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[1].
  - Important to balance survival and quality of life

CONTEXT

"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"[2]

ADVANCE CARE PLANNING

- Important to recognise when a condition is life-limiting and to start related discussions early[3]

- 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"*[4]**
  - Usually involves multiple discussions
  - At some stage may lead to completion of a formal advance care plan document

BENEFITS OF ACP IN PAEDIATRICS

- 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[1]
  - 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

OUR STUDY

- 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?

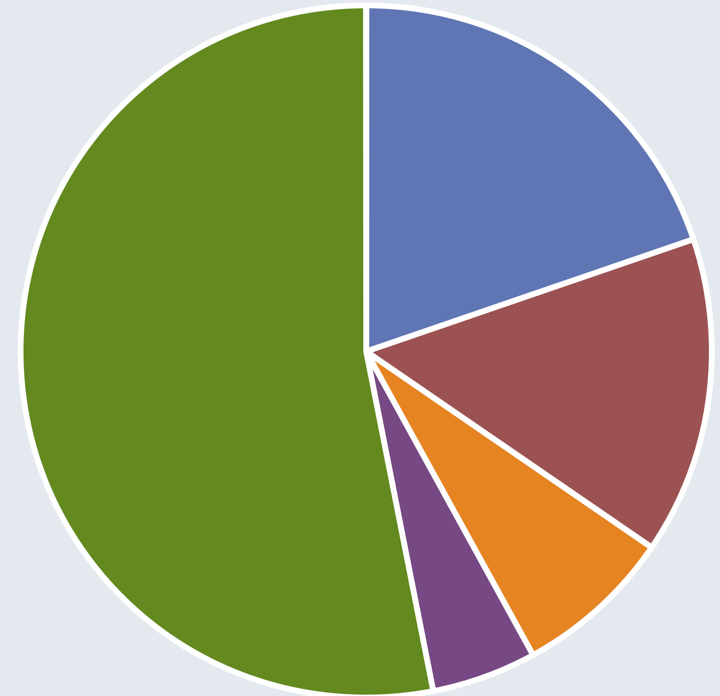
STUDY DESIGN

- Clinician survey
  - Survey written after review of relevant literature
  - Link to online survey emailed to all advanced trainees, general paediatricians and and sub-specialist paediatricians at Sydney Children's Hospital
  - Responses collected over 10 week period from July to September 2015

RESPONDENTS

- 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).



