# A qualitative study exploring use of the surprise question in the care of older people; perceptions of General Practitioners and challenges for practice

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Key words: end of life, older people, surprise question, advance care plan, primary care

Word count: 3430

**ABSTRACT**

**Objective:** The question “Would you be surprised if this patient were to die in the next 6-12 months?” has been included in United Kingdom palliative care guidance with the aim of supporting the identification and care planning of those nearing the end of life. Little is known about how the surprise question is utilised in the care of older people within primary care. This study sought to explore the perceptions and experiences of General Practitioners (GPs).

**Method:**Semi-structured interviews were conducted with 12 GPs. Each interview reflected on the care of two people, aged 80 years or older, selected by the GP as possibly being in the last year of life. Analysis followed a grounded theory approach within a framework of interpretive thematic analysis.

**Results:** Data discussing 22 clinical cases revealed the difficulties experienced by GPs when assessing prognosis for older people with non-malignant conditions, despite their recognition of multiple mortality risk factors and high symptom burden. GPs did not appear to include the surprise question within their usual practice and expressed concerns regarding its use to facilitate discussion of advance care plans. These concerns highlighted the subjective nature of the surprise question and potential barriers to conducting discussions of preferences for future care.

**Conclusions:** Greater understanding is needed as to the difficulties experienced by GPs when assessing prognosis in older people. We propose a thematic model which could support GPs by focussing assessment on the supportive and palliative care needs of older people nearing the end of life.

**INTRODUCTION**

Population ageing has been widely recognised as a global issue and means that more people are both living and dying at older ages.([1](#_ENREF_1)) During the last decade in England and Wales the population aged between eighty and eighty-nine years has increased by 13% and those aged ninety years and over by 26%.([2](#_ENREF_2)) Currently 37.7% of deaths in England and Wales occur in those aged eighty-five years and older([2](#_ENREF_2)) and this is projected to rise to 44% by 2030.([3](#_ENREF_3)) Within the United Kingdom (UK) the NHS Mandate 2012 recognised care of older people nearing the end of life as a national priority and the key role that General Practitioners (GPs) play in providing such care has been highlighted.([4](#_ENREF_4), [5](#_ENREF_5)) UK policy states that, whenever possible and appropriate, those nearing the end of life should, be offered the opportunity to discuss their care preferences.([6](#_ENREF_6), [7](#_ENREF_7)) Reports have suggested that advance care planning can improve both the quality of care received and the likelihood of dying in the preferred place of care.([8](#_ENREF_8), [9](#_ENREF_9)) However, for advance care planning to take place those approaching the end of life must first be identified. Within the UK this has led to the promotion of the screening question, “Would you be surprised if this patient were to die in the next 6-12months?” The surprise question is included in the Gold Standards Framework Prognostic Indicator Guidance and until recently was part of the Supportive and Palliative Care Indicator Tool.([10](#_ENREF_10), [11](#_ENREF_11)) It forms part of the “*Find your 1%”* campaign, launched in 2012 by the Dying Matters Coalition and National Council for Palliative Care (NCPC), which aims to help GPs to identify the approximately 1% of the population who die each year and to support them in delivering quality end of life care.([12](#_ENREF_12))

The first report describing the surprise question was published in 2001 and discussed its use within a community setting in the United States (US).([13](#_ENREF_13)) Primary care physicians were given lists of patients seen recently with diagnoses such as Alzheimer’s disease, cancer and chronic lung or heart disease. They were asked to identify those for whom they perceived death in the next 12 months would not be a surprise and consider referral to a community palliative care clinic. The author described that the question seemed to allow doctors to think in a new way about their patients and their needs. The surprise question has subsequently been used within secondary care clinics in the US, UK and Hong Kong for the assessment of patients with cancer([14](#_ENREF_14)) and renal disease,([15-17](#_ENREF_15)) when it has been reported to improve identification of those with increased mortality risk. However, others have cautioned that the predictive power of the surprise question may show variability dependent on clinical discipline, setting and doctor’s seniority([15](#_ENREF_15)) and that clinician prediction may be inaccurate and over-optimistic regarding duration of likely survival.([18](#_ENREF_18), [19](#_ENREF_19))

Little is known about how the surprise question may be used by GPs in the UK and we could find no published evidence regarding its use in older age groups. Both these factors are integral to the success of current UK end of life care policy initiatives, and will assume even greater importance as the population continues to age. We therefore sought to explore the perceptions and experiences of GPs when using the surprise question in the context of people aged 80 years and over, and to consider whether its use could facilitate anticipatory care planning.

