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A health economics response to the review of the Liverpool Care Pathway

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Abstract

Background: In 2011 the Palliative Care Funding Review highlighted concerns about the funding, provision and quality of care at the end of life. Two years on, an Independent Review of the Liverpool Care Pathway – prompted by a storm of negative media coverage – has raised concerns around a lack of: funding, availability of support for the dying and their relatives, and patient centred care. There are recommendations to increase funding through a national tariff for palliative care services, address inconsistencies, and replace the Liverpool Care Pathway with individual end of life care plans.

Objective: This paper explores the economic implications of the review's recommendations and links these to inadequacies with the current economic framework currently recommended for use in the UK by the National Institute for Health and Care Excellence, before highlighting aspects of ongoing research aimed at addressing these inadequacies.

Methods: As well as the published report '*More Care, Less Pathway*', we draw upon preliminary qualitative evidence from 19 semi-structured interviews conducted with academics specialising in economics and/or end of life care.

Conclusions: Whilst there is a need for increased funding in the short-term (highlighted in recent reviews), increasing funding to services which have little evidence base appears to be an irresponsible long-term strategy. Hence there should also be increased investment in research and increased emphasis in particular on developing economic tools to evaluate services.

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Background

The Palliative Care Funding Review (published in 2011) highlighted the importance of ensuring 24/7 access to services, integration of services across health and social care, a reduction in inequalities, , and a simplified/standardised funding model¹. Two years on and attention has turned to Baroness Neuberger's review of the Liverpool Care Pathway (LCP). The LCP relates to the last two to three days of a patient's life, and so this latest review is somewhat narrower in its focus, but (as can be seen from Table 1) there are striking similarities nonetheless.

[Insert Table 1 here]

This paper highlights the economic implications of the LCP review (in the context of broader issues identified through interviews with stakeholders), sets out reasons why the most widely used health economics framework is ill-equipped to deal with the complexities of end of life care, and introduces work which aims to expand the health economist's toolkit.

As part of the European Research Council funded Economics of End of Life Care (EconEndLife) project, 19 semi-structured interviews have been conducted to date with academics representing a number of disciplines (health economics, health psychology, nursing, clinical and allied health professions). University ethics approval was obtained for the interviews, which have been transcribed and analysed using constant comparative analysis.

Economic issues around end of life care

Healthcare is an economic good in the sense that delivering more of one type of care (from a fixed budget) displaces care elsewhere in the system. To inform policy-makers about resource allocation decisions, health economists in the UK and other countries use quality-adjusted life years (QALYs), which incorporate length of life and societal values reflecting health-related quality of life. The QALY is a widely used practical tool, but has a number of limitations which make it particularly restrictive in the context of end of life care. We match the limitations of the QALY to recommendations from the LCP review.

Perspective:

The LCP review states that clinicians bear some responsibility for relatives and carers as well as patients^{2, p9}. As well as recommending that funding be made available to improve accessibility of services to support relatives caring for patients at home, the review recommends that greater attention be given to the welfare and privacy of relatives in the period immediately after death. The stakeholders we interviewed also acknowledged the hugely important contribution of and need to support unpaid carers.

...whether the carer felt well supported... IS an end of life care outcome because you see the patient and the family as an indivisible unit. (ID8, Nursing)

However, in line with the National Institute for Health and Care Excellence (NICE) reference case, health interventions are currently evaluated only with respect to costs incurred through providing health or social care services and changes in patient outcomes³. The emotional, psychological or even health impact on family and carers would not usually be captured or included, suggesting that no priority would be given to funding services with these objectives.

Economists are only in the early stages of suggesting how non-patient outcomes would be measured or included conceptually in their analyses.

Non-health outcomes

The LCP review makes reference to a person's dignity and to clinicians being mindful of the emotional, social and spiritual needs of dying patients². Just as the LCP review places emphasis on the importance of non-health outcomes, so did the stakeholders interviewed as part of the EconEndLife study, with common examples of broader outcomes being social aspects/relationships, spirituality/meaning making, and accomplishing goals. Other suggestions included dignity and identity. If these outcomes are to carry weight in economic evaluation then they need to be incorporated into the quality ('Q') element of the QALY.

