‘Emergency’ Palliative Care

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Points of discussion

- What is palliative care? What are some of the myths?
- Advance Care Planning
- Scenarios you are likely to encounter in the ED
- Key aspects of care
Why would you want to do that job?
Because…

- There is a high (but eminently treatable) symptom burden among dying paediatric patients even in world class facilities
- Events during the child’s life and around the time of their death affect parents long into bereavement
- The death of a child is sad, but it doesn’t have to be bad
- There is a growing evidence base
- You can help children and parents go through the hardest thing imaginable
## Myths and Misconceptions

<table>
<thead>
<tr>
<th>Misconception</th>
<th>Correction</th>
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<tbody>
<tr>
<td>For the elderly</td>
<td>Any age</td>
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<tr>
<td>Cancer only</td>
<td>Any life limiting illness</td>
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<tr>
<td>Passive</td>
<td>Active</td>
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<tr>
<td>Terminal care</td>
<td>Living well with a bad illness</td>
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<tr>
<td>Giving up hope</td>
<td>Holding on to hope</td>
</tr>
<tr>
<td>Forgoing ongoing efforts to treat/cure disease</td>
<td>Integrated with disease-oriented treatment</td>
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<tr>
<td>Euthanasia</td>
<td>Palliative care does NOT hasten death (in fact, may prolong life slightly)</td>
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Opioids/sedatives and death causation

- No evidence that the appropriate use of opioids or sedatives hastens death

  *Sykes N, Thornes A. (review) Lancet Oncol 2003;4:312–18*
  - Doctrine of ‘double effect’ irrelevant in the setting of symptom control

- Chan, J et al. Narcotic and benzodiazepine use after withdrawal of life-support: Association with time to death. Chest 2004;126;286-293
  - Morphine: no association
  - Benzodiazepine: inverse association
Early Palliative Care for Patients with Metastatic Non–Small-Cell Lung Cancer


ABSTRACT

BACKGROUND
Patients with metastatic non–small-cell lung cancer have a substantial symptom burden and may receive aggressive care at the end of life. We examined the effect of introducing palliative care early after diagnosis on patient-reported outcomes and end-of-life care among ambulatory patients with newly diagnosed disease.

METHODS
We randomly assigned patients with newly diagnosed metastatic non–small-cell lung cancer to receive either early palliative care integrated with standard oncologic care or standard oncologic care alone. Quality of life and mood were assessed at baseline and at 12 weeks with the use of the Functional Assessment of Cancer Therapy–Lung (FACT-L) scale and the Hospital Anxiety and Depression Scale, respectively. The primary outcome was the change in the quality of life at 12 weeks. Data on end-of-life care were collected from electronic medical records.

RESULTS
Of the 151 patients who underwent randomization, 27 died by 12 weeks and 107 (66% of the remaining patients) completed assessments. Patients assigned to early palliative care had a better quality of life than did patients assigned to standard care (mean score on the FACT-L scale [in which scores range from 0 to 136, with higher scores indicating better quality of life], 98.0 vs. 91.5; P=0.05). In addition, fewer patients in the palliative care group than in the standard care group had depressive symptoms (16% vs. 38%, P=0.01). Despite the fact that fewer patients in the early palliative care group than in the standard care group received aggressive end-of-life care (33% vs. 54%, P=0.05), median survival was longer among patients receiving early palliative care (11.6 months vs. 8.9 months, P=0.02).

CONCLUSIONS
Among patients with metastatic non–small-cell lung cancer, early palliative care led to significant improvements in both quality of life and mood. As compared with patients receiving standard care, patients receiving early palliative care had less aggressive care at the end of life but longer survival. (Funded by an American Society of Clinical Oncology Career Development Award and philanthropic gifts; ClinicalTrials.gov number, NCT01090271.)
Causes of suffering

- The illness
- The things we do to the child
- The things we don’t do
Old model of palliative care: clear transition from curative to palliative care
(adapted from Frager, G. Palliative care and terminal care of children.)
Mixed Model of Care (adapted from Approaching Death: Improving Care at the End of Life)
Who might benefit?

Ask yourself:

‘Would I be surprised if, in one year from now, someone told me this child had died?’