**METHODS**

**Research design:** A qualitative methodology was chosen to explore these issues in depth and from the perspective of the individual GP.([20](#_ENREF_20), [21](#_ENREF_21)) Semi-structured interviews using open questions provided a consistent framework for each interview and maintained a focus on the clinical relevance of the surprise question, whilst still allowing GPs to speak at length and reflectively. GPs were asked to select two cases to discuss, aged eighty years or older, whose condition they perceived to be deteriorating and for whom they considered that death in the next twelve months would not be a surprise. It was suggested they select one case in which they were quite confident in their prediction and one in which they were less certain. Patient confidentiality was maintained at all times by removing any details which might identify the individual. Interviews followed the format shown in Box 1; a topic guide containing factors from current literature associated with mortality risk prediction and end of life care facilitated exploration of issues raised.

**Box 1: Interview guide**

* Could you tell me about the first/second case you have selected to discuss?
* Can you remember when you first thought that you would not be surprised if this patient were to die in the next 12 months?
* Do you feel that the surprise question is useful in the management of your patient? And why?

**Setting and sample:** The study was conducted within a University City and surrounding rural area, from May to July 2013. A research invitation was sent to all GP practices via the local email network. Fifteen GPs responded and were provided with further information; twelve agreed to participate and gave informed signed consent. The characteristics of GP participants are shown in Box 2. All interviews were conducted by the first author, who had completed training in qualitative research methods and who was a local GP herself. Interviews took place at the participant’s place of work, lasted 45-60 minutes, were audio recorded and transcribed verbatim. Field notes were kept to record impressions, insights and questions raised during interviews. All participants received a copy of the research findings; none requested alterations.

**Box 2: Characteristics of GP Participants**

* 12 GP Principals, 12 white British, 7 male 5 female
* 2-32 years of experience in partnership (median 23 years)
* 11/12 from teaching practices (GP Registrar & medical students)
* 7/12 provided regular sessional care to nursing home residents as part of a local enhanced service

**Ethical considerations:** Participants were aware that the research was conducted as part of a dissertation study MSc Gerontology. Ethical approval was granted by The King’s College London GSSHM Research Ethics Panel, 22/03.2013, ref KCL/12/13-317.

**Data analysis:** A grounded theory approach was taken within a framework of interpretive thematic analysis;([22](#_ENREF_22)) NVivo software was used to organise the transcript data and assist data analysis. Line by line coding broke down the interview data and codes were grouped into categories of shared meaning.([23](#_ENREF_23)) Codes and categories were reviewed and refined after each interview and checked by the second author to maximise internal validity and ensure consistency.([20](#_ENREF_20)) Interpretive themes were developed iteratively and inductively; the entire data set was analysed critically using the constant comparative method and by searching for negative or deviant examples.([21](#_ENREF_21)) Analysis was continued until data saturation and theoretical sampling was achieved.

**RESULTS**

Interviews discussed the care of twenty-four older people. Twenty-two cases were analysed, two were found to be aged less than 80 years and excluded. The characteristics of the cases analysed are shown in Box 3. Individual case summaries are detailed in appendix 1; GP case identification codes are attached to quotations.

|  |  |
| --- | --- |
| **Box 3: Characteristics of clinical cases** | |
| Gender | 10 Male, 12 Female |
| Age | 80-101 years (median 88 years, mean 93 years) |
| Residence | 15 Community dwelling, 7 Care Home |
| Dominant diagnostic trajectory([10](#_ENREF_10)) | 6 Cancer, 6 Organ Failure, 10 Frailty/Dementia, |

Doctors discussed a wide range of clinical, social and psychological factors; however, two major themes emerged. First the difficulties experienced by GPs when considering prognosis and second their concerns when considering advance care plans. There was strong consistency in the content of case discussions and category headings included clinical history, symptom burden, acute events, psychosocial considerations and advance care planning. Data within these categories were explored to consider how they might be associated with expressions of certainty or confidence.

