Terminal Care in CKD
Edwina Brown
A good quality death

• Characteristics of care during the last days of life, which are important from the patient’s perspective are:
  – receiving adequate pain and symptom management
  – avoiding inappropriate prolongation of dying
  – achieving a sense of control
  – relieving burden on loved ones
  – strengthening relationships with loved ones
Measuring the quality of end of life management in patients with advanced kidney disease: results from the pan-Thames renal audit group

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Palliative Aim by Centre (inpatients)
### Unexpected death and quality of dying (inpatients)

<table>
<thead>
<tr>
<th>Variable</th>
<th>Unexpected death</th>
<th>Expected death</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number of patients</td>
<td>34 patients</td>
<td>56 patients</td>
</tr>
<tr>
<td>Age at death</td>
<td>62 (42-84) years</td>
<td>72 (40-92) years</td>
</tr>
<tr>
<td>Length of admission prior to death</td>
<td>13 (0-76) days</td>
<td>23 (0-87) days</td>
</tr>
<tr>
<td>“Do not resuscitate” order in place</td>
<td>23%</td>
<td>91%</td>
</tr>
<tr>
<td>Dialysis discontinued prior to death</td>
<td>18%</td>
<td>58%</td>
</tr>
<tr>
<td>Management changed to palliative care</td>
<td>18%</td>
<td>67%</td>
</tr>
<tr>
<td>Liverpool Care Pathway used</td>
<td>13%</td>
<td>44%</td>
</tr>
<tr>
<td>Patient/Relatives told patient is dying</td>
<td>35%</td>
<td>89%</td>
</tr>
<tr>
<td>Good symptom control achieved</td>
<td>47%</td>
<td>58%</td>
</tr>
<tr>
<td>Relatives present at death</td>
<td>50%</td>
<td>63%</td>
</tr>
<tr>
<td>“Good quality death” as judged by person completing proforma</td>
<td>32%</td>
<td>56%</td>
</tr>
</tbody>
</table>
Hans Baldung: “Three Ages of Women and Death” (circa 1484-1545). Kunsthistorisches Museum, Vienna
What affects dying?

- Culture, religion, ethnicity
- Diagnosis of last few days
- Communication
- Patient
- Place of death; presence of loved ones
- Avoidance of unnecessary treatments
- Symptom control; avoidance
- Avoidance of unnecessary treatments
• Culture is important part of context within which people understand their world and make decisions about how to act.

• Failure to take culture seriously may lead to problems such as lack of trust, increased desire for futile aggressive care, unnecessary physical/emotional and spiritual suffering, lack of faith in physician, lack of adherence to treatment regime and dissatisfaction with care.

Cultural competence

- Distrust
- Autonomy
- Decision making and communication

- Truth telling
- Filial responsibility
- Religion/spirituality
Decision-making: cultural differences and the medical system

• Balance of autonomy and beneficence:
  – UK/USA:
    • emphasis on AUTONOMY
  – Europe/Asia:
    • emphasis on BENEFICENCE

• Primary locus of decision-making:
  – UK/Western Europe/USA:
    • more often the patient
  – Asia/Southern Europe and other cultures:
    • more often the family
Truth telling

• Informed consent major tenet in UK/USA health care, but truth telling re diagnosis/prognosis, like cancer, not norm in some cultures:
  – Italy, France, Eastern Europe, Asia, Central and South America, and Middle East, HCPs and patients - withholding medical information more humane, ethical (Kagawa Singer 2001)

• USA - in the early 1970s, physicians commonly withheld diagnosis of cancer (Oken 1971)
Cultural differences: survey of 800 patients (Murphy et al 1996)

Should a patient....

- Be told of a cancer dx?
- Decide about withdrawing LST?

African American
European American
Mexican American
Korean American
Filial responsibility

- Expectation that children will care for parents without question in gratitude for parent's caring and sacrifices.

- Hospice may dishonour parents - send message to family as well as to the community that family unable to provide adequate care.
Canadian data: HR (95% CI) for race as variable associated with dialysis withdrawal

<table>
<thead>
<tr>
<th>Race</th>
<th>All patients</th>
<th>Age &lt; 75 years</th>
<th>Age &gt; 75 years</th>
</tr>
</thead>
<tbody>
<tr>
<td>White (reference)</td>
<td>1.00</td>
<td>1.00</td>
<td>1.00</td>
</tr>
<tr>
<td>Black</td>
<td>0.31 (0.22-0.44)</td>
<td>0.29 (0.19-0.43)</td>
<td>0.37 (0.24-0.56)</td>
</tr>
<tr>
<td>Asian</td>
<td>0.38 (0.28-0.51)</td>
<td>0.42 (0.29-0.59)</td>
<td>0.36 (0.25-0.51)</td>
</tr>
<tr>
<td>Native Canadian</td>
<td>0.76 (0.59-0.99)</td>
<td>0.87 (0.63-1.20)</td>
<td>0.58 (0.35-0.97)</td>
</tr>
</tbody>
</table>