The Q in QALYs is typically assessed using generic health status classification systems, such as the EQ-5D (recommended by NICE in the UK³), which assesses health in terms of: anxiety and depression; pain and discomfort; usual activities; mobility; and self-care⁴. Whilst economic instruments such as the EQ-5D may be too limited in their focus (failing

to capture aspects such as spirituality), condition-specific measures currently available are not helpful for economic evaluation as they are too long to easily attach values to, and/or are insufficiently generic (for example focusing on particular groups of patients at end of life)⁵.

In our interviews, those favourable to the QALY felt that restricting the focus of economic evaluation to health alone is appropriate. Some felt that the use of QALYs in-line with the NICE reference case is as appropriate in the context of end of life care as it is for other temporary health states where the focus is on maximising health (for example by relieving pain) rather than extending life.

...I don't think there's anything particular about end of life care that makes the EQ-5D strong or weak ...[T]he driving force is always going to be around how we extend life and improve quality of life. (ID12, Health Economist)

Others expressed the view that the inevitability of declining health and importance to the patient and family of broader outcomes makes end of life care different and the use of the QALY, as it is typically operationalised, problematic.

...inevitably they're going to get sicker as they approach death so if you're using as an outcome measure how sick they are, all of our studies are going to fail (ID4, Health Psychologist)

Some health economists suggested the QALY framework, despite having the potential for broad use, is too restrictive in its current form. Stakeholders also raised concerns about the 'LY' element of QALYs, an issue which has been debated elsewhere^{6,7}.

Generally, a fundamental question to address is whether society deems the maximisation of health to be the sole legitimate objective of the health system. If the objectives of services funded from a fixed healthcare budget are to include broader outcomes and processes how these are to be traded off against health gain?

(Lack of) a national tariff for palliative care services; the tip of the iceberg

Both reviews recommend the establishment of a national Payment by Results (PbR) tariff for palliative care services. PbR is a "payment system in England under which

commissioners pay healthcare providers for each patient seen or treated, taking into account the complexity of the patient's healthcare needs.”⁸ Guidance by the Department of Health states that: “Not all services ...have a national tariff, for a number of reasons, including the quality of available costing and activity data”^{9, P15}. Lack of a mandatory tariff has meant some Trusts operating palliative care services as loss making activity¹. The lack of available data may arise in part from inconsistency in the delivery of palliative care services and complexity in the funding model, as highlighted by the Funding Review. We would expect to see a link between the provision of healthcare services and available evidence relating to clinical and cost-effectiveness, but the development of an evidence base in the context of end of life care is hindered by the practical and ethical difficulties of conducting trials, a perceived lack of health economics interest, and, as some stakeholders suggested in our interviews, by a lack of funding:

...there's... different models of care in place, some of which have been tested and others not... we're still a long way off having good investment in research in palliative care. Let alone health economic evaluations in palliative care. (ID14, Clinical)

Whilst there is clearly a short-term need to increase funding for end of life care, pumping funding into services which have no evidence base seems to be an irresponsible long-term strategy. Increased funding for services should be matched by investment in research and, given the difficulty in conducting research in this context, there is a need for innovative methodology.

Rising to the challenge

There are important methodological questions around the economic evaluation of end of life care. What should be measured at end of life – for patients and the people close to them? Who should count in an evaluation? How should the benefits of end of life care be valued? Who should do this valuation? And how should the results be brought into decision making? These challenging, but important, questions are currently being tackled in the EconEndLife programme of research, the first output of which is a new measure developed to evaluate palliative and supportive care for patients, the ICECAP Supportive Care Measure (ICECAP-SCM). The instrument measures patients' wellbeing in terms of an individual's 'capability' (a term referring to ability, rather than achieved outcomes)¹⁰. The descriptive system was developed through talking to people about

what is important to them at the end of life, and covers seven attributes: Autonomy (having a say); Love (being with people who care about you); Physical suffering; Emotional suffering; Dignity; Support (having help and support); Preparation. Values for use of the measure in economic evaluation are currently being developed. Attributes capture issues important at the end of life, not or only partially captured by measures of health functioning. ICECAP-SCM will enable inclusion of more meaningful information within economic evaluations.

These methodological developments will provide a way forward for the evaluation of end of life care. Ultimately, however, the more fundamental question of whether the health budget should be spent on providing care at the end of life, even if health gain is not an outcome of that care, must be explicitly tackled. As long as health gain is the only valued outcome for organisations such as NICE, care for patients and their families at the end of life will never have the priority that recent reviews suggest it should have.

Author Disclosure Statement

No competing financial interests exist

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