Palliative care in non-malignant disease

End stage kidney disease (ESKD)
Lung disease
2017

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ESKD and palliative care

- Common and increasing problem
- Similar to other organ failures in that end-stage leads to death
- Also that many have co-morbidities (IHD, diabetes)
  - 2010 25% of those starting dialysis had diabetic nephropathy)
- Different in that life prolonging renal replacement therapy is widely available
- Definition – advanced = eGFR < 17mls/min

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Symptoms and ESKD

- Symptom *burden* is similar to advanced cancer
- MSAS – 17 (renal) vs 15 (cancer) – mean number of symptoms
- Qol (EQ-5D) – 60 (renal) vs 60 (cancer)
- Levels of psychological distress/performance status equal
- Regular symptom assessment is not routine in usual UK nephrology care services
  - Saini et al Pall Med 2006
  - Murtagh et al Adv Chronic Kidney Dis 2007
  - Murtagh et al JPall Med 2007

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symptoms

- Symptom *profile* different
  - Mean Hb lower in renal (11.1g/dL vs 13.3g/dl) – and symptoms such as fatigue and dizziness more common
  - Although some uraemic symptoms relieved by dialysis, symptom burden remains high in those undergoing dialysis
  - 65% restless legs in last month (12% quite or very distressing)
  - 61% muscle cramps; 61% joint/bone pain
  - 51% dry skin
- Symptom identification and amelioration is a high priority for patients and carers
- Some may be less easy to see and manage for non renal specialists.
  - use of a structured symptom assessment tool may be helpful
  - http://pos-pal.org/ for the POS-S renal

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symptoms

- Declining renal function has major implications for drug prescribing
- Renal physicians are good at this
- They will be trying to address both renal related and other symptoms
- Often long lasting clinician-patient relationship
- A joint approach with palliative care physicians and their teams is therefore optimum

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trajectory

- Often stable even in stage 5 CKD
- “tipping point” where possibility of re-stabilisation
- If not – then 1-2 months often precipitous decline.
- Recognition of this point is crucial in order to put necessary supports in place
- If withdrawal of long term renal support then unlikely to be any remaining renal function and death occurs 7 – 10 days
- This results in particular issues.

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Palliative care for who

- Those who opt for conservative management
  - Aim is slowing renal deterioration, maximising QoL, and involve patient in advance care planning
- Those who deteriorate although they started renal replacement therapy in reasonable health
  - Symptom control, support, difficult decisions/plans
- Those who deteriorate rapidly (eg severe poorly controlled diabetes) despite offer of RRT
  - Poor prognosis, symptom management carer support, plans

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Conservative or Renal Replacement Therapy (RRT)?

- Your turn
  - Whose choice?
  - How make decisions? – what factors influence the decision
  - How does this addressed in your local health service?

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Conservative or RRT

- Whose choice?
- How make decisions?
  - Quick (intuitive) or slow (reasoned)
  - Default (choose life, or able to choose death)
  - How is the service set up to allow choice
  - Significant burden of treatment
  - What factors feed into decision (burden of uraemic symptom, age, co-morbidities, rurality, ethnicity/religion, bridge to transplant?)

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Food for thought

- Retrospective cross-sectional cohort (N=441)
- 269 = RRT; 172 = CM; 19 in RRT group then changed mind for CM
- CM group older, lower albumin, worse performance status
- For the group as a whole, RRT gave a median 2.4 year survival advantage

Jamilla A Hussain, Andrew Mooney and Lynne Russon. Palliat Med October 2013 27: 829-839. First published on May 7, 2013 doi:10.1177/0269216313484380

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But...

- for those over 80 years, or a WHO PS of ≥3, there was no survival advantage with RRT
- RRT more likely
  - to be admitted to hospital
  - to die in hospital (69% vs 47%)
- RRT less support from community palliative care (0% vs 79%)

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Care of the dying or RRT

- A different decision
- Conservative vs RRT decision is usually made in the context of counselling/information clinics, with nurse specialist support
- Decision is choose life or not, but the survival may be reasonable
- How is this done when the burden of RRT is starting to outweigh benefits?
- Survival will be 7-10 days....