Ellwood, CJASN 2013
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- Communication
- Avoidance of unnecessary treatments
- Symptom control; avoidance
- Patient

Supportive Care Controversies Conference | December 6-8, 2013 | Mexico City, Mexico
Story of Liverpool Care Pathway

- Attempt in UK to provide “hospice care” for patients dying in hospital
- Paperwork provided pathway to guide inpatient team through communication, symptom control etc of dying process
- Often worked very well and supported by NICE
- BUT not always implemented as planned and became tick box culture
Daily Mail 13th Oct 2012

DID NHS KILL MY MOTHER TO FREE BED? THE PROFOUNDLY DISTURBING STORY BY SON OF PATIENT AT CONTROVERSIAL TERMINAL CARE HOME
Daily Mail 14th Oct 2012

CARE? NO THIS IS A PATHWAY TO KILLING THAT DOCTORS DEEM WORTHLESS
Snapshot Review of Complaints in End of Life Care

Key findings

There are few complaints made by bereaved relatives for patients who died in hospital (3 to 7 per cent of all complaints). Even fewer complaints have the Liverpool Care Pathway for the Dying Patient (LCP) as a contributing factor to the complaint.
Contributing factors to complaints: awareness and involvement
Contributing factors to complaints

- Staff not appearing to be caring / breaking bad news
- Not enough contact eg feeling abandoned
- Inconsistent messages from team providing care

LCP
Not LCP / unknown
Sue Ryder Care Centre for the Study of Supportive, Palliative and End of Life Care ... Understanding and improving palliative and end of life care

RAPID EVIDENCE REVIEW:

PATHWAYS FOCUSED ON THE DYING PHASE IN END OF LIFE CARE AND THEIR KEY COMPONENTS
What is known about predicting death in the next few days or hours?

- Very limited evidence on how to accurately diagnose imminent dying
- Organisational, personal and social factors as well as clinical ones often work against formal diagnosis of imminent dying, particularly in non-cancer patients
- Seems clear that whatever new evidence is produced, there will always be situations where it is not possible to be certain
What is known about communication in last few days and hours?

- Increasing participation in decision-making increases satisfaction but does not necessarily reduce distress.
- Professionals underestimate patients’ information needs.
- Doctors tend to focus on medical and technological rather than emotional and quality of life.
- Style and content affect patients’ ability to participate in decision-making.
- Good and bad communication experiences have lasting effect on bereaved relatives.
MORE CARE, LESS PATHWAY
A REVIEW OF THE LIVERPOOL CARE PATHWAY

July 2013
Diagnosis of dying

- No precise ways of telling accurately when patient is in last days of life
- Therefore placing patients on LCP can lead to considerable distress in relatives when patient does not die in days or hours
- Doctors and nurses must communicate more honestly about these clinical uncertainties
- More use of, and education and training about evidence-based prognostic tools are needed
- More research is needed into improving accuracy of these tools
Decision Making

- Review panel heard many instances of good and bad decision making
- Repeatedly heard stories of relatives or carers visiting a patient, only to discover that there had been dramatic change in treatment
- Unless unavoidable, decision to withdraw or not to start life-prolonging treatment should be taken in cool light of day by senior responsible clinician in consultation with healthcare team – should not be made in middle of night, weekends etc
Sedation and pain management

• Review heard that, if patient became agitated or in greater pain as they died, they often became peaceful because right drugs given at right dose
• Complaints that opiates and tranquilisers being used inappropriately as soon as LCP initiated
• Some of distress experienced could have been mitigated by better communication
• Before syringe driver commenced, this must be discussed as far as possible with patient’s relatives or carer and reasoning documented
Ethical issues

- Some people believe that implementing LCP is a way of deliberately hastening death.
- LCP entirely reflects ethical principles that should provide a basis for good quality care in the last days and hours of life.
- Any attempt to shorten life is illegal, but no obligation, moral or legal, to preserve life at all costs.
What affects dying?

Culture, religion, ethnicity

Place of death; presence of loved ones

Communication

Avoidance of unnecessary treatments

Diagnosis of last few days

Symptom control; avoidance

Patient
Edward Munch: Death in the Sickroom, 1893