

GPs' perceptions of advance care planning with frail and older people:

a qualitative study

Abstract

Background

Frail and older people are estimated to account for 40% of deaths. Despite conversations about end-of-life care being an important component of the national End of Life Care Strategy, there is a marked disparity between the majority who would like to discuss advance care plans, and the minority who currently have this opportunity.

Aim

To investigate the attitudes of GPs to advance care planning (ACP) discussions with frail and older individuals.

Design and setting

Focus group study with GPs in Cambridgeshire between September 2015 and January 2016.

Method

Five focus groups with 21 GPs were purposively sampled to maximise diversity. Framework analysis was used to analyse transcripts and develop themes.

Results

Although some GPs were concerned it might cause distress, the majority felt that raising ACP was important, especially as preparation for future emergencies. Knowing the individuals, introducing the idea as part of ongoing discussions, and public awareness campaigns were all facilitators identified. Several considered that service limitations made it difficult to fulfil patients' wishes and risked raising unrealistic patient expectations. Other barriers identified included uncertainty over prognosis and difficulties ensuring that individuals' wishes were respected.

Conclusion

Most GPs viewed ACP as important. However, their enthusiasm was tempered by experience. This study highlights the difficulties for GPs of encouraging dialogue and respecting individuals' wishes within the constraints of the existing health and social care system. National publicity campaigns and encouraging patients to prioritise healthcare outcomes could help GPs raise care preferences without causing a detrimental impact on patients or raising unrealistic expectations. Once patients agree their care preferences, they need to be documented, accessible, and reviewed by all relevant health and social care providers to ensure that their wishes are respected, and plans amended as their circumstances change.

Keywords

advance care planning; focus groups; frail elderly; general practice; palliative care.

INTRODUCTION

For an unwell older patient, a simple call for help may initiate a rapid series of events. An ambulance or clinician may be called, admission to hospital may be arranged, and a range of investigations undertaken. Although hospitals may well be a good place to care for many older patients, some may prefer not to be admitted and to be cared for in other ways. Finding ways of understanding and responding to individuals' preferences represents a challenge for healthcare professionals, especially at points of crisis when their ability to make decisions over their care may be limited.

Advance care planning (ACP) is the process that allows individuals and their healthcare professionals to develop a shared understanding of their health and potential future care needs. It allows the individual the opportunity to understand their personal care goals, and to think about preferences for future care. This can be recorded as a statement of preferences and wishes or a more formal legal document.

The national End of Life Care Strategy¹ highlighted the importance of care planning, and the recent *Ambitions for Palliative and End of Life Care*² included an ambition for individualised care, with each person being offered the opportunity to create an individualised care plan. ACP is perceived to empower patients and enhance rather

than diminish hope,³ with growing evidence that it improves end-of-life care, including increasing satisfaction among patients and their relatives.^{4,5} In Scotland, the NHS launched a major campaign to promote care planning, to encourage conversations, and to help people have more control and make informed choices over the care they want to receive.⁶

An increasing proportion of the UK population are living into frail old age, with multiple comorbidities but no single overriding diagnosis; this 'frailty trajectory' is estimated to account for 40% of deaths⁷ and is often associated with unpredictability over a prolonged time course.⁸ However, a recent review found that most specialist palliative care remains focused on patients with cancer, even though they account for only one-third of deaths, and that the 'oldest old' were the least likely to access specialist palliative care.⁹

A systematic review by the authors⁷ found a marked disparity between the majority of frail and older individuals who would like to discuss advance care plans, and the minority who currently have this opportunity. This raises important questions if the wishes of this patient group are to be respected.

GPs have a central role in leading and coordinating the care of frail older individuals in the community. The recent '2% Direct Enhanced Service'¹⁰ from NHS England incentivised GPs to identify and develop

T Sharp, MA, MRCP, GP, former academic clinical fellow in general practice; **S Barclay**, MA, MD, MSc, FRCGP, university senior lecturer in palliative care and general practice, Primary Care Unit, Department of Public Health and Primary Care, University of Cambridge, Cambridge.

