Nephrology – Ethical Challenges

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Overview

- What are Ethics ?
- How can they be applied in Nephrology ?
- Ethics and discussions around commencing dialysis or choosing a conservative pathway
- Raising the topic of Palliative/Supportive Care
- Advance Care Planning

- Ethics and discussions around withdrawing from dialysis
- Ethics and discussions around the process of dying
- Bereavement

What are Ethics in medicine ?

Guiding principles

Ways of thinking

Ways of relating to our patients

A set of rules ?

Reaching an exact solution ?

“Given the complex decisions facing seriously ill patients and their health providers, application of ethical principles frequently fails to reveal an unambiguous “right” course of action. Instead, shades of gray abound…

…Clinicians who require ethical purity or absolute coherence to a treatment plan are likely to be frustrated …often, it seems, the only certainty is that taking action in the real world involves the need to balance several applicable ethical principles.”

Byock I. *Am. J. of Hospice and Palliative Care*. July/Aug. 1994.

There are several “schools” of ethics

- Principilist “school”
- Virtue Ethics “school”
- Utilitarian “school”

MEDICAL ETHICS

Four fundamental principles

- Autonomy
- Beneficience
- Non-maleficence
- Justice

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- Autonomy –self determination
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MEDICAL ETHICS

Four fundamental principles

- Autonomy –self determination
- Beneficience – always do good
- Non-maleficence – do not harm
- Justice – fair access to health services

Virtue Ethics

What would a virtuous health professional do ?

Virtues of a health professional

- Compassion
- Trustworthiness
- Good judgement
- Integrity
- Being true to your professional conscience

Utilitarianism

Actions are right or wrong
according to the balance
of their good and bad consequences.

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Autonomy

Both ethics and the law respect the autonomy of a competent patient

Every competent patient has the ethical and legal right to :

accept or

refuse medical treatment.

Ethics and Informed Consent

A 51 year old woman.

- Ig A Nephropathy
- Hypertension.
- Worsening renal function

- Dialysis is discussed.
- In those discussions a full and clear explanation is made to her of what to expect with dialysis, the need for vascular access, the possible complications of dialysis and changes to her life.
- The Nephrologist and Pre-dialysis Nurse ask her to repeat back what she has been told to check she understands.
- Her family take part in these discussions.

A 79 y.o. man. Wife has died.

- Type II DM
- Hypertension
- ESKD secondary to ischaemic nephrosclerosis, DM
- eGFR 12.
- Told he will need dialysis.
- No other discussion.
- Vascular access arranged.

Ethically, what are the differences between these two approaches ?

Ethics and refusal of treatment

A 73 y.o. woman

- Type II DM
- Diabetic Nephropathy
- ESKD
- Dialysis recommended but she refuses.
- She is cognitively intact and not depressed.

Ethically, what is the right thing to do ?

What are the limits to Autonomy ?

A patient requests specific treatment -

Should a patient be given everything they request ?

No doctor is legally obliged to provide treatment to a patient where that treatment is illegal, unethical or excessively burdensome to the patient.

A family requests specific treatment -

Should a family be given everything they request ?

Nephrologist

“I think it is time to stop dialysis
but the family insist I keep giving with dialysis…
I will do what the family wants.”

No doctor is legally obliged to provide treatment to a patient where that treatment is illegal, unethical or excessively burdensome to the patient.

Another critique of autonomy is the cultural and religious dimensions of decision making.

The example of informed consent

The doctrine of Informed Consent is very much based on a western sense of the individual.

“Every human being of adult years and sound mind has a right to determine what shall be done with his own body; and a surgeon who performs an operation without his patient's consent commits an assault for which he is liable in damages. This is true except in cases of emergency...“

Justice Cardozo, 1914.

But what if the “I” has a profound sense of the “us” ?

“My sense of self is profoundly, principally and inextricably bound to a sense of my family, my people, my culture, my language, my land.”

The entire process of decision making is complex.

