PATIENTS WHO WITHDRAW FROM DIALYSIS

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Title: Patients who withdraw from dialysis in a Sydney centre with Palliative Care Support: Who, Why, and How do our patients die?

Retrospective chart review of St George Renal Unit patients on RRT who died in the calendar year 2010

Deaths due to withdrawal

- Significant proportion of deaths of patients on RRT are due to withdrawal from dialysis
- First described in 1986 (Neu and Kjellstrand)
- Multiple papers since then looking at characteristics of these patients
- 16-26% of all deaths of patients on RRT in the literature
- Average survival 8-10 days after ceasing RRT

Withdrawal – Australia

- 2010 ANZDATA report – 37% of all deaths of patients on RRT attributed to withdrawal (15% recorded as due to psychosocial issues, the rest due to access problems, CVA, malignancy and PVD)
- Withdrawal the most common cause of death in >75 year age group for both PD and HD

RPA guidelines (USA)

- Accepted that withdrawal reasonable in certain circumstances
  - patients with capacity who choose to cease
  - irreversible profound neurological impairment
  - patients without capacity with ACD/proxy indicating wish to cease in certain circumstances
- Advance care planning and shared decision making is recommended
  - patient/person responsible must understand consequences of stopping RRT
- Palliative care services/interventions should be offered

What is known

- Not much data from Australia (US/UK)
- factors suggested to be associated:
  - older age (>75)
  - cancer
  - poor QOL
  - white race
  - co-morbidity
  - dementia
  - functional impairment
  - longer duration of dialysis

What is known

- Literature suggests 50-80% of patients where RRT is withdrawn are incompetent at time of decision
- Definition of 'withdrawal' varies
  - any pt where RRT not given as scheduled
  - any pt surviving >3 days from hast HD
  - where death is due to uraemia and not other co-morbid condition
- High symptom burden towards end of life

What I wanted to know:

- How do our patients compare?
- How do we define withdrawal?
  - 'Elective' vs inevitable/appropriate
- What proportion of deaths?
- Who initiates the discussion/competence
- Precipitants
- Palliative Care involved?
- What happens afterwards?
  - Prognosis
  - Symptom burden

Methods

- Retrospective chart review of all adult patients on chronic RRT who died in 2010 calendar year
- Information collected:
  - demographics
  - dialysis modality
  - cause of ESKD
  - competence
  - co-morbidities (especially diabetes and dementia)

Methods

- For patients who had RRT ceased:
  - decision making
  - precipitants
  - symptom burden
  - involvement of the Palliative Care Team
  - medications used for symptoms
  - survival
  - place of death

Withdrawal?

- Studies define this in different ways
- My definition of 'elective withdrawal' (EW): **Death occurring after ceasing RRT with evidence of uraemia where no other medical condition was active and progressing to cause imminent death**
- Often a precipitant could be identified for withdrawal – but only counted as elective IF NOT IMMINENTLY CAUSING DEATH
- SO: These patients died of renal failure

