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The importance of recognising dying: audit and subsequent service developments to improve earlier recognition of the dying patient

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Abstract

Early recognition of the dying patient leads to better end-of-life care for patients and their relatives. In 2019, the National Audit for Care at the End of Life (NACEL) identified several areas for improvement in a large NHS acute trust, including delays in recognition of the dying patient. The audit showed that in this trust, 22% of dying patients were only recognised to be dying in the last 8 h of life compared to 17% nationally. This has significant consequences on the quality of end-of-life care.

This article examines the challenges associated with recognising when a patient is approaching the end of life and highlights the significance of timely identification. In response to the findings of the 2019 NACEL audit, the Trust introduced several service developments, including the expansion of palliative care services, enhanced staff training with an emphasis on early recognition of dying and improved processes for referring patients to palliative care. We have used descriptive statistical analysis, which is appropriate for an audit-based evaluation.

A subsequent reaudit conducted in 2022 demonstrated significant improvement; the proportion of patients for whom dying was recognised less than 8 h before death decreased from 22 to 10.4%. Additionally, in 94% of cases, it was acknowledged that the patient may be dying, an increase from 85% in 2019. This article will summarise the key findings from NACEL, discuss their implications and outline the interventions implemented that contributed to these improvements.

Keywords: *advance care planning*; *attitude to death*; *hospital referral*; *palliative care*; *quality improvement*

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Recognising dying early is essential, as it provides better care for patients and clarity of purpose for staff and reduces distress for relatives. The 2019 National Audit of Care at the End of Life (NACEL) revealed a delay in recognising dying in our hospitals compared to the national average. This article summarises the key NACEL findings, their significance and the actions taken to improve results at County Durham and Darlington NHS Foundation Trust (CDDFT). It explores the challenges related to recognising the dying patient and the importance of getting it right.

Method

The National Audit of Care at the End of Life [1] (NACEL) is a national comparative audit of the quality and outcomes of care experienced by the dying person and those important to them during the last admission leading to death, aimed at improving the quality of care for dying adults in the NHS. The audit questions are derived from 'One Chance to Get It Right' [2], a 2014 UK national report on care at the end of life and the NICE Quality Standard 144 [3] to ensure high-quality of care at the end of life.

The audit includes the following population: all adult patients in a hospital where death is anticipated in the next few days, and this study compares it to the standard that dying should be explicitly recognised, documented and communicated to families (and if appropriate, to patients) as early as clinically feasible.

Following the 2019 NACEL results, the trust initiated a series of interventions aimed at improving areas of palliative care provision. These are fully described in the interventions section later.

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The survey has been conducted annually since 2018, except in 2020, due to the COVID-19 pandemic, and in 2023, when the audit tool was redesigned. Data are collected through four primary methods: (1) a bereavement survey completed by relatives; (2) a case note review assessing 10 indicators of care, including recognition of dying, timeliness of review and patient demographics; (3) a hospital-level overview focusing on the palliative care team, staff training and quality and outcomes at the site; and (4) a staff survey completed by individuals involved in the care of dying patients. This blend of quantitative and qualitative data enables a comprehensive analysis of the numerous, nuanced aspects of end-of-life care in the acute hospital setting.

Following analysis, the data are disseminated to each trust, enabling comparison with national performance standards and providing tailored feedback to identify areas for improvement and guide service development. Information in this paper is principally derived from the case note review and the bereaved relatives survey.

Results

Data from the 2019 audit showed that of all the audited hospital deaths in CDDFT, 85% were noted to be at risk of dying imminently (i.e. within hours to days), compared to 88% nationally. Further analysis of the data revealed that the interval between recognition of dying and the time of death was significantly shorter than the national average. In 22% of cases, dying was only recognised in the last 8 h of life compared to 15% nationally. Conversely, 47% of deaths were recognised more than 2 days before death nationally compared to 34% in CDDFT. The mean time from recognition of dying to death in our sample was 50 h; the median was 28 h Figure 1. Nationally, the mean was 89 h; the median was 41 h.

Importantly, in CDDFT, 70% of patients were unconscious or lacked capacity when recognised to be dying, which is a higher proportion than the national average of 59%. This is likely to be a consequence of late recognition of dying and reduces the opportunity for patients to be involved in discussions surrounding their wishes for end-of-life care.