**The difficulties experienced by GPs when considering prognosis:** Diagnosis, rate of decline, treatment options, co-morbidity and past medical history were discussed in all cases. A clear diagnosis, rapid rate of decline and information communicated by secondary care to suggest active treatment options were not possible were strongly associated with expressions of confidence when considering prognosis. This typically occurred when discussing cases with a diagnosis of cancer but much less frequently in non-malignant disease.

*“So it all feels a little bit tentative and I don’t have the confidence… you end up saying I think it’s a little bit of a lot of things, rather than in the previous case where you can say, well you’ve got a tumour growing on your pancreas.”* (GPA P2)

Symptoms commonly described included breathlessness, fatigue, weakness, reduced appetite, weight loss, poor mobility, cognitive impairment and dependency for activities of daily living. A high symptom burden and poor functional capacity were reported in all the cases with non-malignant disease, however, these factors alone did not appear to give prognostic confidence.

*“She’s completely bed bound, eats and drinks sometimes, a little. I’ve been expecting her to die for about a year but she hasn’t…. She hasn’t really got much in the way of past medical history. I don’t know if she’s one I’m sure about or not, because if she were here in a year it wouldn’t necessarily surprise me, I don’t know.”* (GPC P1)

A recent hospital admission had occurred in nine cases. However, the possibility of an acute event or hospital admission was discussed in all cases with non-malignant disease.

*“She’s clearly been going downhill, just gradually, steadily over quite a long period of time and the amount of care package has been steadily escalating. But she hasn’t been acutely unwell, a simple UTI or a cold that’s going to probably tip the balance.”* (GPG P1)

It was perceived that such events could occur at any time, but might not for many months, adding further to a sense of unpredictability. This was illustrated when the case a GP had selected to discuss, “unexpectedly” died the night before our interview:

*“I suppose thinking about it, it’s funny that although you are expecting something to happen it does take you by surprise. So why did it happen on Thursday when it hasn’t happened for six months?”* (GPF P1)

Social circumstances, support structures, mental state and cognitive capacity were discussed in all cases. In four cases a perceived change in demeanour was described as a feature of concern but in most cases the sentiment expressed by GPs was of a “fighting spirit”. This revealed an apparent paradox that these older people who were in one sense perceived as frail and vulnerable were in another admired for their “strong character” and ability to “keep going”; in one case this was described as “defying” prognostication.

When GPs were asked if they could remember when they first thought the case discussed might not survive the next 12 months examples given related to a new diagnosis, hospital admission, acute event or a change in condition. However, many struggled to define a precise point in time and none reported this as being linked to use of the surprise question prior to the study.

**Concerns when considering advance care plans:** Advance care planning had taken place in thirteen of the twenty-two cases. This included all those with a diagnosis of cancer or who were resident within a care home, but only one case with non-malignant disease residing in the community. In the study area a local enhanced service requires GPs to consider advance care plans for all nursing homes residents. Thus for these cases, and those with a diagnosis of cancer, advance care planning had been incorporated in to usual practice but this did not appear to have occurred in other situations.

*“And it’s the same old issue that I always seem to have, with a cancer the moment the diagnosis is made you start to talk about palliative care, but with somebody who is gradually going downhill you don’t quite clock the point as to when to.”* (GPG P1)

The only exception to this finding related to an 88 year old woman with heart failure. The GP assumed that following a hospital admission she understood that treatment options were limited and another such episode may prove fatal.

