Advance care planning: the foundation of a new model of palliative care for the 21st century?

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The historical contingency of death


The concentration of death in old age

Unmet needs for palliative care in England

Palliative Care Funding Review, 2011, see: http://palliativecarefunding.org.uk
This talk

- Frailty, mortality and palliative care needs: the new challenge
- Lost in transition: recent findings from studies of older people
- How can ACP help?
- Original goals
- Conceptual issues
- ACP as part of a whole systems approach
- Starting the conversation
- Encouraging attitudinal change
- A new model of palliative care: 'preventive and proactive palliative care’ with ACP as the anchor

The 20th century model of palliative care

- Relies on moments of ‘truth’ about prognosis
- Relies on ‘diagnosing dying’
- Relies on a typical cancer type trajectory that no longer exists for many ¹

This means 4 key problems

- Palliative care remains separate from the mainstream and delivered close to the end of life
- Too much emphasis on ‘diagnosing dying’ as a key to palliative care transition means a disease focus
- Concerns about palliative care as a scare resource leads to risk of over specialisation (nursing and medicine) instead of partnership working
- Emphasis on choice should be replaced by emphasis on negotiation ²

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Frailty, disability and comorbidity

- 7% of 4317 were frail; 30% of over 80s
- Majority (2762) had co-morbidity, and/ or disability / frailty
- Frailty prevalence similar to English results: see, Syddal et al Age and Ageing, 2010, 39, (2), 197-203


Trajectories of disability in the last year of life

383 community dwelling older decedents (Gill et al, NEJM 2010;362:1173-1180)

Lost in transition: studies of older patients with palliative care needs (1)

- A 2010 census of hospital patients in Lancaster and Sheffield shows that a third of patients have palliative care needs (according to GSF criteria)
- Higher than previous research has suggested: other surveys have suggested 9.4%, 13% and 23% of inpatients as having palliative care needs
- Patients with palliative care needs are overwhelmingly frail, older people, with multiple co-morbidities and multiple previous admissions to hospital


Lost in transition: studies of older patients with palliative care needs (2)

- 30 older adults with lung cancer, stroke or heart failure: 67 moves in the 3 months before interview \(^1\)
- Important care decisions transferred at the same time as patients
- Crisis care, rather than anticipatory care the norm


\(^1\) Hanratty et al
How could ACP help?

Advance care planning: original goals

- Ensuring that clinical care is in keeping with a patient’s preferences when the patient has become incapable of decision making;
- Improving the health care decision making process by facilitating shared decision making;
- Improving patients’ well being by reducing the frequency of either under or over treatment


Understanding ACP

English model

Possible outcomes of ACP

- The setting out of general values/ preferences/ views : non legally binding
- An ‘instructional’ directive (or ‘living will’): advance refusals can have legal force
- The nomination of a ‘proxy’ or ‘attorney’


Words of caution…

- Mere information about choices/ preferences does not change clinical practice
- Communication/ availability of ACP records imperfect
- Undue emphasis on directives not helpful: either too vague or too narrow
- Not all patients wish to exert antecedent control or predict future
- Complex interventions (attitudes; communication; systems support) can reduce hospital stays and promote use of palliative care options

Wide recognition and adoption of ACP as one aspect of policy

One example of a ‘whole systems’ approach

‘Respecting your choices’

- To help people understand what options and decisions might be faced, when they are ill and lack capacity
- To help people reflect on those, make decisions and communicate / record these
- To enable systems to track and make use of ACP documents
- To make sure retrieval from the medical record was possible.
- To influence care so that ACP records are considered in decision making.

Romer AL, Hammes BJ. J Palliat Med 2004; 7:335-40

Mixed methods evidence from RCT involving hospitalised patients aged 80+

- Coordinated/ facilitated advance care planning improves end of life care
- Advance care planning reduces the incidence of anxiety, depression, and post-traumatic stress in surviving relatives
- Advance care planning improves patient and family satisfaction with hospital care

Detering et al. The impact of advance care planning on end of life care in elderly patients: randomised controlled trial. BMJ 2010;340:c1345
doi:10.1136/bmj.c1345
Initiation of ACP discussions

- Clinicians fear raising ACP (time/risk)
- Clinicians and patients wait for each; missed opportunities
- Evidence that a matter of fact ‘step wise’ discussion works

Intervener: Has anybody had discussions about the future with you?
Patient: No … Even the Macmillan nurse hasn’t really … which I thought she would be the one … it’s strange. I expected more on that side in the early days. Because it’s not happened, I suppose I stop thinking about it.

Almack et al, BMC Palliative Care, 2012

One useful way of thinking about aims of ACP

- Assess person’s understanding of illness
- Determine how the person expects to make decisions
- Determine their expectations regarding outcomes of end-of-life care
- Determine the values underlying any care/end-of-life preferences


Qualitative evidence about the process of ACP

ACP may improve quality of life by contributing to:
- Mutual understanding
- Enhancing openness
- Enabling discussion of concerns
- Enhancing hope
- Relieving fears about the ‘burden’ of decision making
- Strengthening family ties


One approach used in Australia

- A- Appoint an agent (Discussion about family; friends etc)
- C- Chat and communicate (what do you value; future situations which you would find unacceptable; who you want involved in your care etc)
- P- Put it on paper (Discussion about options and how information might be used)

“What would happen if you became ill (again) and could not talk to your doctor about your treatment/ let us know what’s important to you?”

“What will make decisions for you?

Public education and culture change
A volunteer training programme about advance care planning
• To develop a ‘peer education’ programme for advance end of life care planning (3 days)
• To evaluate acceptability/ feasibility
• To follow up volunteers: impact/ activities over 18 months
• To revise programme and make available, see: http://www.endoflifecareforadults.nhs.uk/education-and-training/acp-for-volunteers

Immediate plans among 32 volunteers
• Working with a community group
  I plan to meet as part of a group to discuss the way forward
  I hope to use what I have learnt and go forward with (community group)
  I would like to participate within groups in my local area
• Finding a way forward
  I would like to go away and re-read the information, think about the subject and look at how I can pass on information
  I wish to find a way of working that matches my strengths and (more importantly) is judged reasonably effective
• Using it with family and friends
  I hope to use it in my personal life, put it to family and friends
  I will talk about the process of my dying with my family

Two case studies
• Older LGB group
  -began with their local support group, their friends and relatives
  -extended to regional activities
  -won funding to continue
  -gained support from national and local agencies
  -now continuing to work locally and nationally
• Seniors forum
  -reported success in engaging at local level, because of direction of national policy
  -then began to network nationally
  -self sustaining across a number of years
**Personal/ emotional implications: at one year**

"It is obviously a very delicate area and it gave me compassion ... a re-education as far as I was concerned because in my working life I was the person giving orders ... so it did educate me on getting down the people's level; I'm not up here talking down to them if anything I'm down here talking up to them and the training taught me to be more sympathetic with more compassion and I am very thankful for that" (Male Older volunteer, 12 months after the Programme).

**Elements of a new model of palliative care**

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Jerant et al, 2004