Patients with any progressive disease may benefit from a palliative care approach in the last phase of their life. This includes patients with advanced heart, lung and kidney disease. National and international policy documents and guidelines now call for earlier identification of patients with all advanced life-threatening diseases and frail older persons. Palliative care should be made available according to need, and not diagnosis or even prognosis.

Many patients who might benefit from a palliative approach are currently not being identified in hospital or in primary care. Late access to palliative care limits opportunities to improve quality of life. For patients with malignant disease, early referral can optimise the timing of final chemotherapy, improve quality of life, reduce the likelihood of depression and even lengthen survival.

We sought to examine to what extent the WHO recommendation of gradually phasing in palliative care from the diagnosis of a life-threatening, progressive illness (illustrated in Figure 1) is actually put into practice in the UK.

We hypothesised that several factors might influence the decision to identify a patient for palliative care:

- Patient choice
- A diagnosis of cancer
- Prognostic uncertainty
- The patient’s need for psychological support
- Accessibility of specialist services
- The clinician’s confidence in their own ability to provide palliative care

The facts that modern palliative care started in the UK and that all patients are registered with a specific GP should help such identification in the UK.

We thus aimed to document and understand variations in two key factors:

- The number of weeks before death at which patients were formally identified for a palliative approach – and placed on the palliative care register – before dying.
- A gradual, holistic and anticipatory approach in caring for people with long-term conditions may be more acceptable to patients and professionals than a sudden and late switch to palliative care.

Identification of patients for palliative care occurs much too late, and predominantly in those with a cancer diagnosis, say Lilin Zheng, Anne M Finucane, David Oxenham, Peter McLoughlin, Hazel McCutcheon and Scott A Murray, who advocate the implementation of a much more gradual and anticipatory palliative care approach.

Key points

- Patients with any progressive disease may benefit from a palliative care approach in the last phase of their life.
- A study conducted across nine Scottish general practices shows that relatively few non-cancer patients are identified for palliative care – and placed on the palliative care register – before dying.
- This study also shows a large care gap between disease-modifying treatment and palliative care, which currently features only in the last two months of life – if at all.
- A gradual, holistic and anticipatory approach in caring for people with long-term conditions may be more acceptable to patients and professionals than a sudden and late switch to palliative care.

Methods

Setting and recruitment
Nine Scottish general practices were recruited to include a range of practice sizes, urban and rural settings and sociodemographic mix.

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A mixed-methods approach was chosen to allow us to quantify and explore these complex issues.

**Quantitative data collection and analysis**
We conducted a case note review of all deaths that had occurred among registered patients during a recent 12-month period. We extracted the following data:

- Age at death
- Illness trajectory (cancer, organ failure, frailty and/or dementia)
- Whether the patient had been placed on the palliative care register (PCR) and, if so, how many weeks before death
- Whether the patient was attending specialist palliative care services and, if so, from how many weeks before death

Lilin Zheng, an experienced GP (and one of the authors of this article), classified patients by identifying the predominant illness trajectory in their case notes.

Data were analysed in SPSS® Statistics version 19. Pearson’s chi-square test was used to explore the relationship between illness trajectory on one hand, and placement on the PCR/referral to specialist palliative care on the other. The Mann–Whitney U test was used to compare the median time between identification for palliative care and death in individuals who had cancer and in those who had organ failure or frailty/dementia. The Kruskal–Wallis test was used to explore whether there was a difference in the median time between referral to specialist palliative care and death across the three illness trajectories.

A subgroup of 310 patients was analysed to estimate whether these patients would have been identified for palliative care had the Supportive and Palliative Care Indicators Tool (SPICT™) Version 20 been used to assess their palliative care needs before death.

**Qualitative data collection and analysis**
We conducted semi-structured interviews with GPs and district nurses to determine the barriers to, and facilitating factors for, identifying patients for palliative care, and how this identification could be increased.

Interviews were recorded digitally, transcribed and analysed using Microsoft Word and Excel. We used a framework approach, which involved identifying key issues, concepts and themes both emerging and derived from the study aims.

The key outcomes were defined as:

- Identification for a palliative approach; patients were deemed to have been identified for palliative care if they had been placed on the practice PCR before death; the length of time between identification for palliative care and death was the time (in weeks) between the point at which the patient had been placed on the PCR and death
- Referral to specialist palliative care; patients were deemed to have been referred to specialist palliative care if they had been referred to their local hospice before death

Excluding cases of sudden deaths and deaths from unknown causes, the practices involved in the study had placed between 26% and 50% of their patients on their PCR, and had referred between 16% and 39% to specialist palliative care, before death.

**Results**

**Sample characteristics**
Data relating to 684 patients were collected. The mean age was 76 years and 77% of patients (n=530) were identified as having been on a cancer (29%), organ failure (25%) or frailty/dementia trajectory (23%). The remaining 23% had either died suddenly (19%) or from an unknown cause (4%).

