

Economics and dementia: challenges and responses

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Abstract

Economics and dementia are interconnected in many ways. There is, for example, accumulating evidence of the ways in which dementia impacts on the economic status of individuals and families, on health and social care system budgets, and on national economies. An individual's economic status can affect their risk of dementia and their ability to respond to it. Governments and other strategic decision-makers are aware of the (growing, indeed urgent) need to take action – whether that is prevention, treatment or care – but also very aware of the limited resources available to them and to the general population. Research evidence can potentially inform the difficult decisions that government and others need to take. We briefly summarise some economic evaluation studies in the dementia area as a basis for identifying the main challenges of moving from evidence to better policy and practice. We then discuss some possible responses (from a range of stakeholders) to these challenges, and how the STRiDE study has sought to contribute to this fast-moving field.

INTRODUCTION

Governments across the world face budget pressures. With population ageing, shrinking working population, and continued growth in dementia prevalence (GBD Dementia Forecasting Collaborators, 2022), policymakers and other stakeholders are already paying close attention to the economics of dementia. Evidence on the costs of dementia is accumulating fast, while evidence on cost-effectiveness of interventions is growing too. *In principle*, this should make it possible to improve the lives of people with dementia and carers by using resources efficiently and distributing benefits and burdens equitably. The reality is that there are major challenges: we discuss these and offer some responses.

Roles for economics

There are multiple ways in which economics can contribute to decision making in relation to dementia, such as analyses of markets for pharmaceutical products, care homes and hospital beds; and studies of alternative ways to finance dementia services (e.g., health insurance and taxation). The topic of economics itself, through its many influences such as costs, prices, employment and poverty, can also impact greatly on how dementia is experienced in society. In this paper, our focus is more specific, on health and care economics related to dementia.

Economic evidence comes in various forms. Some studies report patterns of service utilisation, productivity losses, carer time and associated costs, either for a sample of individuals or aggregated nationally. For example, Mattap et al (2022) reviewed such studies in low- and middle-income countries (LMICs), while Wimo et al. (2023) used cost studies from across the world to calculate global as well as national total and component costs of dementia. Such studies helpfully summarise the resources being used to support people living with dementia, but they do not provide sufficient evidence to inform decision-making because they do not consider the health or quality of life of individuals, and they do not have a counterfactual in that they do not compare alternative scenarios.

Economics studies are more useful when they combine cost data with evidence on the effects of those costs on people's lives and health. Economic evaluations provide 'value-for-money' information to inform discussions of resource allocation. These include cost-effectiveness analysis (CEA; costs compared to a single outcome in 'natural' units, such as cognition), cost-utility analysis (CUA; costs compared with a generic outcome such as quality-adjusted life years (QALYs) which is assumed to be valid across all health conditions), and cost-benefit analysis (CBA; costs compared to the monetary values of outcomes). CEAs are useful in choosing between intervention options with the same target (e.g., slowing down cognitive decline), CUAs support decisions within the wider health sector (e.g., allocating the health budget), and CBAs inform cross-sectoral resource allocation discussions. These decisions are central to complex issues regarding affordability, targeting, access, equity and efficiency. Despite the important roles of economic evidence, their use in decision-making remains limited. We outline below some examples to illustrate – as noted in several recent systematic reviews and meta-analyses (Huo et al., 2021a; Huo et al., 2021b; Huo et al., 2022; Walsh et al., 2022) – the current lack of economic evidence to support informed decisions.

Economic evidence in dementia: examples

There are still too few economic evaluations, either because governments have not asked for them or because the research community has not wanted to do them. The consequence is that important decisions are still being taken with little idea of the resource implications. But today it is much more likely that an effectiveness study would try to include an economics component. Here we discuss some illustrative examples from the dementia field organised under six headings: pharmacological treatment, psychosocial interventions and preventive measures, carer support, post-diagnostic support, digital technologies, and congregate care.

