do you think the parents want to play in future decision-making?
- Why do you think that?
- What role do you want to play in future decision-making? Why?

Questions related to trust

- To what extent did your approach try and establish trust from the parents?
- How did you do that?

Questions related to the use of simulation in the research method

- How similar was this simulation compared to reality?
- To what extent were there differences between this simulated encounter and reality?

Interview guide: ACTORS

Questions related to performance in simulation
(viewing playback from key time points in the simulation to seek participant's reflection)

- How did the doctor try to explore your character's understanding of the child's condition and prognosis?
- How did the doctor try to share information about their assessment of the child's condition and prognosis?
- How did your character feel about this approach?

Questions related to potential differences with parents' opinion in future care and expectations

- What did the doctor do when there was a difference of opinions?
- How did your character feel about this approach?

Question related to roles in decision-making

- What role do you think your character wants to play in future decision-making?
- Why do you think that?
- What role do you think the doctor wants to play in future decision-making?
- Did you get a sense that the doctor was trying to negotiate roles in decision-making?
- How did the doctor try and do that?
- How did your character feel about that approach?

Questions related to trust

- To what extent did the doctor try and establish trust from your character?
- How did they do that?
- How did your character feel about that approach?