Excluding cases of sudden deaths and deaths from unknown causes, the practices involved in the study had placed between 26% and 50% of their patients on their PCR, and had referred between 16% and 39% to specialist palliative care, before death.
Overall, 40% of patients with cancer, organ failure or frailty/dementia had been identified for a palliative approach, and 31% had been referred to specialist palliative care.

**Descriptive data**

Patients with cancer died on average 27 weeks after diagnosis. Those who were formally identified for palliative care were identified seven weeks (median) before death, and referrals to specialist palliative care were made five weeks (median) before death. Figure 2 maps these results against the WHO recommended model and highlights a long gap during which palliative care was not mentioned to patients. Twenty-five per cent of patients with cancer were not identified for a palliative approach.

Patients with organ failure died on average six years (317 weeks) after diagnosis. Those who were formally identified for palliative care were identified 13 weeks (median) before death. Referrals to specialist palliative care were made five weeks (median) before death. Figure 3 highlights a very long gap before patients were formally identified for palliative care, and even then only 19% of patients were identified. Eighty-one per cent of patients with organ failure were not identified for a palliative approach.

Patients with frailty/dementia died on average three years (159 weeks) after diagnosis. Those who were formally identified for palliative care were identified only 2.4 weeks (median) before death. Specialist palliative care referrals were made, on average, two weeks before death. Figure 4 highlights an exceedingly long gap before palliative care was formally introduced, and even then it was only introduced to 20% of patients. Eighty per cent of patients with frailty/dementia were not identified for a palliative approach.

**Statistical analysis**

Analysis of the outcome ‘identification of patients for a palliative care approach’ by illness trajectory showed that patients with cancer were significantly more likely to have been formally identified for a palliative care approach and included on the PCR compared with those with organ failure ($\chi^2(1)=114; p<0.001$; odds ratio [OR]=12.6) or frailty/dementia ($\chi^2(1)=106; p<0.001$; OR=11.7). Seventy-five per cent of patients with cancer were formally identified for palliative care, compared with just 20% of those on the other two trajectories (see Table 1). Patients on a frailty/dementia trajectory were placed on the PCR significantly later than those with cancer ($U=1,551; p=0.002$) or organ failure ($U=357; p=0.038$).

Analysis of the outcome ‘referral of patients to specialist palliative care’ by illness trajectory showed that the proportion of patients referred to specialist palliative care was also significantly higher among those with cancer than among those with organ failure ($\chi^2(1)=127; p<0.001$; OR=18.4) or frailty/dementia ($\chi^2(1)=149; p<0.001$; OR=41.3). Approximately 69% of patients with cancer were referred to specialist
palliative care, compared with 11% of those with organ failure and 5% of those with frailty and/or dementia. Median time between referral to specialist palliative care and death did not significantly differ across illness trajectories (H(2)=1.6; p=0.45).

Subgroup analysis using the Supportive and Palliative Care Indicators Tool
The SPICT was retrospectively used to estimate the proportion of patients who would have been formally identified for palliative care had this tool been used. The computerised primary care patient records of 310 deceased patients across three practices were examined in depth. Analysis showed that using the SPICT would have potentially increased the identification of patients with cancer from 77% to 88%, of those with organ failure from 28% to 80%, and of those with frailty and/or dementia from 18% to 88%.

Qualitative findings
Six GPs, three district nurses and two practice nurses took part in face-to-face interviews lasting between 20 and 40 minutes.

Facilitating factors for the formal identification of patients for palliative care
The interviews showed that identifying patients for palliative care was fairly straightforward in those with cancer, who typically had a clear terminal phase.

‘You link cancer or advanced cancer with imminent death and palliative care much more readily, historically, than these other diseases. Of course that’s not quite right.’ (GP 1)

Clear practical guidance, specific tools, frequent multidisciplinary practice meetings and alerts from the hospital that palliative care is indicated were helpful.

‘We’ve got various tools, advance care plans. I think people are aware of this question where you ask yourself, “Would you be surprised if …?” and if the answer is “No, I would not be surprised”, then [people know that palliative care is indicated].’ (GP 2)

‘During that meeting, we don’t just go through the palliative care list. [...] There’s opportunity for anybody who wishes to bring up any problems to discuss [those patients] who are not on that list or who may be heading towards palliative care.’ (GP 1)

‘If someone else [that is, a hospital specialist] has made that [palliative] diagnosis, then this is obviously a prompt [for inclusion on the palliative care register].’ (GP 2)

Other factors helping in the identification of patients for palliative care were national guidance and payment structures.

