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
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
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- Literature suggests 50-80% of patients where RRT is withdrawn are incompetent at time of decision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
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

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

- EW
- RRT ceased
- Others

Duration:
- <1yr
- 1-3 yrs
- >3 yrs
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

<table>
<thead>
<tr>
<th>Symptom</th>
<th>At time of withdrawal</th>
<th>Last 24 hours</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pain</td>
<td>60%</td>
<td>20%</td>
</tr>
<tr>
<td>Nausea</td>
<td>10%</td>
<td>0</td>
</tr>
<tr>
<td>Dyspnoea/cough</td>
<td>40%</td>
<td>10%</td>
</tr>
<tr>
<td>Restless legs</td>
<td>10%</td>
<td>0</td>
</tr>
<tr>
<td>Fatigue</td>
<td>40%</td>
<td>Unable to assess</td>
</tr>
<tr>
<td>Insomnia</td>
<td>20%</td>
<td>Unable to assess</td>
</tr>
<tr>
<td>Pruritus</td>
<td>10%</td>
<td>0</td>
</tr>
<tr>
<td>Secretions</td>
<td>0</td>
<td>20%</td>
</tr>
<tr>
<td>Bowels</td>
<td>20%</td>
<td>10%</td>
</tr>
<tr>
<td>Anorexia</td>
<td>40%</td>
<td>Unable to assess</td>
</tr>
<tr>
<td>Confusion/agitation</td>
<td>40%</td>
<td>10%</td>
</tr>
</tbody>
</table>
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
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 elsewhere
- 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!