That complexity should never excuse health professionals in failing to embark on the process.

When it comes to informed consent
and all other discussions about future plans of care,
health professionals need to metaphorically meet
patients on their land.

“The principles of truth telling and autonomy are embedded in… Anglo-American ethics.

In contrast, in many parts of the world, the cultural norm is protection of the patient from the truth, decision-making by the family, and a tradition of familial piety, where it is dishonourable not to do as much as possible for parents.”

Brown E et al. *CJASN* 2016; 11: 1902-1908.

- Beneficence
- Non-malficience

Decision making around starting dialysis

A 81 year old woman

- Slightly more frail over the past year.
- IHD – AMI 4 years ago; occasional angina
- CCF
- ESKD - Ischaemic Nephrosclerosis
- eGFR - 14

You want to make a recommendation to the patient and her family that is medically and ethically good.

Weighing up

the benefits versus the burdens

to the patient of a specific treatment

Commence with the facts of a case

Bedside approach –

- Patient’s condition
- The aims of treatment
- Potential benefits
- Potential risks
- Patient’s wishes

After assembling the “facts” of a case
the principles of medical ethics
can guide towards a therapeutic option
that is both medically and ethically valid.

Bedside approach –

- **Patient's condition**
- **The aims of treatment**
- **Potential benefits**
- **Potential risks**
- Patient's wishes

A series of studies have shown that :

In patients over 75 years with Ischaemic Heart Disease there was no survival advantage with dialysis compared to those who did not commence dialysis.

Overall effect on the patient of dialysis

- Large change in routine
- Post dialysis fatigue and other symptoms.
- Travel to come to dialysis.
- Role of carers.

Bedside approach –

- Patient’s condition
- The aims of treatment
- Potential benefits
- Potential risks
- **Patient’s wishes**

“What do you think ?”

After assembling the “facts” of a case
the principles of medical ethics
can guide towards a therapeutic option
that is both medically and ethically valid.

“Some particular cases will inevitably provoke agonizing discussions, intricate deliberations and difficult decisions if, for no other reason than that persons, both in their bodies and their biographies are simply too complex to be reduced to principles.”

Oxford Textbook of Palliative Medicine.

An 83 year old woman

- Widow.
- Lives with her youngest daughter in Bangkok.
- Three children – one in Australia, two in Bangkok. Five grandchildren.
- Supportive neighbours.

Medical history

- Osteoarthritis both knees
- Osteoporosis
- Ex-smoker – gave up 20 years ago
- Hypertension for 15 years.
- Cholesterol levels difficult to control
- Mild PVD
- TIA 2 years ago.
- Angina over the past year – reluctant to have this investigated

Family Doctor notices her renal function

has been deteriorating for some time … Now eGFR 16

Refers her to a Nephrologist.

Possible responses by the Nephrologist :

- *Nephrologist A*
  - “You are heading for dialysis – you will feel much better then
  - I’ve see many old people on dialysis and they do really well
    - I know this because I see their blood results every month.”

- *Nephrologist B*
  - “We want to slow your kidney disease decline
    - Here’s an ACEI, antihypertensives, bicarbonate, phosphate binder
      - And by the way, don’t eat anything much…….”

Nephrologist C

- “I can’t cure you but we can make you feel better.
- We’ll have more consultations and keep discussing this.
- What is it out of life that you would like from here on?”

Nephrologist D thinks :

- “I hate these referrals, I never really know what to do
- I’ll go home feeling bad about this case no matter what I do.”

Two and a half months later :

eGFR = 12

- Patient is more fatigued, less interested in food, itchy, difficulty sleeping because her legs “keep moving at night and I have to get up to walk around the house…I fell over once – it scared me.”

- Patient returns to the Nephrologist.

- Patient is ambivalent about dialysis

- Her children have a divided view – 2 support dialysis “as soon as its needed”; one feels it would be “too much for her.”