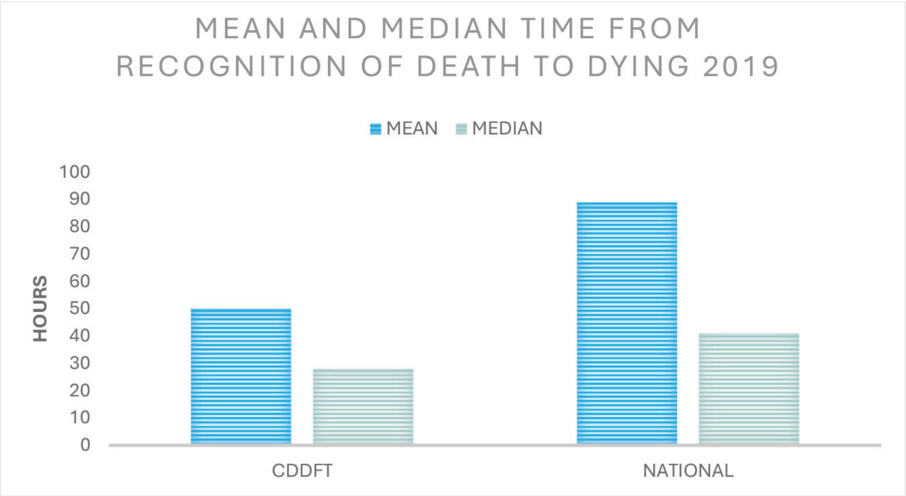
Feedback from bereaved relatives provides context for these figures and demonstrates the importance of early recognition that a patient is dying, as well as the clarity with which this is communicated. For the relatives, when imminent death is not recognised or clearly communicated, there is uncertainty about what is happening, possible delays in visiting for other family members, the grieving process can be more traumatic and this can lead to dissatisfaction surrounding care and complaints.

A quote from a family member embodying this message from the 2019 NACEL VOICES survey of bereaved relatives:

> *'I feel we were all misled; always told he had a chance of survival. The last week was horrific he was in a lot of pain, had we known he was going to die then we would have liked to have brought him home we were not given this option'.*

For staff, there can be a lack of clarity on the aims of care and conflicting messages. Inappropriate treatments and investigations may be carried out due to the absence of a clear direction of care, resulting in an inconsistent message being communicated to the patient and their relatives.

When the dying patient is recognised in a timely manner, and the appropriate care is given to the patient and their family, overwhelmingly positive feedback is received. The following are some quotes from relatives who had a positive experience of end-of-life care in hospital.



[AQ7] *Fig. 1.* Mean and median time from recognition of dying to death in CCDFT and nationally from the 2019 NACEL data.

> *'My late father's care was the best it could have been… Fortunately we were allowed to stay within him for the last 24 hours of his life, and we were looked after with love by ward staff both day and night'*
>
> *'All the staff were wonderful and nothing was too much trouble. It made a difficult situation a little easier to cope with. I just hope when it is my turn to leave this world that I have the same level of care and compassion'*
>
> *'Excellent staff made a terrible time more comfortable for my father and the whole family'*

Interventions

In response to the audit results, the Palliative Care Service at CDDFT implemented a range of changes, with a specific focus on earlier recognition of patients nearing the end of life. All these changes were aimed at reducing barriers to discussion about palliative care and increasing awareness of the importance of earlier recognition. There is a presumption that the involvement of a specialist palliative care service increases the chances of earlier recognition of dying and, subsequently, positively impacts the quality of end-of-life care.

Immediate access to senior palliative care advice 24/7

Previously, out of hours palliative care consultant advice was obtained from another clinical organisation, and staff would need to speak to a nurse and middle-grade doctor before they were able to access consultant advice. In 2020, the trust moved to an inhouse consultant led on call system, accessible to all clinicians by phoning a single widely advertised mobile phone number. This ensures that senior advice was easily accessible for all clinicians throughout the day and night.

Automatic referral systems

Automatic referral systems are increasingly recognised as both useful and acceptable as a way of identifying patients who may be appropriate for palliative care team review [4]. Electronic patient records (EPRs) facilitate the automatic creation of referrals when a clinician performs specific actions within the patient record. With the introduction of a new EPR (electronic in 2022), automatic referrals to palliative care were created for the following:

- a change of escalation status to end-of-life care
- prescribing of 'anticipatory medications'
- Readmission of a patient previously known to the specialist palliative care service.

