

Should we adopt a Groningen like Protocol in Australia?

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Introduction – outline

- Present a recent neonatal palliative care case to support the argument that there are some cases which would strongly benefit from a Groningen like protocol
- withholding hydration and nutrition and its special problem in the setting of neonatal palliative care
- Summarize some important aspects of the Groningen Protocol
- I am going to suggest that these cases can resist significant objections to such a protocol
- I will try to emphasize some of the benefits we could reasonably expect from a Groningen like protocol, based on the empirical evidence that is now available



Trigger
warning

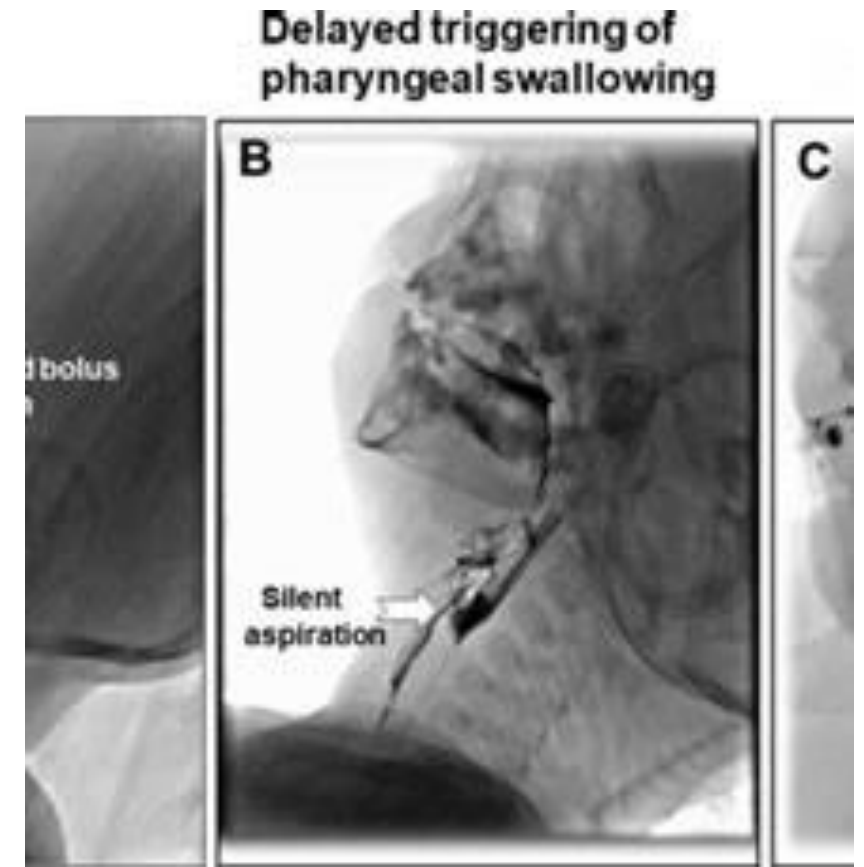
Neonatal Palliative Care Case

- Baby born at term after normal pregnancy, sustained severe hypoxic ischaemic encephalopathy (HIE) because of birth complications
- Maximal resuscitation at birth with state-of-the-art therapy methods
- Early onset of treatment refractory seizures and very poor long-term prognosis because of extensive hypoxic brain injury
- On day 10 of life decision for comfort care only, withdrawal of all life support measures & withdrawal artificial nutrition and hydration
- **Decision of withholding all (not just artificial) hydration and nutrition, except medication delivery**



Possible variable oral feeding capacities

- no swallowing/ sucking
- swallowing/coughing/sucking mechanisms impaired with risk of choking or aspirating (resulting in further distress or pathology)
- suck and swallow safely, but insufficient amounts (failure to thrive)
- feeding safely and sufficiently with ongoing biological survival (in setting of extremely poor quality of life prognosis)
- All of the above may fluctuate



Case progression



- Baby survived withdrawal of medical therapy - no other organ pathology & brainstem intact
- Swallowing ability was not established;
 - palliative care advice : not to feed at all irrespective of capacity to feed orally
- Baby was transferred to peripheral hospital unit closer to home on day 12
- Comfort care involved medication infusions to control symptoms:
 - Seizures, pain & distress (sedation/opioids), secretions
 - No monitoring, parents could have taken the baby out, but did not wish to
- baby died on day 34, after 24 days of no feeding

Suffering without feasible benefit

- Initial care was well established, and parents felt well supported and appreciated having some quality time with their child
- From about day 18 of life increasing parental distress because of the lengthy dying process
 - “can’t stand the sight, just wasting away”
 - “it is too cruel to literally be starving my baby to death”
 - “Prefer my baby in long sleeved onesies”
 - Wanting to do mouth care with watered down formula
- Signs of baby’s distress:
 - low respiratory rate, fluctuations in colour
 - Some nights agitated, seizures, moaning
 - From day 31 agonal breathing and cyanotic looking
 - Death on day 34



Salient points

- Death is certain once decision for no feeding is evident (hopelessness)
- Time to death may vary from 2-37 days, unpredictable (unbearable suffering)
- ‘no feeding’ as part of palliative care is legal, considered good practice at least in some cases
- The decision not to feed is in a significant sense separate from the decision for palliation



