

Dissonance and consonance about death

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In their three thoughtful commentaries on my essay, Trisha Prentice, Dan Mahoney, and Bryanna Moore & John Lantos reflect on the challenges that I set out: can we make sense of the notion of a good death, and can we use art and music to provide any insights into it? [1-3]

I was thinking about these questions again while reading this week of yet another UK legal dispute relating to life sustaining treatment for a child. In January, the High Court heard the case of Pippa Knight, a five year old girl with profound brain injury who is in a persistent vegetative state, and has been ventilated in an intensive care unit for a protracted period [4] All of the experts giving evidence in the case agreed that Pippa lacks any ability to feel pain and that there is sadly no prospect of improvement. Her mother (and some of the experts) believed that, given the absence of pain, it would not be harmful and would be in Pippa's best interests to attempt to transition her to long-term ventilation at home. Pippa's treating doctors contended that it would be in her best interests to withdraw treatment and allow her to die.

At the heart of the ruling is a question that I addressed in my paper: is it objectively harmful to prolong the dying of a child?[5] Justice Poole rejected the idea that the absence of pain is the same as the absence of harm. He did not refer to the concept of a good death, or to the idea (described in my paper as the 'temporal element' to the value of a death) that it might be better for Pippa to die sooner rather than later. But it did seem to him to be wrong to prolong her life, even if she had no negative experiences. Poole J emphasised that "[b]oth her ongoing condition and her necessary treatments in the PICU constitute burdens upon her person notwithstanding her lack of conscious awareness", [para 76] concluding that treatment should discontinue for Pippa. (The case is currently being appealed)

One question raised in the Pippa Knight case, is how to make decisions in the face of dissonant views and voices. The court heard different professional views about how to weigh up the balance of benefits and burdens (though all of those looking after Pippa were of one voice in opposing continued treatment). Her mother believes strongly that it would benefit Pippa to be in her own home with her family around her.

As Prentice highlights, disharmony between those caring for a child can engender distressing long-term consequences for all involved – perhaps particularly the parents. It is a crucial part of paediatric palliative care to take into account the interests of the family. Mahoney suggests (and I agree), that "when I am confident that the child is not suffering, nor experiencing pain or distress... empathy expands my ethical latitude".[2] However, he goes on to suggest that giving parents time to make meaning does not and should not mean giving them a "blank cheque" to prolong dying in a "technologically supported void".[2] Mahoney's analogy of the blank cheque is particularly apt to the Knight case for two reasons. It is important to give parents discretion about these terrible decisions because they have such profound effects on the parents' lives. But allowing some prolonging of the dying process does not mean indefinite prolongation in a technologically dependent liminal state. Pippa has already been sustained in intensive care for more than two years. If there is a harm to her in prolonging her dying in this way – to do so over such a long period of time seems profoundly wrong. Moreover, (and perhaps even more importantly) prolonging intensive treatment for a child who lacks any ability to gain meaningful benefit comes at the

cost of other children also needing treatment.[6] No individual, whether they are doctor or judge or parent, can write a blank cheque for treatment to be provided within a publicly funded healthcare system. Some treatments cannot be provided, no matter how strongly they are desired.

Cases of protracted disagreement, like Pippa Knight's, are thankfully rare. But as challenging as they are, they provide some useful reminders about end of life care for children. While professionals seek to work together with parents to ensure a good death (or the "least bad" one)[1] for the child, it is not unusual or unexpected to find ourselves in different places or with different views. Perhaps (following the German philosopher and musicologist Theodor Adorno) "dissonance is the truth about harmony".[7]

Our struggle to find a common path reflects a normal and natural struggle against premature death as well as the different world views that we each bring to questions relating to mortality, meaning and loss. We should not see that struggle as a failing. On the contrary, careful patient attention to the disharmonies and dissonances that we find in our mutual response to the death of a child can help us, together, to find peace when the silence comes.

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