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**Preparing paediatric healthcare professionals for end-of-life  
care discussions: An exploratory study**

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## Preparing paediatric healthcare professionals for end-of-life care discussions: An exploratory study

### Abstract

**Background:** Preparedness to initiate end-of-life (EoL) discussions is a confronting and daunting task for all healthcare professionals. We conducted a group interview to explore healthcare professionals' experiences of preparing for EoL discussions with the patient and their family in a paediatric context.

**Aim:** To identify what paediatric healthcare professionals consider important when preparing for an EoL discussion.

**Methods:** A qualitative design using a group interview. Two open ended questions were asked: 1) How could preparedness to initiate end-of-life care discussions between healthcare professionals and the patient and family be enhanced? 2) What education resources/strategies could be developed to support preparation for end-of-life care discussions?

**Setting/Subjects:** Healthcare professionals including medical, nursing and allied health professionals working in paediatric palliative care settings across Queensland, Australia. These settings included major tertiary hospitals, general practice, community, and non-government organisations. A convenience sample of 36 healthcare professionals consented to participate in the study.

**Results:** Analysis of the data identified seven themes that had relevance for preparing for an EoL discussion: communication, healthcare professional perspectives, interdisciplinary team role, patient and family perspectives, practical issues, addressing mistakes, healthcare professional education.

**Conclusions:** Paediatric healthcare professionals confirmed that gaps exist in preparing for an EoL discussion. The findings support a need for further research in two areas. Firstly, a systematic review of interdisciplinary resources available to support healthcare professionals prepare for EoL discussions is recommended. Secondly, evidence-based interdisciplinary interventions to support paediatric EoL discussions need to be developed and evaluated.

### Introduction

Preparing for an end-of-life (EoL) care discussion with patients and their families and/or carers requires careful planning to ensure that healthcare professionals are able to effectively and confidently conduct each unique discussion. This report examines a particularly confronting and difficult scenario for healthcare professionals; preparation for an EoL discussion with children or adolescents with a life-limiting illness. A life-limiting illness is defined as "an illness where it is expected that death, before adulthood, will be a direct consequence of the illness and therefore is expected to shorten the child's life".<sup>1(p18)</sup> A paediatric EoL discussion necessarily includes the parents and may also involve other members of the family. We have chosen a broad and inclusive definition of family, meaning any person(s) who plays a significant role in an individual's life. The child's parents have a legal and moral responsibility for caring for their child and need to be partners in all aspects of the planning of care.<sup>2(p14)</sup> The context of paediatric palliative care has differences to adult palliative care; paediatric palliative care "embraces the whole family as well as the child, involves health professionals with specialised skills in the care of children, supports families as they care for their sick child and their other children, [and] understands the different responses by children to symptoms and their treatments".<sup>1(p30)</sup>

Communicating with patients and their family is at the heart of the EoL discussion and must recognise and support the needs of patients and their families and health professionals.<sup>3,4</sup> Recent work related to paediatrics and young people including the "End of life planning series"<sup>5</sup> and "Difficult Conversations"<sup>6</sup> provide information on preparation for EoL care discussions. Information written for patients and families is shown to be useful for both health care professionals and families in preparing

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3 for EoL discussions.<sup>1,7</sup> For example, a review of a written resource “Caring Decisions” showed that  
4 written resources could be of significant benefit to both parents and clinicians.<sup>7,8</sup> The use of specific  
5 clinical tools, that draw together the key principles of guidelines, have also been shown to assist  
6 palliative care provision.<sup>9,10,11</sup> However, many existing tools are focused on clinical interventions; for  
7 example, pain management, quality of life, EoL decision-making, rather than on supporting paediatric  
8 healthcare professionals to prepare for EoL discussions. Although elements for preparing paediatric  
9 EoL discussions are discussed in the literature, healthcare professionals anecdotally report difficulty in  
10 practice. Furthermore, there is paucity in published literature describing the preparation for EoL  
11 discussions. Uncertainty in preparing for EoL discussions is compounded by a lack of targeted  
12 research addressing the efficacy of preparation interventions. The aim of this exploratory study was to  
13 identify what paediatric healthcare professionals consider important when preparing for an EoL  
14 discussion.

## 15 **Methods**

16  
17 A qualitative design, using a group interview, was adopted to elicit healthcare professionals’  
18 experiences and opinions regarding the preparation for EoL discussions. Two questions framed the  
19 interview: 1) How could preparedness to initiate end-of-life care discussions between healthcare  
20 professionals and the patient and family be enhanced? 2) What education resources/strategies could be  
21 developed to support the initiation of end-of-life care discussions? The study was approved by the  
22 local Human Research Ethics Committee (A/15/688).