A Malyon, BA(Hons), MSc, RGN, nurse researcher, Cambridge University Hospitals NHS Foundation Trust, Cambridge, Cambridge.

Address for correspondence

Tim Sharp, Department of Public Health and

Primary Care, Institute of Public Health, Forvie Site, Cambridge Biomedical Campus, Cambridge, CB2 0SR, UK

E-mail: timsharp@nhs.net

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How this fits in

This focus group study investigated the reasons for the disparity between the majority of frail and older people who would like discussions over their future care and the minority who have the opportunity to do so. It found that, although a minority of doctors are concerned that these conversations can cause distress, the majority view them as important. This enthusiasm was often tempered by their experience, in particular the impact of limitations in services and concerns over raising unrealistic expectations, concerns not well documented by other studies.

care plans, and to offer more support to at least 2% of their practice population felt to be most at risk of an unplanned hospital admission. The 2017–2018 GP contract in England requires practices to identify patients who are living with moderate or severe frailty.⁸ For those living with severe frailty the practices will deliver a clinical review including an annual medication review, a falls risk assessment, and, where appropriate, individualised goal setting.

Aims

This study focused on frail older people who have no single overriding diagnosis, seeking to understand more about doctors' attitudes to discussions between individuals and healthcare professionals about their future care. With regard to conversations with frail or older people about care at the end of life, it sought to understand:

- What are GPs' experiences of these conversations?
- What are GPs' attitudes to holding these conversations?
- What are GPs' attitudes to the timing of these conversations?
- What are the barriers to these conversations?
- What might facilitate these conversations?

METHOD

Focus groups were held with GPs across Cambridgeshire between September 2015 and January 2016. They were purposively sampled to maximise participant diversity by sex, practice location, and years in practice. Groups comprised between three and six GPs; they were held following a local commissioning group (LCG) clinical governance meeting ($n = 1$), after LCG board meetings ($n = 2$), in a rural practice ($n = 1$),

and during a 'First5' meeting of GPs in their first 5 years in practice ($n = 1$). Participation was voluntary and written informed consent was obtained. No financial inducement was offered, but participants were given a certificate to recognise their involvement.

Twenty-one GPs participated in five focus group discussions from 15 different practices across Cambridgeshire, representing the cities of Cambridge and Peterborough, Fenland towns, and villages to the north and south of the county. Twelve were male and nine female; 14 were practice partners and seven salaried doctors. Time since qualifying as a GP ranged from 4 months to 31 years with a mean of 14 years. Sixteen participants considered themselves white, two were Asian or Asian British, two were black or black British, and one was Chinese.

One researcher facilitated all the group discussions, supported by another researcher adopting a flexible approach to explore group members' experiences and perspectives while ensuring the discussion covered the outline schedule (Appendix 1). A focus group approach was adopted as it enabled free discussion and allowed participants to respond to each other's comments and perspectives. It was emphasised that the purpose was not to reach consensus but to understand the range of views and experiences of participants.

Each discussion lasted between 35 and 45 minutes, and was digitally recorded, transcribed verbatim, anonymised, and uploaded into NVivo 10 software for analysis. A Framework analysis approach was adopted⁹ using a framework developed from the literature, including the authors' systematic review of ACP with frail and older individuals [Appendix 2],⁷ adding further themes that emerged from the data during analysis. Framework analysis is widely used in applied health services research, where the research has a clear focus of enquiry while using an inductive approach. Transcripts were initially coded within the framework and then summarised within themes and subthemes. Initial coding of two transcripts was independently reviewed by two researchers, with disagreements resolved by discussion. Themes were then reviewed and validated by one researcher against the original focus group transcripts and their notes taken at each group discussion.

RESULTS

The results are presented in five themes:

- GPs' attitudes and how they feel their

patients perceive ACP;

- GPs' experience and training;
- timing of discussions;
- facilitators of ACP; and
- barriers to ACP.

Participants are quoted according to the group they were in (A–E) and study ID number.

