

# How good are we at identifying patients who need palliative care?

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## Background

Patients with all advanced progressive diseases may benefit from an early palliative care approach. Traditionally palliative care services have served cancer patients in their last weeks of life. The WHO recommends gradually phasing in palliative care from diagnosis of any life-threatening progressive illness.<sup>1</sup>

## Aims

To document, and understand variations in two key activities in Scotland

- the number of weeks before death that patients are identified for a palliative approach
- the frequency and timing of referrals to specialist palliative care.

## Design

Retrospective case note review of all patients who had died in nine GP practices in the UK over 12 months; semi-structured interviews with health care professionals; statistical and thematic analysis. Identification was defined as the patient being included on the practice palliative care register (PCR).

## Results

The nine practices yielded 684 deaths: 29% from cancer, 25% from organ failure, and 23% predominantly from frailty or dementia. The remaining patients died suddenly (19%) or from an unknown cause (4%). At death, 75% of patients with cancer had been identified formally for palliative care compared with 20% of non-cancer patients. Patients were formally identified for a palliative approach seven weeks (median) before death (Table 1). A cancer diagnosis, practice multi-disciplinary meetings, and financial incentives facilitated identification. Patients' and doctors' association of palliative care with imminent dying were barriers.

**Table 1:** Percentage and number of patients identified for palliative care and length of time identified before death according to illness trajectory

	Cancer (n=200)	Organ failure (n=170)	Frailty and/or dementia (n=160)	All trajectories (n=530)
No. identified on the palliative care register (PCR)	149	32	32	213
% of all patients identified for palliative care	75%	19%	20%	40%
Median time identified on the PCR before death (weeks)	7.3	13.4	2.4	6.6
No (%) referred for specialist palliative care (SPC)	137	18	8	163
% of all patients referred for SPC	69%	11%	5%	31%
% of patients on the PCR referred for SPC	92%	56%	25%	77%
Median time referred for SPC prior to death (weeks)	5.3	5.2	2.0	4.9

## Discussion

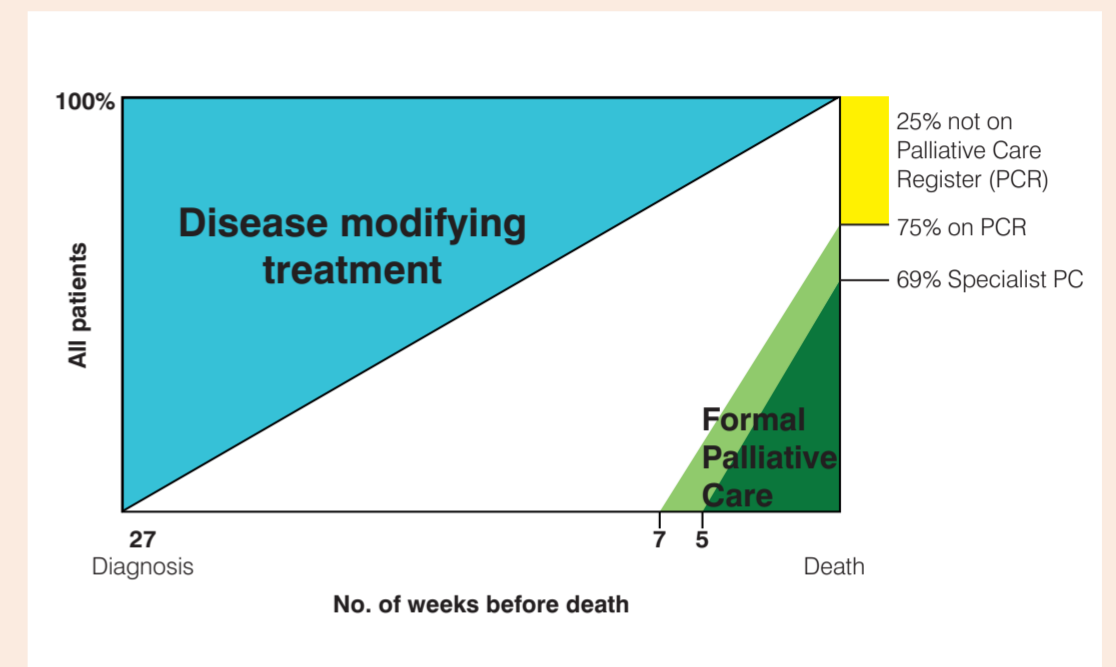
Around 75% of patients with cancer were formally identified for palliative care, but only in the last weeks of life. Only 20% of people with non-malignant disease were formally identified, and they were also identified in the last weeks. Identification remains late for all conditions and is closely associated and sometimes triggered by referral to specialist palliative care. The extensive white areas in figures indicate visually that most patients in the last months and years of life are not formally identified for palliative care. If they are identified, this identification is much later than the WHO recommends. Many patients in this white area may suffer from a care gap.

