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CONSENSUS CONFERENCE PAPER

Economic outcomes and levers: impacts for individuals and society

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ABSTRACT

The pervasive scarcity of resources relative to the demands upon them makes it necessary for decision makers to think carefully about choices. Evidence from economics can help to inform such choices, particularly as it relates to costs, outcomes, the efficiency with which resources are used, the distribution of benefits and burdens across different individuals and budgets, and the processes by which care and treatment are delivered. However, there is still insufficient economic evidence to inform the full range of decisions to be taken in the dementia field; indeed the accumulated volume of evidence remains very modest. The measurement of cost is often too narrow, and there is some disagreement about whether and how to include the costs (direct or indirect) incurred by caregivers. The conceptualization of outcomes for certain purposes has generated argument, especially when attempts are made to introduce generic measures that apply across many clinical areas. It has not always been demonstrated that such measures have any validity in the dementia field. Other comparatively neglected areas have been research on equity and the processes by which care is delivered. Finally, the paper looks at economic barriers to implementation of evidence-based interventions, and the policy levers that might prove influential.

Introduction

It is now widely recognized that, for better or for worse, economics is always lurking in the background of policy and practice discussions in health and related care systems. Although the health professional delivering one-to-one therapy, prescribing a medication or arranging a group activity might not have to be concerned about the immediate costs of their decisions (although increasingly many *will* be aware of them), further along the management chain someone will be keeping a very watchful eye on expenditure. And while this latter budget holder will be focused on balancing the books at the end of the financial year,

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someone even further along the chain in the health system will need to consider wider strategic options and will be intent on achieving “value for money” (in some sense) in the use of resources. For example, when a new treatment becomes available and is found to be effective in, say, symptom alleviation or improving personal functioning, someone will have to decide whether it is affordable and whether it generates health improvements that are worth what it costs to purchase or use the treatment.

Occasionally, economic issues will move to the foreground. An example would be the recent debate in England and Wales over the decision by the National Institute of Health and Clinical Excellence (NICE) not to recommend use of the Alzheimer’s medications on the grounds of cost-effectiveness. I will come back to that debate about NICE later. Economic considerations also get an airing when there is discussion about some of the wider impacts of health problems, such as the crime costs associated with substance addiction or the welfare payment costs associated with unemployment arising from long-term depression. These too will be discussed later in this paper, as they help us to understand how politicians and other decision-makers do (or do not) take notice of different types of evidence.

The underlying challenge is scarcity: there are not enough resources to meet all of a society’s needs. This is a blindingly obvious statement of reality that many people (including some clinicians, families, advocacy bodies and others) surprisingly still manage to forget. It is also the most fundamental, pervasive, durable and relevant justification for a better understanding of the economics of treating dementia. Because scarcity is a permanent feature of all health and related systems, difficult choices have to be made between alternative uses of any particular resource or service. Those choices give meaning to costs, as described in the next section. But economists are not “glorified accountants” and are concerned with much more than just costs. In particular, economic evaluation aims to provide evidence that can inform both clinical practice and strategic decisions about how to allocate available resources so as to get more out of them in terms of better outcomes (for example, in relation to symptom alleviation, improved personal functioning, relief of caregiver burden).

There are perhaps five dimensions to be considered when discussing the economic aspects of health care interventions and policies in general and in relation to dementia care: costs, outcomes, efficiency, equity, and process. Each is considered in turn in the sections below, followed by discussion of the levers that might be pulled in order to bring about change.

Costs

The dimension most commonly associated with economics is cost. What, for example, are the costs of dementia if unrecognized or under-treated? What are the costs of delivering treatment and providing supportive care? Where do these costs fall? Are they actual expenditures or notional costs?

There are a number ways to categorize the costs associated with dementia. There are direct costs associated with the pharmacological and psychological treatments and associated support services, some of them delivered by non-health agencies. There are also indirect costs, which may fall to families as out-of-pocket expenses or lost income because of disruptions to employment. There may also be some unmeasured costs, associated with lost leisure time or psychological burden for family members.

