



Pocock, L. V., Wye, L., French, L. R. M., & Purdy, S. (2019). Barriers to GPs identifying patients at the end-of-life and discussions about their care: a qualitative study. *Family Practice*, 36(5), 639-643.
<https://doi.org/10.1093/fampra/cmy135>

Peer reviewed version

Link to published version (if available):
[10.1093/fampra/cmy135](https://doi.org/10.1093/fampra/cmy135)

[Link to publication record in Explore Bristol Research](#)
PDF-document

This is the accepted author manuscript (AAM). The final published version (version of record) is available online via Oxford University Press at <https://academic.oup.com/fampra/article/36/5/639/5289238> . Please refer to any applicable terms of use of the publisher.

University of Bristol - Explore Bristol Research

General rights

This document is made available in accordance with publisher policies. Please cite only the published version using the reference above. Full terms of use are available: <http://www.bristol.ac.uk/pure/user-guides/explore-bristol-research/ebr-terms/>

**Barriers to GPs identifying patients at the End-of-Life and
discussions about their care: A qualitative study**

Running head: Barriers to GPs identifying patients at the End-of-Life

Qualitative Research

Authors

Lucy V Pocock (LP), Lesley Wye (LW), Lydia R M French (LF) and Sarah Purdy (SP)

Centre for Academic Primary Care, University of Bristol, UK

Corresponding author

Dr LV Pocock, Centre for Academic Primary Care, Population Health Sciences,
Bristol Medical School, University of Bristol, Canynge Hall, 39 Whatley Road, Bristol,
BS8 2PS, UK. Email: lucy.pocock@bristol.ac.uk

Key Messages (3-6 bullet points, 83 characters per bullet point)

- GP Palliative Care Registers are largely composed of cancer patients
- GPs rarely use prognostication tools to identify patients at the end-of-life
- GPs want guidance from secondary care to identify patients at the end-of-life
- End-of-life conversations with patients with non-malignant disease is challenging

Abstract

Background: Identification of patients at the end-of-life is the first step in care planning and many general practices have Palliative Care Registers. There is evidence these largely comprise of patients with cancer diagnoses, but little is known about the identification process.

Objective: To explore the barriers that hinder GPs from identifying and registering patients on Palliative Care Registers.

Methods: An exploratory qualitative approach was undertaken using semi-structured interviews with GPs in South West England. GPs were asked about their experiences of identifying, registering and discussing end of life care with patients. Interviews were audio recorded, transcribed and analysed thematically.

Results: Most practices had a Palliative Care Register, which were mainly composed of patients with cancer. They reported identifying non-malignant patients at the end-of-life as challenging and were reluctant to include frail or elderly patients due to resource implications. GPs described rarely using prognostication tools to identify patients and conveyed that poor communication between secondary and primary care made prognostication difficult. GPs also detailed challenges around talking to patients about end-of-life care.

Conclusions: Palliative Care Registers are widely used by GPs for patients with malignant diagnoses, but seldom for other patients. The findings from our study

suggest this arises because GPs find prognosticating for patients with non-malignant disease more challenging. GPs would value better communication from secondary care, tools for prognostication and training in speaking with patients at the end-of life to enable them to better identify non-malignant patients at the end-of-life.

Keywords: Advanced care planning, general practice, primary health care, family practice, palliative care, terminal care

Introduction

Identification of patients approaching the end-of-life (taken here to mean likely to die within the next 12 months) is central to improving end-of-life (EOL) care. Early identification is associated with improved outcomes for patients and their carers (1-3). General practices in England are financially rewarded, through the Quality and Outcomes Framework (QOF), for maintaining a Palliative Care Register (PCR) of patients with palliative care needs (in practice, this is usually synonymous with patients thought to be at the EOL), and for discussing these patients at regular meetings. Most general practices now have a PCR and regular meetings (4), however, it is accepted that identifying which patients are at the EOL can be difficult, particularly those with a non-malignant diagnosis (5).

In recent years, there have been numerous, UK-based, initiatives to improve care at the EOL. These initiatives all share a common first step – the identification of

patients at the EOL. However, a lack of prognostic indicators to help GPs decide when EOL care should start was identified as a barrier by a national consultation exercise (6). The consultation also concluded that the difficulties in prognosticating, particularly in non-malignant disease, hindered access to appropriate help.