Pharmacological treatment

Understandably, pharmaceutical companies use research evidence to support product marketing, and so there is more economic evidence for pharmacological treatments than for other areas. Broadly speaking, the acetylcholinesterase inhibitors (such as donepezil) are today considered to be cost-effective for mild-to-moderate Alzheimer's disease (Hyde et al., 2013). A key consideration in economic evaluations of commercial products is the market price; when these medications come off-patent, their price falls markedly. Evidence is now accumulating across numerous countries (e.g., da Silva et al., 2019). There is also evidence from a complex trial which shows that continued treatment with donepezil for people with moderate-to-severe Alzheimer's disease is highly cost-effective in achieving cognitive, functioning and QALY outcomes (Knapp et al., 2017). A recent systematic review and meta-analysis of ten studies of pharmacological therapies concluded that acetylcholinesterase inhibitors and memantine are cost-effective and may be cost-saving (Huo et al., 2022), but cautioned that more rigorous evidence from studies without industrial support is needed.

A lot of attention is currently focused on potential new disease-modifying treatments that might slow down, stop or even reverse declines in cognition and health. If there is a scientific breakthrough and if these new treatments are widely available, they will completely transform dementia care, but there must not be any let-up in efforts to improve preventive strategies and deliver effective care (Wong & Knapp, 2020).

Psychosocial interventions and preventive measures

For non-pharmacological interventions, there is less economic evaluation evidence. The main reason is probably because these interventions tend not to have product champions: there are no shareholders or owners seeking to make profits from sales of the treatments. Another

reason could be that some non-pharmacological approaches are ‘complex interventions’ which tend to be intrinsically harder to evaluate. In a recent systematic review and meta-analysis, the authors noted that therapies targeting cognition, psychological intervention and behavioural management substantially increase costs, and their cost-effectiveness would depend largely on society’s willingness to pay (Huo et al, 2021a).

An early economic evaluation of psychosocial interventions for people living with dementia looked at cognitive stimulation therapy (CST), with a CEA built into a randomised controlled trial (RCT) comparing CST with usual care. CST was both more effective and cost-effective by reference to cognitive change and quality of life gains (Knapp et al., 2006), supporting the later inclusion of CST in national clinical guidelines in England (NICE, 2018). Subsequent projection modelling showed that making CST available to the full eligible population in England would increase service costs and carer responsibilities, but also improve health and wellbeing for about 54,000 people with mild-to-moderate dementia each year (Knapp, Bauer, et al., 2022). This raises a familiar question in economic evaluation: are the higher costs (in this case, those associated with CST) justified by the better outcomes? The National Institute for Health and Care Excellence (NICE), which is the national body in England charged with considering these trade-offs, uses a pre-set cost-per-QALY threshold to inform its recommendations.

The same guideline (NICE, 2018) suggested considering several other psychosocial interventions without giving a strong recommendation to offer, including occupational therapy to support functional ability in people living with mild-to-moderate dementia. However, a recent CUA did not provide supportive economic evidence. Community occupational therapy was compared with care as usual in the COTiD-UK study: cost per QALY gain was relatively high, suggesting a low likelihood that the occupational therapy was cost-effective (Pizzo et al., 2022). Increasing evidence points to the promise of preventive strategies in dementia. A recent systematic review and meta-analysis found that population- or community-based prevention targeting smoking, education, and physical activities would be cost-effective – and may be cost-saving – in high- and low- and middle-income countries (Walsh et al., 2022).

Carer support

Several evidence-based multicomponent programmes are available to support dementia carers. Common elements in these programmes, such as education and brief psychotherapy, could have both short-term benefits (improved carer wellbeing and mental health) and longer-term benefits (e.g., delayed nursing home admissions).