*“And she hadn’t! But when I went to visit her at home the next time she said that she was glad I’d raised it because it had made her think about it. She’d remembered her parents dying and feeling really guilty at not being prepared for it and it had enabled her to talk about it with her family. And she said they weren’t surprised!”* (GPD P1)

In all cases where advanced care planning had taken place, the GP discussed the involvement of other health care professionals; this was much less evident in remaining cases. This appeared to be related in two ways, firstly that their involvement meant that end of life issues were more likely to be recognised and secondly, that once recognised other health care professionals were more likely to be asked to provide support.

When GPs were asked if, having now considered their response to the surprise question, this could facilitate discussion of advance care plans, only two replied that it might.

*“That’s why this is valuable, recognising you need to be asking yourself those questions and realising whenever I do, nearly always, I should have been doing this already.”* (GPG P1)

*“I haven’t discussed the prospect of his condition deteriorating. The surprise question could, perhaps should, lead me to having that discussion with him, where nothing else perhaps says there is a need for that discussion or that kind of planning.”* (GPA P2)

However, most expressed concern that the surprise question was too subjective to be the basis for such decisions and there was a sense that it had identified cases earlier than many GPs felt comfortable to consider advance care plans. Concerns discussed included the difficulty of knowing what to say when there was prognostic uncertainty, of identifying when was the “right” time and of not wishing to cause anxiety or upset prematurely. Some GPs felt that discussion would not be wanted and others that their patient might feel it “odd” or that they were “giving up” on them. A few perceived that advance care plans heralded a shift to a different “framework” of care and that once this had taken place their patient might be denied treatment from which they could still potentially benefit.

*“He would be somebody I would find it difficult having that sort of discussion with….. And I think actually if he did suddenly become acutely unwell, I would want to be active.”* (GPG P2)

GPs consistently reported their understanding of advance care plans to include consideration of preferred priorities of care, place of death, resuscitation wishes and “just-in-case” medications; there was a sense conveyed of a practical tool to prepare for an expected or imminent death.

**DISCUSSION**

Our findings reveal the difficulties GPs experience when assessing prognosis for older people, despite their recognition of multiple mortality risk factors and high symptom burden. This was particularly evident for older people with non-malignant conditions, who may lack a clear diagnosis, have a slow or variable rate of decline and be at risk of acute events. We propose a thematic model that could provide a structure for GPs when considering mortality risk in older people (Figure 1).

***(insert figure 1)***

This model brings together the key factors discussed when considering cases identified by the surprise question and also suggests possible outcomes following assessment that could help to bridge the apparent gap between identification of increased mortality risk and discussion of advance care plans. It includes clinical history, symptom burden and risk of acute events but also acknowledges the complexity of such assessments and suggests seeking the opinions of other healthcare professional, the patient, family and carers, to support assessment and shared decision making. This model could be used following triggers, such as a new diagnosis or acute event, but could also form part of a holistic assessment during review appointments. The possible outcomes suggested reflect considerations described by GPs when discussions of future care preferences had taken place and also take into account current end of life care guidance ([9](#_ENREF_9), [11](#_ENREF_11), [12](#_ENREF_12)). It aims to place advance care plans within a broader context that allows time for meaningful discussions and enhances care whilst also preparing appropriately for death. Possible outcomes include the development of care plans combining the supportive, palliative and active care needs of the individual, the pro-active management of identified risks, and the provision of integrated interdisciplinary support. As far we are aware this is the first study within the UK to consider the views of General Practitioners when using the surprise question in older people. Our findings suggest that GPs may not currently include the surprise question within their usual practice. Their responses highlighted concerns regarding the subjective nature of the question and potential barriers to conducting discussions of preferences for future care and advance care plans. The finding that GPs experience difficulties in assessing prognosis concurs with other studies which have delineated risk factors associated with increased mortality in older people, but have been unable to develop a mortality risk prediction tool of sufficient accuracy or validity for use within clinical practice.([24-27](#_ENREF_24)) This finding also supports the conclusions of others that for older people with non-malignant conditions accurate mortality risk prediction may be unrealistic,([28](#_ENREF_28)) that certainty in prognosis may not be possible until a late stage of disease([29](#_ENREF_29), [30](#_ENREF_30)) and that palliative care assessment should be considered on the basis of need rather than prognosis.([31](#_ENREF_31)) Our findings regarding the barriers which may impede the provision of palliative care, such as the influence of prognostic uncertainty, not wishing to cause anxiety and difficulties in conducting end of life care discussions, have been reported previously.([32-35](#_ENREF_32)) Initiatives such as those developed by Dying Matters and the NCPC are working to support doctors in holding these “difficult conversations”.([12](#_ENREF_12), [36](#_ENREF_36)) However, the issue discussed by some GPs that advance care plans may be interpreted to preclude active interventions or even as a withdrawal of care, is of particular concern in light of recent misunderstandings with regard to the implementation of the Liverpool Care Pathway.([37](#_ENREF_37)) Furthermore, our findings highlight that whilst for many of the older people discussed GPs perceived that death would not be a surprise, they could continue to live for an unexpected length of time. This has been described by Lynn as “Living long in fragile health”,([38](#_ENREF_38)) and by Nicholson et al as simultaneously occupying a space of both living and dying which challenges binary medical thinking.([39](#_ENREF_39)) The possible divide between active treatment and palliative care may represent just such binary medical practice. We suggest models of care, such as the AMBER care bundle currently being developed within secondary care,([40](#_ENREF_40)) that can combine active treatments and palliative care may also be required to meet the needs of older people within a community setting.