One of the initiatives, the Gold Standards Framework, includes a prognostic indicator guidance paper, to aid identification of patients in their final 6-12 months of life (7). This includes use of “the surprise question” (would you be surprised if this patient were to die in the next few months, weeks, days?) and specific indicators of advanced disease for each of the three main EOL patient groups – cancer, organ failure and elderly frail/dementia. Whether GPs use such guidance to identify patients in practice is not clear. Nor is it clear what issues confront GPs when they attempt to identify patients at the EOL. Therefore, the aim of this study was to explore the barriers that may hinder GPs from identifying and registering patients on PCRs.

Methods

Recruitment of participants

Purposeful sampling was used to recruit GPs, from practices in three counties in South West England, including urban and rural areas. Maximum variation was aimed for in terms of the participants' gender and age, geographical region and deprivation

level of the practice. Practices and potential participants were identified with assistance from the Marie Curie Delivering Choice Programme (8). All GPs who were invited to participate accepted and were interviewed. The aim of the study was to continue to sample until no new issues or themes were emerging (9).

Data collection

The interviews took place over six months, within GPs' own practices and lasted up to one hour. All participants were interviewed individually. Interviews were conducted by LP, an academic junior doctor, under the supervision of experienced academic and clinical staff. Data collection continued until data saturation had been reached.

A topic guide was used to ensure consistency across interviews. Topics areas explored included GPs' views of caring for patients at the end of their life, GPs experiences of identifying patients in need of palliative care, what if any prognostication tools/guidelines GPs used to identify patients at the end of their life, how, why and which patients GPs registered on their PCR, what GPs experiences were in talking to patients about EOL care, what, if any, additional support they needed to help identify and register patient on PCRs. All the interviews were audiotaped and transcribed verbatim.

Analysis

Interview transcripts were analysed thematically by LP using the constant comparison method. Themes were developed using an inductive approach that allowed for the analysis to be driven by what interviewees said rather than pre-existing theory. Codes

were identified by looking across all the interview transcripts to compare views. This process led to a coding frame being developed that was later refined and tested.

Transcripts from half of the interviews were read by a second researcher, either LW, an experienced qualitative researcher, or SP, a senior academic GP. Themes were discussed within the research team and with the wider primary care community, when early data were presented at conferences and research meetings.

Once the coding frame had been agreed, the transcripts were then all fully coded, and comparisons made across and within the interviews to identify key themes and deviant cases.

Results

Twelve interviews were conducted with GPs from eleven practices, ranging in age from 39 to 64 and approximately equal numbers of men and women (see Table 1).

Analysis of the data led to four broad themes being identified that make clear some of the barriers for GPs identifying and registering patients on PCRs.

Palliative Care Registers are mainly populated by patients with malignant diagnoses

Except for one GP, all the GPs interviewed stated that their practice used a PCR. Similarly, nearly all the GPs interviewed, described their registers as being largely composed of patients with malignant diagnoses:

“It’s very much aimed at cancer palliative care because, I mean we have to do that for QOF anyway because we have to have at least quarterly meetings with the primary healthcare team about patients with palliative care needs...”

Participant 2

“We’ve probably got 18 [patients at the EOL] on our list... probably three out of those 18 would be non-malignant”

Participant 9

Indeed, many GPs admitted that they struggled to put patients with non-malignant diagnoses on the register, which they reported as being a consequence of there not being the same intellectual connection between these patients and the need for EOL care.

“I think in your mind there’s a very clear link between palliative care cancer...when it’s beyond a curative point then you instantly think this is palliative you know, it just comes to mind they need palliative care. Whereas... [with non-malignant patients] there’s not such an easy link in your mind.”

Participant 3

GPs also described being reluctant to include very frail, elderly patients onto the register as they were apprehensive about the resource implication of this.

“Supposing you put all this in place... we’ve got to see this patient more often, we’ve got to send the Community Matron round more often, we’ve got to have access to the palliative care team, who are beginning to branch out a bit just for cancer... I mean if those resources aren’t there then there is no point.”