Four rather different interventions illustrate the tremendous potential to improve the lives of carers and the people they support through interventions that are affordable and cost-effective. Recently, Birkenhager-Gillesse et al. (2022) showed that an intensive multicomponent training intervention delivered in holiday accommodation over 5 days for dyads of people with dementia and their co-resident carers was effective and saved costs by delaying nursing home admissions and by reducing use of other care services by carers and people with dementia. A different approach is used in the START programme, which supports family carers in their own homes through a structured programme over 8 weeks. The economic evaluation, nested within a pragmatic RCT, showed short-term cost-effectiveness in affective symptoms and carer QALYs over 8 months (Knapp et al., 2013), and longer-term outcome improvement and wider cost-effectiveness gains up to 6 years after randomisation (Livingston et al., 2020).

The third example points to what might become the longer-term norm: delivering carer support remotely, an approach that has gained obvious traction because of the Covid pandemic. Henderson et al. (2022) report that cognitive behavioural therapy (CBT) can be delivered cost-effectively online (with telephone support) to dementia carers with anxiety/depressive symptoms.

Finally, Vandepitte et al. (2020) used simulation modelling to estimate cost per QALY gained by an in-home respite care programme added to standard community-based dementia care pointing to potential benefits of integration across health and social care sectors in Belgium.

In a recent systematic review and meta-analysis of interventions supporting unpaid carers, Huo et al. (2021b) concluded that, while psychosocial interventions could improve outcomes, they also significantly increase costs and their cost-effectiveness very much depends on intervention aspects (e.g., carer characteristics, follow-up period) and society's willingness to pay.

Post-diagnostic support

There is mixed economic evidence on post-diagnostic support. Using simulation modelling, Banerjee & Wittenberg (2009) suggested that early diagnosis and treatment through memory services in England would generate savings associated with delayed care home admissions. An RCT in Germany concluded that care management was both more effective (increased QALYs) and less expensive (reduced costs) than usual care (Michalowsky et al., 2019). Interestingly, subsequent analysis of the trial data showed that the economic outcomes are dependent on the sociodemographic and clinical characteristics of the person with dementia: care management is more likely to be cost-effective for females, people living alone, those with moderate-to-severe cognitive impairment, functional impairment, and with multiple long-term conditions (Radke et al., 2020). These findings differ from the conclusions of an earlier systematic review, which did not find convincing cost-effectiveness evidence (Pimouguet et al., 2010). In a more recent meta-analysis and systematic review, care coordination and case management programmes were found to be probably cost-effective, with savings in healthcare costs and QALY gains (Huo et al, 2021a).

Digital technologies

In a recent rapid review of digital technologies commissioned by the English government, we found very little economic evidence, despite probably thousands of such technologies being developed (Knapp, Shehaj, et al., 2022). Among the few economic evaluations, an RCT found that a video-initiated carer intervention ('FamTechCare') was possibly more cost-effectiveness than telephone support: outcomes (depression and competence) were better but costs higher with the video intervention, but the better outcomes appeared to justify the higher costs (Shaw et al., 2021). This study illustrates the need for comprehensive cost information: utilization of other services was not measured, which probably meant that some relevant cost savings (from carer mental health improvements) were missed. But not every technological development proves effective or cost-effective when implemented in real-world contexts (Howard et al., 2021).

Congregate care

Person-centred models in congregate care settings (nursing homes and similar) can improve residents' quality of life and help staff to manage some of the behavioural symptoms of dementia such as agitation. In the MARQUE study, supervised graduate psychologists delivered the intervention to care home staff, proving to be cost-effective in terms of QALY gains but had no impact on agitation, perhaps because a more intensive intervention is needed

over a longer period (Livingston et al., 2019). In the WHELD study, staff were given supplementary training in person-centred care, social interaction and antipsychotic review (Ballard et al., 2018). Outcomes were improved (compared with usual care) in terms of agitation management and quality of life, and the intervention cost was offset by health and social care savings (Romeo et al., 2019). In contrast, Dementia Care Mapping (DCM) in congregate settings has not been found to be more cost-effective than usual care (Meads et al., 2020).

