How unpaid carers “pay” the costs of dementia

by Adelina Comas-Herrera

Our recent “Dementia UK” 2014 report for the Alzheimer’s Society, in collaboration with King’s College London suggests that two-thirds of our estimated £26.3 billion cost of dementia in the UK is shouldered by carers and people with dementia. These results, which are also discussed in Martin Knapp’s recent blog post have been reported widely in the media as a “dementia tax”, and contrasted with the fact that most of the care needed by people diagnosed with conditions such as cancer is funded publicly through the NHS.

Of the estimated £17.8 billion that people with dementia and their families bear themselves, £11.6 billion is accounted for by provision of 1,340 billion of hours of “unpaid care”. These figures may seem large, yet we know that caring for a person with dementia involves very long hours, some spent assisting with basic activities of daily living (such as getting dressed, feeding, toileting), some on household tasks (such as cooking), and many ensuring that the person with dementia is safe and comfortable. The fact that people with dementia require this “supervision” element of caring means that they tend to need care for much longer hours than people with other types of care needs.

Methodological and data challenges

It is very difficult to calculate the cost to unpaid carers – or to society more generally – of providing care. Unpaid carers, usually spouses or adult children, experience often quite heavy demands on their time, emotions and energy, which can affect their own health, employment and well-being. Understanding how to estimate the impact on carers of providing care is challenging, as it is very complex to attach a monetary value to an activity that is carried out “free of charge”. We are continuing to work on improving the methods we use to calculate the costs of unpaid care and increasingly gaining a better understanding of the implications of different methods in the case of caring for people with dementia. As we progress with the methodology, better data on the impact of caring for people with dementia on unpaid carers would enable us to improve the estimates considerably.

Unpaid care and funding long-term care

Because of the non-monetary nature of the costs of unpaid care, debates on how to finance long-term care have rarely given enough weight to the costs borne by carers, despite the fact that unpaid care is one of the largest resources that “fund” long-term care. In England, for example, there will soon be a life-time “cap” on the amounts that people have to pay towards their own social care costs, with the aim of protecting people against the risk of facing huge “monetary” costs if they need intensive long-term care for a long time. But the costs of unpaid care will not count toward the cap and as a result personal budgets will continue to be lower for people receiving unpaid care than for those without carers. This means that the cap may not give adequate protection to unpaid carers from the risk of bearing huge costs if they need to care for very long hours for an extended period of time.

About the author

Adelina Comas-Herrera is Research Fellow within the Personal Social Services Research Unit at the London School of Economics and Political Science. She is Academic Project Manager for the ESRC/NIHR-funded study “MODEM: Modelling Outcome and Cost Impacts of Interventions for Dementia”. Adelina would like to thank Martin Knapp and Raphael Wittenberg for very helpful comments on a previous draft.

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