Participant 2

Formal prognostication tools are not used by GPs to identify patients at the EOL

Very few GPs reported using any formal prognostication tools to help them identify patients in need of EOL care. Only two GPs were aware of the GSF’s prognostic indicator guidance paper. One GP welcomed it and felt it gave him *“a framework to work within” (participant 9)*, that enabled him to better anticipate and coordinate EOL care for his patients. Conversely, another GP felt it was not very useful, presented an additional burden to GPs, and considered it to be: *“...another bloody thing to count.” (Participant 7)*.

Only a couple of GPs described using the “Surprise Question” to help them identify patients at the end of their life. In the main GPs described softer markers of deterioration in functional status, such as becoming housebound or requiring an increase in care, as more likely to prompt them to think about EOL issues.

“Regardless of what the diagnosis is... you get to the point where they’re not able to come to the surgery any more, they’re increasingly needing help from neighbours and calling upon the community nurses to visit and spending more time in bed... weight loss is certainly one of the biggest predictors of EOL.”

One GP mentioned wishing for “a set of flags” (participant 12), for individual diseases that would cumulate in a prompt to consider whether the patient was at the EOL.

GPs want help from secondary care to help identify EOL patients

Many GPs described there being a lack of clear communication at the primary/secondary care interface regarding patients that were at the end of their life. Several GPs felt this to be an issue in the early identification of EOL patients and relayed examples of cases where they had to actively seek information from hospital clinicians about their patient’s prognosis

“And that’s what I’m asking you as a consultant, what’s your ceiling here for this person, what are you going to do if I ever send them into hospital? We’ve asked the consultants, if you’ve got someone with COPD that you’d never put on ITU, never used non-invasive ... then tell us.”

There was also agreement that it was often unclear what a patient had been told, by secondary care teams, regarding their diagnosis and/or prognosis making it difficult for the GP to speak with the patient themselves.

“The communication is very poor in terms of prognosis. And in fact that whole communication between “what we have told your patient” we find very difficult

so we have to go in very tentatively because we are often, despite of having you know, a full discharge or a clinic letter, very unclear as to how much of this... the patient or the patient's partner or whoever is with the patient has been told and what they know and what language has been used and whether any timescales have been mentioned."

Participant 12

Talking to patients about death is difficult

Many GPs described the challenges they felt in discussing EOL care with their patients, particularly patients they did not know well or had not seen regularly.

"I think a GP who has known them for a long time perhaps, has seen the decline, and also feels confident and comfortable with the patient, who perhaps they have known for a long time, because it is quite difficult sometimes to... have that conversation. At what point do you say "and where would you like to die?" It is not an easy thing to just put in... and if you know them well and it is actually so much easier having that conversation."

Participant 6

Several GPs expressed concern that they might raise EOL issues at the wrong time, causing emotional distress to the patient and their family. They described being

reluctant to talk to their patient about EOL care for fear of forcing the patient to confront their own mortality before they perceived the patient to be ready.

“Forcing those sort of discussions... I think can really have a fairly devastating effect sometimes in some patients ... they sometimes give up hope or whatever... if you force people in to facing up to their own mortality when they’re not ready to do so, I think that can have a detrimental effect on the rest of their life.”

Participant 1

Indeed, the majority of GPs reported finding it easier to talk to patients with a malignant diagnosis about palliative care than patients with a non-malignant diagnosis because they felt patients with a malignant diagnosis had a better understanding of their prognosis and would cope better with the notion of their care being either curative or palliative.

“Actually as soon as you start to have the conversation with someone with a malignancy they know ... people with heart failure, people with COPD, you have to spell it out because they don’t have that sort of folklore understanding of what you’re trying to say to them.”

Participant 7

However, many did report feeling, that overall, when they had spoken to the patient about EOL care, the patient was indeed ready to have the conversation.

“I suspect I mean the ones I have had the conversation with, they sort of kind of know it really and they are waiting for someone to say it.”

Participant 6

A number of GPs also described struggling to switch from a curative to a palliative approach when talking to patients who were approaching the EOL, sometimes giving them over-optimistic or unrealistic information.