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Decision making

- Systematic review and qualitative synthesis: how and why different factors mediate the choices about dialysis treatment
- 12 studies; 206 predominantly haemodialysis patients and 64 healthcare professionals
- (i) *Commencing dialysis:*
  - patients based their choice on 'gut-instinct' as well as weighing-up the impact of treatment on quality-of-life and survival depending how individuals coped with decision-making.
  - Healthcare professionals weighed up biomedical factors and were led by an instinct to prolong life.
  - Both patients and healthcare professionals expressed feeling powerless.

Hussain J, Flemming K, Murtagh F, Johnson MJ. "The lesser of two evils"- decision-making in end stage kidney disease: a qualitative synthesis. Clinical Journal of the American Society of Nephrology 2015 May 5

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Decision making

- (ii) *Life on dialysis:*
  - Only after prolonged periods of time on dialysis were the realities of life on dialysis fully appreciated and past choice questioned,
  - by this stage patients were physically dependent on treatment.
- *(iii) Dialysis withdrawal*:
  - Individuals coped with facing treatment withdrawal in a problem or emotion-controlling way.
  - Families struggled to differentiate choosing versus allowing death.
  - Healthcare teams avoided and queried discussions regarding dialysis withdrawal.
  - Patients missed the dialogue they experienced during pre-dialysis education.

Hussain J, Flemming K, Murtagh F, Johnson MJ. "The lesser of two evils"- decision-making in end stage kidney disease: a qualitative synthesis. Clinical Journal of the American Society of Nephrology 2015 *May 5*

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Stop to review

- What new information have you learned?
- What information has been reinforced?
- What one thing from this session can you put into practice in your own setting?

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Advanced lung disease

- High mortality
- Highly symptomatic
- Variety of pathologies
  - Chronic obstructive pulmonary disease (COPD)
  - Interstitial pulmonary fibrosis
  - Pulmonary hypertension
  - Cystic fibrosis

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General points

- Diverse group of conditions with different trajectories
- Management primarily aimed at slowing progression of underlying disease, or even halting it for a time
- Again - uncertainty about prognosis can lead to poor communication in advanced disease, poor access to palliative care services, or even approach to care
- Again – issue of possibility of transplant gives dichotomy of care (palliation and end of life care vs active treatment and cure)
- Focus of research underlying disease (although good evidence base for pulmonary rehabilitation particularly in COPD)

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Stop for discussion

- In your own area
  - When do you think people with non-cancer lung disease need palliative care?
  - What do these patients need palliative care for?
  - What palliative care management do patients with non-cancer lung disease get?
  - What are the things that prevent access to palliative care?
  - What are the things which help access to palliative care?

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COPD

- COPD = 4th leading cause of death worldwide
- UK 25,000 die each year (population = 60 million)
- Many cared for and die in hospitals (respiratory cases of death is our biggest "in hospital" death)
- 75% experience breathlessness, and most do not have relief of breathlessness in last 6 months of life (Walke LM, et al. Arch Intern Med. 2007).

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Cancer and COPD –: Bausewein et al 2010

- 49 patients with cancer
- 69 with COPD
- Comparative symptom burden, distress and palliative care needs
- Median survival:
  - Cancer – 107 days
  - COPD – **589 days**

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Patients' experience of services – Gysels M et al JPSM 2010

- Delay in accessing medical help until severe
- Process to access specialist help often tortuous
- Diagnosis given as "good news" – you don't have lung cancer
- Poor information in rushed biomedical centred clinics

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Experience of clinics

- ".. I had prepared my questions to ask. But I didn't come to asking them, because there is no time. He has to run his clinic of course, that's why in the end he got up and didn't listen any more."
- " and then you sit there, and he asks "how're things?","OK" you say, " No, not OK. Why do you think we were there...sometimes I hardly get through the day!"

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Challenge for hospices

- "...so I asked him [director of hospice], " so how many patients have you got with COPD in your hospices at this present moment?"... "I don't think we've got any.....its very hard to estimate when we're needed". And so this is it, you see, its an excellent get-out clause."