23  
24 The study target population was specialist healthcare professionals including medical, nursing and  
25 allied health professionals working in paediatric palliative care settings across the State of  
26 Queensland, Australia. Settings included major tertiary hospitals, general practice, community and  
27 non-government organisations. Eighty-five healthcare professionals attending a 2-day Paediatric  
28 Palliative Care Education Workshop in May 2015 were invited to participate in a group interview.  
29 Potential participants were informed about the plan for an EoL discussion through the workshop  
30 program, and provide with written study information and a face-to-face briefing on Day 1 of the  
31 workshop. A convenience sample of 36 healthcare professionals voluntarily consented to participate in  
32 the group interview which was scheduled on Day 2 of the workshop.

33  
34 The group interview was conducted over 35 minutes and the data were collected using a secure  
35 electronic application, which supported a digital “wall” that was projected during the interview. A  
36 secure link to this application was provided to all participants to use on their personal mobile devices;  
37 the link was disabled following the interview. The interview scribe posted real-time summary notes  
38 onto the digital wall during the interview. All participants could anonymously post comments during  
39 the discussion. The digital wall allowed all participants to continuously view all comments being  
40 posted as the interview progressed. Participants were invited to send any further comments regarding  
41 this information to the study team; no further comments were received.

42  
43 Following the interview the data were electronically exported into a PDF file for data analysis. A  
44 descriptive content analysis was conducted to identify and describe the main content of the interview  
45 data; themes were derived from the data.<sup>12</sup> Study participants were provided with a summary of the  
46 findings and were encouraged to discuss any queries with any member of the study team.  
47 Consolidated criteria for reporting qualitative research (COREQ) informed the reporting of this  
48 study.<sup>13</sup>

## 49 **Results**

50  
51 Participants were asked two research questions in the interview; these questions supported wide  
52 discussion. Thirty-four comments were posted during the interview. Typically, these comments were  
53 short statements. The scribe’s comments, summarising key points of the group discussion, were more  
54 extensively reported. Analysis of the data identified seven themes that had relevance for preparing for  
55 an EoL discussion: communication, healthcare professional perspectives, interdisciplinary team role,  
56 patient and family perspectives, practical issues, addressing mistakes, and healthcare professional  
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education. Key themes, illustrated by italicised examples of anonymous comments, are presented in Table 1 below.

Table 1: Themes illustrated by the italicised examples of comments posted by participants

### Discussion

Seven themes were identified as important when preparing for EoL discussions. These themes were generally discussed as both enablers and barriers; they were identified as barriers if they were not included for discussion in the EoL preparation. The themes were mapped to prompts in the “End of Life Planning Series” published by Together for Short Lives.<sup>5</sup> This series addresses practice for healthcare professionals from care before death through to bereavement support and provided a contemporary benchmark for our work.

Table 2 below compares each study theme with related information for practice in the “End of Life Planning Series”.<sup>5</sup> For example; our study concept of acknowledging anxiety (Theme 2—Health professional perspectives) is aligned to the specific prompt “Work through your own reaction to the news before preparing yourself to share this with someone else – put aside your own “baggage” and personal feelings”.<sup>5</sup> Only one theme—addressing mistakes—and two concepts from the communication theme—cultural awareness, managing conflict—could not be mapped to the prompts.

Table 2: Study findings aligned to prompts published in the End of Life Planning Series: A guide to End of Life Care.<sup>5</sup>

While the majority of results could be aligned with previous work, the connectedness of the themes requires further consideration. *Addressing mistakes*, is an important theme to consider and whilst influencing an EoL discussion, this topic could be considered a unique focus for further work. Importantly, two concepts in the communication theme—cultural awareness and managing conflict—also need further exploration. The theme *interdisciplinary team role* can be considered to be at the centre of exploring the preparation of the EoL discussion. The theme *healthcare professional education* is a foundation for continually developing the interdisciplinary EoL discussion practice. The remaining four themes, *communication*, *healthcare professional perspectives*, *patient and family perspectives* and *practical issues*, are important input requirements for supporting the preparation for an EoL discussion.