GPs' attitudes and how they feel their patients perceive ACP

GPs' attitudes to ACP. Most GPs felt advance care plans are important as they enable professionals to respond to individuals' wishes. Plans were felt to be especially important in an emergency or when things go wrong:

'Feel very strongly that it's important to discuss this area with them because a lot of them, when you do talk about it, have quite fixed views about how much they want to be treated and what they want to do if they have problems.' (E3)

'So for me it is about planning for when things go wrong, it is about knowing the patient wishes.' (D4)

GPs' perceptions of patients' attitudes to ACP. Many GPs felt that patients welcomed discussions, which often came as a relief, and helped give individuals and their families an understanding to help them plan for the future:

'I think often it comes as a relief to patients when you talk about it because it takes away some unknowns for them.' (A2)

'... if you've got a plan it means you've got some idea of expectation and prognosis ... I think half that time the frail and elderly get scared and afraid and end up in the wrong place for care is because they don't know the expectation of what's coming up for them.' (D3)

Some GPs noted that patients sometimes raise the issue themselves, while others reported that planning was being done that GPs are not aware of:

'I've noticed the number of frail and elderly or indeed elderly who are asking for their wishes with regard to what should happen in the event of them becoming unwell.' (B3)

'I suspect there's a lot of planning being done that we're not aware of and would

there be a way of knowing those, that might be useful for us too.' (C2)

Some GPs were concerned that individuals may be reluctant to discuss ACP, feeling that such discussions may cause distress or make people feel guilty about using healthcare services:

'It could completely adjust their mindset. 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.' (B2)

'We have a lot of elderly patients who feel guilty about using resources of the NHS and having these conversations at the wrong time with them and their families ... can be really damaging to the doctor–patient relationship.' (E7)

There was also concern that people may make decisions and subsequently change their minds:

'There's always the danger patients may feel bamboozled into making choices that perhaps on reflection they'd consider differently.' (B2)

GPs' experience and training

Most GPs felt they had sufficient experience to be able to raise ACP. Some thought they could rely on learning through experience, whereas others felt experience did not necessarily make good training:

'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.' (A5)

'Even as GPs when they start, they don't get specific training on things like that. You kind of learn as you go on, and as you gain more experience you're more comfortable with doing that.' (A3)

'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.' (B3)

Timing of discussions

The GPs strongly supported raising ACP early as part of a natural ongoing discussion, giving people the opportunity to think about and plan their future, and avoid unplanned emergencies. However, some who were concerned about the potential

adverse impact of raising ACP on patients' outlook preferred to leave discussions until later:

'If we start getting people thinking ahead about their health and their care for the future it's easier to get people to organise themselves.' (D6)

'Any event can only be a crisis if it's not planned for ... if you've got a plan that's 5 years old that's still better than no plan because it meant you've had the conversation and prompted the family to have the conversation.' (D3)

'I think it could cause anxiety when a patient's living in blissful ignorance for a while and actually enjoying their life, and they may think they've got 5 years ahead, and I'm sure they'd feel happier still believing they had 5 years ahead than them being told, by the way, we think you're probably going to die in the next 6 months.' (B2)

Facilitators of ACP

The GPs identified four major themes that help facilitate ACP discussions:

- knowing the patient and their family;
- 'planting seeds' and having flexible ongoing discussions;
- public awareness campaigns; and
- standardising ACP.

Knowing the patient and their family. There was agreement that where GPs know their patients well, it is easier to gauge when to raise ACP, and more natural to introduce the topic. Most GPs also felt that knowing an individual's family and getting them involved early made discussions more straightforward and helped prevent future difficulties:

'... if we are still in a position of knowing our patients, which I think all of us will be, then these discussions are fairly intuitive and natural and just require the space and time to do them.' (D4)

'If you get the relatives involved and the relatives present when you're talking to them it's easier to paint a picture of what the future holds and to let them think about it and what might or might not happen.' (D6)

'I think having conflict within families can make it quite difficult because sometimes you might have had this discussion with

the patient themselves and they're quite happy with it and they've got a plan and then the, the son or the daughter finds out and disagrees.' (C2)

