PHYSICIAN EXPERIENCE & CONFIDENCE IN PAEDIATRIC ADVANCE CARE PLANNING

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**CONTEXT**

- Changing population of paediatric patients
  - Higher survival rates in children with complex conditions

- Children with chronic and complex conditions
  - May have reduced life expectancy
  - Many require multiple interventions and hospitalisations to maintain health
  - Important to balance survival and quality of life
“our aim as paediatric health care providers should be to add life to the child’s years, not simply years to the child’s life”"
Important to recognise when a condition is life-limiting and to start related discussions early.

Advance care planning

- Defined as "the process of discussing issues and planning ahead in anticipation of a change in future condition...[which]... for some families will include discussions about the possibility of premature death"
- Usually involves multiple discussions
- At some stage may lead to completion of a formal advance care plan document
Evidence of benefit largely from adult population

For families
- Involves parents in decision making
- Allows parents to state wishes\(^4\)
- Provides opportunity to discuss choices in a non-crisis situation\(^5\)

For physicians
- Provides clear direction regarding emergency procedures
- Helps to reduce perceived unnecessary suffering for the child\(^6\)

Further studies still required surrounding paediatric ACP
USE OF ADVANCE CARE PLANNING

- Practice not reflective of perceived advantages
  - Qualitative studies:
    - doctors generally feel ACP occurs too late
  - Most children still dying in hospital in the ICU environment despite more common parental preference for death at home
  - UK Surveys of records assessing compliance with recommendations
    - Deficiency in ACPs ranging from absent to incomplete

- Our study interested in experience of staff in our hospital
Research questions:

- Do clinicians feel advance care planning is being used effectively?
- What level of confidence do clinicians have to initiate such discussions?
- Do clinicians identify a lack of education and resources as contributing to difficulties initiating advance care planning?
- Would improved availability of resources be positively received by trainees and physicians?
STUDY DESIGN

- Clinician survey
  - Survey written after review of relevant literature
  - Link to online survey emailed to all advanced trainees, general paediatricians and sub-specialist paediatricians at Sydney Children’s Hospital
  - Responses collected over 10 week period from July to September 2015
92 responses obtained
- 8 responses excluded as incomplete (<5 out of 20 questions answered)
- Response rate 30%

Demographic data for 81 of 84
- Majority trainees (53%, n=43)
- General paediatricians 19.7% (n=16)
- Subspecialty paediatricians 14.8% (n=12)
- Remainder intensive care physicians (n=6) or emergency physicians (n=4).
Vast majority of respondents (98.8%) have encountered patients with life-limiting illnesses
- 57% of respondents have cared for >10 patients with life limiting conditions over last 2 years
- 34.5% caring for more than 20 patients

Low proportion of these patients with an ACP in place
- 64% reported less than half such patients had an ACP in place
- 18% reported more than half or all patients having an ACP in place
## TIMING OF ACP

### Observed vs Optimal timing of ACP Discussions

<table>
<thead>
<tr>
<th>Timing of First ACP Discussions</th>
<th>Observed timing (multi-answer)</th>
<th>Perceived optimal timing (single-answer)</th>
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<tbody>
<tr>
<td>At the time or soon after diagnosis</td>
<td>20%</td>
<td>17%</td>
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<tr>
<td>After diagnosis and during a period of stability</td>
<td>20%</td>
<td>47%</td>
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<tr>
<td>After a period of gradual deterioration</td>
<td>35%</td>
<td>30%</td>
</tr>
<tr>
<td>After first acute, severe deterioration</td>
<td>37%</td>
<td>5%</td>
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<tr>
<td>After multiple acute, severe deteriorations +/- ICU admission</td>
<td><strong>57%</strong></td>
<td>0%</td>
</tr>
<tr>
<td>When death is imminent</td>
<td>35%</td>
<td>0%</td>
</tr>
<tr>
<td>Not at all</td>
<td>10%</td>
<td>0%</td>
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RESPONSIBILITY FOR ACP

Clinician Usually Responsible for Initiating ACP Discussion

- Multi-disciplinary team: 20.70%
- Consultant General Paediatrician: 40.20%
- Subspecialist Paediatrician: 18.30%
- Palliative Care physician: 3.70%
- Emergency physician: 1.20%
- Intensivist: 13.40%
- Paediatric Trainee: 1.20%
- Patient’s family: 0.00%
- General Practitioner: 1.20%
**Responsibility for ACP**

