Exploring GP Attitudes to Advance Care Planning with Frail & Elderly individuals

Dr Tim Sharp
GP and former Academic Clinical Fellow
Primary Care Unit
University of Cambridge
If he was given the choice would he have chosen to be admitted?
LSE Report\textsuperscript{1}

- 100,000/yr who would benefit, not getting EoL care
- “Oldest old” likely to miss out
- Most palliative care goes to cancer patients even though accounts for less than a third of deaths
- Only a fifth of referrals for non-cancer diagnoses

\textsuperscript{1}Dixon J, King D, Matosevic T, Clark M, Knapp M (2015)
\textit{Equity in the Provision of Palliative Care in the UK: Review of Evidence}
PSSRU Discussion Paper 2894, London School of Economics
Gold Standards Framework

- Over 90% of UK GP practices have a register of patients approaching end of life
- Only 27% of patients who died were included in the register before death\(^1\)
- Of those included, 77% had cancer\(^1\)
- Only 25% of UK deaths from malignant disease\(^2\)


Advance care planning (ACP)

Process:
1. Shared understanding of illness, prognosis
2. Values or personal goals of care
3. Specific preferences for future care (place, treatments)

Outcomes:
1. Statement of wishes and preferences
2. Advance decision to refuse treatment (ADRT)
3. Lasting Power of Attorney (LPA)
Earlier Study: Advance care planning discussions with frail & elderly individuals$^2$

A systematic review and literature search

Focused on:

- Frail & elderly with no overriding diagnosis
- Advanced care planning/conversation about end of life care

$^2$Do the elderly have a voice? Advance care planning discussions with frail and older individuals: systematic literature review and narrative synthesis.

Sharp T, Moran E, Kuhn I, Barclay S. Br J Gen Pract. 2013 Oct;63(615)
Older peoples’ attitude to ACP discussions

- Between 61% & 91% wanted to discuss end of life care.
- Between 2% & 29% had discussed end of life care
- Comfort, even enthusiasm for such conversations
- Although some had a reluctance for discussions:
  - preferred to “live one day at a time” or
  - “postpone...until they were older or in worse health”
- Felt benefits are:
  - assurance that wishes would be respected
  - address issues before cognitively impaired or seriously ill
  - assist loved ones in making a decision
- Felt responsibility for initiating lies with doctor
- Want Dr to talk in honest & straightforward manner
Older peoples attitudes - timing

- Most wanted discussions sooner rather than later
- Perceive risk of “leaving it too late”
- Benefits of early talks outweighed any discomfort
- Some felt discussions should happen routinely
  “Advance care planning discussions should be routine questions such as screenings like mammograms and colonoscopies. When somebody is X years old, discussions should begin.”
- Minority found individuals would rather defer discussions & ‘cross that bridge’ only when had to.
Health Professionals attitudes

- Felt discussions an important part of professional responsibility
- View discussions important with patients who have:
  - Severe chronic illness (91%)
  - Terminal illness (97%)
  - Older people (64%)
- Many Doctors do not find conversations stressful
- Others commented on difficulty with older people given uncertainty over prognosis
Health Professionals attitude - timing

- Diversity of opinion
- Some thought discussions should start early before onset of serious problems
- Others describe lack of clear threshold event to prompt discussions
- Acknowledging their responsibility, many feared early discussions may damage hope & doctor/patient relationship
Barriers to ACP Discussions

- Families – unwilling to discuss or family breakdown
- Professional and time limitations
- Patient reluctance – feeling others would decide
- Difficulty planning for uncertain future
- Administrative barriers
More recent study

- Focus Groups with GPs
- Interested in GPs attitudes to advance care planning
- Focus on frail & elderly loosely defined

Method

- Five focus groups held, with 21 GPs from 15 practices across Cambridgeshire
- Initially invitations through six Local Commissioning Groups (LCGs)
- Data analysed using framework approach
- Coded and summarised in Nvivo
Results - GPs attitudes

- Most GPs felt Advance Care Plans are important
- Enable healthcare professionals to respond to individuals’ wishes.
- Felt to be especially important in an emergency or when things go wrong.