‘I suppose the DES [direct enhanced service] has become more predominant within the contract. It’s like you need to kind of push people to be doing it a wee bit [more], a wee bit sooner. People are just a bit more aware of it and we have the [palliative care multidisciplinary team] meeting every week.’ (GP 2)

Patients requesting information about their prognosis and future care, or occasionally patients themselves requesting referral to palliative care, further facilitated specialist palliative care input.

Identifying patients for palliative care was fairly straightforward in those with cancer

<table>
<thead>
<tr>
<th>Number and percentage of patients identified for palliative care and referred to specialist palliative care, and median time before death</th>
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<tr>
<td>Cancer (n=200)</td>
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<tr>
<td>Number of patients identified for palliative care (ie, placed on the PCR)</td>
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<tr>
<td>% of patients identified for palliative care</td>
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<td>Median time between identification and death (weeks)</td>
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<tr>
<td>Number of patients referred to SPC</td>
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<td>% of patients on the PCR referred to SPC</td>
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<tr>
<td>Median time between referral to SPC and death (weeks)</td>
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PCR = palliative care register; SPC = specialist palliative care
‘Sometimes it’s something that patients ask about, or their family ask for information about having out-of-hours [care] and we discuss [placement on] the palliative care register.’ (GP 3)

Challenges to the formal identification of patients for palliative care
From the interviews, it also emerged that a reluctance to discuss issues around death and dying hindered open end-of-life conversations. Both patients and some professionals struggled with palliative care concepts and the negative connotations associated with words such as ‘palliative’, ‘hospice’, ‘resuscitation status’ and ‘Liverpool Care Pathway’.

‘The word palliative – they don’t know what it means, or [they think] that it’s just [something used] to pacify [them].’ (Practice nurse 1)

This in turn led to reluctance to initiate conversations, which impeded formal inclusion on the PCR.

‘[People may have] a perception that the patient may not be willing to accept it, but [they do] not actually test it out or broach it with the patient.’ (GP 3)

Having open end-of-life conversations was even more challenging in patients with non-malignant disease, who often have a relapsing, uneven trajectory with no clear terminal phase.

‘It remains more challenging to bring up palliative care issues with patients with, for example, heart failure or COPD [chronic obstructive pulmonary disease].’ (GP 1)

‘You could end up with half the nursing home on the palliative care list … and maybe they should be!’ (GP 1)

The cumbersome paperwork involved in adding patients to the palliative care register was also a hindrance.

‘The ePCS [electronic palliative care summary] … it is a clunky bit of software.’ (GP 3)

Suggestions to improve identification of patients
All interviewees expressed a need for simpler, practical guidance on how and when to identify patients.

‘Some more guidance or prompts [would be useful].’ (GP 1)

They also stressed the need for more training in identifying and managing the palliative care needs of patients in the community.

‘I think [we need] regular updates on issues that we should be discussing with patients, to make sure that we’re all remembering to do all that and do it well.’ (GP 1)

Most interviewees mentioned that a more open discourse about end-of-life care in society would make it easier for them to discuss palliative care with patients.

‘You could look at making sure it’s spoken a bit more openly about dying, as a nation; that, from the bigger picture, would be helpful.’ (District nurse 1)

Discussion
Principal findings
Around 75% of patients with cancer were formally identified for palliative care, but only in the last weeks of life. Among those with non-malignant disease, only 20% were formally identified and, again, only in the last weeks of life. Formal identification remains late for all conditions and closely associated with – and sometimes triggered by – referral to specialist palliative care. The extensive white areas in Figures 2, 3 and 4 indicate visually that most patients in the last years and months of their lives are not formally identified for palliative care. If patients are identified, this occurs much later than the WHO recommends.18

Strengths and limitations
We interviewed staff members from a range of general practices with varied sociodemographic characteristics. This allowed us to interpret the quantitative data using the perceptions of local primary care staff. Interviewees shared similar concerns and no new themes emerged in the final interviews. The fact that the researcher was a GP helped facilitate rapport and speedy and meaningful interviews. Wider quantitative data from the region are consistent with the findings.8

However, this was a small Scottish study in general practices. Data concerning the use of other services (care from district nurses, organ failure nurse and care home staff) for patients who had not been identified for a palliative care approach were not captured. Some patients may have benefited from some aspects of supportive and palliative care without being placed on the PCR.
In patients with multiple morbidities, we identified the dominant trajectory. Deciding whether to allocate patients to the organ failure or the dementia/frailty trajectory was sometimes difficult, but misallocation would have had little impact on our conclusions.

The results of the retrospective use of the SPICT must be interpreted with caution, as it is designed as a prospective tool.