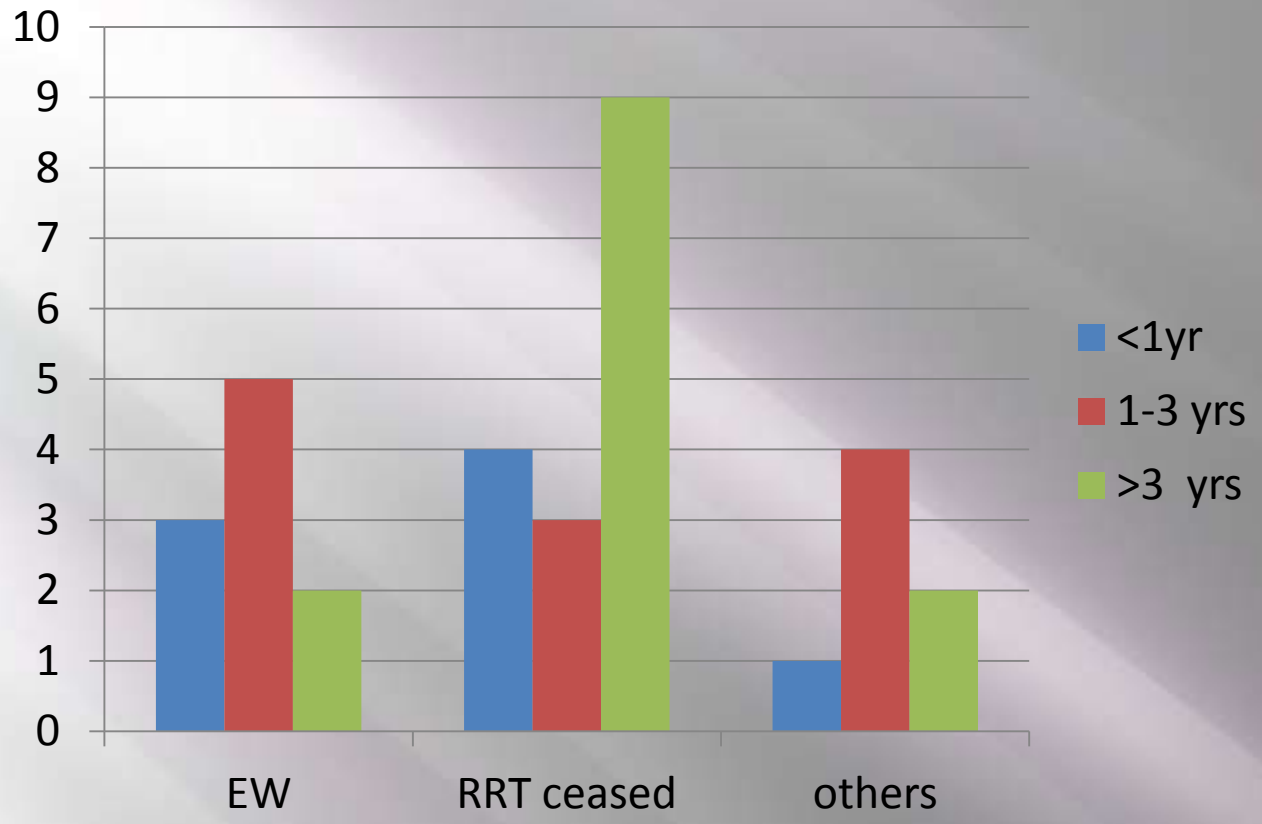
Results

- 283 patients on RRT in 2010
- 33 deaths
  - 10 deaths following elective withdrawal
- 16 where dying was diagnosed and thus RRT not given
  - all died within 4 days of ceasing HD and 6 days of ceasing PD
- 3 sudden out of hospital
- 4 in hospital seriously ill but RRT continued until death

Demographics

	EW group	Dying diagnosed	RRT continued	P value
Number	10	16	7	
Sex (male) (%)	80	67	43	0.21
Age at death	77 (11)	74 (11)	73 (8)	0.69
Time on RRT (years)	2.9(2.5)	5.2 (4.3)	4 (3.9)	0.34
Mode of RRT	70% HD	87% HD	71% HD	0.32
DM (%)	68	63	71	0.38
Mod CCS	8.6 (2.6)	8.9 (2)	9 (2.3)	0.94
Dementia (%)	40	6	0	**0.03**
Living alone	20	0	14	0.19
English speaker	55	56	50	0.38

Time on RRT



Results

- Dementia significantly higher in the EW group
- If compare EW group with all other patients together – living alone also significant
- Co-morbidity score not significantly different
- In EW group – 4/10 competent, 5/10 not competent, 1 not possible to discern from file
  - importance of documentation