### Strengths and limitations

The strength of this exploratory study is that the study sample achieved interdisciplinary representation comprising clinicians working across a range of tertiary and regional services in Queensland. A potential limitation of the study is that not all participants spoke in the interview; however, anonymous posting of comments ensured that all participants were able to have their opinions included. Results are limited to the experiences of clinicians working in palliative care services in one Australian state and it cannot be confirmed that the data were saturated. However, results also showed that responses from these clinicians could be mapped to most of the key prompts contained in the End of Life Planning Series.<sup>5</sup>

### Conclusion

Our study aim was to identify the areas that paediatric healthcare professionals considered important when preparing for an EoL care discussion with the patient and their family. Paediatric healthcare professionals confirmed that gaps exist in preparing for an EoL discussion. The findings support a need for further research in two areas. Firstly, a systematic review of interdisciplinary resources available to support healthcare professionals prepare for EoL discussions is recommended. Secondly, evidence-based interdisciplinary interventions to support paediatric EoL discussions need to be developed and evaluated. This work would potentially support healthcare professionals whose practice

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3 involves confronting and difficult EoL discussions with children or adolescents with a life-limiting  
4 illness.

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12 the work, *Together for Short Lives: End of Life Planning Series*, in our paper.

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## Preparing paediatric healthcare professionals for end-of-life care discussions: An exploratory study

Table 1: Themes illustrated by the italicised examples of comments posted by participants

| Theme 1 Communication                        |  |
|--|--|
| General communication skills                 | <ul style="list-style-type: none"> <li><i>it takes more than one discussion</i></li> <li><i>hard discussions but [you have] to step up</i></li> <li><i>importance of active listening with all 5 senses</i></li> <li><i>think before you speak</i></li> <li><i>[reflect on] where you [could] go wrong with a [EoL] discussion</i></li> <li><i>palliative care professionals may be more habituated to these [EoL] discussions - is that good or bad?</i></li> </ul>   |
| Language                                     | <ul style="list-style-type: none"> <li><i>use the right language</i></li> <li><i>what not to say like, things happen for a reason</i></li> </ul>   |
| Cultural awareness                           | <ul style="list-style-type: none"> <li><i>cultural humility and curiosity</i></li> <li><i>knowing the culture; being aware of cultural awareness and language, how is it used, [and] what is said.</i></li> </ul>  |
| Managing conflict                            | <ul style="list-style-type: none"> <li><i>conflict with what is being said adds to the difficulty</i></li> </ul>   |
| Theme 2 Healthcare professional perspectives |  |
| Acknowledging anxiety                        | <ul style="list-style-type: none"> <li><i>acknowledge own anxieties to ensure I have space for listening and observing what the family is experiencing in the complex multilayered moment</i></li> <li><i>it is okay to say you don't know and acknowledge the uncertainty of each and every case</i></li> </ul>   |
| Ability and expertise                        | <ul style="list-style-type: none"> <li><i>knowing your professional expertise and areas you lack then when to refer and admit when you don't know what to do</i></li> </ul>  |
| Theme 3 Interdisciplinary team role          |  |
| Team pre-briefing                            | <ul style="list-style-type: none"> <li><i>preparing behind the scenes</i></li> <li><i>build strong foundations [for the EoL discussion]</i></li> <li><i>working out who is the most appropriate person [to lead the discussion]</i></li> <li><i>choosing who will go to meeting</i></li> <li><i>reinforce the treating team's discussions</i></li> <li><i>not [passing] the buck to another professional or group &amp; encouraging you &amp; your colleagues to have the talk, make referrals, do paperwork etc.</i></li> </ul>         |
| Collaboratively work across settings         | <ul style="list-style-type: none"> <li><i>being able to work collaboratively with community services and hospital—communication can be lacking re prognosis</i></li> <li><i>knowing what the previous discussions have been with treating team</i></li> <li><i>community - if [you]work in [the] country areas [there are] not many resources e.g. medications, equipment - difficult having an EoL conversation when there are more practical issues that need addressing</i></li> </ul>  |
| Information provision                        | <ul style="list-style-type: none"> <li><i>clinical history - being aware of expectations of family</i></li> <li><i>have an understanding of what [the] end of life period will look like</i></li> <li><i>have facts correct</i></li> <li><i>parents often ask time frames</i></li> <li><i>what key supports are there for families e.g. grandparents, close friend, elder from community, spiritual adviser."</i></li> <li><i>to know the family from the start; it is then easier to prepare and journey with the family</i></li> </ul> |
| Theme 4 Patient and carers                   |  |
| General                                      | <ul style="list-style-type: none"> <li><i>we have our agenda of what we need to achieve</i></li> <li><i>be mindful of [the] importance of needs of the child and family including significant others</i></li> </ul>  |