“I fail to think, gosh, yes I’m probably denying it to myself aren’t I? I’m immediately saying COPD and heart failure doesn’t have to shorten your life, it depends when you develop it and what else is going on. But yes the chance, there’s a significant chance it will shorten your life... And it’s dishonest to deny that.”

Participant 10

Many GPs described wider cultural attitudes towards death and how they perceived that medicalising death had led to patients and their relatives becoming less comfortable with the process of dying. One GP described how he felt wider public views seemed focused on assisted dying, which prevented important wider public discussions about improving EOL care. Another felt simply that *“there needs to be more discussion about death, more openness about it.”* Participant 7.

“Dignitas applies to an incredibly small minority of people. And for me, it distorts the entire care industry about EOL care, which is mostly about non-cancer, non-diagnosed illnesses where you just get old and die.”

Participant 9

Discussion

Summary

All but one of the practices within this sample have a register for recording patients whom are thought to be at the EOL and regular meetings to discuss their care, however, EOL care, in most practices here, is still largely focused on patients with a diagnosis of cancer. GPs admitted that they struggled to put patients with non-malignant diagnoses on the register, which they reported as being a consequence of there not being the same intellectual link between these patients and the need for EOL care. They also described being reluctant to include very frail, elderly patients onto the register as they were apprehensive about the resource implications of doing so.

GPs described rarely using any formal prognostication tools to identify patients and welcomed a more collaborative approach, with their secondary care colleagues, to the process of prognostication and advance care planning.

GPs detailed the challenges they faced when talking to patients about EOL care. Some GPs expressed finding it hard to accept that a patient had reached the EOL, with several admitting that knowing when to broach this discussion with the patient was problematic.

Strengths and limitations

This qualitative study involved interviews with 12 GPs from a wide variety of practice settings. All GPs interviewed were over the age of 39 and it would be interesting to

know if younger GPs, trained more recently, would have contributed differently. The identification of patients at the EOL is not the sole remit of GPs and it is possible that a greater diversity of views would have been found if data had been collected from other team members, such as district nurses.

Although this study includes only 12 participants, the findings are concordant with other studies in the literature (1, 11,12). The GPs interviewed represented eleven very different practices, in 3 counties.

The primary researcher was a junior doctor, with an interest in EOL care, which is an advantage in that communication with the participants was conducted on a peer-peer basis and the researcher's own clinical experience was able to shape the data and its interpretation. However, this researcher-participant relationship, may lead to collusion or avoidance of tackling more difficult issues regarding the role of the GP. The research team undertook regular feedback on data collection and emerging analysis and early data were discussed at several conferences and research meetings to mitigate this.

Comparison with existing literature

Our findings lend support to two Scottish studies, which found patients dying of cancer were much more likely to be included in the practice PCR before death compared to those with non-malignant conditions (1, 11). The same study also found that health professionals were not using a systematic approach or guidelines in the identification of EOL patients, relying instead on more subjective judgments (1).

More recent work on the use of 'the surprise question', QMortality and EFI as prognostication tools demonstrates that they detect a significant number of false

positives, i.e. identify a substantial number of patients who are not in the last year of life (13-15). These findings bear relevance to our study, where GPs voiced concerns about the resource implications associated with increasing the number of patients on their PCRs, particularly when their prognosis was not clear, and might explain why there might be a reluctance to use this approach in prognosticating in non-malignant disease.

Our findings also highlight a lack of communication at the interface between primary and secondary care for patients at the EOL. This is echoed by two recent publications; a Canadian study, which concluded that “conversations and goals of care planning are part of everyone’s job, and they need to be well coordinated and communicated across healthcare providers and settings” (12) and a recent Royal College of Physicians report highlighting a need to identify how best to record Advance Care Planning conversations, and then share this information across the secondary care and community interface (16). It is an area which needs further work, and innovations such as the ‘Poor Prognosis Letter’ piloted at a Bristol hospital (17) should be subject to further study.