“So for me it is about planning for when things go wrong, it is about knowing the patient wishes” S4 0611
Results – Patients attitudes

- Many felt patients welcomed discussions
- Patients often felt relief when planning was raised.
- Discussions helped individuals and their families understand & plan for the future.
- Sometimes patients raised issue themselves
- Felt patients often had plans GPs were unaware of

“more often than not you don’t get a bad reaction, you get a grateful reaction, it’s like ‘At last someone’s talking about this.’” S3 0611
Results – Patients attitudes (2)

- A minority of GPs were concerned that discussions may cause distress or have detrimental impact.
  “It could completely adjust their mind set. They may be feeling quite positive about the future and then suddenly to be told that actually you’re nearer the end than you thought” S2 2409

- There was also concern that individuals may make decisions and then subsequently change their minds.
  “There’s always the danger patients may feel bamboozled into making choices that perhaps on reflection they’d consider differently.” S2 2409
Results - Timing

Most view earlier as preferable, but those concerned about detrimental affects on patient preferred later

“I think increasingly I’m struck by how earlier is better when it comes to the discussions about advance care planning. I’d love to think about how we can make it earlier yet more of a natural discussion. I think it’s an ongoing challenge for us all.” S2 1709

“I don’t personally think it’s a great idea to bring it up very early because it can be upsetting to the patient plus when they’re kind of being ill and getting better, you just don’t know what’s going to happen and they don’t need someone to knock them back and say, well, actually you might not be here in twelve months” S4 2409
Results - GPs experience & training

- Most GPs felt they had sufficient experience to raise ACP.
- Differing views on whether GPs should receive more training or rely on learning through experience.

“I’ve found it usually reasonably easy to broach the subject or talk around it anyway and see how far I get and then perhaps bring it up another time.” S5 1709

“I don’t think experience necessarily makes a good training, unfortunately. I think you can do the same thing over and over again, but it doesn’t mean you’re any good at it.” S3 2409
Results - facilitators

Four major themes that help facilitate ACP:

1) Knowing the patient & their family
   Strong agreement that where GPs know their patients well, it is easier to raise ACP
   “if we are still in a position of knowing our patients [...] then these discussions are fairly intuitive and natural and just require the space and time to do them” S4 0611

2) ‘Planting seeds’ & having flexible ongoing discussions
   “I might not say all at once, you just mention it when you might see them every two months or something” S5 1709
Results – facilitators (2)

3) Public awareness campaigns
   - Broad support for raising public awareness
   - Mentioned TV, radio, newspapers, leaflets & posters
   - “I think raising public awareness is a really good idea and that’s something that could happen.” S3 1801

4) Standardising Advance Care Planning
   - Felt helpful if discussing ACP was more standardised. However some were concerned individuals could feel targeted
   - “in the same way that kidney donor cards are dished out when you apply for a driving licence & then that sort of makes it something that people think about” S3 1801
Results - Barriers

Four main barriers to advance care planning were identified:

1) Unclear prognosis & unclear future needs

“Everything’s very ambiguous, everything is uncertain and trying to give them some idea for them to make a decision about how to plan when they don’t have any idea of why it is they’re deteriorating is very hard.” S3 1709

2) Lack of services

“one of the worst things in terms of your relationship with a patient is the promise that you can’t do, you know, “We’ll respect your wishes,” when in reality... It’s not that you don’t want to respect their wishes but...The system lets us down.....you’d feel you were letting them down if you offered them stuff you couldn’t fulfil” S4 1801
Results - Barriers

3) Issues documenting & ensuring wishes respected
“I’m sure there are probably quite a lot of instances of advanced care planning that have occurred and are documented but to find a template, put it in when you’re not necessarily thinking about it as advanced care planning” S3 0510

4) Pressure on GP time
“It’s a very time-consuming process, and the normal consultation doesn’t really allow you to wander down that road in a graceful way.” S4 2701
Summary findings

- Most GPs felt ACP is important to respond to patients wishes
- Believe frail elderly patients are mostly receptive to ACP
- Most felt had experience, not necessarily the training, to raise
- Earlier discussions were preferable for most
- However some concerned by detrimental impact on patients
- Main potential facilitors:
  - Knowing the patient & their family
  - “planting seeds”/ having a flexible ongoing discussion
  - Raising public awareness
  - Potential to be standardised in some way
- Main barriers identified:
  - Multiple morbidity with unclear prognosis/care needs
  - Lack of services esp in community
  - Difficulty to document or communicate
  - Limitations on GP time