Opportunity costs

In economic evaluations, the usual and theoretically correct approach is to try to measure these elements as long-run marginal opportunity costs (Knapp, 1993). This helps to ensure that a long-term perspective on resource implications is employed, that only those effects on resources attributable to the program or service user are counted, and that costs are reckoned as opportunities forgone, not just money expended (although the two will sometimes be the same). How broadly the costs are measured will depend upon the perspective taken for the evaluation, which in turn depends upon the purpose of the study – points to which I return in a moment.

Measuring costs

In carrying out evaluations in practice, the economist would be looking for data on service use patterns from one or more source. The data might come from a "billing" system, recording the amounts that are transferred between a payer and a provider for services used by individual people. This is a generally feasible approach in U.S. research, for example, where billing or similar data are commonly available. In care systems without such payment mechanisms there might nevertheless be routine information systems that record service contacts and referrals which provide the necessary data. However, in most countries there are no such billing data and information systems are too rudimentary or unreliable to provide a basis for cost calculation. In these circumstances, the usual approach is to collect information on patterns of service use through interviews with family members or service professionals. There are a number of research tools for this purpose. One that my colleagues and I have developed and which has been used in hundreds of studies across the mental health and other fields is the Client Service Receipt Inventory (Beecham and Knapp, 2000). A specific and also widely used tool is the Resource Utilization in Dementia tool (Wimo *et al.*, 2000).

To the service use levels generated by information systems or from these research tools, the researcher then needs to attach unit cost estimates. It is not always necessary to calculate these unit costs anew. In England, we are fortunate in having the annual Personal Social Services Research Unit (PSSRU) compendium of unit costs for health and social care, and this is now widely employed (Curtis and Netten, 2006). A similar compendium is currently under development in Spain, and I am aware of off-the-shelf collections of unit costs (for some services at least) for Finland, Italy and the Netherlands.

This approach to cost calculation (using a questionnaire to collect retrospective or prospective service use data, and then attaching unit costs mostly drawn from the published annual compendium) is now quite commonly employed. It was the approach employed in, for example, the AD 2000 (AD 2000 Collaborative Group, 2004) study of donepezil, in a recent cost-effectiveness evaluation of cognitive stimulation therapy (Knapp *et al.*, 2006), and in a study of memantine costs (Wimo *et al.*, 2003).

Breadth of costs

People with dementia are likely to use a number of services, each of which needs to be captured for a fully comprehensive economic evaluation. In addition, there will be many and important inputs from family and other (unpaid) caregivers. How those latter inputs are costed is a source of contention. Many studies have shown the costs of informal care to be considerably greater than the costs of services provided to people with dementia (e.g. see Lowin *et al.*, 2001; Jönsson *et al.*, 2002), but the costing of caregiver inputs is not straightforward.

One reason is that it is difficult to measure the input: how many hours of informal care are actually delivered, and how easy is it to distinguish informal care from the normal patterns of interaction of a marriage or family life? Second, it is difficult to put a value on those hours. One approach is to use a replacement cost method, assuming that informal caregivers would be replaced by paid staff. However, this is not very realistic, particularly if applied to every caregiver hour within a society, because such a major change to the employment pattern for care workers would undoubtedly alter the market wage rate. On the other hand, the "opportunity cost" method which assigns a value equivalent to what is given up by the caregiver, is likely to under-estimate the true cost because many caregivers of older people with dementia are not forgoing paid employment, and may put a relatively low marginal value on lost leisure time (Brouwer *et al.*, 2001). Third, there is the more general difficulty of the *perspective* employed within an evaluation. Bodies such as NICE are required to take a health and social care system perspective, which means that they necessarily attach a zero value to caregiver inputs (and see below). But the inclusion of such costs can change the overall pattern of differences, as demonstrated in a related context by Schneider *et al.* (2003).

