South African Children’s Palliative Care Network (SACPCN)

- **The Vision** of the SACPCN is to ensure that the right of every child with a life-threatening or life-limiting condition to access quality palliative care in Southern Africa, is met.

- **The Mission** of the SACPCN is to mobilize and support a network of existing organisations, professionals and caregivers to ensure that all children with life-threatening and life-limiting conditions receive holistic, family-centred and culturally appropriate palliative care from the time of diagnosis till bereavement.
What the SACPCN hopes to provide

- Networking and learning opportunities
- Website and resources
- Seminars and conferences
- Support for parents
- Advocacy effort
- Training (on line EPEC-paeds)
- Research

**PLEASE SIGN UP IF YOU ARE INTERESTED**
Dr Khaliah Johnson

- Paediatrician board certified in Hospice and Palliative Medicine (2012)
- Completed her fellowship in Paediatric Palliative Medicine at the Children’s Hospital of Philadelphia (CHOP)
- Initially decided to do the Palliative Care fellowship in preparation for specializing in critical care
- Interest in Global Medicine and esp in PPC development in Africa
- Completed her elective at RCWMCH (SA) in 2012
- Returned to help with APCA Paeds POS Validation study
- Busy working on withdrawal guidelines for ICUs
Children’s Hospital Of Philadelphia (CHOP)
CHOP

- One of the world's largest and oldest children's hospitals
- Founded in 1855
- Over 500 beds
- 100 ICU beds: neonates, cardiac, general (40% of beds)
- 1 million in and out-patients treated per year
- Major referral centre
- Voted no 1 children's hospital in the USA in 6/10 disciplines
Palliative Care at CHOP

- Provided by their PACT team:
  - Pediatric Advanced Care Team
  - Our mission is to improve the quality of life for children with life-limiting conditions and that of their families.

Chris Feudtner is assistant professor of Pediatrics at UPenn
Attending physician, director of research for PACT and the Integrated Care Service, Co-scientific director of Policy Lab at CHOP
Director of the new Department of Medical Ethics at Children’s Hospital
Steven D. Handler Endowed Chair of Medical Ethics.
PACT’s MODEL

- We achieve our mission by:
  - Facilitating communication between patients, family members, and health care providers
  - Assisting families in decisions that best reflect the values and preferences of the patients and family members
  - Improving patients' and families' quality of life
  - Improving the management of symptoms that cause discomfort
  - Providing emotional, social, spiritual, and bereavement support
  - Promoting the continuity of care for patients and their families
  - Delivering effective educational programs to health care staff
  - Conducting research to better inform how we can best care for children with life-limiting conditions and support their families.
PPC need in the States

- Approximately 500,000 children cope with life-threatening conditions annually in the United States\textsuperscript{1}
- Over 50,000 infants and children die annually in the United States\textsuperscript{2}
- Most Paediatric deaths occur in hospitals
- In Some centres up to 75% of deaths occur in the ICU

Panel B

Angus DC et al. *Crit Care Med* 2004; 32:638
## Place of death

### Table 1: Site of Death Varies by Age

<table>
<thead>
<tr>
<th>Age</th>
<th>Hospital</th>
<th>Nursing Facility</th>
<th>Home</th>
<th>Emergency Department</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>&lt;1 mo</td>
<td>3527 (92.9)</td>
<td>7 (0.2)</td>
<td>185 (4.9)</td>
<td>77 (2.0)</td>
<td>3796 (100)</td>
</tr>
<tr>
<td>1–11 mo</td>
<td>1145 (45.6)</td>
<td>8 (0.3)</td>
<td>864 (34.4)</td>
<td>493 (19.6)</td>
<td>2510 (100)</td>
</tr>
<tr>
<td>1–9 y</td>
<td>1060 (53.4)</td>
<td>15 (0.8)</td>
<td>632 (31.8)</td>
<td>279 (14.1)</td>
<td>1986 (100)</td>
</tr>
<tr>
<td>10–19 y</td>
<td>1473 (53.3)</td>
<td>23 (0.8)</td>
<td>864 (31.3)</td>
<td>405 (14.7)</td>
<td>2765 (100)</td>
</tr>
<tr>
<td>20–39 y</td>
<td>7770 (44.9)</td>
<td>1135 (6.6)</td>
<td>7062 (40.8)</td>
<td>1348 (7.8)</td>
<td>17315 (100)</td>
</tr>
<tr>
<td>40–59 y</td>
<td>27141 (45.2)</td>
<td>5624 (9.4)</td>
<td>24459 (40.7)</td>
<td>2846 (4.7)</td>
<td>60070 (100)</td>
</tr>
<tr>
<td>60–79 y</td>
<td>87539 (42.7)</td>
<td>44640 (21.8)</td>
<td>66958 (32.7)</td>
<td>5803 (2.8)</td>
<td>204940 (100)</td>
</tr>
<tr>
<td>&gt;79 y</td>
<td>60227 (27.6)</td>
<td>108872 (49.9)</td>
<td>46379 (21.2)</td>
<td>2931 (1.3)</td>
<td>218409 (100)</td>
</tr>
<tr>
<td>Total</td>
<td>189882 (37.1)</td>
<td>160324 (31.3)</td>
<td>147403 (28.8)</td>
<td>14182 (2.8)</td>
<td>511791 (100)</td>
</tr>
</tbody>
</table>

Feudtner C et al *Pediatrics* 2006; 117:e932
DEATH BY ICU

- 1 in 5 Americans die in ICU
- 540,000 per year
- End-of-life care is often dictated by provider needs and perceptions rather than patients' wishes.
- This report explores the evidence suggesting that fully informed dying patients almost always reject dying in an ICU.

