

REFRAMING END-OF-LIFE CARE IN A CHANGING CONTEXT

The way we care for people in the last chapter of their lives has been said to be a litmus test for our society. Lifespan now outstrips healthspan, and, with increasing complexity, symptom burden, and rising mortality, the context of end-of-life care (EOLC) is changing and broadening. It is time for a new approach — a reframed, inclusive, big-picture population-based approach to EOLC to meet the challenges of the 21st century.

The year 2017 marked 50 years of the UK's outstanding hospice and palliative care services. Building on this, yet addressing the challenges of today, there is a shift in thinking towards reframing concepts of EOLC to meet the growing needs of the ageing population, and fully integrating EOLC into mainstream care by all providers.

People now live longer, with more complex conditions into old age, and with post-baby-boomer demographics our morbidity and mortality rates are rising. The era of the single disease is over¹ and with increasing frailty and multimorbidities, the focus shifts from pure survival to outcomes that matter to people. For many people quality of life is more important than quantity of life. With increased access to complex interventions towards the end of life, with potential over-medicalisation and 'physician-assisted survival', we face a new tipping point — just because we can, doesn't mean we should. There is a delicate balance here for all clinicians, particularly GPs, in orchestrating appropriate care, avoiding both over-use of hospital interventions and under-provision of care and support.

Stark differences remain between the poorest and the wealthiest in our society, and prolonged ill health pre-dates pensionable ages. Now with more protracted trajectories of decline we have more time to consider how to live well before we die² and clarify our wishes for the final stage of life. It is estimated that a third of NHS spending goes on care for people in the last year of their life. As sustainability and transformation partnerships (STPs) and accountable care organisations (ACOs) focus on improved outcomes and best use of scarce resources across wider areas, a broader whole-system approach to population-based EOLC is required.

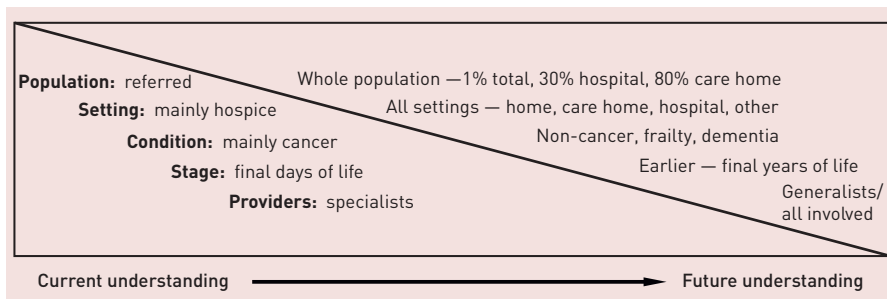


Figure 1. A population-based approach to end-of-life care.

POPULATION-BASED END-OF-LIFE CARE

Population-based EOLC builds on well-documented public health approaches to population-based medicine,³ including consideration of the whole population's current and likely future needs. The aim of population health care is to maximise value and equity by focusing not on institutions, specialties, or technologies, but on population-based systems defined around certain criteria — in this case all people in the last year of life, possibly in an STP/ACO-sized area. We still cannot answer simple questions such as, 'Is care for people in the last year of life better in Herefordshire or Worcestershire?'; better in terms of outcomes and the resources used, but we are learning more about some key differentiating factors through the excellent NHS EOLC Intelligence Network's resources.

A population-based EOLC approach includes many key elements: strategic proactive planning with early identification, whole-system thinking, value-based health care, and an inclusive approach, supported by population-based outcomes metrics, the building blocks for a national momentum of best practice encouraging and inspiring the spread of excellence across all settings.

CARE IN THE FINAL YEAR OF LIFE

EOLC, as defined in GMC EOLC guidance,⁴ NHSE Ambitions,⁵ and other national policy directives, includes care for people in the final year of life, rather than, as is often misunderstood, just the final days, extending beyond cancer care to any life-limiting condition in any setting. Holding both a population-based and person-centred approach means including every person approaching their final year or so of life in a wider area, across all settings, and including health and social care (Figure 1). EOLC is everybody's business.

