
Right to refuse medical treatment:

Legal and Ethical Considerations in

End-of-life Care of Mentally Incompetent Patients

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Law and Ethics in health care

- Health care practice needs to comply with the law but what is legally permissible does not always directly determine ethical practice.
 - Ethical climate in a society interacts with legal rulings.
 - Over time, professional norm is formed based on prevailing legal rulings and ethical guidelines. It continues to evolve.
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Law and Ethics in the US

- “In case-based common law, applying accepted legal principles to decide a specific case is substantially identical process to applying ethical principles to decide a specific case.”
- “Law sides with patients to oppose the arbitrary use of power whether by physicians or the government; the rubric is patient rights. This is why American law, not philosophy or medicine, is primarily responsible for the agenda, development and current state of American bioethics.”

■ (G. J. Annas, *Standard of Care*, 1993)

Interests of the State

- The prime concern of the State is **respect for sanctity of life**.
 - In dealing with complex cases brought to the court for decision, a '**qualified sanctity of life**' is often adopted.
 - The Law recognises that the doctor's duty to employ life-prolonging measures in patient care is not an absolute one.
 - In the landmark ***Quinlan case (1975)*** the NJ Supreme Court ruled in favour of the father to withdraw mechanical ventilation (on the basis of previously expressed wish) established the right to refuse medical treatment even in a PVS patient.
 - Quinlan lived for another 10 years off respirator, in coma.
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Right to refuse medical treatment

- Right to refuse medical treatment by a mentally competent patient is the basis of modern Informed Consent.
 - Advance directives is a kind of **advance refusal** of specified life-sustaining treatments.
 - In mentally incompetent patients without advance directives, medical treatment decisions are often made based **on best interests principle**.
 - Legal guardian (healthcare proxy in the US), if appointed, gives consent to (and hence may refuse) medical treatments for the patient assessed to be mentally incapable of decision-making.
 - Disputes may arise when there is no consensus.
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Tube feeding: Ethical position influenced by judicial position

AMERICAN COLLEGE OF PHYSICIANS (ACP)

Position on tube feeding at the end of life (1989)

- “It is not unethical to discontinue or withhold fluids and nutritional support under certain circumstances. An emerging clinical and judicial position is that enteral and parenteral nutrition and hydration should be likened to other medical interventions and may be withheld or withdrawn according to general principles for decision making outlined above.” (ACP 1989: 333)

<http://www2.dickinson.edu/endoflife/EthicsACP.html>

The 1980's: New Jersey Supreme Court rulings on the *Peter* case and *Jobes* case

- *Peter* case: Hilda Peter was a 65 year-old nursing home patient in PVS on NG tube feeding. A durable power of attorney is held by a close friend who is also the appointed legal guardian in 1985. Ombudsman refused permission to withdraw treatment including tube feeding. The guardian appealed.
 - *Jobes* case: Nancy Jobes was in PVS state due to an auto accident in 1980. In 1986, her husband requested that tube feedings be ceased as this was not what she would have wanted. Nursing home refused, husband filed suit.
 - In both cases the NJ Supreme Court ruled that tube feeding could be removed in these cases.
 - Such cases and others constituted the legal background of the 1989 ACP statement of 'an emerging ethical and judicial position...'
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Court ruling can be problematic: the *Nancy Cruzan* case

- ***Cruzan*** case: In 1983, Nancy Beth Cruzan was involved in an auto accident which left her in a PVS state. She was sustained by feedings through an implanted gastronomy tube. In 1988 Cruzan's parents requested to terminate the life-support system, state hospital officials refused to do so without court approval. The Missouri Supreme Court ruled in favor of the state's policy over Cruzan's right to refuse treatment. The court maintained that life rather than quality of life was the prime consideration, and it did not find convincing evidence of Cruzan's prior wish.

(G. Smith: *Bioethics and the Law*)

Why the Missouri court ruling on *Cruzan* case led to public outcry

- The court treated the case as a ‘right-to-die’ dispute (rather than ‘right to refuse medical treatment’), and focused on the State’s interests in life.
- The issue was defined as “May a guardian order that all nutrition and hydration be withheld from an incompetent ward who is in a persistent vegetative state, who is neither dead...nor terminally ill?”
- It made a wrong distinction from the 1975 *Quinlan* case, referring to it as a ‘terminally ill case’
- The ruling was upheld by US Supreme Court but the basis of the ruling continued to be disputed.

(G. J. Annas: *Standard of Care*, Chapters 7 & 8)

Nancy Cruzan case: Part II

- ***Cruzan*** case 'Part II': In Aug 1990 Cruzan's parents filed a court petition for a new hearing as three of Nancy's friends came forward to assert that Nancy had expressed that she would never have wanted to live 'like a vegetable'. The Court acceded to the petition. Nancy Cruzan died two weeks later, on Dec 26, 1990.
- The issue was not 'right-to-die', but whether there was clear evidence of what the patient would have wanted.