Learn more at OurHealthcareSucks.com
How do children die in PICU?

Duncan, CCM(A), 2001,
CPR

• “From the very beginning, it was not the intention of experts that CPR was to evolve as a routine at the time of death so as to include case of irreversible illness for which death was expected”
• There is no obligation to allow or perform futile CPR
• Even if the family demands it
• Potentially painful way to die

Weil, CCM, 2000, Luce, CCM 1995
Withholding and withdrawing

- It is justifiable to forego (withhold or withdraw) life-sustaining treatment when the burdens outweigh the benefits and continue treatment is not in the best interests of the child.
- Ethically, morally, and legally the same.
- **BUT**
- So much more difficult to withdraw than to withhold as it feels like you are actively terminating life even though you are not.
What is life sustaining treatment (LST)

- Mechanical Ventilation
- Vasoactive Infusions
- Renal Replacement Therapies
- Invasive Catheters
- Extracorporeal Membrane Oxygenation
- Antibiotics
- Intravenous Fluids
- Blood products
- Feeds
Mechanical Ventilation

- Most common LST withdrawn
- Pediatricians are more likely to withdraw mechanical ventilation than surgeons or anaesthetists
- Methods of withdraw include:
  - Terminal Extubation
  - Terminal Wean

Terminal Extubation

- Endotracheal tube is removed usually after administration of sedatives or analgesics
- Commonly used by pediatricians & physicians
- Advantages:
  - Does not prolong the dying process
  - Allows patient to be free of the endotracheal tube

Terminal Wean

- Oxygen and/or the ventilator rate are weaned over a variable amount of time
- Leads to progressive hypoxemia and hypercarbia
- Advantages:
  - No upper airway obstruction develops
  - Symptoms of air hunger do not develop
  - May be perceived as being less active than terminal extubation
  - May be perceived by families as an attempt to have the patient successfully survive separation from the ventilator

Pain and Symptom Management as LST is Withdrawn

- Sedatives and/or analgesics are frequently administered after withdrawal of LST
- Comatose patients are less likely to receive analgesics or sedatives
- Although much of pain perception happens sub-cortically (thalamus) therefore a comatose patient may not necessarily be a pain free patient
- Fear over hastening death /causing respiratory depression/killing the patient often leads to under-dosing after withdrawal

THE DOCTRINE OF DOUBLE EFFECT:

- The doctrine of double effect is a set of principles that was developed hundreds of years ago, primarily through Catholic theologians.
- However, it now has broader application throughout philosophy and is no longer regarded as a religious principle.
- Knowledge of it is critical for anyone working in end-of-life care.
- The doctrine of double effect is used to justify actions that have two (or “double”) effects, one good and one bad.

With acknowledgement
1. Act morally good or neutral
2. Good effect is intended
3. Bad effect is merely foreseen
4. Bad effect is not the means to the good effect
5. Proportionality: good effect must outweigh the bad

With acknowledgement International PPC Initiative
Clinicians’ Satisfaction with Pain Control During Withdrawal of LST

• In most cases, both nurses & physicians agree that the analgesics & sedatives given were sufficient to ensure patient comfort

• In 13% of the cases, nurses thought the amount of analgesia & sedation was inadequate

Parental Satisfaction with Pain Control at EOL

Adequacy of Pain Control

- 55% of parents reported that their child was comfortable in his or her final days
- 25% were neutral
- 20% disagreed

Fluids and feeds at the end of life

- Difficult, controversial topic
- Feeding by many parents and doctors alike is considered a basic human right
- Instinctively want to feed children
- Paediatricians surveyed:
  - 98% could deal with decisions not to resuscitate
  - 86% could deal with decisions to withdraw ventilation
  - Only 42% could face a decision to withdraw feeds/fluids
Feeds and fluids at the end of life?

- Is there a moral distinction between the withdrawal of an ET tube compared to an NG tube?
- Is not oxygen, ventilation as basic a right to life as food?
- We are probably “happier” to withdraw ventilation because the patient usually dies quickly whereas death is often slower in patients after withdrawing feeds (max 2 – 3 weeks)
How to we look at feeding at the end of life?