### Most Appropriate Clinician to Initiate ACP Discussion

- **Multi-disciplinary team**: 45.80%
- **Consultant General Paediatrician**: 39.80%
- **Subspecialist Paediatrician**: 12.00%
- **Palliative Care physician**: 2.40%
- **Emergency physician**: 0.00%
- **Intensivist**: 0.00%
- **Paediatric Trainee**: 0.00%
- **Patient’s family**: 0.00%
- **General Practitioner**: 0.00%

*“I feel that advanced care planning discussions should be initiated with families by the most appropriate clinician known to the family”*

- **Respondent comment**
<table>
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<th>Barriers</th>
<th>Percentage</th>
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<tr>
<td>Uncertainty regarding patient’s prognosis</td>
<td>73%</td>
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<td>Lack of established rapport/relationship with the family</td>
<td>49%</td>
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<td>Clinicians not wanting to upset parents</td>
<td>43%</td>
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<td>Lack of clinician experience in raising advanced care planning</td>
<td>43%</td>
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<td>Clinicians not feeling the ‘right time’ ever arises</td>
<td>42%</td>
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<td>Clinicians’ personal discomfort with advance care planning discussions</td>
<td>41%</td>
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<td>Lack of time during clinical encounters</td>
<td>39%</td>
</tr>
<tr>
<td>Clinician concern that raising discussions will adversely affect doctor-patient relationship</td>
<td>35%</td>
</tr>
<tr>
<td>Lack of clinician education regarding how to best initiate advance care planning</td>
<td>32%</td>
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EXPOSURE AND EDUCATION

Exposure during training

- Majority (75.6%) of respondents exposed to ACP discussion initiation
- Majority (56.1%) of respondents felt they had inadequate exposure
- Only 4.5% of respondents felt their exposure to ACP planning discussions during training was very adequate.

Education during training

- 81.2% of respondents reported having received either no education or inadequate education regarding initiating ACP discussions during medical training.
- Of the 28% of respondents who did receive some education, 58.3% considered this education inadequate.
RESOURCES

- **Awareness of resources**
  - 83% unaware of any resources within Sydney Children’s Hospital
  - 87% of respondents unaware of any resources outside of network that could be used to assist with initiating ACP

- **Resources that clinicians would find helpful to improve ACP discussions**
  - Booklets introducing the concept of ACP to families 78%
  - Documents for clinicians outlining the aspects of discussion required in advance care planning 83%
  - Documents to be filled out with families regarding their wishes in key areas of care including advance care planning 79%
What forms of education regarding advance care planning would you find helpful in your practice?

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<th>Educational Form</th>
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<tr>
<td>Clinician discussion groups regarding experiences of advance care planning</td>
<td>60%</td>
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<td>Written education resources on how to initiate advance care planning</td>
<td>54%</td>
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<td>Communication tutorials focused on advance care planning</td>
<td>52%</td>
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<td>Lecture-based education from expert clinicians</td>
<td>44%</td>
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<td>Video or simulation sessions on advance care planning</td>
<td>33%</td>
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<tr>
<td>I would not find education helpful</td>
<td>4%</td>
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LIMITATIONS

- Small study
- Single hospital site
  - Tertiary centre
  - Mitigated by all clinicians practicing at peripheral and rural sites
- Voluntary response bias
Disparity between perceived best practice and actual clinical experiences
- ACP discussions occurring late in illness
- Least likely to occur at the ‘optimal’ time

Barriers to ACP
- Prognosis a major concern for clinicians, despite preference for early discussion
- Lack of experience and education a significant area for improvement
Experience and Education

- Inpatient bias
- Preference for shared decision making in initial discussions
  - ?additional barrier
  - ?availability in non-tertiary settings
- Education not formalised
  - risk of inadequate preparation during training
- Awareness of available resources overall poor
  - Easily targeted area for improvement
ACKNOWLEDGEMENTS

- Dr Kevin Swil
  - Project Supervisor & Paediatric Intensivist, SCH
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