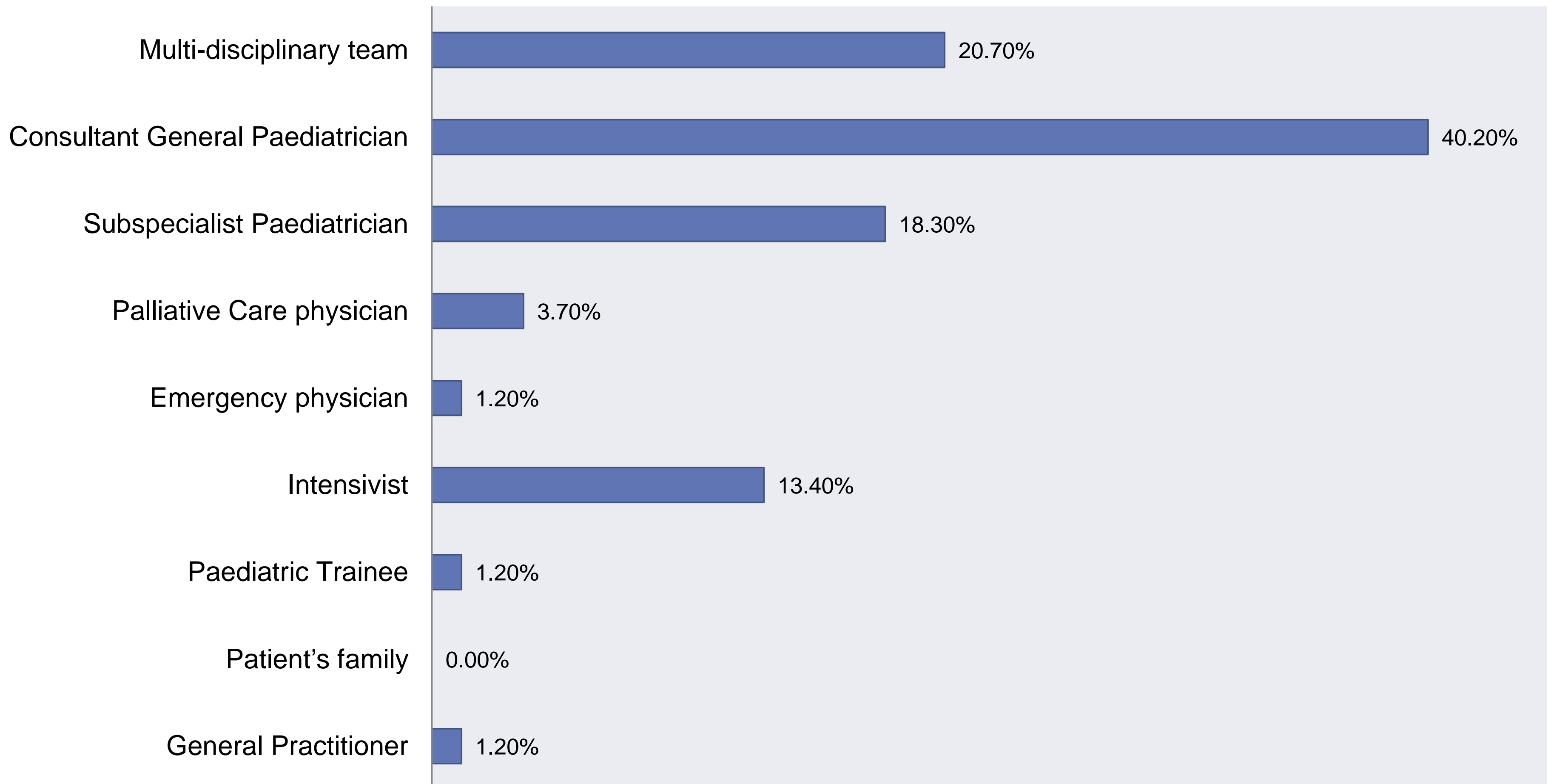
EXPERIENCE WITH END OF LIFE

- 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

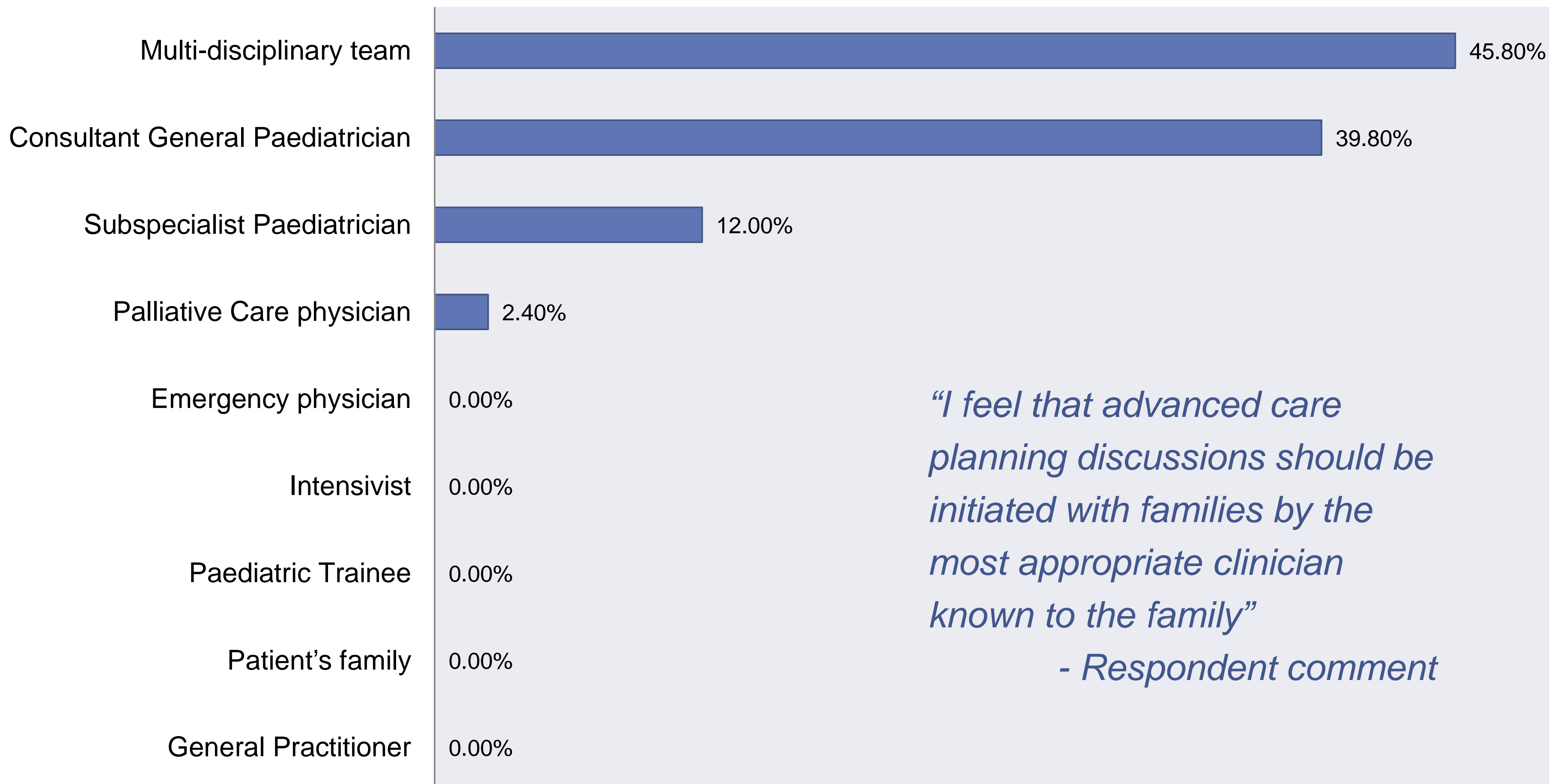
TIMING OF ACP

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

RESPONSIBILITY FOR ACP



RESPONSIBILITY FOR ACP



BARRIERS TO ADVANCE CARE PLANNING

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

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%

EDUCATION

What forms of education regarding advance care planning would you find helpful in your practice?	
Clinician discussion groups regarding experiences of advance care planning	60%
Written education resources on how to initiate advance care planning	54%
Communication tutorials focused on advance care planning	52%
Lecture-based education from expert clinicians	44%
Video or simulation sessions on advance care planning	33%
I would not find education helpful	4%

LIMITATIONS

- Small study
- Single hospital site
  - Tertiary centre
  - Mitigated by all clinicians practicing at peripheral and rural sites
- Voluntary response bias

CONCLUSIONS (1)

- 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

CONCLUSIONS (2)

- 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

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