- Do we consider the withdrawal of artificially administered nutrition as starving the child to death?
- Could medically administered nutrition at the end of life be seen as force feeding/form of torture?
- Can feeding at the end of life prolong death/suffering?
- Do we see artificial nutrition at the end of life as any another medical intervention (like ventilation) that could be withdrawn or do we see it as a basic human right?
Feeding at the end of life

• BENEFITS OF NOT FEEDING:
  • Decreased metabolic rate
  • Decreased urea load
  • Decreased respiratory secretions: less cough
  • Less nausea and vomiting
  • Less diarrhoea
  • Fasting: releases endogenous endorphins which have an analgesic effect and actually increase pain threshold
Feeding at the end of life

- BENEFITS OF NOT FEEDING:
  - Ketosis decreases hunger
  - Acidosis and ketosis depress level of consciousness: decrease pain and other distressing symptoms
  - Most patients “slip away” quietly
  - Although electrolyte disturbances do occur these seldom cause fits in the child without CNS pathology, if fits can be treated (rectal valium)
In the olden days...

- Before nasogastric tubes and IV fluids...
- Part of the natural dying process was that oral intake decreased-led to dehydration and coma which have beneficial effects at the end of life
- Most dying people are NOT hungry
- “How God intended us to die?”
- Normal pathophysiology of the dying process
- Artificially administered fluids can actually be detrimental in the dying patient: prolong dying and increase likelihood of excessive secretions/pulmonary oedema: frightening death
After the child has died

- Support immediately after the event
- Mortuary care
- Bereavement support/closure
- Grieving is a gradual process passing through various phase
  - Early grief
    - Characterized by disbelief, confusion, and unreality
  - Subsequent phases
    - Overlap
    - Include periods of intense emotional release, physical and mental exhaustion, restructuring of personal identity and eventual beginning of life without the child
Factors Influencing Parental Grief

- The ability to cope with loss may be influenced by the parents’
  - Personality traits
  - Cognitive skills
  - Social supports
  - Religious beliefs
  - Physical health

Parental Grief & Coping after Death of a Child in the PICU

- Acute versus Chronic Disease
  - Parents whose child died acutely had greater intensity of early and long-term grief than those whose child died of chronic illness

- Quality of Care
  - The emotional attitudes of staff influenced the intensity of early and long-term grief
  - The adequacy of information provided to parents predicted long-term grief

- Parents’ Coping Ability
  - Parents’ physical coping resources (physical well being) predicted the intensity of early grief
  - Parents’ cognitive coping resources (self worth) predicted the intensity of long term grief

Spiritual Needs of Bereaved Parents of a Child in the PICU

- The most prominent parental spiritual need was maintaining connection with their child before, during, & after their death.
- Parents maintained connection during the child’s last hospitalization through death by physical presence.
- Parents maintained connection after death through memories, mementos, memorials, and altruistic acts.

So how can we help?

- **PALLIATIVE CARE INTEGRATION**

- The term “integration” is used to indicate the incorporation of palliative care principles into daily practice, with or without the involvement of a dedicated hospital palliative care team or inpatient palliative care unit.

- Even where there are palliative care teams they usually take on a consultative role supporting the primary team who have a relationship with the family.
Before the child gets to ICU

- Discussions with Interdisciplinary teams
- Advance care planning
- Assistance with defining goals of care
- Addressing distressing symptoms
- Improving quality of life
- Avoiding inappropriate interventions and resuscitation
In the ICU

- Assistance with management of pain and other distressing symptoms
- Extra pair of hands/ears
- Time
- External objective observer
- Facilitate discussions and ethics discussions
- Transitioning between ICU and back to wards
- Transitioning between hospital and hospice or home
- Compassionate extubation in the home
- Home care visits
What do families want?

- Family telephone interviews after 150 deaths revealed
  - 19% wanted more information
  - 30% complained about poor communication
  - Many had persistent sleep, work, emotional issues

- 1to2-Year Follow-up found
  - 46% report perceived conflict between family and medical staff
  - Need for better space for family discussions reported by 27%

Cuthbertson, CCM, 2000, Abbott, CCM, 2001
Staff debriefing

- How much debriefing did you receive during
  - Undergraduate training?
  - Postgraduate training?

- How much support do you have now?
  - Is this provided by the institution?
  - Do you pay for it elsewhere?
  - Do you use your family?
  - Does your faith community provide you with this?
Debrief Phases

- **Fact phase**
  - Ask participants to describe the event from their own perspective. What was their role in this event?

- **Thought phase**
  - What was your first thought at the scene (or when you heard about it)? When you came off autopilot what do you recall thinking?

- **Reaction phase**
  - What was the worst thing about the event? What do you recall feeling?

- **Symptom phase**
  - Describe probable cognitive, physical, and emotional behavioral responses —
    - at the scene
    - a few days afterward

- **Teaching phase**
  - Relay information regarding stress reactions and what can be done about them

- **Wrapup phase**
  - Reaffirm positive things
  - Summarize
  - Be available & accessible.
Best debrief...

- Informal chat over coffee or a meal
- Corridor consult
- Not all staff enjoy formal group discussions
- Mortality and morbidity meetings can be a useful platform
- “Physician heal thyself”
- Self care is important
- Consideration for protected time
That’s all folks!

THANK YOU FOR YOUR ATTENTION