Precipitants

- 8/10 EW patients had a precipitant
  - 3/10 cancer diagnosis
  - 2/10 CVA
  - 1/10 need for NH placement
  - 1/10 dementia with behavioural issues
  - 1/10 chronic infection
- 7/10 had documented quality of life issues (chronic pain/complications of co-morbid illness)
- None with documented depression

Decision making

- 3/4 competent patients raised ceasing RRT themselves
- 1/4 given as option by medical team and patient agreed
- in 4/5 non-competent patients, raised by medical team and family agreed, in 1/5 family raised it
  - difficult for families to suggest ceasing a life-sustaining treatment for a loved one
- 1/10 not possible to determine competence

Palliative Care

- In EW group, Palliative Care team involved with all 10, and in 6/10 prior to withdrawal of RRT
- In the group where dying was diagnosed, 14/16 patients had a Palliative Care consult
- Overall, 73% of all the patients who died had a Palliative Care consult prior to death (compared with 34% in a recent study by McAdoo and Brown looking at quality of EOL in patients with ESKD)

Survival and place of death

- Mean survival time in EW group was 34 days (6-104) overall (median 21)
- Patients is the group where dying was diagnosed all died within 4 days of ceasing HD and 6 days of ceasing PD (mean 3 days)
- in EW group, 2 died at home, 1 in a nursing home (their usual residence), 3 in acute hospital and 4 in a Palliative Care Unit
- Of the other 23 patients, 21 died in acute hospital and 2 unexpectedly at home

Symptoms

Symptom	At time of withdrawal	Last 24 hours
Pain	60%	20%
Nausea	10%	0
Dyspnoea/cough	40%	10%
Restless legs	10%	0
Fatigue	40%	Unable to assess
Insomnia	20%	Unable to assess
Pruritus	10%	0
Secretions	0	20%
Bowels	20%	10%
Anorexia	40%	Unable to assess
Confusion/agitation	40%	10%

Symptoms

- Common at time of ceasing RRT
- Most patients had multiple symptoms
- Pain most common
- Less common in last day of life
- Possibly due to reduced level of consciousness
- Also good symptom management?
- Consistent with other studies

End of life

- 7/10 patients in EW group had opioids prescribed (hydromorphone/fentanyl/methadone)
- Average opioid dose equivalent to 64mg po morphine/24 hours
- Other medications prescribed commonly at end of life
  - benzodiazepines
  - anticholinergics
  - neuroleptics

Limitations

- Small study – difficult to draw conclusions
- Retrospective – a lot of missing information
- Only one centre – practices likely to differ eslewhere
- Not much documentation about assessment of capacity and depression

Conclusions

- EW from dialysis is a common cause of death – similar in this population to that reported elsewhere
  - 30% of all deaths
  - 1 in 25 of patients on RRT
- Cognitive impairment more common in EW group
- Family less likely to raise withdrawal than medical team in incompetent patients

Conclusions

- Most patients had an identifiable precipitant that caused a change in quality of life/prognosis
- Length of time on RRT not a factor
- 50% of patients are not competent at the time the decision to withdraw is made
  - Importance of advance care planning
- High level of diagnosing death
- Frequent referral to the Palliative Care team

Conclusions

- Symptoms common around time of withdrawal and death
  - pain 60%
  - dyspnoea, confusion/agitation 40%
- Prognosis longer than reported elsewhere
  - 6-104 days (mean 34)
- Not different between HD/PD patients
- Longer survival in patients with residual urine output

Conclusions

- The majority of patients dying from an acute medical condition had RRT appropriately ceased in the terminal stage (16 out of 20)
- Of all deaths 73% were referred to PC – this is more than for cancer deaths!
- Likely to have had a better quality death as a result
  - no invasive procedures peri-death
  - symptoms assessed/managed
  - family aware

And finally…

- Longer prognosis than accepted - Why?
- Possible that dialysis practices have changed
- Improved management of fluid/electrolyte balance/other complications
- Care shared between Renal and Palliative Care teams
- Relationship between the teams
- Need prospective multi-centre data!