“We didn’t do anything wrong, we tried our best, but they just died...we tried, we really tried.”

End-of-Life Decisions in the Paediatric Intensive Care Unit (PICU), Red Cross Children’s Hospital, Cape Town, South Africa.

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The PICU

- In January 2003 the unit had 22 beds, was staffed by a total of 85 nurses, 4 paediatric consultants and 8 registrars.

- The PICU treats between 1,200 and 1,400 patients per annum—approximately 10% will die in care.

- The majority of deaths are related to severe paediatric illness.

- The majority of deaths occur early in the PICU stay.

- Generally children were assumed to be well until their illness.

- "Sometimes children just die regardless of what we do. We have to deal with that. Sometimes children are ‘stuck’ on ventilators and we make decisions to remove ventilatory support, and sometimes we make decisions not to reinstitute life supporting therapy if a child were to deteriorate."

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Discourse Analysis

- 2003 - Participatory Action Research was used to gather data on Care-Giving practices from focus groups within disciplines, ethnographic observations and interviews (Vivian et al, 2009).

- The research showed that across all disciplines without being elicited, select words dominated the conversation:
  - die
  - death
  - decisions
  - end-of-life
  - resuscitation
  - CPR
  - ventilator

- Die and death were used 4-5 times more frequently, but in conjunction with stress, decisions, end-of-life, & resuscitation.
- Themes on supportive relationships & management procedures were integral to these.
- Responsibility was evident when doctors had to make a clinical decision but also in questions about who should take responsibility.
- Responsibility was sometimes associated with blame or guilt.
- This was suggestive of profound moral struggle.

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The consultant’s decision required intellectual acuity, biomedical proficiency and procedure in conjunction with ethical and legal thinking and moral reasoning. End-of-Life decisions were taken in consultation with specialist physicians, registrars and negotiated within the multi-disciplinary team and the child’s family.

“That’s one of the things that underlie the hierarchy. Because when push comes to shove, it’s actually the consultant who makes the decision. Everyone else has got a right to be part of that and participate in it. But when it comes to the signature on the piece of paper, it is actually the consultant who will carry the legal responsibility, all responsibility. And that has, at times, been a source of conflict as there has been one or two people who have said, ‘I don’t know why these doctors don’t do this or that,’ but they haven’t looked at the reality of what it feels like to be the person who, in the final analysis, will actually carry the can, pull the tube out, or who will potentially, in three years time, stand in court and say, ‘that’s why I did it.’ And every now and then you feel a bit sore about it.”
End-of-Life Decisions

• Decisions were made when there was no hope the child would recover, the child was brain dead, or that living would be unbearable to the child. These deaths required a decision to stop treatment and not to prolong suffering.

• “The problem is that some children are taken off ventilators because they are brain dead. In most cases that is pretty clear cut (we have evidence of devastating brain injury, we have evidence of no blood flow to the brain on radio-isotope tests etc). The really challenging problems relate to children who are normal from a brain perspective, but are stuck on a ventilator – then there is the dilemma that if they seem to have no (or little) chance of recovery then continuing ventilation is prolonging suffering, but with little chance of survival. That process is much more traumatic than the brain dead child. The other problem is the concern about whether we are being affected by resource constraints – and the truth is that we are (probably appropriately).”

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This discourse was important because it suggested that consultants took ownership for end-of-life decisions, yet were aware of negotiating, valuing, and evaluating their rationale not only from a biomedical and moral perspective but a social one.

“Decisions,” one consultant told us, “are made to or include...hoping they will die, this comes into end of life decisions. It does not influence action or make me feel bad. It does not seem to be a big issue to pick on. But it definitely does come into some decisions. What matters in terms of action is the withdrawing of life saving care and making sure the patient does not suffer by giving morphine to prevent suffocation and pain.”

The use of the word ‘hope’ is social in nature and linked to the consultant’s belief about what it is to be human and whether the child had an ability to engage in social relationships.
Social Negotiation

- The social negotiation of a child’s dying was a harrowing experience for all staff.

- Nurses were deeply affected because they had to care for the child during his or her dying process.

- One said, “What I do find is sometimes they still ‘resuss’ a patient, which is very sad, because you as a nurse or a sister dealing with a baby, you know you are dealing with a body that is ice cold. And basically, all you’re seeing on the monitor is keeping that patient alive, but there is nothing, no matter what you do.”

- End-of-life decisions for nurses were complicated by their not being fully informed about a decision because of shift changes or staff shortages.

- One nurse said, “When we are busy with our patient at five in the morning, and six... we didn’t know that the patient was informed (?)... and we did say, this one is not doing so well.”
The Distress of Death

- Mourning and loss were inherent because end-of-life decisions were incredibly intense and happened over hours.

- A major problem was that triage demanded that no sooner had a child died than staff had to move on to care for another. One consultant said, "even while one child is dying, there are other children who require attention. There is never time for anyone to process the meaning, the emotion and the implications of a death."

- Child deaths therefore impacted on the health of workers. Some accepted stress and distress saying it was part of their ‘job’. But, for many it was a burden. "You never deal with those things, but all of a sudden you become grumpy, and moody or whatever. And sometimes it gets you,” said one nurse.

- Distress was often related to an absence of supportive relations, ongoing resuscitation procedures and emotion, in particular anger.

- In relation to this staff spoke about conflict, guilt, coping mechanisms, trauma and "could I have done something.”
The Distress of Death

- Conflict and distress was reflected in one nurse saying, "And he (the consultant) might have come to a decision or getting close towards it, and then I take over. Now I don’t know if I…..and simply the fact that I haven’t been on that weekend, and not had experience with that patient, I might have a different angle."

- Stress and conflict also reflected the nature of death in South Africa and a lack of respect for health practitioners.

- “And, you can’t go out and share that (a child’s traumatic death) with someone in your family, or your colleague, because there is just no mutual level of understanding. And in a way, I think all that stuff is confined within us, and within the nurses. That is one thing we share. It’s quite an intense thing that we share; yet we have these divisions. And for me, this hierarchy thing, this difference ethically. I just can’t handle the disrespect that society shows to nurses. They are devalued, and must be amongst the most exploited group of people in existence - nurses in South Africa, and I think it applies to nurses in other third world countries as well.”

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• Deaths at times were so pervasive that if the word ‘death’ was highlighted and descriptions run together, the text would read as follows:

• “dead…the baby died… about three deaths on one day…numbers, because I can go through so many deaths in one day, but it’s where I’m at on that day, and the patient, and how much I can identify for whatever reason with the patient…you’re sitting there with a dead baby, and that is just awful…there were three deaths in two days…the consultant was in fact saying, ‘this is terrible. We’ve lost three kids. Let’s talk about it.’...Because you get to the point where we didn’t do anything wrong, we tried our best, but they just died. There was nothing you could do, and we tried, we really tried. And that was a first for me in a long time of working in ICU.”

• The number and nature of deaths raises a question about definitions for end-of-life decisions and whether it would be ethically more acceptable if these were more ‘societal’ and not biological (Bartlett & Youngner, 1988).

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