We believe the qualitative methodology used within this study, which encouraged GPs to speak reflectively about mortality risk assessment in the context of their own practice, was a key strength enabling the development of these findings. However, the study does have a number of limitations. The study was small, exploratory and conducted within one locality, with GP principals of whom many had additional expertise in care of the older person or medical education. As such findings may not confer generalizability or be representative of other groups of GPs; however, qualitative research is concerned with exploring ideas from data and information richness. The researcher was known to participants as a local GP and this may have influenced the information shared and the interaction with the researcher during interviews; however, this could also have facilitated a greater openness in discussing the difficulties experienced in the “real world” of general practice. Finally the authors’ interest in care of the fail older person will have influenced the interpretation of data and development of findings.

We suggest this study raises important considerations for policy initiatives which aim to improve the identification of those nearing the end of life and most importantly if such initiatives are to improve the quality of care delivered to older people. This has particular relevance in light of predictions that the number of deaths occurring in those aged eighty-five years and older will continue to increase([3](#_ENREF_3)) and that up to 80% of such deaths may follow a trajectory of frailty and gradual decline.([27](#_ENREF_27)) We suggest that greater understanding is required as to the difficulties experienced in assessing prognosis in older people and as to the validity and reliability of using the surprise question in this context. Our proposed thematic model requires testing but aims to support GPs by providing a structure for assessment that includes supportive and palliative care needs, which may be of greater relevance than prognosis, when considering the development of advance care plans for older people approaching the end of life.([31](#_ENREF_31))

**CONCLUSION**

The surprise question forms part of UK palliative care guidance which aims to improve the identification of those nearing the end of life and facilitate the planning of future care. Our findings reveal the difficulties that GPs may experience when using the surprise question to assess older patients, suggest that they may not currently include the surprise question within their usual practice and that they have concerns regarding its use to facilitate advance care planning. We propose a thematic model that could support GPs in the assessment of older people who may be nearing the end of life and facilitate the development of person-centred end of life care during what may be an uncertain and unpredictable period of time.

**Acknowledgements**

We would like to thank the interviewees for their time and openness. We would like to acknowledge the support of Dr Karen Lowton, Institute of Gerontology, King’s College London in developing the research question and research methodology; Dr Louise Jones and Dr Liz Sampson, Marie Curie Palliative Care Research Unit, University College London for their advice in developing the manuscript; and the reviewers for their helpful suggestions with regard to manuscript revisions.

**Competing Interest:** None declared

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