The Groningen Protocol

- Explicit Medical Aim: “allow parents and doctors to end the life of infants in cases where the infant is suffering unbearably with no hope for improvement, but is neither actively dying nor dependent on medical technology for life [...]
- Implicit Social Aim: avoid covert unregulated practices of bringing about death
- Implementation: “physicians may administer substances to the infant to rapidly and painlessly end the infant’s life when specific criteria are met”



Groningen Protocol Requirements

- Diagnosis must be certain
- Hopeless and unbearable suffering must be present
- Diagnosis, prognosis, and unbearable suffering must be confirmed by at least one other doctor
- Both parents must give informed consent
- Procedure must be performed in accordance with the accepted medical standard
- Plus procedural specifications for documentation and auditing



Objections to Groningen Protocol

- **Reservations about defining the ‘subjective concept’ of unbearable suffering**
- Reservations about predictability of future outcomes and certainty of diagnoses
- Inability to accommodate self-determination concerns in neonatal setting
- Violation of doctors (and parental) duties of care – do not harm
- **Varieties of slippery slope arguments**



Empirical information from Groningen protocol legacy

- Case numbers have gone down
 - Original prediction was 10-15 cases/year
 - Actual number: 2 cases in 5 years after Groningen protocol established (both for EB), none for congenital malformations
 - 1 case in 2017 for progressive neurodegenerative condition, parents requested access to Groningen protocol because deep sedation and cessation of nutrition and hydration was felt to constitute unbearable suffering
 - No cases were prosecuted (felt to be inappropriate by review)
- Neonatal palliative care services have increased and improved
- Neonatal palliative care techniques have become more transparent, unified and evidence based
 - E.g. neuromuscular blocking agents are no longer in use 'to mask' the appearance of suffering
 - Sedation is used more liberally, better patient centred care



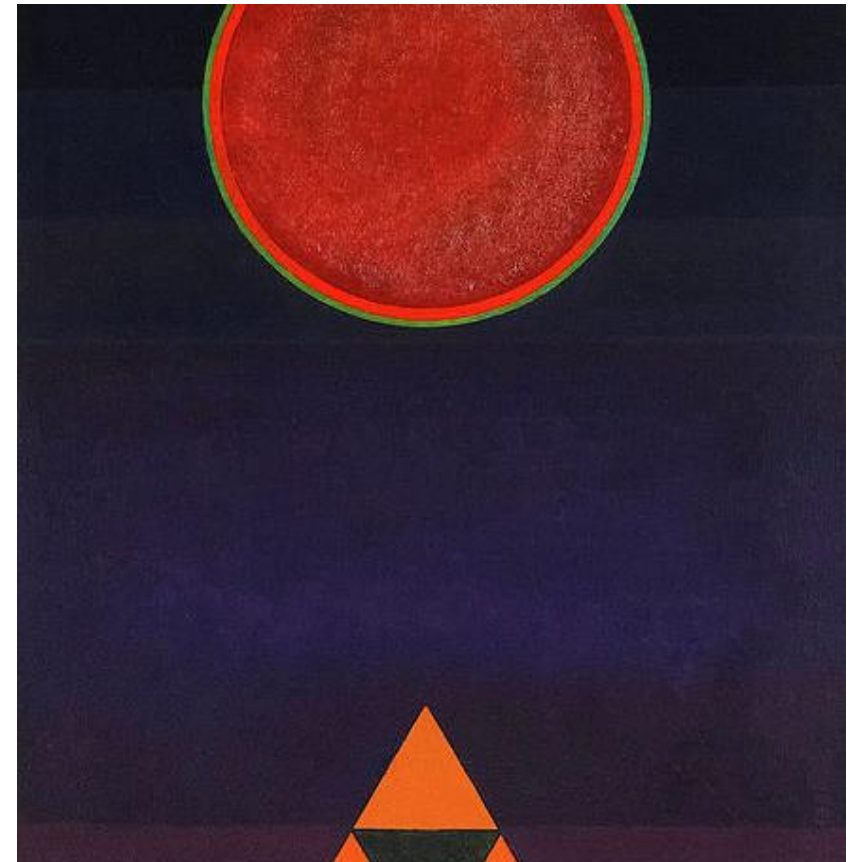
Benefits of the Groningen Protocol

- Transparency and regulated auditing processes
- No prior indemnification, indemnification only after procedural reporting to a strictly regulated review body (such as the coroner)
- Improvement of palliative care & support services
- Generation of relevant local knowledge and improved communication
- Parental empowerment in situations of severe distress
- Reduction of suffering
- Specific decision making by relevant stakeholders; targeted individualized care



Conclusion

- A Groningen like Protocol can be safe and culturally sensitive, because it relies of unanimity of decision-making process, considers the input of those who are in the best position to make the best decision for neonates & infants and has avenues to scrutinize those conditions
- It fosters transparency and is likely to counteract the practice of covert euthanasia
- It has been shown to promote good medical practice, enhance support services and increase medical knowledge
- It applies rarely, but in those rare can support beneficent practice and make a significant difference to very distressed families in tragic circumstances
- Slippery slope arguments are neither supported by empirical evidence nor rational deliberation



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