

Advance Care Planning



Multiple Perspectives on Medical Futility

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Perspectives on Medical Futility

- Difficulty in defining
- Historical
- Social and community issues
- Medical perspectives
- Ethical/Legal issues
- Palliative philosophy
- The future.....



Some cases to consider...

- 55 yr old married woman with progressive MND
- Totally paralysed below neck, increasing dysphagia – has PEG feeding
- Now develops end-stage renal failure
- She wishes to have ongoing haemodialysis.



Further cases...

Charlie Gard case: Why Donald Trump and the Pope are right !!

- **How can you tell if life is worth living?**

“If we had to consign Charlie to 10 years of life in his current state, we would agree with withdrawal of treatment.”

“In the face of such reasonable disagreement, we believe that we should accede to the wishes of the parents and err on the side of a chance of life. The alternative is certain death.”

“There is general agreement among all clinicians, most ethicists (including us) and the parents that Charlie Gard's life is currently not worth living. The key disagreement is about what chance is worth taking of crossing the line to have a life worth living.”



Historical Perspectives

- Hippocrates – “ To attempt futile treatment is to display an ignorance that is allied to madness”
- Plato – “ Asclepius did not attempt to prescribe a regime to make their life a prolonged misery”



Historical Perspectives

- Life and death viewed as natural cycles
- 17th Century – science began being viewed as a “power to be exerted against nature”
- Goal of prolonging life began
- Not until modern times that “states between health and death” became common
- Example “ Persistent vegetative state” term did not exist until 1972
- **Prolonging life therefore has ambiguous meanings and not supported by classical traditions of medicine**



Historical Perspectives

- Post WW2 – explosion of life sustaining technologies
- 1950-60's – IV fluids, TPN, ICU/Cardiac monitoring, C-P bypass, ECMO
- 1960-70's – dialysis – 1st bioethics committees
- 1980's – PEG feeding
- Quinlan, Schiavo and Cruzan cases
- 2000's – ICD's, Genetic/molecular targeted therapies
- All organ systems can be sustained except hepatic



Historical Perspectives

- Increasing challenges of advancing technologies with increasing medical costs
- Community expectations
- Utility and futility issues
- Doctor-patient relationship changes
- How does this relate to obligations to “heal” and “alleviate suffering”?

Sociological and Community Perspectives



- What are the sociological changes since WW2?
- Multicultural and global travel
- Feminism, decline nuclear family, individualism, secularism
- Death attitude changes
- “War on illness”, “fighting” symbolism
- What are current norms or attitudes??



Social changes

- Individualism, autonomy as dominant ethical imperative
- Rise of Narcissism...
- Loss of empathy ?
- Loss of community values/education with regard to dying
- Less value placed on humility, sadness, reflection, care and compassion – replaced by materialistic and scientific notions



Social Perspectives

- Anne Manne “ The Life of I”
- David Brooks “ The Road to Character”
- Celebration of Narcissism – “the new terror is to be invisible”
- “ You were made to excel. You were made to leave a mark on this generation”
- Our health professionals as well as our patients have become part of this social change – death avoidance and narcissistic traits !!

Medical Perspectives



- Futile treatment at EOL is an entrenched problem in Western healthcare
- What is driving this futile treatment?
- What do doctors think about when providing futile treatments at the EOL?....

“Reasons doctors prescribe futile treatment..”

Willmott L et al, J Med Ethics 2016;0:1-8



Doctor related factors

1. Trained to treat
2. Aversion to death
3. Inexperience
4. Don't want to give up hope
5. Legal worries
6. Poor communication
7. Emotional attachment
8. Personality/cultural/religious reasons

Patient-related reasons



1. Patient/family requests
2. Prognostic uncertainty
3. Lack of information about patient wishes



Hospital-related factors

1. Specialisation/ fragmentation
2. Designed for “acute care”
3. Hard to stop once started
4. Time pressures
5. Medical hierarchy
6. After-hours care



Futile treatment problems

- Initiation and prolonging of patient suffering
- Waste of scarce health care resources
- Moral distress to healthcare workers
- Damage to doctor-patient relationships
- Precedents are being set
- Society's belief in "miracles" ever-increasing



Medical Conclusions

- “ for the harm from futile treatment to decrease, requires the medical profession to better demonstrate its allegiance to scientific method... It also requires strong and courageous leadership”
- “ an important area of medicine has in large part been neglected- COMFORT CARE- alleviate suffering, enhance well being and support the dignity of the patient in the last few days of life”

Ethical/Legal Perspectives



- Ethical debates about defining “medical futility”
- Avoidance is akin to denying death
- “ For each of us some determination of futility by any other name will become a reality ... it is a mark of our mortality”
- How do we define it ethically or legally?



Definitions of Medical Futility

- “ clinical action serving no useful purpose in attaining a specified goal”
- “Unacceptable likelihood of achieving an *effect* that the patient has the capacity to appreciate as a *benefit*”
- Does it depend on patient goals? – autonomy ethics
- Is it to do with “prolonging life”?
- Quantitative and qualitative aspects
- Or is it about a virtuous society??



Quantitative Aspects

- Quantitative – difficulty of “never saying never” argument and absolute certainty impossible
- Is it $< 1\%$ or 5% or 10% ??
- The denominator – subjecting large numbers of patients to painful, burdensome treatment
- Violates ethical duty of care and proportionality
- Legal notion “beyond reasonable doubt”



Qualitative Aspects

- Patient needs to have capacity to appreciate benefit
- Goals of patient - shared decision-making
- Physician obligations
- Should not be just physiologic goals but rather quality of life goals
- Priority should also be on comfort, well being, dignity

“A particular treatment may be futile but palliative or comfort care is never futile.”

Legal Aspects (Willmott et al MJA 201(9) 3/11/2014)



- Supreme Court jurisprudence evidence from Case law in Australia
- Futile or overly burdensome medical treatment is not in patient “best interests”
- Although they consider patient and family wishes – generally defer to views of medical practitioners (preferably multiple)
- Quality of life relevant in “best interests”

Withholding/Withdrawing Life Sustaining Treatment (WWLST)



- Legally and ethically regarded as identical – but for patient/decision-maker often seen differently
- 40,000 deaths in Australia each year from decisions WWLST
- Legal responsibilities for medical team – laws regarding EOL, decision-making
- Studies suggest Palliative Care more knowledgeable and less concerned about legal issues
- Advanced Care Planning imperative

Palliative Care Skills and Philosophy



- Care of terminal illness – physical, social, psychological and spiritual rooms of care
- High level communication skills in context of advanced disease
- Acceptance of patient as unique in context of our humanity – dying normal part of life
- Expert opinion about care particularly in last 3 months of life – prognostication skills
- Ethical and legal teaching about EOL
- Support for “natural dying” and bereavement care

Palliative Care and Medical Futility



- The specialty should be one of the major opinions asked when speaking of “best interests” or “best practice”
- Earlier referral and discussions with palliative care leads to better decision-making , less aggressive EOL treatments and improved QOL and quality of dying
- Communication skills improve patient/family outcomes

SHOULD PALLIATIVE CARE BE THE LEADER
IN THESE DISCUSSIONS ??

The Future



- Rather than defining medical futility we should work towards greater community understanding of limits of medicine and mortality, but also the limitless possibilities of comfort, dignity and compassion at the end-of-life
- Education
- “Compassionate Communities”
- Greater engagement regarding new life-sustaining technologies
- Sociologic changes and political will required

The Nature of Suffering and the Goals of Medicine - Eric Cassell



“ The individual is whole only in a world of others.”

- Each individual has a particular moral experience or narrative which usually reflects upon relationships in their life.



References

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