'Planting seeds' and having flexible ongoing discussions. A recurring theme in all the groups was that raising ACP with individuals gives them opportunity to think about and discuss it, potentially at a later date. Many GPs also remarked on the importance of making ACP part of an ongoing discussion, giving people the opportunity to amend their plans as their perspectives changed:

'I might not say all at once, right, we need to discuss a plan for you, but you just mention it when you might see them every 2 months or something.' (A5)

'Is this something you've thought about. If so, please let us know if you've got particular wishes or otherwise feel free to discuss it with us.' (C4)

'And it's helpful to remember, isn't it, that advance care planning isn't a one-off consultation.' (A2)

Public awareness campaigns. There was broad support for raising public awareness of ACP. Television, radio, and newspapers, as well as leaflets and posters, were all mentioned as good ways to encourage individuals to think about planning their care:

'I think raising public awareness is a really good idea and that's something that could happen.' (E3)

'I think perhaps if more is spoken about it in the press and so on ... so some patients will comment on those.' (A5)

Standardising ACP. Many GPs felt that it would be helpful if discussing ACP was more standardised; others were concerned that, despite a standardised approach, individuals could feel personally targeted:

'It would be interesting if it was standardised somehow because it would be part of a normal conversation.' (A2)

'In the same way that kidney donor cards are dished out when you apply for a driving licence and then that sort of makes it something that people think about.' (E3)

'Even though you can say it's standardised I think they'd still feel quite targeted.' (C4)

There was a general feeling that identifying frail older patients or those most at risk of admission was different from ACP.

Barriers to ACP

Four main barriers to ACP with frail and older patients were identified:

- unclear prognosis and unclear future needs;
- lack of services;
- issues documenting and ensuring wishes are respected; and
- pressure on GP time.

Unclear prognosis and unclear future needs. A major theme was the difficulty of raising ACP where there is no overriding diagnosis and where prognosis and future care needs remain uncertain. Some GPs questioned the relevance of discussions where circumstances may change:

'It has to be handled very carefully and actually it's perhaps a bit more difficult to handle than if you have a concrete diagnosis ... Having said that, I don't think it's any less relevant to do it than it is in those, it's just harder to do it.' (E4)

'Everything's very ambiguous, everything is uncertain and trying to give them some idea of how to plan, or 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.' (A3)

'You could have that discussion with me now but that's not really a relevant discussion because it depends on my circumstances as to what exactly happens and I can't answer that for myself now.' (B4)

Lack of services. Several GPs raised the limitations of the community services available, highlighting that, even if patients have care plans, a lack of services can mean it is difficult to fulfil patients' wishes. Some raised concerns that falsely raising patients' expectations in care planning could have a detrimental impact on the doctor-patient relationship:

'I would agree that 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.' (E4)

'If we could truly deliver what we promise

and allow people to die at home, which I think is the right thing to do, it requires system change at a level above GPs going and completing a form with people ... The problem of the frail elderly and hospital admissions isn't about the fact we never ask the question, often it's about the fact that the safety net isn't there to actually truly respect their wishes and treat them as an individual, and until we address that we can do it all at 75 and ... This is why I say I have mixed feelings. I think in principle it's a wonderful thing to do but perhaps the resources are not there to meet those needs as they stand.' (E7)

Issues documenting and ensuring wishes respected. Several GPs mentioned practical problems of documenting patients' wishes in their notes. In particular, many felt templates can be restrictive and become a 'tick-box' exercise. Where planning had taken place there was frustration that it could be overlooked or that individuals did not have access to the plans:

'Those forms when you had to fill in preferred place of care, I found those very, very prescriptive and quite difficult because people have got their own way of expressing that, and now with QOF and tick-boxing kind of stuff it felt very much like "palliative care: tick".' (E5)

'Plans have to be accessible and used because you can go to an awful lot of effort, you can do all the groundwork, but when it does come to the event, that's still a crisis till that plan is produced. And that's where the system's falling short.' (D3)

'... often when I think of ACP in terms of documentation I don't know what they're sending out right now just that it's never very user friendly on the computer.' (C5)

