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## Bringing the economic cost of informal caregiving into focus

Do specialised palliative care services improve outcomes for patients with advanced progressive illness at the end of life and their families at lower or acceptable cost compared with traditional health and social care services? Health economics research can help answer this question. Economic evaluations systematically compare the relative costs and benefits of competing options and thus provide information about how best to improve patient and family outcomes within funding constraints. Costs and outcomes are jointly considered to evaluate how best to achieve value for money from scarce resources. However, there is sparse evidence on the efficiency and equity of palliative and end-of-life care, in part due to the difficulties associated with conducting research in this context, particularly measuring costs and outcomes.<sup>1</sup>

Four papers in this issue of *Palliative Medicine* make important contributions to the study of costs in palliative care, and between them, highlight one of the key issues in measuring these costs: how to capture and value impacts on informal caregivers, often family members. In this context, an informal caregiver is someone who provides regular, ongoing assistance to a person with advanced progressive illness at the end of life without receiving payment for the care given.<sup>2</sup> Informal caregivers, not healthcare systems, provide the majority of care for people at the end of life, yet health service evaluations often ignore both the outcomes and costs borne by this group. Family members and friends are integral to palliative care service provision. Without their support, patient preferences for home-based care at the end of life would often be unachievable.<sup>3</sup> Broad social changes such as smaller, more geographically dispersed families, higher divorce rates and changing communities are likely to reduce the availability of informal caregivers at a time when demand is rising. Furthermore, as the population ages, informal caregivers may be called upon to care repeatedly but their willingness to care more than once declines with age.<sup>4</sup> These factors may be particularly important where changes in policy deliberately, or inadvertently, shift costs onto patients and their families. There is, however, limited evidence of the economic impact of caring for individuals receiving palliative and end-of-life care.<sup>5</sup>

In this edition of *Palliative Medicine*, two studies illustrate nicely the difficulties of obtaining information about the costs of informal caregiving. The paper by Bremner et al.<sup>6</sup> provides important information about costs in the last 6 months of life for patients with advanced non-small cell lung cancer. This study, using health administrative data, provides excellent information from a public payer perspective showing that these costs are slightly higher in the United States than Canada until the final month. However, the findings also highlight a major limitation of administrative datasets, as informal care costs could not be estimated due to lack of details.

The second paper by Dixon, Matosevic and Knapp<sup>7</sup> presents a systematic review of the economic evidence for advance care planning, suggesting that such evidence is ‘limited and equivocal’ with no published cost-effectiveness studies identified by the search. Among other issues, these authors highlight the lack of any estimation of informal care costs in any of the 18 papers included in the review and call for further research on the quality and economic benefits of advance care planning, including generating cost estimates of the broader impacts on social services and informal care.

Two further papers in this issue do, however, provide new evidence about informal care costs in different settings. Round, Jones and Morris<sup>8</sup> estimate the health, social and informal care costs at the end of life for lung, breast, colorectal and prostate cancer patients in England and Wales; Dumont et al.<sup>9</sup> compare public health, patient, family and not-for-profit organisational costs occurring during 6 months participation in a Canadian palliative care programme. The findings from these studies suggest that between one-fifth and one-third of the overall costs of caring for people at the end of life fall on informal caregivers. Round, Jones and Morris modelled the costs of care associated with the end-of-life period defined as the time between initiation of strong opioids and death, whereas Dumont et al. investigated costs related to palliative care in patients enrolled in a regional palliative care programme near the end of life, where approximately 72% of participants died during the longitudinal study. Furthermore, informal care costs included the value of care provided and lost employment income in the former study but only time spent providing care was valued in the latter study. The distinct

jurisdictions, healthcare systems, disparity in time period and study design may account for the difference in estimates, but nevertheless, it is clear that in both studies, the costs of informal caregiving constitute a substantial and important component of total cost.

Typically, economic evaluations are conducted from a provider or healthcare perspective, thereby excluding indirect costs on patients and families. This is for a number of reasons. Often evaluations are commissioned by private health service providers or public providers with siloed budgets, and thus there is no imperative or incentive to include indirect costs of this type (in fact, quite the opposite!). Internationally, some countries such as Australia and the United Kingdom have been slow to adopt a societal perspective in guidelines on the conduct of economic evaluations for regulatory and reimbursement purposes, impeding consideration of the broader impacts of interventions, particularly pertinent in the palliative and end-of-life setting.

The challenges of conducting high-quality research in palliative and end-of-life care are well-established. Collecting data on informal caregiver outcomes and costs places additional demands on research staff and family members at a time when informal caregivers may be emotionally and physically compromised and distress is high. Furthermore, as Bremner and colleagues illustrated, little or no informal caregiver data are routinely collected in healthcare administrative databases and acquiring such data prospectively requires additional resourcing. Finally, there are unresolved philosophical, theoretical and methodological issues such as the appropriate evaluative space (utility, health, capability),<sup>10</sup> how to allocate the costs of joint activities and care specific to palliation, the choice of informal caregiver outcome measure and accounting for interdependent and potentially conflicting patient and caregiver preferences.<sup>2</sup>

Economic evaluations in the palliative and end-of-life care setting are rare and seldom include informal caregiver costs and outcomes. We urgently need to understand how to maximise the value of palliative and end-of-life care services and how best to invest limited resources to improve population-wide outcomes, including the resource of informal caregiving. While articles published in this edition of *Palliative Medicine* both illustrate the problems in the existing literature and start to fill some of the gaps, much more research is needed. Continuing to ignore the economic burden of informal caregiving is likely to lead to cost-shifting and over-burdened family and friends, ultimately threatening the provision of high-quality palliative care. We hope that this will be one of the issues that is addressed in the forthcoming special issue of *Palliative Medicine* on the Economics of Palliative and End of Life Care. Please see our Call for Papers.

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