Outcomes

Economists are interested in the effectiveness of interventions as a key component of the evaluation of the performance of health systems. The most well-known form of such evaluation is *cost-effectiveness analysis*. The term is used as both a generic term for economic evaluation as well as being a particular type of evaluation, the types being distinguishable by the way that they conceptualize and measure outcomes.

Outcomes and cost-effectiveness analysis

Cost-effectiveness analysis (CEA) as a type of evaluation measures costs as set out above, and measures outcomes using instruments and scales familiar from clinical studies. A CEA can help decision-makers choose between alternative interventions aimed at a specific disorder. A CEA would look at a single outcome dimension – such as change in cognition or behavior, or symptom-free days – and then compute the ratio of the difference in costs between two interventions to the difference in outcome (the *incremental cost-effectiveness ratio* or ICER). A second ICER could be calculated for a second outcome. For example, our evaluation of cognitive stimulation therapy (CST) measured costs quite broadly and compared changes in costs between CST and treatment as usual with changes in cognition as the primary outcome, and changes in quality of life as the secondary outcome (Knapp *et al.*, 2006)

More broadly, the choice of effectiveness measure(s) depends on the question to be addressed. If the question is essentially clinical – what is the most appropriate treatment for a dementia patient in a particular circumstance, and which therapeutic package to opt for – then information is needed on the comparative costs of the different therapies and the comparative outcomes measured in terms of (dementia-specific) symptom alleviation, improved functioning or quality of life enhancement. In these circumstances, a CEA of the kind just set out would be appropriate.

Utility

However, if a broader question needs to be addressed, such as whether to invest health care resources in treatment of either dementia or stroke or breast cancer, then decision-makers need an effectiveness measure that uses a common metric across these clinical fields. The most commonly employed such measure is "utility," generated from health-related quality of life scales. Combining such a measure with information on costs allows the economist to carry out what is often called a *cost-utility analysis*. The best-known and most robust measure of "utility" is the Quality-Adjusted Life Year (QALY). Cost-utility analyses can inform health care resource allocation decisions or priority setting, of the kind carried out by the National Institute for Clinical Excellence (NICE), which has responsibility for providing guidance in England and Wales on how to promote health and treat ill-health.

Cost-utility analyses have strengths, including using a generic unidimensional measure that allows comparisons across diagnostic or clinical groups, and a methodology for weighting preferences and valuing health states. The QALY is also a measure with attractive "cardinal" properties, unlike most clinical measures in the dementia field. But these same features may also generate weaknesses: the utility measure may be seen as too reductionist; the generic quality of life indicator may be insufficiently sensitive to the kinds of change expected in dementia treatment; and a transparent approach to scale construction paradoxically opens the approach to criticism from those who question the values thereby obtained. In particular, there are worries that the generic utility-generating instruments, such as the EQ-5D (EuroQol Group, 1990) and the SF-6D (Brazier *et al.*, 2002) which are the only two currently recommended for use by NICE, are insufficiently sensitive to pick up symptom and functioning changes expected in dementia patients.

There is thus a quandary for researchers and decision-makers in England and Wales today, and in some other countries that have chosen a strategic evidence-based approach to resource allocation in the health system. On the one hand, a generic outcome measure such as the QALY, when combined with cost estimates, can point to ways of improving efficiency. On the other hand, if that QALY measure is not reflecting the underlying effectiveness changes in the clinical area to which it is applied, then it must surely be of limited use. This is proving quite an issue, because the QALY measures advocated and employed by NICE have no proven validity in the dementia field.

Benefits

To address a still broader question, about whether to invest more money in the health system or in improving transport or launching a new environmental policy, then another measure of outcome is needed. In this case, where "outcome" needs to be measured in a common unit relevant across all of these areas of public policy, the usual choice is a monetary measure. *Cost-benefit analysis* asks whether the monetary benefits of a treatment or policy exceed the costs. All costs and outcomes (benefits) are valued in the same units – money. If benefits exceed costs, the evaluation would recommend providing the treatment, and vice versa. With two or more alternatives (comparing, say, health care with education), the intervention with the greatest net benefit would be deemed the most efficient. Cost-benefit analyses are thus intrinsically attractive, but conducting them is especially problematic because of the difficulties associated with valuing outcomes in monetary terms.