Pressure on GP time. Many GPs highlighted how pressure on their time and the need for full discussions limit their ability to undertake ACP discussions:

'It does take a long time to go through this. You're always conscious how you're running behind. Realistically, this is something that you'll probably want a separate appointment to do if you were going to do it properly.' (E4)

'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.' (B4)

DISCUSSION

Summary

This study investigated the reasons for the disparity between the preference of the majority of frail and older individuals to have discussions concerning their future care and the minority who in practice have the opportunity to do so. Although most of the GP participants viewed ACP as important, many were concerned that ensuring patients' wishes were respected was limited by community service availability and were concerned not to raise false expectations. As their prognosis is often unclear, and their care needs can frequently change, there are significant barriers to ACP with frail and older people, alongside GP time pressures and a reluctance to complete 'tick-box exercises'. The GPs saw that their long-term relationships with patients and their families facilitated ACP, with the possibility of 'planting seeds' concerning ACP, providing longitudinal opportunities for discussions, and flexibility in peoples' care priorities as their perspectives and health change over time.

Strengths and limitations

The views of GPs concerning ACP with frail and older individuals have been little studied to date. A diverse sample of Cambridgeshire GPs was obtained to maximise conceptual generalisability, though not statistical representativeness. Focus group methods sought to enable participants to develop their thinking and respond to the ideas of others, with encouragement of individuals to express differing opinions. The authors sought to mitigate the potential for participants being more interested in the topic by enabling participation through arranging the groups around existing GP meetings.

Although participants were repeatedly reminded to focus on issues around frail and older individuals, discussion at times moved on to ACP more broadly. The authors sought to be reflexive throughout the study, recognising that, as practising clinicians, data collection and analysis might be influenced by opinions and clinical experience; a rigorous, structured approach, reinforced by independent review and comprehensive use of quotations, supports the validity of the analysis presented.

Comparison with existing literature

This study reinforces the need identified in the authors' previous systematic review⁷ for doctors to understand and respond to the care planning wishes of their patients. Their focus on frail and older patients is unique.

The barriers identified, such as prognostic uncertainty and resistance to a tick-box approach, fit with studies of ACP in patients with cancer.⁹ The challenges highlighted for GPs of striking a balance between maintaining hope and preparing for the additional care needs as an individual's health declines are common to studies across wider populations.^{11,12}

Concerns over limitations in the availability of community services have been raised in other studies;¹³ however, the impact on GPs is a new finding, highlighting the need for GPs to be pragmatic and realistic in helping patients to get the best available services. Long-term GP-patient relationships can enable ongoing, flexible ACP discussions, supporting patients and their relatives to re-evaluate their care needs and consider potential crisis situations, helping people to make the best 'in the moment' decisions.¹⁴

Implications for research and practice

This study highlights the multiple and compounding difficulties for GPs in discussing ACP with frail and older individuals. It is challenging for GPs to find ways of giving people opportunities to express their future care preferences in a nuanced, flexible, patient-centred and ongoing manner. Public campaigns, such as the Anticipatory Care Planning Campaign by NHS Inform in Scotland,⁶ are to be welcomed. They can play an important role in helping people understand how care planning can improve their quality of life and enable them to put their own plans in place. A high-profile campaign across all of the UK would encourage many more people to consider the benefits of care planning.

It is difficult to judge the right time to enquire about future care wishes: too soon may create premature anxiety, whereas too late may limit patient involvement in crisis care decisions. The requirement of the new GP contract in England will encourage GPs to use an appropriate tool to identify frail patients.⁸ For most practices this is likely to be an electronic tool embedded in their patient records system,⁸ which may help practices identify patients who might benefit from care plans.

Once identified, the challenge for GPs is to consider asking frail patients about their priorities for care. They could consider broad questions such as *'Can you tell me what things are most important to you, now and in the future?'* or more focused outcome prioritisation tools that ask individuals to prioritise universal outcomes, such as remaining alive, maintaining independence, and reducing pain and other symptoms.¹⁵

Planning for an unpredictable and uncertain future may only be possible in general terms, with the risk of raising unrealistic expectations of service availability. However, only if patients' preferences are documented and shared is there a chance that they can be implemented and used to drive future care provision.