- Four adult grandchildren say “Of course Grandma should start.” One says “I couldn’t bear to lose her…”

After discussions with patient and her children
the Nephrologist finally says to the patient :

“It’s up to you, if you would like to start dialysis we’ll start.”

Ethically, what you think of this statement ?

- Two children in favour of dialysis commencing for their mother persuade the third child to agree.
- They sit with their mother and discuss with her, and finally plead with her to start Dialysis.

- Patient agrees to commence dialysis.

What do you think about the above process and discussions ?

Elements of a valid informed consent

1. Capacity

2. Made voluntarily

3. With sufficient information

From the start of dialysis the patient struggles.

Issues of :

- Vascular access procedures
- Hypotension on dialysis
- Herpes Zoster (Shingles) at the three week point – very painful.
- Fatigued after dialysis
- Progressively worsening itch and restless legs at night.

- Dialysis nurses are becoming more aware of her struggle

At a clinical meeting, a senior Nephrology Nurse asks the Nephrologist :

“Mrs A is really struggling – do you think we should have started her on dialysis in the first place ?”

Nephrologist responds : “Well my personal view from the beginning was that she wasn’t a good candidate for dialysis… but, you see, I have an obligation to offer dialysis.”

- Senior Nurse : “An obligation ? Medical, ethical or legal ?”
- Nephrologist : “Oh, all three.”
- Senior Nurse : “So, when you say legal obligation do you mean…”
- Nephrologist : “Yes, being sued…I could see the writing on the wall from the family. They could ruin my career.”

Does the Nephrologist have an ethical obligation to offer dialysis ?

No doctor is ethically obliged to provide treatment to a patient where that treatment is illegal, unethical or excessively burdensome to the patient.

The principal ethical obligation of a doctor is to act in the best interests of the patient.

- *Does the Nephrologist have a legal obligation to offer dialysis ?*

- *Could the Nephrologist be sued if he don’t acquiesce to the patient’s and family’s wishes?*

No doctor is legally obliged to provide treatment to a patient where that treatment is illegal, unethical or excessively burdensome to the patient.

- Patient declines physically.
- Less mobile.
- Struggling coming in to dialysis.

What would you advise ?

- The patient’s grand-daughter announces her engagement.
- Her fiancé works in the oil industry in Alaska.
- They plan their wedding for 5 months time in Bangkok when both partners are free from their work commitments.

A day after receiving the Wedding Invitation

Mrs A has a further TIA.

- One morning, five months after commencing dialysis Mrs A bursts into tears with one of the Dialysis Nurses…

- “I don’t know how long I can keep going on like this…I have good days and bad days and I shouldn’t complain.”

- “But I have to keep going…The wedding is coming up and stopping would be suicide or euthanasia.”

Ethics and withdrawal of treatment

Ethically, is it reasonable to withdraw treatment ?

If so, in what circumstances ?

- *Is withdrawing from dialysis suicide ?*

- *Is withdrawing from dialysis euthanasia ?*

- Mrs A is increasingly distraught by dialysis and regrets her decision to have started.

- One of the daughters says to her mother :

"Mum, when you die is God's will, not ours. You can't stop. When you die is God's decision."

Role of culture and religion

End of life issues for different religions

Multi-part series

Lancet 2005; 366

Mrs A is due to see her Nephrologist…

- Mrs A is nervous prior to the meeting - says to her family that she “will do what everyone thinks is best.”

- Two of her children and one grandchild come to the meeting, tense.

Nephrologist congratulates Mrs A on her biochemistry

- Adjusts her BP medications
- Adjusts ESA dosing schedule
- No discussion about the future

What do think about this consultation ?

Dialysis continues

- After one dialysis session one of Mrs A's daughter asks to speak privately to her Dialysis Nurse. She asks :

- "If my mother were to stop dialysis how long would she have to live ? And what would she feel through that time ? To be honest that scares me. No one has told us about that."