Comparing costs incurred (for example on treatments) with costs saved (for example on future health services no longer needed) is not a cost-benefit analysis but a cost-offset comparison. This confusion is unfortunately still quite common. A cost-benefit analysis must measure outcomes (in terms of improved health or improved quality of life) and then convert them to monetary values.

The problem is that attaching values to the outcomes of treatments for dementia is inherently complicated. In due course, methodological developments in health economics may offer a way to obtain direct valuations of health outcomes by patients, relatives or the general public. There are techniques that ask individuals to state the amount they would be prepared to pay (hypothetically) to achieve a given health state or health gain, or they involve the observation of actual behavior and impute values (Olsen and Smith, 2001). Such methods are likely to be difficult to apply in mental health contexts, and especially for people with moderate to severe cognitive impairment. The same applies to another approach that is used to value health interventions. *Conjoint analysis* asks individuals to rank different real world scenarios, which may consist of several dimensions (including, for instance, health outcomes, quality of life, time inputs, discomfort and stigma) and includes cost as one of these dimensions so that a monetary value can be elicited.

There are no published cost-benefit analyses of dementia interventions.

Question and perspective

The choice of question therefore clearly influences the type of evaluation needed and the type of effectiveness measure needed, and therein lie many of the controversies that have surfaced in this field recently. But it is important to note that the choices of evaluation variant are not mutually exclusive: a single study could support more than one type of analysis. Thus a study designed to conduct a cost-effectiveness analysis could – with the right supplementary collection of information – also generate cost-utility findings. However, and slightly in contradiction, evidence which is well located within the clinical domain and which is exactly what the treating professional needs may not always be appropriate for a higher level decision-making body, such as the health ministry. Generally speaking, the broader the research question, the more demanding are the data needs: cost-benefit analyses are harder to do (well) than cost-utility analyses, which in turn are tougher than cost-effectiveness analyses.

Linked to the specification of the question to be addressed is the *perspective* to be adopted. Is the evaluative information needed to help resource allocation within a particular agency (such as a psychogeriatric service), or within a particular system (such as the health care system) or within the wider economy or society? The breadth of perspective will determine the breadth of both the measurement of costs and the effectiveness or outcomes.

Efficiency

Knowing the wide-ranging costs of dementia helps decision-makers to gauge the overall societal impact of this set of illnesses. Knowing whether a treatment might "pay for itself" by reducing expenditures in later periods or on other services helps decision-makers focus their minds on the need for better preventive or treatment interventions. But neither of these can tell a decision-maker how to make better or best use of available resources. For this purpose it is necessary to examine both the costs and the outcomes of different uses of those resources. As discussed above, this is what economists would recognize as the examination of cost-effectiveness, which is addressing the efficiency question.

Is it worth it?

Consider what happens following the development or introduction of (say) a new medication. Decision-makers face two key questions when considering whether to use or recommend this new drug as part of the treatment range. The first is the clinical question: is the medication effective in alleviating dementia symptoms, slowing cognitive decline or generally improving patient functioning? Or, when considering two or more different drugs, which has the better outcomes along these dimensions? If the answer to the clinical question is that the new medication is no better or perhaps actually worse than existing treatment options, then there is usually no need to consider its use any further. But if the new medication looks clinically effective, the decision-maker will want an answer to a second question: is it cost-effective? That is, does the treatment achieve the improved outcomes at a cost that is worth paying?

