

MEDICAL FUTILITY PALLIATIVE CARE IN ONCOLOGY 2016

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QUALITY VERSUS QUANTITY

- Modern day medicine has impacted on our community
- The expectation is:
 - Everything can be cured
 - Death can be delayed
 - Need to die with everything possible done
 - Die with drips in place

.....More emphasis on Quantity of life

THE MEDICAL LITERATURE

- Places more importance on
 - Survival
 - Less on quality of life
- Till recently few cancer studies looked at quality of life as an outcome measure
 - Survival
 - Response rate
 - Progression free survival

THE REQUEST FOR EVERYTHING.....

- What is this based on?
 - Intrinsic faith in the power in medicine
 - Born out of fear
 - Of the unknown
 - Of uncontrolled symptoms
 - Of dying
 - Of death
- No one has explored their understanding of the medical situation
- No one has discussed prognosis
- Hope
- What should our response be?

CONFLICT:

WHAT CAN AND CAN'T BE DONE

QUANTITY VERSUS QUALITY

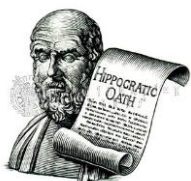


EVOLUTION IN THE CONCEPT OF CARE

- Not everything is curative
- Burden of symptoms are significant
- Relief of suffering is a big goal of medicine
- Palliative care is core business
- Physicians duty of care and responsibilities are articulated
- Patients and carers have information at their finger tips.....

“I WILL DEFINE WHAT I CONCEIVE MEDICINE TO BE. IN GENERAL TERMS, IT IS TO DO AWAY WITH THE SUFFERINGS OF THE SICK, TO LESSEN THE VIOLENCE OF THEIR DISEASE”

HIPPOCRATES. *THE ART*



MEDICINE

- Seen as a failure if death occurs
 - Is this right?
- Should all forms of treatment be offered to patients because we have them?
- Should the dying process be prolonged because we can medically?

TODAY.....

- Large numbers of patients still die distressed with high burden of symptoms
- Are inappropriately resuscitated
- Have futile interventions commenced or continued
- ‘Dying’ is still not diagnosed
 - Large complaints in hospitals about care during the ‘dying’ phase (53% UK in hospitals)
- 78% patients think the health professional’s job to discuss where they would like to be cared for and to die (*Lakhani BMJ 2011*)

A PERSON’S RIGHTS IN HEALTH

- Access to good care
- High standard of care
- Respect for the individual
- Cultural context
- To access information
- Involved in decision making including advanced care planning
- Pain relief and relief of suffering
- Right to access palliative care
- Right to know they are dying
- Right to a dignified death

PHYSICIAN’S RESPONSIBILITY

- Assess if a patient is medically competent / capacity to make that decision
- Has adequate information to consent or refuse
- Dispel inconsistent and irrational beliefs
- Address misinformation or irrational fear
- Educate the patient
- Ultimate responsibility is to the patient not the family
 - Palliative care goals?

PATIENT WITH CAPACITY TO...

- If they do.....
- Has the right to make health care decisions
- Has the right to refuse any and all medical interventions
- Constitutional right to refuse
 - ‘Abuse’
- Has the right to refuse palliative care / symptom control interventions

HOW DO WE PROVIDE BEST CARE FOR PATIENTS?

-and still know it is the right thing to do
- Autonomy
- Beneficence
- Non-maleficence
- Justice
- Medical restraint

PROFESSIONAL'S RIGHTS

- Moral and ethical code
 - Personal
 - Professional
- Safety for health professional
- Personal vs. professional time and commitment: balance
- Community expectations on a professional
 - Duty of care
 - Professional standards and conduct
- Right to refuse to provide treatments against own ethics and morals
 - Right to hand over care
- Does not have the right to refuse basic care

MEDICAL ETHICS

- MEDICAL FUTILITY
 - Treatment that will not produce the benefits sought by the patient
 - Therapy that results in temporary and fleeting benefits that do not improve conditions
 - Treatment which prolongs the dying process and offers no realistic chance of improvement

MEDICAL FUTILITY

- "Medical futility" refers to interventions that are unlikely to produce any significant benefit for the patient. Two kinds of medical futility are often distinguished:
- *quantitative futility*, where the likelihood that an intervention will benefit the patient is exceedingly poor, and
- *qualitative futility*, where the quality of benefit an intervention will produce is exceedingly poor.

ETHICS IN MEDICINE University of Washington School of Medicine

MEDICAL FUTILITY

- Quality of life
 - Never should be a value judgement about the worth of a person or their lifestyle
 - 'good' or 'bad' based on a patient's prognosis or medical outcome
 - Determined by the patient
- Good and basic medical care is never futile
- Assessment of the intervention
- There is a difference in treatment that prolongs life compared to treatment that prolongs the dying process
 - Eg: the ICU patient

MEDICAL FUTILITY

- Distinct difference between the stopping of futile treatment and euthanasia
- Principle of Double Effect
 - My personal experience: uncommon

NON ABANDONMENT

- Right to non abandonment
- Important ethical duty
- Feelings of failure: patient Vs clinician
- Lack of skills to care for the dying
- Lack the communication skills at EOL
- Families: Not know how else to care or 'what else to do'

NOT DOING ENOUGH OR DOING TOO MUCH: EQUALLY WRONG



WHAT DID WE LEARN FROM THIS CASE?