This is a further step in removing barriers to palliative care team involvement and allows the Specialist Palliative Care Team (SPCT) to be involved earlier in a patient's admission and as soon as possible when dying is recognised by the treating team.

Palliative care training and support for acute intervention team

From 2016, the hospital Acute Intervention Team (AI Team) (a modified form of Critical Care Outreach Team) received comprehensive training in palliative care, with an emphasis on the identification of and support for patients nearing the end of life. This training enabled them to identify patients whose deterioration was irreversible and who were approaching the end of life, leading to the timely initiation of appropriate palliative care. The updated referral process also empowered the AI Team to directly initiate referrals, thereby minimising delays in obtaining specialist palliative care input. From 2019, the AI Team promoted the earlier recognition of dying.

Direct referral to palliative care is available to all clinicians

Before 2019, a referral to the hospital palliative care service required the agreement of the patient's consultant, which created a delay in the referral process and subsequent discussions around end-of-life care. Furthermore, it did not acknowledge the expertise of nursing, allied health professionals and resident doctors in recognising a patient who is dying or has specialist palliative care needs. The referral process was modified to allow any clinician to refer a patient to a specialist in palliative care. A referral can be made through a short form within the EPR system, without the requirement of consultant agreement (though discussion with the consultant, if available, is still encouraged). This enables any clinician who is concerned that a patient may be dying to refer directly to the palliative care service.

Staff education with a focus on recognition of the dying patient

Improving staff education on the indications that a patient is ill enough to die leads to earlier recognition of the dying patient and subsequently improves communication of this with patients and their families, enabling a consistent message and a clear direction of care.

Key messages for this programme of education:

- **Listening to others to aid recognition of the dying patient.** The NHS workforce comprises a diverse range of professionals, each with a distinct set of skills and unique expertise. Nurses, through their continuous patient contact and clinical experience, may be particularly adept at recognising subtle signs a patient is approaching the terminal phase, with Health Care Assistants [5] perhaps even more so. Part of the education emphasised the importance of acknowledging concerns raised by any member of the multidisciplinary team regarding the possibility of impending death. Continuity of care can be challenging due to shift patterns, making it even more important to recognise and value the contributions of every team member.

- **Do not wait for certainty.** It may be more feasible in practice to identify a patient as being 'at risk of dying' rather than making a definitive prognostic determination. This can serve as an initial signal of the seriousness of the condition to relatives and the wider clinical team. It is essential to communicate the possibility that the current deterioration may be irreversible to facilitate timely and meaningful discussions around patient preferences and the goals of treatment.
- **It is possible to combine comfort with continuing active treatments.** Adopting a dual approach – continuing active treatment whilst concurrently acknowledging the risk of clinical deterioration and employing the term 'ill enough to die' – enables healthcare professionals to communicate with families when a patient is considered at significant risk of dying, without necessitating an immediate transition to a purely palliative treatment approach.

These messages were delivered through a rolling programme of mandatory education for all levels of clinical staff, led by medical and nursing members of the palliative care team, with support from end-of-life education facilitators since 2019, and remain a key focus of the palliative care education programme.

7-day face-to-face service

Prior to 2019, a 5-day palliative care face-to-face assessment service was available. In 2021, this was expanded to a 7-day face-to-face assessment in line with UK national guidance.

Repeat audit

The audit is repeated each year (though paused in 2020 due to the COVID pandemic pressures and in 2023 whilst the audit was redesigned). The data showed that the changes implemented in previous years resulted in a significant improvement in the earlier recognition of dying. The local data from the 2022 round of data collection for NACEL found that in 94% of deaths, it was recognised that the patient may die. This compares to 87% nationally and represents an improvement from 85% locally in 2019.

47.2% of patients were recognised to be dying more than 48 h before death, an improvement from 34% in 2019 Figure 2. Fewer patients were recognised to be dying late (4–8 h before death), 10. 4% compared to 22% in 2019.