These two questions (*Is the treatment effective*? *Is it worth it*?) sit at the heart of economic evaluation. It is important to emphasize that cost-effectiveness analysis aims to do just what it says: it looks at *both* costs and effectiveness (outcomes). Comparing the costs of one intervention with the costs of another, without any evidence on outcomes, might be interesting but does not constitute an economic evaluation because it does not provide enough information to assist service professionals, managers or others to make choices between alternative uses of their scarce resources. Similarly, calculating the costs and outcomes of a single intervention could be revealing, but again is not especially helpful (and not strictly an economic evaluation) unless comparison is made with equivalent data for another intervention, for otherwise the decision-maker will have no benchmark against which to judge whether the observed costs and outcomes are attractive.

Trade-offs

Deciding what is or is not "worth" the cost is far from straightforward and not without controversy, as amply demonstrated by recent discussion of the decision by NICE not to recommend the Alzheimer's drugs for use in the health service in England and Wales.

Many evaluations of new interventions find them to be both more effective (the outcome profiles are better than for old or current interventions) but simultaneously more expensive. For example, our cognitive stimulation therapy study mentioned earlier found that CST had better outcomes but also slightly higher costs than treatment as usual. How is the trade-off to be made between the better outcomes and the higher expenditure necessary to achieve them? The methodological approach now widely used is to construct *cost-effectiveness acceptability curves* (CEACs). These show the probability that a new intervention will be cost-effective for each of a number of pre-specified or implicit valuations of an outcome improvement by the decision-maker. The CEAC is a comparatively recent development, and there are as yet few published applications of it in the dementia field, but its use will grow. One advantage of the approach is that it makes transparent the trade-offs faced by decision-makers.

Equity

Equity refers to fairness, whether in relation to paying for treatment, or in getting access to care, or in the distribution of resources across a country, or in the health-related quality of life of different groups within a population. Recent examples of equity discussions in the U.K. have focused on postcode prescribing (access to new medications depending on the area in which someone lives), income-related inequalities in prevalence of mental illness and in treatment access, and the long-rumbling arguments about whether people with dementia should be asked to pay for their long-term care (because social care in the U.K. is means-tested while health care is not).

There is not space here to go into detail on the equity question, but it is important to emphasize the need for evaluators and policy-makers alike to consider not just the efficiency with which needs are addressed and treatments delivered, but also the *distribution* of resource burdens and of health and quality of life outcomes across the population. Do different people within the population have different opportunities to access particular treatments? Do they have to carry different burdens of payment? Is there an imbalance between quality of life outcomes enjoyed by patients and family caregivers?

Process

Many people would argue that it is not just a question of *what* is achieved in a health system but *how* it is achieved. Changing the process of delivery and treatment could be beneficial and cost-effective in its own right. A good example would be the growing emphasis on consumer-directed services (or perhaps caregiver-directed services if proxy decision-makers are considered) (Knapp, 2007).

Consumer-directed services are being developed in the Netherlands, in Germany with the long-term care insurance arrangements introduced in 1996, in various parts of the U.S.A., and in the U.K. Individuals are given the cash to choose their own services and providers, with different consumer-directed arrangements having different constraints on the use of such devolved funds. There is some controversy, with advocates arguing for the increased choice and control that comes with such arrangements, while critics point to the risks for vulnerable individuals, including those with cognitive impairment, from abuse and neglect, and also the risk that payments may simply be used to supplement family income rather than support care for individuals.

In the U.K. there has been some investment in the system of direct payments, which transfers social care funding to service users, who then have the opportunity to spend their budgets on a range of services to meet their personal (care) needs. Direct payments were made available to older people in England and Wales in 2000. More recently, there has been experimentation with *individual budgets*. These pull in a wide range of funding streams and give the individuals holding them considerable freedom as to how to use them. Dissatisfaction with direct payments, particularly the restrictions imposed on how funding can be used, was one reason for the experimental introduction of individual budgets (Glendinning *et al.*, 2006). However, people with dementia are less likely than other older people to get these opportunities to control their budgets (Fernandez *et al.*, 2007). The evidence base on whether such approaches are efficient and equitable remains embryonic. But, as advocates of consumer-directed services would assert, there are intrinsic benefits from the very *process* of exercising choice and having control of one's life.

