

Costs to informal carers for people in the last three months of life are large

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Findings from an international study into the costs and outcomes of informal end of life care have today been published *BMC Medicine*.

The study found that in the UK, Ireland and the US, care provided by informal carers, meaning family and friends, accounted for more than half of total care costs in the last three months of life.

Researchers concluded that there was an urgent need in all three countries to improve the integration and support for dedicated community [palliative care services](#) to improve the care quality and support people across the whole journey of care.

The study surveyed 767 carers in three countries about the last three months of life for the person they cared for. This is the first study of its kind and found:

- Costs to informal carers are larger than those to formal care services (health, social and voluntary combined) for people in the last three months of life.

- Poor quality home care was associated with greater burden to carers.
- If well supported informal carers can play an important role in providing care, and this can be done without detriment to them, providing that they are helped.
- Improving community palliative care and informal carer support should be a focus for future investment.

The study was led by researchers from the Cicely Saunders Institute at King's College London in collaboration with King's College Hospital Foundation Trust (UK), Trinity College Dublin (Ireland), Mater Misericordiae Hospital (Ireland), Beaumont Hospital (Ireland), University of Bristol (UK), University of California, San Francisco (USA) and Icahn School of Medicine at Mount Sinai (USA).

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In the last three months of life, formal care costs are high, but little is known about the costs of informal care and their effects on outcomes. This research is an important contribution to increasing the recognition and understanding of the effort and costs of informal carers, such as families and friends, who do so much. As well as identifying areas where support and investment could help improve care for both the patient and informal and formal carers.

The study Associations between informal care costs, care quality, carer rewards, burden and subsequent grief: the international, access, rights and empowerment mortality follow-back study of the last three months of life (IARE I study) uses the experiences reported by informal carers to determine and compare the informal care costs and their associations with the burden, rewards and

subsequent grief, taking the quality of care into account.

The study surveyed 767 carers in London, Dublin, New York and San Francisco. Participants reported the hours and activities of informal care they gave, care quality, the positive aspects and burdens of caregiving, and completed the Texas Revised Inventory of Grief (TRIG).

All costs (formal, informal) were calculated by multiplying reported hours of activities by country specific costs for that activity. Informal care costs used country-specific shadow prices, e.g. average hourly wages, unit costs for nursing care. The study also examined the positive aspects and burdens of caregiving, and the carer's subsequent grief.

Professor Irene Higginson lead of the study said: "Family and friend carers do so much in helping people who need palliative care. Alongside being a wife, husband, partner, daughter, son, friend or other relation, our study shows the huge amount of practical help, advocacy, co-ordination and 'being there' that they provide. This [costs](#) more to society that do the formal care services, and when home care is of poor quality the burden on informal carers increases."

Dr. Steve Pantilat, from the University of California, San Francisco said: "Family and friends provide tremendous help with the practical and emotional issues that people need as they approach the end of life. We know that this kind of help is priceless and unpaid. We learned that, if paid, the care provided by family and friends would cost more than all the formal care provided by the healthcare system. In addition, caregiving while seen as a privilege for many, also takes its toll on the caregiver. As a society we need to recognize and support these caregivers to keep them healthy and to allow them to continue to care for their loved ones. Palliative care services are among the ways that we can better support caregivers to improve the quality of life for them and the person they are caring for."

More information: Irene J. Higginson et al, Associations between informal care costs, care quality, carer rewards, burden and subsequent

grief: the international, access, rights and empowerment mortality follow-back study of the last 3 months of life (IARE I study), *BMC Medicine* (2020). [DOI: 10.1186/s12916-020-01768-7](https://doi.org/10.1186/s12916-020-01768-7)

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