- *How would you respond to Mrs A's daughter ?*
- *In terms of symptoms what is likely to occur and how could you manage them ?*

Dialysis continues …

- Two weeks later Mrs A presents with chest pain
  - extensive Acute Myocardial Infarction…
- Cardiogenic Shock – CCU ---Inotropes

- Mrs A semi-conscious.

  Family Conference

  Doctors inform family that Mrs A is seriously ill.

- Two of the daughters ask doctors that “Do all you can to keep her alive.”
- Nephrologists raise the issue of ceasing dialysis.
- In a separate meeting one hour later, the Cardiology Fellow says “We can still do more…don’t give up hope.”
- Family divided.
- Family confused by mixed messages from medical teams.

Two daughters insist on the dialysis continuing –

“you must keep going.”

A nephew arrives from Canada and says to the Nephrologist :

“If you stop dialysis that would be murder and we will sue you.”

Is withdrawal of treatment murder ?

Mrs A has a cardiac arrest.

One daughter says :

“Look, we haven’t said goodbye…at least keep her going until my daughter arrives from Fiji.”

What is your response ?

Patient dies

- Some family members express anger to the ward staff.
- Others are grateful for the care.

- Fiance of grand-daughter arrives from Alaska.
- At the funeral he meets the Canadian nephew.
- They agree that together they will approach a criminal lawyer after the funeral.

The end result of this case

- There was a major pressure placed on the patient to start dialysis.
- Was her consent to dialysis truly voluntary ?
- The patient suffered
- She would have likely lived longer and better without dialysis
- The family suffered

- The family is now fractured
- The family will remember a ‘bad’ death
- The nursing staff have been traumatised
- The nephrologist just hopes he/she isn’t sued and tries to forget the whole thing

How else might we have managed this case?

1. Be realistic with the patient and family up front
   - Use objective indices of likely survival
   - Be gentle, use repeated consultations

2. Guide the patient and the family in the decision

- Do not leave them with that burden

3. Find out what the patient wants for the remainder of her life.

Aim to achieve these things

4. Provide a positive and active alternative to dialysis

- If dialysis is not offered what shall be done ?

- The conservative, non-dialytic management of ESKD

The ethics of medical decision making

Without a clear medical recommendation by the Nephrologist the patient and family drift without direction…

There are clear ethical dimensions
to clinicians not making a recommendation,
especially where that silence or passivity,
results in a patient entering a labyrinth of suffering.

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Virtues of a health professional

- Compassion
- Trustworthiness
- Good judgement
- Integrity
- Being true to your professional conscience

Utilitarianism

Actions are right or wrong
according to the balance
of their good and bad consequences.

If the Nephrologist considers that it is time to consider ceasing dialysis then that should be stated clearly.

Conclusion

Ethics assist us in thinking through clinical issues.

Everyday we work ethically without necessarily using the word “Ethics.”

Clinician decision making

Informed Consent to treatment

Declining the initiation of treatment

Withdrawal from treatment

Advance Care Planning

The dying phase

Patient decision making

Informed Consent to treatment

Declining the initiation of treatment

Withdrawal from treatment

Advance Care Planning

The dying phase

Patient decision- making ⇄ **Clinician decision-making**

Informed Consent to treatment

Declining the initiation of treatment

Withdrawal from treatment

Advance Care Planning

The phase of dying

Decision making by patient ⇄ **Clinician decision-making in context**

Informed Consent to treatment

Declining the initiation of treatment

Withdrawal from treatment

Advance Care Planning

The phase of dying

The ethical synergy of Nephrology and Palliative Care

A close collaboration between the two disciplines

widens not only the choices that are possible for patients and clinicians

but makes those choices more medically and ethically coherent, more solidly based.

“Physicians should try to keep their eye on their main business, restoring and correcting what can be corrected and restored, always acknowledging that death will and must come…and that as embodied beings we are frail beings that must snap sooner or later, medicine or no medicine. To keep the strings in tune, not to stretch them out of shape attempting to make them last forever, is the doctor’s primary and proper goal.”

L. Kass, *JAMA,* 1980