- Treat reversible conditions if they are
 - Relatively easy to treat
 - Minimally invasive compared to outcome effect
 - Do not cause unacceptable side effects
 - Do not prolong dying
 - Improve quality of life as much as quantity of life
- We have a duty of care to provide the above
- Cannot think of Hospice care as the
 - 'Soft option'
 - 'Do nothing'
 - Only provide 'comfort and hand holding'
- Practise good 'medicine'

HOW DO WE KNOW

- Based on good medical judgements and expertise
 - Evidenced based practice
- Principles of good medical ethics
 - Doing no harm
 - Medical futility
 - Patient centred care
 - Individualised
- Measured by patient's perceptions of quality of life

EVIDENCE BASED PRACTICE

- Increase in good clinical, quantitative and qualitative research in palliative care and end of life care (assessment, treatment and communication)
- Strong evidence in related fields: cancer, cardiac, renal, etc.
- Strong evidence for pharmacological treatments/symptom control (opioids, antidepressants, dyspnoea management, heart failure)
- Increasing evidence for advanced care planning and service delivery models
- We cannot ignore these changes in palliative care practice

DIAGNOSING DYING

- Prognostication
- Training in diagnosing 'active dying'
- Withdrawal of medically futile treatment
- Minimising observations and interventions
- Institution of appropriate end of life care
 - Medications, mouth and pressure care
- Discussion of end of life care with patient and family
- Documentation of DNR / NFR
- All elements of EOL care pathways but steps before.....

MEDICINE



LAW

MEDICINE VS LAW

- Duty of care: professional standards
- Judged by peers
- Not practice defensive medicine
- Ethical principle: Futility
- Not required to perform or offer any treatments that are considered futile or not in the best interest of the patient

THE LEGAL SYSTEM

- No consistent legal solutions to these difficult concerns at the end of life
 - Case examples: differing rulings (Cruzan, Shiuvo, USA, Northbridge Aus)
 - Precedents rather than clinical assistance
- Should not look to law for clinical answers
- In fact should see the use of courts as a failure of good communication, discussions and clinical consensus

LEGAL CONCEPTS

- Legal duty to uphold refusal of treatments
 - Right to be left alone
 - Right not to receive treatment or other intervention
 - Constitute battery or harm to continue or implement
- No legal duty to provide for patient requests
 - No right to have something that one requests
- There is also a moral difference between the two

Table 2. Attributes Rated as Important by More Than 70% of All Participants

Attributes	Participants Who Agreed That Attribute Is Very Important at End of Life, %			
	Patients (n = 248)	Diverse Family Members (n = 332)	Physicians (n = 361)	Other Care Providers (n = 429)
Be kept clean	92	93	92	92
Name a decision maker	98	98	98	99
Have a nurse with whom one feels comfortable	97	98	91	98
Know what to expect about one's physical condition	96	93	88	94
Have someone who will listen	95	96	99	99
Maintain one's dignity	95	98	99	99
Trust one's physician	94	97	99	97
Have financial affairs in order	94	94	91	90
Be free of pain	93	95	99	97
Maintain sense of humor	93	87	79	85
Say goodbye to important people	90	89	95	99
Be free of shortness of breath	90	87	93	87
Be free of anxiety	90	91	90	90
Have physician with whom one can discuss fears	90	91	94	93
Have physician who knows one as a whole person	88	92	92	95
Resolve unfinished business with family or friends	86	85	87	97
Have physical touch	86	94	90	97
Know that one's physician is comfortable talking about death and dying	86	85	93	97
Share time with close friends	85	91	91	96
Believe family is prepared for one's death	85	88	83	90
Feel prepared to die	84	81	79	87
Presence of family	81	95	95	98
Treatment preferences in writing	81	85	73	90
Not die alone	75	90	84	88
Remember personal accomplishments	74	80	78	91
Receive care from personal physician	73	77	82	82

Factors Considered Important at the End of Life by Patients, Family, Physicians, and Other Care Providers

JAMA. 2000;284(19):2476-2482.

SUMMARY

WHY THE NEED FOR WITHHOLDING AND WITHDRAWING TREATMENTS?

- To acknowledge, discuss and put into place patients choices, (goals and priorities) in health care
- To prevent further suffering from inappropriate treatments
- To remove the burden of futile treatments
- To commence appropriate end of life treatments
- To remove burdensome decisions in a crisis situation
- To improve quality of life
- To prevent prolonging the dying phase
- To maintain standards of practice and ethical conduct