CHALLENGES AND RESPONSES

Economic evidence is necessary but not sufficient for better policy and practice decisions. In each step of the transition – from evidence to recommendations, action and impact – challenges arise. These challenges are common in mental health problems (see Knapp & Wong, 2020), although the complex nature of dementia care and intervention, such as the key role of unpaid carers, exacerbates such challenges.

Challenges

The most obvious challenge is simply lack of robust evidence. As noted above, there is more economic evidence for some types of intervention than others. Research gaps mean key resource allocation decisions get taken without knowing whether they improve outcomes, or represent efficient uses of scarce resources or support disadvantaged groups. A complication is that economic evidence is context-specific: what is good value for money in one country might be a waste of resources in another because of differences in service availability and relative costs. Generally, therefore, local evidence is needed. This particularly applies to LMICs where service, funding and cultural contexts are very different from those countries where economic studies have been conducted to date. This difficulty adds to the challenge of generalisability or external validity of complex interventions commonly used in dementia. For example, while scaling up CST to the full eligible population would require additional funding and skilled workforce, there may be ways to reduce costs by service integration or online delivery of service (Knapp et al., 2022). However, changes to aspects of intervention design (e.g., implementation strategies, target groups, staff qualifications and training) might also change the balance between costs and treatment effects, and would require new economic evaluation to assess their cost-effectiveness.

Even if there is evidence of cost-effectiveness – i.e., the cost of an intervention is seen to be justified by the outcomes achieved – there may not be enough resources to deliver it. We noted earlier that CST produces better outcomes than usual care but at a higher cost. Even if the ratio of improved outcome to higher cost is considered ‘worth it’, there is still a need for a larger budget and more staff. With the huge demand for dementia services and insufficient resources to meet all needs, especially in low-resource settings, this might not be possible.

This challenge makes it easy to understand why decisions are clearly easier when a service delivers better outcomes *and* saves cost. But this leads us to a third challenge: are these savings *real*? The economic case for acetylcholinesterase inhibitor medications is mainly driven by delays in admission to nursing homes, but there will only be *real* resource savings if some nursing homes are closed. Interventions which reduce carer time in supporting people with dementia, and thereby reduce the costs associated with unpaid care time, are saving notional rather than real (‘cashable’) costs. (Of course, reductions in out-of-pocket payments by carers are real savings.) But decision-makers who ignore carer impacts when choosing how to allocate their resources – i.e., adopt a rather narrow perspective – risk

under-estimating the true value of some interventions when a societal perspective is taken (cf. Vandepitte et al., 2020).

A common challenge is when an intervention is funded from one budget, but the main economic benefits accrue elsewhere. For example, carer support programmes delivered by social care bodies could make it easier for some carers to remain in the workforce (delivering productivity gains to the national economy) and could improve their mental health (reducing their utilisation of health services). This ‘silo mismatch’ can be a disincentive to invest in interventions that represent good value for money *overall* but appear expensive to the funding body.

The fifth challenge arises when the pay-offs from an intervention occur much later than the costs. This is best illustrated with preventive measures, which are mostly mid-life interventions that reduce later-life dementia risk (Mukadam et al., 2020), although the multidomain lifestyle intervention evaluated in the FINGER study targeted an older group, with encouraging economic findings (Wimo et al., 2022). It may be hard to persuade decision-makers to spend heavily on prevention when the health gains and resource savings are many years into the future (and certainly beyond the current election cycle). Delayed pay-offs become even more of a disincentive when combined with ‘silo budgeting’: why should a budget-holder invest in strategies that bring benefits only in the long-term and then mainly in *other* sectors?