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Life with COPD

- the need for better understanding of condition
- sustained symptom burden
  - breathlessness, fatigue, frailty, anxiety, social isolation, and loss of hope
- unrelenting psychological impact of living with COPD including the need to maintain meaning.

Disler RT et al. Experience of Advanced Chronic Obstructive Pulmonary Disease: Meta-synthesis of Qualitative Research JPSM 2014

Disler RT et al. Interventions to support a palliative care approach in patients with chronic obstructive pulmonary disease: an integrative review. International Journal of Nursing Studies 2012; 49(11); 1443-1458

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Interstitial lung disease

- ILD – group of diseases resulting in fibrosis (included idiopathic, asbestosis, autoimmune, sarcoid etc)
- Biggest group in UK is idiopathic pulmonary fibrosis
- Trajectory similar to lung cancer – relentless and progressive

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Idiopathic Pulmonary Fibrosis

- Main symptoms: breathlessness and cough
- Patients report poor information
- Significant spousal strain, and adverse impact on relationship
- Frustration and anger at the way the illness seriously affected independence and activities
- Very little access to palliative care services, and often too unwell for formal pulmonary rehab

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trajectory

- More clear in IPF, but still assessment and management of symptoms and need for palliative care services are not routine
- Like COPD, HF, renal disease – need for usual team to gain generic palliative care competencies
  - Symptom control
  - Communication skills
  - End of life support and planning
- Again – benefits of *integrated* working with palliative care team

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Some references

- Swigris JJ, Stewart AL, Gould MK, Wilson SR. Patients' perspectives on how idiopathic pulmonary fibrosis affects the quality of their lives. Health and quality of life outcomes. 2005;3:61. PubMed PMID: 16212668. Pubmed Central PMCID: 1276807.
- Bajwah S, Higginson IJ, Ross JR, Wells AU, Birring SS, Patel A, et al. Specialist palliative care is more than drugs: a retrospective study of ILD patients. Lung. 2012 Apr;190(2):215-20. PubMed PMID: 22218887. Epub 2012/01/06. eng.
- Bajwah, S; Higginson, I; Ross, J; Wells, A. U.; Riley, J; Koffman, J. The palliative care needs for fibrotic interstitial lung disease : a qualitative study of patients, informal caregivers and health professionals. / In: Palliative Medicine, Vol. 27, No. 9, 10.2013, p. 869-876.

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Cystic fibrosis

- 84% had pain, 83% cough and 64% breathlessness
- Qualitative interviews with caregivers
  - lack of information
  - challenge of maintain hope whilst planning for death
  - caregivers' helplessness re symptom control
  - caregivers worried about use of opioids and their potential for hastening death

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Additional evidence for COPD and ILD

- In COPD, use of bi-level NIV in COPD at the end of life is controversial with regard to managing distressing symptoms.
- As NIV is a significant barrier to communication, goals of care need to be established with a clear management plan.
- In ILD, the evidence base for symptom management is poor. A systematic review shows:
  - strong evidence for pulmonary rehabilitation and pirfenidone to improve functional outcomes
  - moderate evidence for both sildenafil and pulmonary rehabilitation in improving QoL
  - Bajwah S et al. Thorax 2013; 68: 867-879

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Working together

- Remember – respiratory teams have known their patients a long time
- Access to specialist respiratory skills is required throughout, although the balance may change as death approached
- Multidisciplinary team meetings – attendance, specific to palliative care?
- Joint ward round, clinic, assessment – at least initially
- Joint teaching, joint training
- Offer placements for trainees in other specialties

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How to provide....?

- comprehensive supportive care
- optimise treatment of underlying disease,
- pulmonary rehabilitation,
- occupational therapy, psychosocial supports, nutritional support,
- consider specific palliative pharmacotherapy (opioids, benzodiazepines and potentially oxygen).

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Time to review

- What are the similarities in people with non-cancer lung disease, and those with cancer?
- What are the differences?
- What new knowledge have you gained from this session?
- What have you learned which you plan to use to change practice in your area?

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Time to review

- What/who are the barriers to providing palliative care for people with non-cancer lung disease in your area?
- What/who are the facilitators?
- What can you do to move the situation forward in your area?

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