

## ORIGINAL ARTICLE

# Improving paediatric advance care planning: Results of a learning needs analysis and simulation-based education programme

Naomi T Katz<sup>1,2,3,4</sup>, Bronwyn H Sacks,<sup>1</sup> Jenny L Hynson,<sup>1,3,4</sup> Melissa Heywood,<sup>1,2</sup> Molly Williams<sup>1</sup> and Jenni Sokol<sup>2,3</sup>

<sup>1</sup>Victorian Paediatric Palliative Care Program, <sup>2</sup>Simulation Program, Royal Children's Hospital, <sup>3</sup>Department of Paediatrics, University of Melbourne and <sup>4</sup>Clinical Paediatrics Group, Murdoch Children's Research Group, Melbourne, Victoria, Australia

**Aim:** To assess clinicians' experience, attitudes and confidence with advance care planning (ACP) at a quaternary paediatric referral centre using a learning-needs survey, and then apply this information to develop and examine the feasibility of simulation-based education for this topic.

**Methods:** An electronic learning-needs survey was distributed to medical, nursing and allied health clinicians from departments who provide primary care for children with life-limiting conditions. Results were incorporated into the design of a simulation-based education session which was piloted with the Royal Children's Hospital Oncology Department.

**Results:** A total of 157 learning-needs surveys were included in analysis, and included quantitative and qualitative responses from nursing, allied health, senior and junior medical staff from intensive care, general and subspecialty medical teams. Most (75.0%) participants had participated in ACP discussions previously. Only 40.1% of participants felt confident to assess appropriate timing of, and 45.2% felt adequately prepared to participate in ACP discussions. Barriers identified were both clinician and patient/parent related, including clinicians not knowing when to address issues (43.9%) or what to say (21.0%). Participants indicated that ACP discussions are most frequently initiated when death is clearly imminent. Following a pilot of simulation-based education with the oncology department, 90% of participants expressed confidence to participate in ACP discussions.

**Conclusions:** Barriers to paediatric ACP, including lack of clinician training, continue to contribute to delayed conversations. Simulation-based education is a valuable and feasible educational tool that can increase clinicians' understanding and confidence in this area.

**Key words:** advance care planning; education; paediatrics; palliative care; simulation.

## What is already known on this topic

1. When completed sensitively and appropriately, advance care planning (ACP) for children with life-limiting conditions benefits clinicians, patients and families.
2. Often a child's deterioration and death can be anticipated.
3. Despite this, ACP tends to happen late in a child's illness course.

## What this paper adds

1. This paper supports clinician appetite for training and education in ACP.
2. This paper also illustrates how simulation-based education is a valuable and feasible tool that can increase clinician understanding and confidence in this area.

Hundreds of children in Victoria live with and/or die from a life-limiting condition each year. While resuscitation plans are important, advance care planning (ACP) is a much broader concept.<sup>1,2</sup> ACP is 'a process of discussions between families and health care providers about preferences for care, treatments and goals in the context of the patient's current and anticipated future health'.<sup>3</sup> Treating physicians generally lead discussions; however, any health professional involved in a child's care may find themselves involved in ACP conversations. ACP allows the treating team to

understand what is important to a patient and their family, and share prognostic information and decision-making ahead of potential deterioration. Often deterioration can be anticipated, yet ACP tends to happen late, sometimes in the last days or hours of life.<sup>1,4,5</sup>

In Durall *et al.*'s study, the top three barriers to paediatric ACP were clinician perceptions of unrealistic parent expectations, differences between clinician and patient/parent understanding of prognosis, and lack of parent readiness to have the discussion.<sup>4</sup> Clinicians also worry about taking away hope, losing trust of the patient/family, and not knowing the right thing to say.<sup>4</sup> While no parent is ever 'ready' for their child to die, many parents consider the possibility that their child might die and the value of life-sustaining treatments prior to physicians initiating ACP.<sup>6</sup> Parents may feel they have little control over their child's last days and

**Correspondence:** Dr Naomi T Katz, Victorian Paediatric Palliative Care Program, Royal Children's Hospital, 50 Flemington Road, Parkville, Vic, 3052, Australia. fax: +614 93456240; email: naomi.katz@rch.org.au

Conflict of interest: None declared.

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# Advanced Planning In Paediatric Care Essays

**Donald Asher**



## **Advanced Planning In Paediatric Care Essays:**

Implementing Evidence-Based Academic Interventions in School Settings Sylvia Rosenfield, Virginia Wise Berninger, 2009-02-26 Designed for both researchers and practitioners this book is a guide to bridging the gap between the knowledge generated by scientific research and application of that knowledge to educational practice With the emphasis on evidence based practice in the schools growing exponentially school practitioners must learn how to understand judge and make use of the research being produced to full effect Conversely researchers must understand what is being used in real world settings and what is still needed The editors of this book have outlined this process as a series of steps beginning with being a critical consumer of current research literature followed by concepts to consider in translating research into practice systems issues at local district and state levels the role of teachers in program implementation evaluation of implementation effectiveness and preservice and inservice professional development of teachers and psychologists Each chapter is written by leaders on the topic and contributors include both researchers and school based practitioners With contributing authors from a variety of disciplines this book is an invaluable treatise on current understanding of the complexities of translating research into educational practice **Health planning reports subject index** United States. Health Resources Administration, 1979

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*Congressional Record* United States. Congress, 2002 The Congressional Record is the official record of the proceedings and debates of the United States Congress It is published daily when Congress is in session The Congressional Record began publication in 1873 Debates for sessions prior to 1873 are recorded in The Debates and Proceedings in the Congress of the United States 1789 1824 the Register of Debates in Congress 1824 1837 and the Congressional Globe 1833 1873

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