Sharing information on patients' care preferences across the health and social care system presents a significant challenge. The erosion of personal continuity

between a doctor and their patient, and the large number of professionals potentially involved in a patient's care, mean there is a need for informational continuity, with ACP conversations being documented in clinical records, discussed in team meetings, and shared across care providers. Future research could helpfully focus on patient views of this approach and evaluation of systems to record and share care plans across the health and social care system.

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Provenance

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Competing interests

The authors have declared no competing interests.

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Appendix 1. Focus group schedule

Introduction

- Introduce yourselves as facilitator and supporter
- Discuss the purpose of the study (advance care planning, frail and elderly, no overriding diagnosis)
- Explain everything discussed will be confidential, except if concerns raised for welfare of patient or others and then professional guidelines will be followed
- Gain informed consent
- Provide structure of the discussion (audiorecording and taking notes)
- Emphasise purpose is not to reach a consensus but to discuss range of experiences and views
- Ask if participants have any questions
- Test audiorecording equipment
- Make the participants feel comfortable!

Opening question (to go round the group)

Is there one or two word(s) to summarise your thoughts on advance care planning?

Topics to cover (with possible prompts as sub-bullets)

Thinking about frail and older individuals who do not have an overriding diagnosis, what experiences do you have of holding these conversations?

How do you feel about discussing care planning with frail and older patients?

- Important?
- Difficult? Or straightforward?

How do you decide when to discuss care planning with frail and older patients?

- Key events in patient's life?
- Particular age?
- When patients prompt?

Are there barriers to these conversations?

- Individuals not ready to discuss;
- time;
- inexperience/lack of training;
- involving others, for example, family and friends; or
- uncertainty over prognosis.

Are there things that would help facilitate these conversations?

- Prompted at a particular age? Or after particular events?
- Public awareness campaign?
- Make discussions routine?

Closing question

Is there one thing that should be done in the area of advanced care planning with frail and older patients?

Closing the interview

- Thank them for their participation
- Reiterate that some issues can be challenging. Remind them if needed they should talk to a trusted colleague, their GP, or the named senior nurse
- Ask if anyone would like a copy of the results when they are published

Appendix 2. Framework for data analysis

1.0	Background
1.1	Setting
1.2	Participants (age, sex, experience, ethnicity)
1.3	Seniority/particular interest
1.4	Facilitation notes
1.5	Components of ACP discussed
1.6	What wasn't said
1.7	Other
2.0	Patients' attitudes to ACP/discussions
2.1	Patients encourage
2.2	Patients reluctant
2.3	Fear/changes patient outlook
2.4	Patients do not have ideas/wishes
2.5	Have discussed with others, for example, family
2.6	Other
3.0	GPs' attitudes to ACP/discussions
3.1	Important/beneficial
3.2	Feel comfortable discussing
3.3	Not convinced helpful
3.4	Find difficult
3.5	Needs flexibility/part of ongoing conversation
3.6	Other
4.0	Timing of discussions
4.1	Early stage (pros and cons)
4.2	Happens later than would like
4.3	When illness progresses/discharge
4.4	Difficult to pick time
4.5	When patient prompts
4.6	Key event in their life/particular age
4.7	Other
5.0	Barriers to ACP
5.1	Lack of training/inexperience
5.2	GP time
5.3	Family disagreement
5.4	Uncertainty/unclear prognosis/wishes may change
5.5	Clinical/cognitive issues
5.6	Bureaucracy/IT
5.7	Money/practical care limitations
5.8	Other
6.0	Facilitators of ACP
6.1	Public awareness/information/change perception of dying
6.2	Standardise/make routine, for example, particular age
6.3	Knowing patient/family/situation (or not)
6.4	Patient discussion with others, for example, HCP, family
6.5	Float early/sowing seeds
6.6	Association with other planning, for example, wills
6.7	Campaigns and initiatives (for example, admission avoidance/2%)
6.8	Other

ACP = advance care planning. HCP = healthcare professional.