Discussion

Early recognition of the dying patient is essential, enables better care for patients and clarity of purpose for staff and reduces distress for relatives. This is emphasised in 'One Chance to Get It Right', a 2014 report that details five key priorities for the care of a dying person, and the NICE Quality Standard 144, a guideline for clinicians providing end-of-life care. Timely recognition of the dying patient can be challenging, and failure to do so can have significant consequences for the patient and their family as well as the staff providing care.

For an individual patient, a delay in recognition can mean they miss out on the opportunity to be a part of discussions surrounding their end-of-life care, as they may be unconscious or unable to communicate as they deteriorate. Appropriate symptom management may be delayed, and inappropriate interventions, such as further invasive investigations, may continue. The opportunity to transfer to an alternative care setting for end-of-life, such as hospice or the patient's own home, may also be missed.

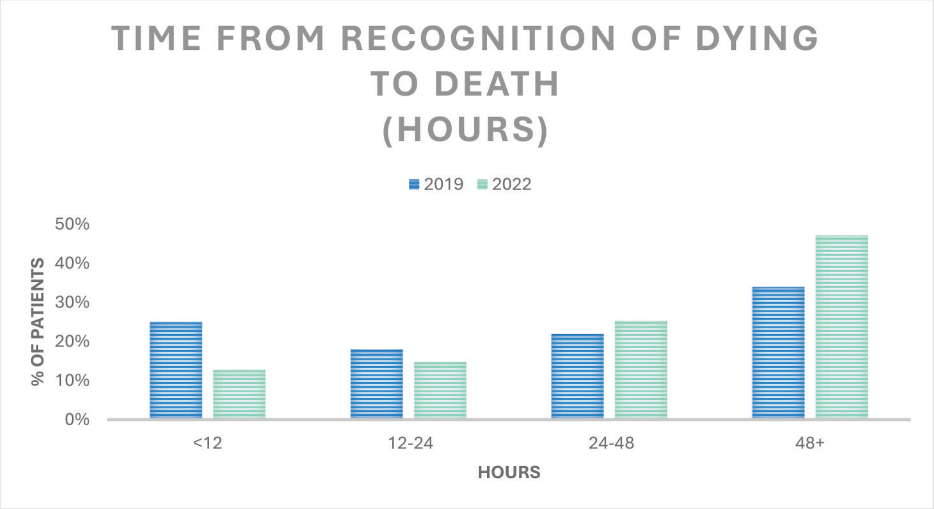


Fig. 2. Graph comparing time from recognition of death to dying in 2019 and 2022 NACEL.

Clinical indicators that a patient may be approaching the end of life include the presence of a life-threatening illness of any aetiology, evidence of disease progression or accelerating decline, multiple comorbidities, frailty, advanced age, poor response to treatment, reduced oral intake and an increasing frequency of exacerbations or repeated MET calls. A Medical Emergency Team (MET) call is initiated by a member of the clinical staff to request an urgent patient review by the on-call medical team, which typically includes the Medical Registrar, the on-call Resident Doctor and a Critical Care Outreach Nurse.

Tools such as the SPICT [6] (Supportive and Palliative Care Indicators Tool) can be used to identify patients with deteriorating health. It is essential to listen to each member of the team, who may express concerns that a patient is approaching the final phase of their illness.

Exploring the underlying reasons why recognition of the dying patient is delayed is challenging for the team. Possible barriers include: the variable disease trajectory for different conditions in each individual; lack of experience of junior staff members in observing the clues a patient is approaching the end of life; a lack of confidence in raising the issue for discussion; concerns regarding withdrawing and withholding treatments by staff, relatives and patients; cultural barriers to palliative care; and fear of foreshortening life.

The expansion of Palliative Care services, as described in the intervention section, requires support from the Medical and nursing directorates, as well as the consultant body. Adequate funding is also needed to staff a 7-day-a-week service. A potential criticism of automatic referrals is the increased staff workload; however, we have taken the view that we would prefer to be aware of all palliative patients in our trust and can take an individual approach to how much input each patient requires.

Earlier recognition and utilising the phrase ‘ill enough to die’ to acknowledge the uncertain trajectory of disease can help direct clinical care in a way that is acceptable for the patient and their relatives, allowing them to spend more time together in their preferred location of care. It ensures optimal symptom control whilst perhaps also continuing active treatments, which can lead to a less traumatic grief reaction for bereaved relatives, as well as fewer complaints about care.

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