(G. J. Annas: *Standard of Care*, p.109-110)

The 1990's – The Patient Self-Determination Act

- “Pushed to act by the public’s reaction to *Cruzan*, Congress and the President decreed ***the Patient Self-Determination Act***, that all hospitals, nursing homes, and HMOs that serve Medicare or Medicaid Patients must provide all their new adult patients with written information describing the patient’s right to make decisions about medical care, right to execute a living will or durable power of attorney.” (G. J. Annas: *Standard of Care*, p.109-110)
 - Patient rights stated in the *Act* include:
 - The right to facilitate their own health care decisions
 - The right to accept or refuse medical treatment
 - The right to make an advance health care directive
 - Facilities must inquire as to the whether the patient already has an advance health care directive, and make note of this in their medical records.
 - Facilities must provide education to their staff and affiliates about advance health care directives.
 - Health care providers are not allowed to discriminately admit or treat patients based on whether or not they have an advance health care directive.
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The US Tradition

- The US, two decades of court cases and public debates on withholding medical treatment were anchored on constitutional right to privacy, and on empowering family members or close friends to take up the health care proxy role.
 - After the Cruzan case, every state has passed durable power of attorney laws to cover health care proxy naming. Some states passed statutes to authorize specific family members to make decisions for their loved ones.
 - Even without statutory proxy, the Supreme Court has in some cases stated that family members are best qualified to make substituted judgments for incompetent patients.
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The UK Tradition

- UK: The traditional focus was on protecting incompetent patient's best interests. The role of doctors is more prominent. In the UK legal framework, there was no place for substituted judgment.
- **Mental Capacity Act 2005** has expanded the concept of 'best interests' to include finding out the patient's view as far as possible.
- It also widened the remit of the powers of attorney (PoA) to cover personal care and treatment (replaced 'Enduring PoA' with 'Lasting PoA')

(M. Stauch, K. Wheat. Text, Cases and Materials on Medical Law and Ethics 2012)

Mental Capacity Act 2005, Section 4

What the decision maker should do to determine "best interests":

- encourage the person to participate or improve their ability to take part in making the decision;
 - identify all the relevant circumstances;
 - find out the person's views;
 - avoid discrimination - not simply make assumptions about someone's best interests on the basis of their age, appearance, condition or behaviour;
 - assess whether the person might regain capacity;
 - if the decision concerns life-sustaining treatment the decision maker should not be motivated in any way by a desire to bring about the person's death;
 - consult others for their views about the person's best interests;
 - avoid restricting the person's rights by seeing if there are other options that may be less restrictive of the person's rights;
 - weigh up all of the above factors in order to determine best interests.
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Underlying the MCA 2005 position: The *Bland* case (1993)

- **Tony Bland** was in PVS for more than 3 years after an irreversible brain haemorrhage in the 1989 football stadium disaster. The Airedale NHS Trust, with his parents' approval, applied for court declaration to withhold further LSTs including artificial nutrition and hydration, and antibiotics. The State objected. The Appeal Court affirmed that ANH should be considered together with other medical treatments rather than purely as nourishment.
- Subsequent to the *Bland* decision, the Law Commission Report on Mental Incapacity recommended that the patient's past wishes should be treated as a relevant factor in determining his best interests.

(M. Stauch, K. Wheat. Text, Cases and Materials on Medical Law and Ethics 2012, p. 595-600.)

The role of the Court was strengthened by the Mental Capacity Act 2005

- Before the Act came into force, the Court could merely confirmed the lawfulness of decisions as to the medical treatment of incapable adults; with the Act the new Court of Protection has been invested with jurisdiction to make decisions.

(M. Stauch, K. Wheat. Text, Cases and Materials on Medical Law and Ethics 2012, p. 588.)

Guidelines in place in Hong Kong

- HA Guidelines on Resuscitation Decision (1996)
 - Medical Council: MCHK Code of Professional Conduct for the Guidance of Registered Medical Practitioners (Revised 2009) Section 34: Care for the terminally ill
 - HA Guidelines on Life-sustaining treatments in the Terminally ill (2002)
 - Guidance for HA Clinicians on Advance Directives in Adults (2010)
 - HA Guideline on Do-not-attempt-Cardiopulmonary Resuscitation (DNACPR) (2003, in draft)
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Hong Kong: Ethical positions underlying HA Guidelines

- Respect of autonomy and careful consideration of patient's best interests.
 - Consensus building with family as far as possible.
 - Competent adult patient: focus is on informed decision.
 - Incompetent patient:
 - Respect valid and applicable Advance Directives
 - Legal guardians if appointed
 - Advance care planning encouraged
 - Best interests principle – burden and benefits of treatment considered; patient's wish explored through family members
 - Durable power of attorney in HK does not cover health care decisions. The Law Reform Commission is consulting the public on this.
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In practice – what can be done besides general ‘better communication’?

Empirical data since late 1990’s point to the followings:

- **Observational studies:** ANH could be futile for terminally ill patients including advanced dementia. No evidence showed extension of life or improved quality of life. Considerable evidence indicated high risk of complications and burdens to patients.
- **Why ANH may be demanded by family:**
 - Family not accepting terminal prognosis
 - Belief in cruelty of dying process without ANH
 - Demand intervention to avoid guilt
- **Why ANH tends to be over-prescribed by doctors:**
 - Not familiar with palliative care
 - No time or avoidance of controversial discussions
 - Fear of litigation

H. Brody et al. 2011: Artificial Nutrition and Hydration: The Evolution of Ethics, Evidence and Policy. JGIM 26(9):1053-8.

In practice – Beyond ‘informing’ relatives

- Helping families understand patient’s dying process is an important physician end-of-life skill.
- Communication strategies should pay attention to families’ distinct emotional needs (similar to adapting strategies in communicating with competent patients).
- Acknowledge the need of family interests to discuss burden of care issues, even though these should not be not the core ethical and legal considerations.

G. Winzelberg et al. 2005: Beyond autonomy: Diversifying end-of-Life decision-making approaches to serve patients and families. JAGS 53:1046-50.

Take home messages

- Whether making reference to the US or UK, judicial positions give ample room for ethical decision making with regard to withholding/withdrawing life sustaining treatments in mentally incompetent patients.
- In Hong Kong, until advances directives (has legal framework) and health powers of attorney (not yet developed) are in use, care planning based on best interests principle (in the broad sense) and skillful communication with family members remain the cornerstone of ethical care.

G. Winzelberg et al. 2005: Beyond autonomy: Diversifying end-of-Life decision-making approaches to serve patients and families. JAGS 53:1046-50.

Thank you for your attention