The final challenges follow from the tendency for researchers to report ‘average findings’ and to give insufficient attention to variations around those averages. *For whom* does an intervention work well or generate more savings? The care management examples above illustrate how effectiveness and cost-effectiveness depend partly on the characteristics of people being supported (e.g., whether living alone, co-occurring conditions) (Radke et al., 2020). The rapid growth of precision medicine in the cancer and other fields shows the benefits of ‘personalised’ approaches to treatment. Care management itself is another example of trying to design support that responds to individual needs, circumstances and (hopefully) preferences. Challenges with these more individualised approaches are the need for more complicated information and budgeting systems and, of course, good individual-specific evidence.

Linked to this last point is the challenge of inequities. Interventions that are effective and cost-effective for the majority may be ineffective or inaccessible for some population subgroups such as people living in more deprived areas or those with different cultural beliefs or languages. Wherever possible, evaluative studies, including economic evaluations, should be highlighting these inequities.

Responses

How should care and related systems respond to these challenges to achieve the best outcomes for people living with dementia and their carers? What is needed is a combination of research, implementation science, investment in appropriate interventions, commitment to fairness and political bravery, held together by strategic national plans.

More and better research is a common recommendation by researchers. Here it is exactly the right recommendation, given the huge knowledge gaps to be filled, especially outside the high-income world. The recently launched dementia research blueprint from WHO (2022) helps identify priority topics globally, with economics questions running through many of them.

Second, findings from well-conducted research need to be shared with decision-makers at all levels in health, social care, housing and related sectors. This should include

people living with dementia and carers. This is where implementation science comes in, guiding the various communication, engagement and involvement activities that will be needed. A core aim of STRiDE, as illustrated by other papers in this issue of *Dementia*, was to help build networks and skills in the seven countries to make it easier for research to be not only useful but also *used*.

Investments in preventive efforts, treatments, services and carer support should, where possible, ‘follow the evidence’. It is not enough for a new digital technology merely to look exciting or for a reconfiguration of community support services to seem sensible: they should only get funded if there is evidence that they improve the lives of people living with dementia and/or carers, represent good value for money, are affordable and, ideally, narrow inequalities of access or impact. Family and other carers often get overlooked, but findings from STRiDE and other studies demonstrate their pivotal roles and therefore the pressing need for policies and arrangements to support them, not just in their caring roles but in other areas of their lives such as employment. Listening to carers’ views as well as the views of people living with dementia and, as far as possible, respecting their individual preferences must be central to decisions on intervention spending.

A growing number of countries have formal health technology assessment (HTA) processes: one of the best known is the National Institute for Health and Care Excellence (NICE) in England. HTA and similar processes must not employ methods or measures that discriminate against older people or overlook carer benefits and contributions. More generally, inequalities are already far too wide in all aspects of dementia care – from delayed diagnosis, poor post-diagnostic support, limited access to good services, to inadequate end-of-life care. Research needs to tackle these inequalities head-on, both documenting the nature and extent of inequality – by reference to socioeconomic status, race, ethnicity, language, sexual preference and so on – and, especially, by finding ways to reduce inequality.

A key ingredient in overcoming the challenges set out earlier is having decision-makers with patience, commitment and flexibility. Successful preventive efforts require long-term commitment: there will probably be no discernible gains (reduced prevalence or budget savings) for many years. Flexibility will need to be built into public finances so that decisions about resource use are *multi-sector*, allowing compensation across budgets or encouraging collaborative, innovative care, as tried in the US Accountable Care Organizations model (Coe et al., 2021).

This leads naturally to our final suggested response, which again links to a core aim of STRiDE: to support the development of national dementia plans or policy frameworks. This is consistent with WHO’s (2017) recommendation to Member States to see dementia as a public health strategy, giving ‘consideration to equity, dignity and the human rights of people with dementia and support the needs of carers, in consultation with people with dementia and other relevant stakeholders’ (p.10). Embedding good research, including studies with economics components, into policy development, implementation, monitoring and refreshment – which was a core principle of STRiDE – is imperative, alongside the full involvement of people living with dementia, their carers and other relevant stakeholders.

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