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EDITORIALS

The need to "carer proof" healthcare decisions

Such decisions may have important effects on family carers; decision making should formally consider them

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Population ageing and fiscal austerity are set to increase the reliance on family carers, who already provide much of the support for people with long term health conditions. Although most carers are willing, providing care can be hugely stressful, affecting mental and physical health[1] and resulting in social isolation and financial hardship.[2] When under strain, carers are less likely to be effective, increasing the risk that the care recipient is admitted to hospital or a care home.[3] Health systems could reduce strain on family carers by routinely considering carers' needs alongside patients' needs in everyday healthcare decisions—a concept we term "carer proofing."

Healthcare interventions (such as a new treatment or a different way of organising care) can affect family carers in various ways (fig 1). Healthcare interventions may reduce the physical demands on carers or make them more (or less) anxious about their loved one's condition.[4] And some interventions—for example, those that target patient lifestyles— are likely to directly affect the lifestyle of carers too.

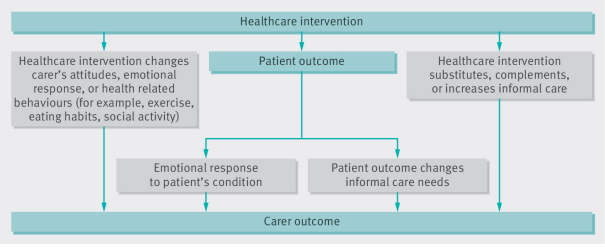

Fig 1 How patient interventions can affect carer outcomes

Few clinical studies have collected data on both patient and carer outcomes,[5] although this is becoming more common. A recent study of stroke follow-up care unexpectedly showed that the intervention reduced carer depression but did not affect patient outcomes.[6] Conversely, a trial of reminiscence therapy for dementia concluded that though quality of life may have improved for people with dementia who attended the sessions, carers' anxiety increased significantly.[7] Other interventions, such as the closure of mental health beds or the promotion of activity among frail older people, could also benefit patients at the expense of carers.

From a research point of view, there needs to be a twin focus on collecting more data on the effect of patient interventions on carers, and routinely using these data to inform reviews, meta-analyses, and economic evaluations. This would help to determine the effectiveness and efficiency of interventions more comprehensively. Better evidence would also provide a stronger foundation for carer proofing policy making and clinical decision making. The National Institute for Health and Care Excellence (NICE) already stipulates that economic evaluations of new healthcare interventions should consider carers' health outcomes as well as patients'.[8] This is rarely done,[9] although recent methodological advances[10 11] ought to support this practice.

At the policy level, how care is organised for people with long term conditions can profoundly affect the lives of carers. The notion of integrated health and care services, for example, holds the hope of reducing the stress that carers experience from lack of joined up care. On the other hand, integrated services might be concentrated on fewer but larger sites, resulting in greater travelling time and less personal service for already stressed family carers.

At the clinical level, guidelines often recommend involving carers in care decisions, where possible. Nonetheless, carers may get squeezed out because of lack of patient consent or busy clinical schedules. If the clinical decision affects the carer, this ought to be taken into account in order to ensure good adherence to the treatment plan. Carer proofing is likely to be particularly valuable at times of change, such as around diagnosis or when someone takes an active caring role.[12]

Enhanced carer proofing could complement existing interventions to support carers, such as respite care, carer support groups, and individual education and training. One problem with existing forms of carer support is that the interventions often come too late, with carer stress treated as an inevitable side effect of the patient's condition. To support carers better,

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carer outcomes should be considered in healthcare decisions for long term conditions from the outset (table⇓).

Carer proofing challenges researchers to provide better evidence of the effectiveness and efficiency of interventions from the perspective of all those affected. It also challenges care professionals and policy makers to focus their thinking on how the wellbeing of the patient-carer dyad could be optimised. There is both a moral and a practical imperative to consider carers in healthcare decisions given the vital role they have in supporting the health system.

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1 Pinquart M, Sörensen S. Differences between caregivers and noncaregivers in psychological health and physical health: a meta-analysis. *Psychol Aging* 2003;18:250-67. doi:10.1037/0882-7974.18.2.250 pmid:12825775.
2 Sörensen S, Duberstein P, Gill D, Pinquart M. Dementia care: mental health effects, intervention strategies, and clinical implications. *Lancet Neurol* 2006;5:961-73. doi:10.1016/S1474-4422(06)70599-3 pmid:17052663.
3 Gaugler JE, Yu F, Krichbaum K, Wyman JF. Predictors of nursing home admission for persons with dementia. *Med Care* 2009;47:191-8. doi:10.1097/MLR.0b013e31818457ce pmid:19169120.
4 Bobinac A, van Exel NJ, Rutten FF, Brouwer WB. Caring for and caring about: disentangling the caregiver effect and the family effect. *J Health Econ* 2010;29:549-56. doi:10.1016/j.jhealeco.2010.05.003 pmid:20579755.
5 Christakis NA. Social networks and collateral health effects. *BMJ* 2004;329:184-5. doi:10.1136/bmj.329.7459.184 pmid:15271805.
6 Fens M, van Heugten CM, Beusmans G, Metsemakers J, Kester A, Limburg M. Effect of a stroke-specific follow-up care model on the quality of life of stroke patients and caregivers: A controlled trial. *J Rehabil Med* 2014;46:7-15. doi:10.2340/16501977-1239 pmid:24241508.
7 Woods RT, Bruce E, Edwards RT, et al. REMCARE: reminiscence groups for people with dementia and their family caregivers - effectiveness and cost-effectiveness pragmatic multicentre randomised trial. *Health Technol Assess* 2012;16:v-xv, 1-116. doi:10.3310/hta16480 pmid:23211271.
8 NICE. Guide to the methods of technology appraisal. NICE, 2013.
9 Goodrich K, Kaambwa B, Al-Janabi H. The inclusion of informal care in applied economic evaluation: a review. *Value Health* 2012;15:975-81. doi:10.1016/j.jval.2012.05.009 pmid:22999150.
10 Al-Janabi H, Van Exel J, Brouwer W, et al. Measuring health spillovers for economic evaluation: a case study in meningitis. *Health Econ* 2015 Oct 14. doi:10.1002/hec.3259 pmid:26464311.
11 Hoefman RJ, van Exel J, Brouwer W. How to include informal care in economic evaluations. *Pharmacoeconomics* 2013;31:1105-19. doi:10.1007/s40273-013-0104-z pmid:24218135.
12 Newbronner L, Chamberlain R, Borthwick R, et al. A road less rocky— supporting carers of people with dementia. 2013. www.carers.org/sites/default/files/dementia_executive_summary_english_only_final_use_this_one.pdf.

Table

Table Table| Examples of carer proofing measures that healthcare decision makers could take

Type of decision	Immediate measures	Future measures
Research decisions	Collect data on carer outcomes in clinical trials and include these data in subsequent evidence syntheses and economic evaluations	Further develop approaches to evidence synthesis and economic evaluation that enable inclusion of carer and patient outcomes and balancing their needs when these are in tension
National policy decisions	Apply a “carer impact” test to major organisational changes, such as initiatives to integrate health and social care	Develop mechanisms that promote a joined-up approach across sectors and organisations to identify and support family carers
Clinical decisions	Involve the family carer when treatment regimens are to be changed, especially when carer is taking on a more active role or patient capacity starts to decline	Evidence based decision making to optimise the outcomes for the patient-carer dyad