A systematic review of the literature considering the barriers for good communication between GPs and their patients regarding end of life care supports our finding that GPs find talking to patients about EOL care challenging (18). Moreover, although the British Social Attitudes 30th Report states that 85% of respondents would like to be told if they were terminally ill and 70% feel comfortable talking about death (19), our participants were concerned that raising EOL issues with patients might destroy hope and have a detrimental effect on their remaining life. These views are echoed by the findings of other studies (20, 21). In a longitudinal qualitative study on living and dying with COPD, it was noted that clinicians tended to collude with patients

about the nature and progression of their illness (22). GPs may require further training in “breaking uncertain news” to cope with the unpredictable trajectories of patients with non-malignant conditions (23).

Conclusions

A greater understanding of the subjective prognosticating judgements that are being made by GPs is required, to make this more explicit and to assist in the development of further education and training. Prognostication tools with greater sensitivity may also aid this process. Further work also needs to be done to facilitate information sharing across healthcare settings and providers, including an understanding of how Electronic Palliative Care Coordination Systems (EPaCCS) (24) and the ReSPECT process (25) might aid this.

Training for doctors in similarly sensitive areas has resulted in a culture change and normalisation of these difficult conversations for many. Undergraduate medical and postgraduate GP training curricula should make EOL issues and advance care planning a priority.

Acknowledgements

We would like to thank the GPs who gave their time, voluntarily, to participate in the study.

Declaration

Funding: This work was supported by a grant from the Severn Faculty RCGP

Ethical approval: Approval for this study was granted by the South West 2 Research Ethics Committee (REC ref: 10/0206/72). A signed informed consent was obtained from each participant before participation in the semi-structured interview

Conflict of interest: There have been no involvements that might raise the question of bias in the work reported or in the conclusions, implications, or opinions stated.

References

1. Harrison N, Cavers D, Campbell C, Murray SA. Are UK primary care teams formally identifying patients for palliative care before they die?. *Br J Gen Pract.* 2012 May 1;62(598):e344-52.
2. Baker A, Leak P, Ritchie LD, Lee AJ, Fielding S. Anticipatory care planning and integration: a primary care pilot study aimed at reducing unplanned hospitalisation. *Br J Gen Pract.* 2012 Feb 1;62(595):e113-20.
3. Thomas K, Noble B. Improving the delivery of palliative care in general practice: an evaluation of the first phase of the Gold Standards Framework. *Palliative medicine.* 2007 Jan;21(1):49-53.
4. Hughes PM, Bath PA, Ahmed N, Noble B. What progress has been made towards implementing national guidance on end of life care? A national survey of UK general practices. *Palliative Medicine.* 2010 Jan;24(1):68-78.
5. Boyd K, Murray SA. Recognising and managing key transitions in end of life care. *BMJ.* 2010 Sep 16;341(16):2.
6. Shipman C, Gysels M, White P, Worth A, Murray SA, Barclay S, et al. Improving generalist end of life care: national consultation with practitioners, commissioners, academics, and service user groups. *BMJ.* 2008 Oct 1;337:a1720.
7. Thomas K et al. Prognostic Indicator Guidance (PIG) 4th Edition Oct 2011, The Gold Standards Framework Centre In EOL Care CIC [cited 24 October 2018]. Available at: <http://www.goldstandardsframework.org.uk/cd-content/uploads/files/General%20Files/Prognostic%20Indicator%20Guidance%20October%202011.pdf>

8. Purdy S, Lasseter G, Griffin T, Wye L. Impact of the Marie Curie Cancer Care Delivering Choice Programme in Somerset and North Somerset on place of death and hospital usage: a retrospective cohort study. *BMJ supportive & palliative care*. 2015 Mar 1;5(1):34-9.
9. Morse JM and Field PA. *Qualitative Research Methods for Health Professionals*, 2nd Ed, London: Sage, 1995
10. Department of Communities and Local Government. English indices of deprivation 2010 [cited 23 August 2018]. Available at: <https://www.gov.uk/government/statistics/english-indices-of-deprivation-2010>
11. Zheng L, Finucane AM, Oxenham D, McLoughlin P, McCutcheon H, Murray SA. How good is primary care at identifying patients who need palliative care? A mixed-methods study. *European Journal of Palliative Care*. 2013 Jan 1;20(5):216-22.
12. Urquhart R, Kotecha J, Kendell C, Martin M, Han H, Lawson B, et al. Stakeholders' views on identifying patients in primary care at risk of dying: a qualitative descriptive study using focus groups and interviews. *Br J Gen Pract*. 2018 Sep 1;68(674):e612-20.
13. White N, Kupeli N, Vickerstaff V, Stone P. How accurate is the 'Surprise Question' at identifying patients at the end of life? A systematic review and meta-analysis. *BMC medicine*. 2017 Dec;15(1):139.
14. Hippisley-Cox J, Coupland C. Development and validation of QMortality risk prediction algorithm to estimate short term risk of death and assess frailty: cohort study. *BMJ*. 2017 Sep 20;358:j4208.

