End of life care for children with heart disease

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The aim of paediatric palliative care

To help children with life-limiting and life-threatening illnesses and their families achieve a good life and a good (enough) death
Patient

Physical
Spiritual

Psychological
Social

Family needs

Respite care
Bereavement support

Quality of care

Advance care planning
Integration of care
Symptom care planning

Adapted from Mularski et al 2007
Children living with life-limiting conditions

<table>
<thead>
<tr>
<th>Condition</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Congenital Anomalies</td>
<td>30.7%</td>
</tr>
<tr>
<td>Oncology</td>
<td>13.7%</td>
</tr>
<tr>
<td>Neurology</td>
<td>12%</td>
</tr>
<tr>
<td>Haematology</td>
<td>9.8%</td>
</tr>
<tr>
<td>Respiratory</td>
<td>8.8%</td>
</tr>
<tr>
<td>Genitourinary</td>
<td>6.2%</td>
</tr>
<tr>
<td>Perinatal</td>
<td>7.7%</td>
</tr>
<tr>
<td>Metabolic</td>
<td>3.8%</td>
</tr>
<tr>
<td>Circulatory</td>
<td>3.8%</td>
</tr>
<tr>
<td>Gastrointestinal</td>
<td>2.4%</td>
</tr>
<tr>
<td>Other</td>
<td>1.1%</td>
</tr>
</tbody>
</table>

Active treatment

Palliative care

Diagnosis

Curative treatment ceases

Death
• Young patients (75.7% <1 year)
• Almost all ventilated
• Half receiving ECMO/VAD support
• 55% underwent CPR during their final hospital admission

• Infants dying in intensive care environments; often at a distance from home
Misperception that cardiac patients die a ‘sudden’ death so the EOL period is short. For this study cohort the mean duration of last admission was 22 days

69% died following withdrawal of disease directed care
Active treatment

Palliative care

Diagnosis

Death
• Initial interaction between families and healthcare teams has a focus on ‘fixing’

• Progressive heart failure often follows an undulating course – the point at which there is no possibility of long term survival is difficult to identify
‘Hope is an expectation of greater than zero of achieving a goal’

Robert Twycross

‘[Heart] transplant is like having a lottery ticket in your back pocket’

Consultant Cardiologist, Heart Transplant Service
Hope vs. Optimism

Optimism
‘An individual’s confidence in achieving a good outcome’

Hope
‘Goal oriented way of thinking that encourages an individual to invest time and energy in achieving their aims’

Bressan et al. Hope is a therapeutic tool. BMJ 2017; 359
‘Hope is not a plan’

Atul Gawande
• 50 bereaved parents surveyed

• Mean age of child at death – 6 months (3.6d – 20.4y)
• At EOL: 86% intubated, 46% receiving mechanical circulatory support
• 78% died following withdrawal of LST, 16% during attempted resus
• 47% felt their child suffered ‘a great deal’ ‘a lot’ or ‘somewhat’ during the EOL period

• Perceived suffering did not vary with degree of consciousness or mode of death (following withdrawal of LST vs during resus. attempt)

• Symptoms

• <2yr olds: breathing and feeding difficulties

• >2yr olds: fatigue and sleep difficulties
Parental Perspectives on Suffering and Quality of Life at End-of-Life in Children With Advanced Heart Disease: An Exploratory Study

Elizabeth D. Blume, MD; Emily Morell Balkin, MD; Ranjit Aiyagari, MD; Sonja Ziniel, PhD; Dorothy M. Beke, RN, MS, CPNP-PC/AC; Ravi Thiagarajan, MD; Laura Taylor, MD; Thomas Kulik, MD; Kenneth Pituch, MD; Joanne Wolfe, MD

Figure 1. Time prior to death when the parent realized their child had no realistic chance for survival. Almost half of parents (47%) realized this either at time of death (never) or within 1 d prior to death.
To provide good EOL care

• Parallel plan – recognise uncertainty and support them through this
• Understand their goals and priorities

• Try to enable choice and control to optimise quality of life and experience of death

• Good symptom management
Thank you

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