

***Adults lacking capacity:
Treatment refusal and
legal role of doctors***

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Context

- Decisions to withhold and withdraw life-sustaining medical treatment from adults who lack decision making-capacity.
- Such decisions are made frequently – although the extent to which they are being lawfully made is unknown.
- Cognitively impaired elderly patients are the largest group in the population for whom these type of decisions may need to be made¹.

1. Hamel, M.B., et al., *Patient age and decisions to withhold life-sustaining treatments from seriously ill, hospitalized adults. Annals of Internal Medicine, 1999. 130(2): p. 116-125*

Context (cont)

- **Consequences of these decisions**
 - Higher rates of withholding life-sustaining treatments reported for older patients in general.¹
 - In severely demented patients - A more aggressive approach to end-of-life care has been observed.^{2,3}
 - Older persons dying with advance dementia in nursing homes 8 times **less likely** to have a DNR order than those of similar age dying with terminal cancer.²
- **Role played by doctors**
 - Clinical
 - Legal

2. Mitchell, S.L., D.K. Kiely, and M.B. Hamel, *Dying with Advanced Dementia in the Nursing Home*. *Archives of Internal Medicine*, 2004. 164(3): p. 321-326.

3. Somogyi-Zalud, E., et al., *The use of life-sustaining treatments in hospitalized persons aged 80 and older*. *Journal of the American Geriatrics Society*, 2002. 50(5): p. 930-934.

Legal Role of Doctors⁴⁻⁶

- Does the patient have capacity to make a treatment decision?
- Is there a valid and applicable advance directive?
- If not, who has authority to make decision?
 - Tribunal appointed guardian?
 - Enduring guardian/attorney?
 - Default decision-maker?

Legal Role of Doctors(cont)⁴⁻⁶

- What principles should guide the decision-making?
- What is the effect of the medical context?

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4. White, B., et al., *The legal role of medical professionals in decisions to withhold or withdraw life-sustaining treatment: Part 1 (New South Wales)*. *Journal of Law and Medicine*, 2011. 18(3): p. 498.
 5. Willmott, L., et al., *The legal role of medical professionals in decisions to withhold or withdraw life-sustaining treatment: Part 2 (Queensland)*. *Journal of Law and Medicine*, 2011. 18(3): p. 523.
 6. Willmott, L., et al., *The Legal Role of Medical Professionals in Decisions to Withhold or Withdraw Life-sustaining Treatment: Part 3 (Victoria)*. *Journal of Law and Medicine*, 2011. 18 (in press).

Potential Implications of Getting the Law Wrong

- **Treatment may be given unlawfully**
 - If a valid advance directive refusing treatment is not followed.
 - If treatment is given without obtaining consent.
 - If the person with authority refuses consent to treatment, but person without authority consents to treatment.
- **Treatment may be unlawfully withheld**
 - If treatment is withheld without consent being obtained (where such consent is required).
 - If person without authority consents to the withdrawal of treatment.

Need for Empirical Research

- **ARC Linkage Project:**
 - “Withholding and withdrawing life-sustaining treatment from adults lacking capacity: Law and Practice”
- **Two central research questions:**
 - When life-sustaining treatment is withheld, are doctors complying with the law?
 - If not, how can compliance be enhanced?
- Research being carried out in Qld, NSW and Vic
- Funded for 2010, 2011 and 2012

Methodology

- Stage 1 – Legal research and analysis
- Stage 2 – Focus groups of medical professionals in Qld, NSW and Vic
 - Develop survey instrument
 - Pre-pilot survey instrument
 - Pilot survey instrument
- Stage 3 – Administration of the survey
- Stage 4 – Data entry and analysis
- Stage 5 – Findings and dissemination

Informing Survey Design

- A range of scenarios to test legal knowledge
- Explore the effect of knowledge of law on practice
- Explore whether doctors think it is important to know the law
 - If no, why not
 - If yes, why
- Explore interplay between law, ethics and clinical practice
- Explore the best way to impart legal knowledge

Survey Design

- Survey will consist of six sections (app 60 questions).
- Sections will examine the following areas:
 - Section A – Knowledge of the law
 - Section B – Application of law in clinical practice
 - Section C – Doctors' experience with the law in clinical setting
 - Section D – Doctors' perspectives on the law
 - Section E – Past and future education and training on the law
 - Section F – Demographic Information
- Specialties - those most likely to be directly involved with decisions to withhold and withdraw life sustaining treatment from adults who lack capacity.



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- Office of the Public Advocate (Qld)
- New South Wales Guardianship Tribunal
- New South Wales Trustee and Guardian (The Public Guardian)
- Victorian Civil and Administrative Tribunal
- Office of the Public Advocate (Vic)

**THANK YOU!
ANY QUESTIONS OR
COMMENT?**

For more information please go to:
www.ljrc.law.qut.edu.au/research/projects/endoflife/