## Conclusion

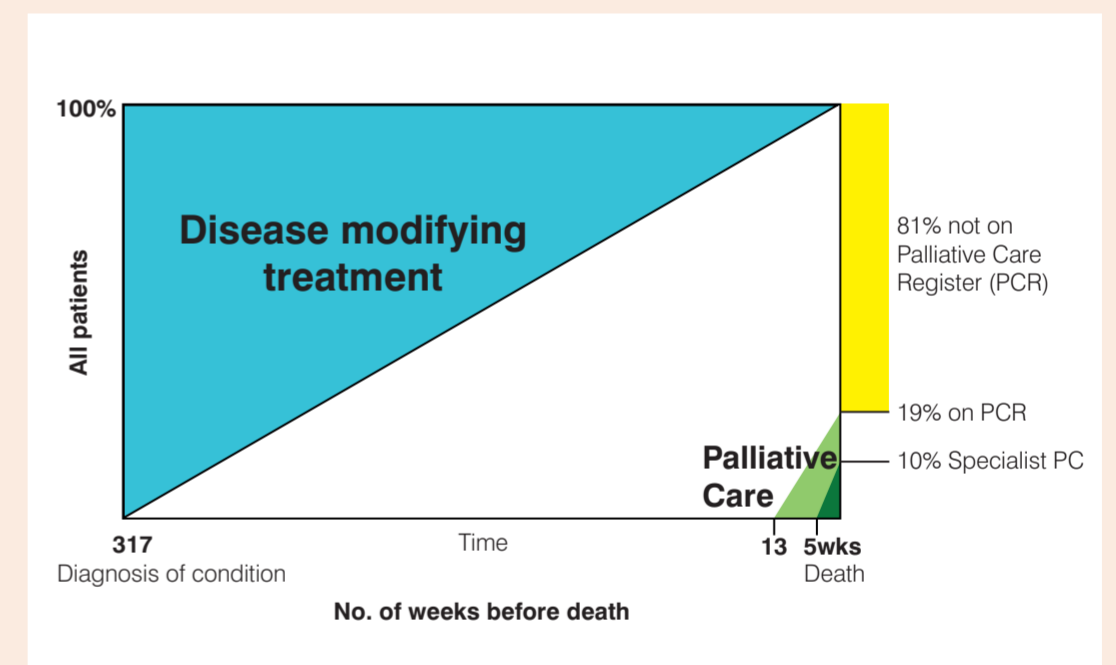
Initiation of palliative care is often too late and often synonymous with care when a patient appears to be starting a terminal decline. The formality of identifying appropriate patients and raising the fact that they might die is a barrier. A gradual holistic and anticipatory approach in caring for people with long-term conditions may be more acceptable to patients and their family and professional carers than the sudden introduction of "palliative care."



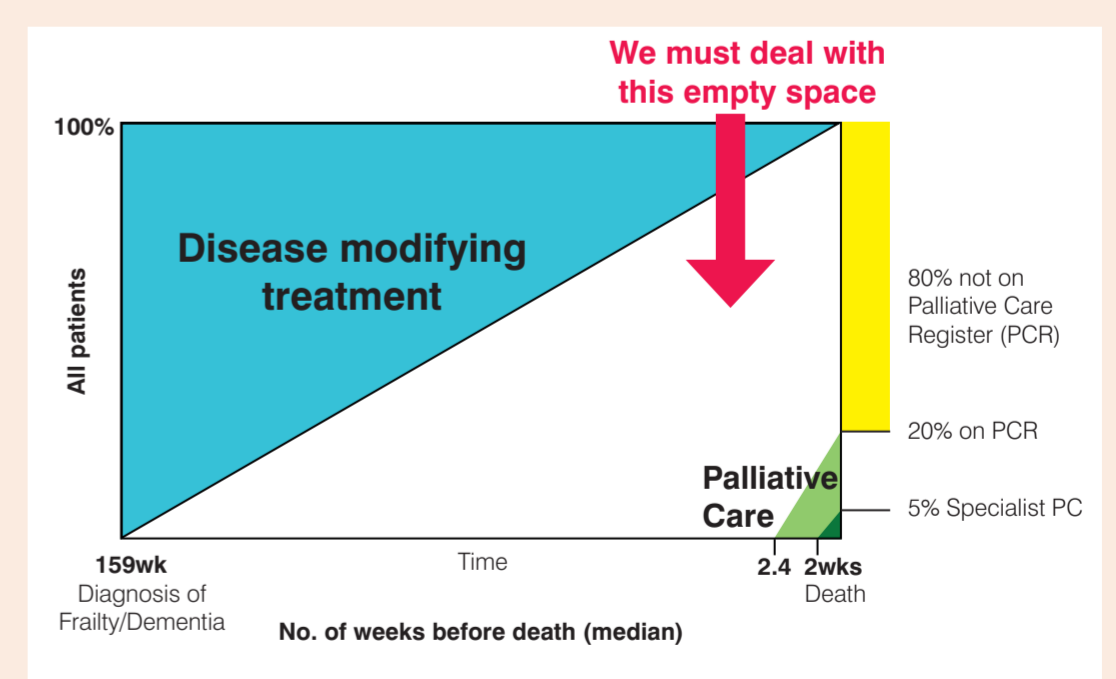
**Cancer Trajectory:** percentage of patients identified for palliative care and time before death they are identified



**Organ Failure:** percentage of patients identified for palliative care and time before death they are identified



**Frailty/Dementia:** percentage of patients identified for palliative care and time before death they are identified



**References:** <sup>1</sup> Murray SA, Kendall M, Boyd K, Sheikh A. Illness trajectories and palliative care. *British Medical Journal*. 2005(7498):1007.

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