15. Clegg A, Bates C, Young J, Ryan R, Nichols L, Ann Teale E, et al.
Development and validation of an electronic frailty index using routine primary care electronic health record data. *Age ageing*. 2016 Mar 3;45(3):353-60.
16. Royal College of Physicians (2018) Talking about dying: How to begin honest conversations about what lies ahead. October 2018 [cited 24 October 2018].
Available at: <https://www.rcplondon.ac.uk/projects/outputs/talking-about-dying-how-begin-honest-conversations-about-what-lies-ahead>
17. Reid C. et al. (2017). The Poor Prognosis Letter Project [cited 05 September 2018]. Available at: <http://www.swscn.org.uk/wp/wp-content/uploads/2018/02/Poor-Prognosis-Letter-Project.pdf>
18. Slort W, Schweitzer BP, Blankenstein AH, Abarshi EA, Riphagen I, Echteld MA, et al. Perceived barriers and facilitators for general practitioner–patient communication in palliative care: a systematic review. *Palliative medicine*. 2011 Sep;25(6):613-29.
19. NatCen Social Research (2013), British Social Attitudes 30th Report [cited 24 October 2018]. Available at:
http://www.bsa.natcen.ac.uk/media/38723/bsa30_full_report_final.pdf
20. Pfeifer MP, Sidorov JE, Smith AC, Boero JF, Evans AT, Settle MB, et al. The discussion of end-of-life medical care by primary care patients and physicians. *Journal of General Internal Medicine*. 1994 Feb 1;9(2):82-8.
21. Hanratty B, Hibbert D, Mair F, May C, Ward C, Capewell S, et al. Doctors' perceptions of palliative care for heart failure: focus group study. *BMJ*. 2002 Sep 14;325(7364):581-5.

22. Pinnock H, Kendall M, Murray SA, Worth A, Levack P, Porter M, et al. Living and dying with severe chronic obstructive pulmonary disease: multi-perspective longitudinal qualitative study. *BMJ*. 2011 Jan 24;342:d142.
23. Samuel DG. Better Education and Resources. In response to: Barclay S and Maher J. Having the difficult conversations about the End of Life. *BMJ*. 2010; 341 :c4862
24. Petrova M, Riley J, Abel J, Barclay S. Crash course in EPaCCS (Electronic Palliative Care Coordination Systems): 8 years of successes and failures in patient data sharing to learn from. *BMJ supportive & palliative care*. 2016 Sep 16:bmjpcare-2015.
25. Resuscitation Council UK. (2018) ReSPECT Process [cited 05 September 2018]. Available at: <https://www.respectprocess.org.uk/>

Table 1. Demographic characteristics of the 12 GPs participating in the study, recruited from general practices in the South West of England in 2011

Participant identifier	Gender	Age	Rural/Urban	No of patients	IMD Score**	Palliative care interest?
1	Male	56	Urban	6300	11.97	Yes
2	Female	58	Urban	8500	14.08	No
3	Male	40	Rural	6600	26.35	No
4	Male	58	Urban	9500	6.75	Yes
5	Female	45	Urban	8000	24.27	No
6	Female	48	Rural	6600	34.09	Yes
7	Female	47	Urban/rural	10,000	23.39	Yes
8	Male	*	Rural	5500	28.95	No
9	Male	39	Rural	4800	18.48	Yes
10	Female	*	Urban	13,500	12.74	No
11	Male	64	Rural	13,500	8.45	Yes
12	Male	55	Urban	6847	11.97	Yes

* Unavailable **Index of Multiple Deprivation Score (10)