|  |  |
|--|--|
|  | <ul style="list-style-type: none"> <li>• <i>[appreciate] pre-existing relationship[s] with [the] family</i></li> <li>• <i>paradigm shift when [a patient] enters [the] Eol period—parents may not be ready, disease progresses faster than you have been able to prepare family</i></li> </ul>   |
| <b>Theme 5 Practical issues</b>                  |  |
| Timing of the discussion                         | <ul style="list-style-type: none"> <li>• <i>the timing has to be right for the family rather than health professionals</i></li> <li>• <i>what do we do if there is limited time?</i></li> <li>• <i>ask the parents “are you ready to have this conversation about...”</i></li> </ul>   |
| Space for discussion                             | <ul style="list-style-type: none"> <li>• <i>nothing worse than having to do discussions in a busy ward area, if possible [you] need to find space</i></li> </ul>   |
| Healthcare professional etiquette                | <ul style="list-style-type: none"> <li>• <i>leave practitioner distractors like mobile phones and pagers with someone else</i></li> </ul>  |
| <b>Theme 6 Addressing mistakes</b>               |  |
| General  | <ul style="list-style-type: none"> <li>• <i>acknowledge your mistakes to family (and also learn from them)</i></li> <li>• <i>it’s OK to admit if you have said something wrong - even if not immediate, it can be helpful to acknowledge</i></li> </ul>  |
| <b>Theme 7 Healthcare professional education</b> |  |
| General  | <ul style="list-style-type: none"> <li>• <i>have a buddy or mentor - have it a compulsory part of the organisation— understanding roles and mentors</i></li> <li>• <i>use of role play can be very effective to learn techniques and practice discussions</i></li> <li>• <i>simulation - filmed and then watch back - identify things done well, things done poorly, good in hindsight - uncomfortable to do</i></li> <li>• <i>if one had a magic wand, or a mentor, who could help you work out how to improve over time</i></li> </ul> |

Table 2: Study findings aligned to prompts published in the End of Life Planning Series: A guide to End of Life Care<sup>5</sup>

| Study Themes and Concepts   | Specific Prompt: End of Life Planning Series <sup>5</sup><br><i>Note: The related prompt sheet is italicised</i>   |
|---|--|
| <b>Theme 1 Communication</b>  |  |
| General communication skills and language<br>Two of the concepts: cultural awareness and managing conflict, are not directly addressed. | Be confident that your experience has made you an expert in how to be empathic, understanding and able to communicate with children who are sick or dying, and their family members. <i>(Staff supervision and support)</i>  |
| <b>Theme 2 Healthcare professional perspective</b>  |  |
| Acknowledging anxiety   | Work through your own reaction to the news before preparing yourself to share this with someone else – put aside your own “baggage” and personal feelings. <i>(Care before death prompt sheet 1: Difficult conversations)</i>  |
| Ability and expertise   | Have a framework for the conversation, and consider rehearsing with a colleague beforehand. <i>(Care before death prompt sheet 1: Difficult conversations)</i><br><br>Remember the importance of team work in order to provide good children’s palliative care. <i>(Staff supervision and support)</i>               |
| <b>Theme 3 Interdisciplinary team role</b>  |  |
| Team pre-briefing   | Remember the importance of team work in order to provide good children’s palliative care. <i>(Staff supervision and support)</i>   |
| Collaboratively work across settings  | Good communication and co-ordination between all relevant professionals and local services is essential to ensure that staff and families are aware of what care is available and that they are able to make informed choices. <i>(Care before death prompt sheet 2: Advance care planning)</i>                      |
| Information provision   | Know your facts and what the issues might be. Be adequately prepared in relation to the clinical situation and the family situation, for example think about what roles different people play in the family and how they process information. <i>(Care before death prompt sheet 1: Difficult conversations)</i>     |
| <b>Theme 4 Patient and carers</b>   |  |
| General   | Good communication is key to providing good care to children and their families, especially at end of life. By carefully listening and responding, you can help by providing information, comfort and understanding at a difficult time. <i>(Care before death prompt sheet 1: Difficult conversations)</i>          |
| <b>Theme 5 Practical issues</b>   |  |
| Timing of the discussion<br>Space for discussion<br>Healthcare professional etiquette   | You need to make the time and space to share the information by allowing enough uninterrupted time. <i>(Care before death prompt sheet 1: Difficult conversations)</i>   |
| <b>Theme 6 Addressing mistakes</b>  |  |
| Addressing mistakes is not addressed.   |  |
| <b>Theme 7 Healthcare professional education</b>  |  |
| General   | Always be prepared to ask for help if you need further support. <i>(Care before death prompt sheet 1: Difficult conversations)</i><br>Get adequate supervision, as this provides a system for talking through difficult cases, sharing problems and planning the way forward. <i>(Staff supervision and support)</i> |