If the answer is ‘No’, consider a referral
‘Certain death at an unknown time’

- Paediatric pall care very different from adult
- Often long, variable illness trajectories
- Multiple life-threatening episodes
  - Many children have recovered from ‘terminal events’
Advance Care Planning
Expectations around Advance Care Planning

- Conversations are often underway

BUT

- The process takes time
- It can be difficult to anticipate every scenario
- Some parents want to make the decision at the time
- Some parents change their minds
- Some parents simply cannot make ‘the decision’
Head and heart

- Parents often intellectually understand their child’s prognosis
  
  BUT

- Their heart won’t abandon hope
ACP is a starting point only

- So, best to consider the Advance Care Plan or whatever conversations have been had as a starting point rather than an end point
- Take the conversation from there
- It is not necessarily a failure if the child goes to PICU and requires withdrawal of treatment later
Scenarios encountered in the ED

- Sudden, unexpected death in a previously well child
- Death of a child with a pre-existing condition
- Expected death in a child receiving palliative care
- A child who needs palliative care but isn’t getting it!
A Case Study
Daniel

- 6 year old boy
- CP (GMFCSV) –HIE
- Severe spastic quadriplegia
- Gastrostomy feeds
- Stridor (Grade II laryngomalacia)
- Complex partial seizures
- Pseudomonas infection
- Recurrent aspiration pneumonia-multiple admissions to ICU for ventilatory support
Receiving palliative care

- Assistance with irritability/pain/dyspnoea
- Home nursing support, provision of equipment and respite
- Conversations regarding benefits/burdens of various interventions
- Parents starting to see that management in ICU no longer in Daniel’s best interests but ‘not quite there yet’. Discussions about options in the event of another RTI
- They have a written plan which involves giving oral morphine
- He develops an RTI. Parents cannot bring themselves to give morphine and ‘panic’
- Daniel presents to ED with significant dyspnoea and is very unwell with an RTI
Options

- Intubation and ventilation (ICU) as previously
- Symptom management
  - On ward
  - In a children’s hospice
  - At home
- Needs to be a discussion at the time
  - Is the child likely to recover from this?
  - What are the ways we can manage this?
Management of Daniel’s pain/dyspnea

- Morphine start at 10mcg/kg/hr as an IV/SC infusion and titrate to effect
- Midazolam start at 10mcg/kg/hr as an IV/SC infusion and titrate to effect
- Suction, positioning, physio
- Oxygen if helpful (O2 sats irrelevant, watch the child)
- Parents decide against any form of ventilatory support
- Transferred home the following day for ongoing management and dies 24 hours later
Death of a Child in the Emergency Dept.

Management of Acute Dying/Death

- Palliative care compressed into a brief window of time
- Same principles i.e.
  - Symptom management (minimising suffering)
  - Making the best possible decisions re what interventions are appropriate (i.e. not adding to the child’s suffering)
  - Communication of information to family, discussion re options
  - Provision of emotional, psychological and spiritual support for parents and siblings
  - Bereavement care (links to supports)
## Communication

**Do**
- Use the child’s name
- Use the ‘D’ word
- Acknowledge emotions
- Sit with silence: just being a presence is supportive
- Sit down if possible

**Don’t**
- Use jargon or euphemisms
- Try to be philosophical
- ‘hit and run’
- Take anger etc personally
Emotional responses

- In the face of death and strong emotion, recognise that it is not within your capability to ‘fix it’

- It is within your capability to;
  - Recognise and acknowledge it
  - Support the family for the time they are with you
  - Provide them with information and guide them through any processes that are necessary
  - Help keep them safe (e.g. organising for a friend to drive them home)
  - Ensure they are linked to ongoing supports

- We are paediatric health providers and the support of any siblings should be prioritised
Dealing with our own emotions

- Parents value knowing that the death of their child has been felt by others
- Showing some emotion is important
- This is hard work. There may be particular scenarios that affect you more than others (e.g. a child the age of your own child)
- Some ‘defenses’ developed by health professionals have a negative impact on the care of families
Organisational issues

- Notifying key individuals
- Ensuring follow-up
- Organ donation
- Medico-legal requirements
Parenting after death

- Washing
- Cuddling
- Dressing
- Just ‘being with’
- Searching
What can we do to help?

- Time!!! (this can be so difficult in the ED)
- Use of a bereavement room
- Taking the child home or to a hospice
- Helping with memory-making, washing etc
Professional Development

- Upskill yourselves
- Most major paediatric hospitals have a palliative care program
- Ask them to provide education about, for example,
  - Symptom management
  - Supports available to families
  - Communicating with and supporting distressed families
  - Looking after self
- Events surrounding the child’s death are indelibly etched into the memory of the family and affect grieving

- What you do at the time can have a profound effect on this (for the better)

- Compassion, empathy, humanity come up repeatedly in the literature as elements that impact positively on parental grief
Humanity

Charles Porter, Pulitzer Prize 1996