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**Title:** Autonomy versus futility? Barriers to good clinical practice in end-of-life care: a Queensland case.

Findings from a Queensland Coroner's case highlight the complex clinical, ethical and legal issues that arise when clinicians and family members disagree about a diagnosis of clinical futility. We identify the need to improve communication between doctors and families, as well as community and professional education to resolve tensions that can arise in these kinds of cases.

The Queensland Inquest into the death of June Woo<sup>1</sup> has highlighted the tensions between good clinical practice, the role of patient autonomy and substitute decision-making, and the legitimate constraints placed on the provision of futile treatment. In this discussion, we summarise the case and its legal implications and argue that improved communication between clinicians and families, as well as education of the community about the dying process are needed to attain an acceptable outcome when clinicians and families initially disagree about treatment.

### **Queensland Law and the Coroner's Findings**

The 2007 coronial inquest into the death of June Woo<sup>1</sup> provided the following case summary:

*“In the early evening of 14 November 2002, Mrs June Woo, an 82 year old woman with a history of pulmonary fibrosis and chronic respiratory failure, was admitted to the Princess Alexandra Hospital in Brisbane. She was assessed in the Emergency Department. Initially, she was minimally responsive. However, after an hour or so she become combative and was confused and distressed. She was sedated. At about midnight she was moved to a respiratory ward. At about 9.10pm the following night Mrs Woo stopped breathing. As a “not for resuscitation” order had been made the evening before, resuscitation was not attempted. One of the attending doctors later issued a cause of death certificate listing hyperkalaemia (higher than normal levels of potassium in the blood) as the principle (sic) cause of death. The family did not accept this and so, after some delay, the death was referred to the Brisbane Coroner for investigation”.*

#### *Findings about medical care: The NFR order*

The Coroner found that Mrs Woo’s medical care was appropriate and that further interventions would have been unlikely to extend the patient’s life. The areas of concern identified by the Coroner related to the process surrounding the making of the NFR order, including the extent and nature of the family’s involvement in this decision. In Queensland, consent to health care for adults who lack decision-making capacity is governed by the *Guardianship and Administration Act 2000* (Qld) (‘GAA’) and the *Powers of Attorney Act 1998* (Qld) (together, Queensland’s

‘guardianship legislation’). The guardianship legislation requires consent to carry out ‘health care’. Significantly and somewhat paradoxically, ‘health care’ is defined in the GAA (schedule 2, section 5) to include ‘withholding or withdrawal of a life-sustaining measure ... if the commencement or continuation of the measure ... would be inconsistent with good medical practice’. ‘Good medical practice’ is defined (schedule 2, section 5B, GAA) by reference to recognised medical and ethical standards of the medical profession in Australia. This means that consent is needed to withhold or withdraw a life-sustaining measure, even if providing that treatment would be inconsistent with good medical practice. If the patient does not have an advance health directive, consent to health care must generally be obtained from a substitute decision-maker on behalf of the patient (section 66 GAA). In this case, consent from one or both of the daughters was therefore required before a NFR order could be made.

In light of the requirement for consent to withhold treatment, the Coroner examined how Mrs Woo’s daughters were involved in the NFR decision. The evidence indicated that when the NFR order was made in the emergency department, the treating emergency physician ‘did not consider the decision was one the relatives could consent or object to’ as further intervention was medically futile. The patient chart recorded: ‘family are aware of prognosis, has been visited by a priest’. The Coroner found that what occurred in the emergency department did not constitute consent by the daughters, and indicated that had the patient arrested in the emergency department and the NFR been followed then ‘significant legal consequences may have followed’. Pursuant to the GAA (section 79), it is an offence to carry out health care (which includes the withholding of health care) without obtaining consent. The patient subsequently died in the respiratory ward, where cardio-pulmonary resuscitation was withheld as per the NFR order. The Coroner held that, by the time of the patient’s death, there had been sufficient discussions with the daughters about the NFR order to constitute ‘tacit consent’, making the NFR lawful.

#### *Recommendation about the hospital’s NFR policy*

The Coroner also reviewed the hospital’s NFR policy, and was critical that it did not require consent for a NFR order to be obtained from the appropriate decision-maker. He recommended the policy be reviewed to ensure compliance with the guardianship

legislation, suggesting that a form be developed to ensure relevant consents are obtained. As a response in part to the Coroner's criticism of the hospital NFR policy, Queensland Health has developed and piloted a state-wide Acute Resuscitation Plan (ARP) form<sup>3</sup> which is to be completed 'where it is reasonably expected that an adult patient ( $\geq 18$ ) may suffer an acute deterioration or critical event (e.g. cardiac or respiratory arrest) in the foreseeable future and require resuscitation planning'.

### **Implications for Clinical Practice**

The findings outlined create practical, professional and ethical challenges for medical staff who believe that resuscitation should not be provided in a particular case. From a clinical perspective, applying interventions such as CPR is inappropriate if no benefit will be achieved. Where doctors have consensus regarding futility of end-of-life care but disagree with family, it appears, perhaps as an unintended consequence, that the Act places clinicians in a difficult position of potentially having to choose between complying with the law and best medical practice. Legally compelling a doctor to seek consent *not* to commence a futile intervention may suggest that a choice exists when, in reality, death is inevitable. Murphy considers that seeking consent *not* to actively treat may create misunderstanding and place an unwarranted burden on a family in crisis, including making them feel complicit in ending the life of their relative.<sup>4</sup> Others argue that grieving persons, including those experiencing anticipatory grief, may use denial as a method of coping<sup>5,6</sup> which can significantly influence their ability to make decisions in the best interests of the dying patient.

For clinical staff, the requirement to provide resuscitation they regard as futile places physical demands and personal burdens recognised as contributory factors leading to emotional exhaustion and burnout.<sup>7,8</sup> In some circumstances, exhaustion and burnout can translate into poor staff retention, absenteeism, poor productivity and workplace conflict.<sup>9,10</sup>

While the law rightly preserves patient autonomy, it also has the potential to exacerbate the conditions for undignified and prolonged deaths. The refusal by a substitute decision-maker to accept the inevitable death of a loved one may result in a dying patient receiving harmful invasive treatment.

But in this complex debate there are also other important values and ethical perspectives to consider. The lack of consensus at times within the medical profession (and advanced specialties) on diagnosing clinical futility is particularly salient. Assessments of futility should also include appraisal of the quality of life to be pursued and, as such, are not the sole remit of clinicians. Conversations with family regarding the patient's quality of life are necessary to decide whether treatment is futile for that individual. The current Queensland regime would promote, indeed require, that engagement. While it should be noted that the Queensland legislation contains a mechanism to resolve intractable disagreement between clinicians and family members by requesting the Adult Guardian, a statutory officer, to consent to the withholding or refusal of treatment (section 43 GAA), clinical experience suggests there are real practical difficulties in obtaining such decisions regarding end-of-life care that may be required in the next few hours.

### **Conclusion**

The Coronial decision in Queensland highlights challenges that exist under the current guardianship legislation: it conflicts with the common law that it replaced and is poorly understood by clinicians.<sup>11</sup> In part because of this lack of familiarity, Queensland's regulation may also have broader implications for practices and policies regarding which patients can access certain types of treatment, such as intensive care. Because reasonable people can have different views on whether treatment is futile in any given situation, good communication and community and professional education are critical to resolving the tensions that arise when clinicians and family initially disagree. Families need to be supported in making difficult decisions to withhold or withdraw treatment, and health professionals need to understand the legal imperative to provide that support.

Competing interests: Dr Sean Lawrence was the treating physician in this case. No other competing interests are identified.

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