Levers

What, then, stops a health system achieving better economic outcomes, whether in terms of reduced costs, improved outcomes, greater efficiency, more acceptable distributional patterns or a more engaging or empowering care process?

A number of barriers get in the way. One of those barriers is undoubtedly the evidence base. Clinicians lament the weak evidence base in relation to many of the treatment options available or being introduced for treating people with dementia (see other papers in this journal issue). The corresponding economic evidence is far weaker (see the paper by Wimo in this issue).

But even when there is an adequate evidence base there are other barriers. One of the most insidious and seemingly insurmountable barriers is resource insufficiency: old age mental health services are under-funded, so that it is impossible to employ enough skilled staff or to purchase appropriate medications. Even when resources are available they might be poorly distributed, available at the wrong place or time relative to the distribution of needs. They may be available only if delivered by specialist clinics. A more general difficulty is that available services do not match what is needed or preferred by service users or their families. An example of such inflexibility is the deep-rooted reluctance to move away from institution-based services in some countries. A linked challenge is resource dislocation: services may potentially be available to meet individual and family needs, but they are poorly coordinated, a situation compounded perhaps by professional rivalry, stultifying bureaucracy or "silo budgeting" (resources held in one agency's "silo" cannot be allocated to other uses). There might also be a problem of ageism within health systems, plus of course the perennial problem of political will.

Each of these barriers could be discussed, but here I want to focus on the last of them – political will – because sometimes it takes more than just an evidence base to win the support of decision-makers for a particular course of action. It is instructive to compare dementia treatment with other areas in the mental health spectrum, and to look at the levers that can and often are pulled to bring about change. For example, in relation to conduct disorder, which is the most prevalent mental health problem among children, public (and therefore political) fear of antisocial behavior and the strong threads of continuity between conduct disorder in childhood, delinquency in adolescence and criminality in adulthood are encouraging decision makers to prioritize the treatment of conduct disorder. Similarly the high societal costs of crime committed by people with heroin and other substance misuse problems have helped to focus decision-makers' minds.

Depression is associated with interrupted patterns of work, absenteeism, and low productivity, in turn leading to heavy reliance on social security payments. Recently, the British government has been particularly concerned to try to improve the employment profiles of people with depression and anxiety in order to reduce reliance on welfare payments. The largest cost element in dementia is caregiver burden, but this does not appear to loom especially large in the minds of the public or decision-makers. Were it to do so, it might prove to be a useful lever for change.

Conclusion

The starting point for an interest in the economics of dementia treatment is clearly scarcity: it is the recognition that there are not, and there never will be, enough resources available to meet all of the needs of people with dementia or their families. There is still a notion abroad in some parts of some health systems that incremental growth in budgets will gradually remove all need, but this is wildly over-optimistic. Health and social care decision-makers cannot and must not avoid facing up to the choices that have to be made in the face of such scarcity. In making those choices decision-makers should aim to be transparent about the criteria they are employing. Are they looking to maximize effectiveness in terms of symptom alleviation or aggregate quality of life, or to redistribute resources to poorer communities within society, or to ensure that access to skilled resources is equally available to every patient?

Within this set of criteria, cost-effectiveness obviously has a role to play. As noted earlier, the cost-effectiveness criterion should probably be seen as secondary. If, for example, a therapeutic intervention has been shown to be effective in improving the health or well-being of people with dementia, and appears to be more effective than currently available treatments, then it ought to be natural to ask about the relative costs of the two options and to compare those costs with the outcome gains. Balancing outcome improvements with higher costs is, however, quite a challenge. A great many economic evaluations across the health spectrum today find that new therapies (whether pharmacological, psychological or organizational) offer better outcome profiles than currently prevalent interventions, but they do so at higher cost. The decision-maker, whether this is a local budget holder or someone near the top of a national health system, then faces a difficult trade-off: are the better outcomes from the new intervention worth the higher cost of introducing that intervention?

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