**Comparison with other studies**

This was the first UK study to specifically examine the point at which patients are formally identified for palliative care. We showed that patients in the UK are formally identified at a late stage, which is similar to findings reported in US studies.10,19

Our study also confirms previous research showing that few patients with non-malignant disease are formally identified for palliative care despite much evidence of need,8 and that this inequality continues despite evidence of need for over a decade.20

Our study quantified the short time between referral to specialist palliative care services and death, as previously described in the UK21 and beyond.19

The data from the interviews support the results of a Dutch study highlighting barriers to identification.22 In line with previous work, we also report a need for practical guidance and training on how and when to identify patients for palliative care support, as well as the continuing association of the terms ‘palliative care’ and ‘hospice’ with dying soon.23 Interviewees called for a more open discourse about death and dying in society and supported recent government initiatives in healthcare that promote palliative care, in Scotland (www.goodlifedeathgrief.org.uk) and in England (www.dyingmatters.org).

**Meaning of the study and implications**

We have shown that only a minority of patients are formally identified for palliative care and that identification, when it occurs, occurs late – although we cannot say that patients are definitely not receiving any supportive care before formal recognition.

Holistic, patient-centred care is a tenet of general practices in many European countries.24,25 Scottish patients with a new cancer diagnosis were recently found to have seen a member of the primary healthcare team, on average, ten times in the first year after diagnosis.26 In the Scottish practices from which our sample was drawn, most patients with various long-term conditions were being reviewed annually, in accordance with the UK Quality and Outcomes Framework (QOF). The QOF reimburses staff for undertaking specific activities, such as screening patients with dementia or heart failure for depression and providing them with information.

Moreover, different regions in the UK have different local enhanced services (LESs). For example, in patients who have had an acute admission for COPD, LESs may involve routine assessment by a community nurse and the introduction of an anticipatory plan. An LES for care homes may involve needs assessment and care planning for all residents. This means that elements of palliative care, such as identifying psychological distress and carrying out anticipatory planning, are being implemented and documented in many UK practices before placement on the PCR.

Unfortunately, assigning the patients to the PCR is often delayed, and this may be related to a reluctance of healthcare professionals to conduct an open conversation with the patient about the possibility of dying, lest the patient becomes more anxious and distressed.

Recent theoretical and empirical work around illness trajectories13 has impacted on national policies: today, a palliative care approach is considered relevant, on average, about one year before death. In England, the ‘Find your 1%’ campaign27 encourages GPs to identify their 1% of patients who have a year or less to live. One year is much longer than the average length of time found in this study – seven weeks – between the moment when patients were identified for a palliative care approach and placed on the PCR and the time of death.

Any campaign to encourage early recognition of the dying phase must emphasise that the purpose of a palliative care approach is to provide more clinical, emotional and practical support to patients and their families, rather than to withdraw treatment. Adequate staff training is also vital to prevent controversies such as that that has recently surrounded the Liverpool Care Pathway for the Dying Patient.28 A palliative...

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Care management should improve end-of-life care and help prevent futile treatments.29

We have also reported tentative findings about the SPICE: if this tool had been applied, more patients, especially non-cancer ones, would have been identified for palliative care. This suggests that clinicians could potentially identify more patients who might be suitable for inclusion on the PCR. Similar tools designed to help clinicians identify patients are currently being developed and tested internationally.23,30

Conclusion

Palliative care is often initiated too late and understood as being the care given when a patient appears to be starting a terminal decline. The formality of identifying appropriate patients and the difficulty of raising the fact that they might die soon are important barriers. A gradual, holistic and anticipatory approach in caring for people with long-term conditions may be more acceptable to patients and their families, as well as to professional carers, than the sudden introduction of palliative care.

Further work in quantifying and qualifying this informal phase could help to clarify existing patterns of care, as well as a framework for initiating acceptable holistic and anticipatory care towards the end of life. Meanwhile, simple practical guidance, support from palliative care specialists, simpler computer software and resources to support the palliative choices of patients and families would all enhance identification.

Also read the editorial comment by Adam Firth on page 213.

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Contributors

All authors helped design the study, were involved in analysing the interviews and drawing out the main themes, and contributed to writing the paper. Lilin Zheng conducted the research and Scott A Murray and Anne M Finucane assisted her with analysis. All authors read the final manuscript. Scott A Murray is the guarantor.

Declaration of interest

The authors have no competing interests to declare.

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Lilin Zheng, Primary Palliative Care Research Group, Centre for Population Health Sciences, University of Edinburgh Medical School; Anne M Finucane, Research Facilitator, Marie Curie Hospice; David Oxenham, Medical Director, Marie Curie Hospice; Peter McLaughlin, Strategic Programme Manager, Lothian NHS Board, Department of Strategic Planning; Hazel McCutcheon, GP Lead for Cancer and Palliative Care in Lothian, Muirhouse Medical Group; Scott A Murray, St Columba’s Hospice Chair of Primary Palliative Care, Primary Palliative Care Research Group, Centre for Population Health Sciences, University of Edinburgh Medical School, Edinburgh, UK

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