IMPLICATION FOR GPs

What are the implications for GPs of this new population-based approach to meet the needs of the ageing population? Ninety-eight per cent of UK practices have QOF palliative care registers, and regular meetings to proactively discuss EOLC, based on the basic-level Gold Standards Framework (GSF), mainstreamed from 2004. However, a 2009 GSF national survey demonstrated that only a quarter of patients who died were identified on the register, and only a quarter were non-cancer patients, but that all identified patients received better coordinated care.⁶ Now, the QOF average identification rate is 34%, a significant advance.⁷ About half the population die in hospital, with a fifth in care homes, but still most do not die where they would choose. Despite significant progress we are still not recognising patients early enough to plan proactive care, although we remain the only country to have progressed this far, contributing to the UK's attainment as the best in the world in EOLC.⁸

EARLY IDENTIFICATION AND PROACTIVE PLANNING

Improved recognition and optimised out-of-hospital services could translate into significant patient benefits and NHS savings,⁹ using tools to help predict patients approaching the end of life including the GSF Proactive Identification Guidance and Needs-based Coding, used since 2004.¹⁰ Earlier identification has the potential to lead to more anticipatory, crisis-preventing care of patients in their last year of life. This includes about 1% of the population, 30% of hospital patients,¹¹ and an estimated 80% of care home residents considered to be in their last year of life. A more realistic population-based estimate, anticipating those likely to die in the coming year with any condition in any setting, is more likely to

ensure greater provision of patient-centred equitable care.

What are the advantages of early identification? In addition to cost-savings and better use of resources, early recognition leads to better patient outcomes. There has been much focus on enabling greater choices for people nearing the end of life,¹² particularly in place of care, with greater control and self-determination, ensuring optimal quality of life and death. Earlier identification enables a more proactive, less crisis-led approach, helping create the space leading to greater attainment of such choices, and smoother planning of care in anticipation of later decline.

NEXT-STAGE GSF AND ACHIEVEMENTS OF ACCREDITED PRACTICES

GSF Gold and Silver Programmes advocate earlier identification and using needs-based coding to trigger specific tasks related to each phase of illness. This includes offering early advance care planning discussions to identified patients on the register, thereby increasing the chances of people's wishes being met. But is such an approach possible in primary care? Findings from the first GSF RCGP-accredited Frontrunner practices demonstrate that this is possible.¹³ On average two-thirds were identified early and offered ACP discussions, with evidence of reduced hospitalisation and more home deaths.¹⁴ Other examples of progress in wider population areas include use of electronic registers, with some GSF cross-boundary care sites demonstrating cumulative effects of proactive care across all settings, with population-based EOLC metrics being piloted, which might support STP area-wide future planning.¹⁵

IMPLICATIONS OF A POPULATION-BASED APPROACH

So how might this population-based approach to EOLC change things? Greater public awareness can help raise the issue of EOLC discussions and earlier planning within families rather than just at the point of medical interventions, for example, with user-friendly Dying Matters materials (<http://www.dyingmatters.org>) or a simple de-medicalised approach to public awareness, such as the GSF 5-step video.¹⁶ Primary care teams might consider whether their register reflects their local population, checking their identification rates of patients with non-cancer, from care homes, or ethnic minorities.

They may also consider how to anticipate and plan care for increasing numbers of patients in the final years of life, many with dementia, supported by improvement

initiatives such as GSF Gold and Silver Programmes with RCGP co-badged accreditation,¹⁴ local CCG incentives or locally enhanced services, or others. Inevitably, there will be a need to re-allocate funding to match the shift towards more home-based care so GPs involved in commissioning might consider increasing investment in community services, such as district nurses, night sitters, and domiciliary care, preventing expensive avoidable hospital admissions. The stark and worrying decline of the community nursing service is particularly significant in some areas, leading to inevitable over-hospitalisation.¹⁷

A population-based, person-centred approach is not just possible but, we argue, is necessary for future planning to meet the needs of our ageing population. This issue is not going away. It consumes billions of pounds of NHS resources and has considerable effects on the lives of us all — as patients, carers, the bereaved, and all affected by the death of someone close. We need to face our mortality as people and as populations, affirm the importance of proactive, population-based, person-centred care, celebrating and affirming life before

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death, while also ensuring a good death, so that: '... when your time comes to die make sure dying is all you have left to do'.

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Provenance

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Competing interests

Keri Thomas is clinical lead and employee of the GSF Centre in End of Life Care, a not-for-profit voluntary-sector Community Interest Company, which emerged from the NHS in 2010, dedicated to improving end-of-life care in all settings.

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