SCIE’s work on economics and the importance of informal care

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Overview

This paper introduces SCIE’s developing approach to economics and highlights one of the main issues that its work in this area has explored: incorporating the costs of informal, or ‘unpaid’, care in economic evaluations. Measuring and valuing unpaid care is fundamental to economic evaluation in social welfare if we wish to form a more complete picture of the true costs and benefits of an intervention and thus aid policy-makers in resource allocation decisions. However, there remains no consensus on the methodology for achieving this. In this brief article we introduce SCIE’s work, highlight the importance of measuring the economic impacts of unpaid care, and reflect on some of the different options available for their quantification and valuation.

Introduction

SCIE’s methods for knowledge building are based on systematic reviews of the evidence base, drawing on knowledge from users’ and carers’ accounts, from professionals, from the experiences of organisations of putting policies into practice and from research. This work provides the basis for developing guides to assist practitioners, policy-makers and people who use services and their carers.

To date, the work has neither attempted to synthesise messages from economic evaluations of social care interventions, nor to cost the recommendations made in SCIE’s guides. Recent work has focused on addressing these gaps in two stages. The first stage involved developing SCIE’s own methodology to incorporate economic evaluations into its knowledge production processes, through a revision of its mapping and systematic review guidelines. Additions to these guidelines include searching, coding and quality appraisal for economic evaluations and a method for extracting resource use data from relevant studies. During the second stage SCIE developed a methodology for the identification and

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presentation of the costs of implementing practice recommendations. Both stages of work have been framed by the development of a statement by SCIE (Francis, 2009) on the type of economic evaluation that can help underpin evidence-based policy and planning in social care.

Whereas SCIE's costing methodology is currently limited to the identification of resources required to implement a recommendation and not any knock-on resource consequences, its position statement differs because it recognises the often complex interaction between social care policies and other public services. In this sense, the statement can be seen as an aspiration, or goal, for the social care sector. It sets out SCIE's view about how the benefits and costs of interventions should be systematically analysed using a methodology that is suitable to the distinct and complex nature of social care.

SCIE's perspective on economic evaluation and implications for informal care

SCIE's statement is written on the premise that due to certain features of the social care system, the way in which economic evaluation is applied in the health sector, although relatively advanced, cannot simply be transferred for use in social care evaluations.

The delivery of social care involves a range of stakeholders and decision-makers and is funded from a combination of central government grants, local tax revenues, unpaid volunteer and family inputs and user charges. Furthermore, sectors other than social care may incur costs and benefits as a result of social services investment in social care interventions. For example, social services expenditure on support for people leaving hospital could improve rates of hospital discharge and ease financial pressure on the health service. Conversely, it could add to the pressure on service users and their families.

SCIE's statement also acknowledges the centrality of services users and their families as stakeholders in the planning, funding and delivery of social care services; this focus is likely to continue to increase with the advent of personalisation. According to the cross-government *Putting People First* agenda (HM Government, 2007), 'personalisation' will enable service users to have more control over their care, becoming commissioners of their own services.

To respond to these complexities it is SCIE's view that economic evaluations in social care should adopt a broad, societal perspective. Taking such a broad approach, the impacts of an intervention on all stakeholders should be evaluated. Thus these analyses should not only include the costs and consequences which accrue to the provider (for example, the council with responsibility for adult social services) but also the costs that fall on health and other sectors, as well as the impacts on service users and their families.

SCIE's position on economic evaluation is also informed by the key challenges facing this kind of analysis in the social care field. The issues are, namely, that the evidence base is lacking and that which does exist is often of lower quality or generated outside the UK (Sefton et al., 2002). It is also the case that methods still require advancement, including the need for the development of suitable outcome measures.

Turning briefly first to work on carer-related outcomes, potentially these might be measured in different ways, for instance, using one or more carer-specific indicators, eliciting monetary values linked to care giving outcomes, or making use of measures reflecting the utility or satisfaction that individuals place on different care-giving outcome states. In the health sector such measures of utility, most notably the quality adjusted life year (QALY) (Phillips & Thompson, 2001), are well established and the preferred outcome measure in technology appraisals in many jurisdictions, including England and Wales. This has included ongoing work to develop specific preference-weighted utility instruments both to measure the quality of life of those engaged in informal care giving (Brouwer, 2006) and also outcomes from adult social care (Netten et al., 2008). Until such work is complete and well-accepted measures are available, SCIE recommends that evaluators in social care should demonstrate how, when measuring outcomes, they have taken account of the opinions of people who use services and their carers.

Briefly, there are two other recommendations in SCIE's statement on economic evaluation in social care which may impact on the way with which informal care is dealt. The first is the importance of taking account of the context in which studies are conducted. SCIE suggests that evaluators should demonstrate how they have taken account of transferability issues between and within countries. This may include very different cultures and infrastructure in respect of the provision of informal and formal care.

The second concerns the legal responsibility to take account of the equality and diversity effects of social welfare interventions. There is also an important need to think of the distributional impacts of interventions, as not all parts of the population will benefit equally from an intervention. SCIE suggests that economic analysis should illustrate who benefits and who loses from any overall gain in outcomes. To achieve this, an evaluation should, where possible, examine the costs and benefits of interventions for different sub-groups of the population and present these findings separately. Again, this could potentially look at the impacts of interventions on different informal care population sub-groups.

The importance of valuing unpaid care

The inclusion of informal care impacts can have a major bearing on the potential cost-effectiveness of social care interventions. Informal care plays a substantial role in the total care provided to those with chronic diseases, the terminally ill and frail older people. Carers UK reports that around 6 million people (1 in 8 adults) are carers, and projects that by 2037 this will have risen to 9 million people (Carers UK, 2009). They estimate that if all these caring responsibilities had instead to be met by the state, the additional costs to the public purse would be £87 billion per year, an average of £15,260 per carer.

So, at a societal level, compounded by demographic developments which suggest both a continued ageing of the population and a reduction in the availability of informal care, there is a clear incentive to support the sustainability of such unpaid care. However, there is also longstanding concern at the individual level about the ability of informal carers to maintain their involvement. In response, strategies have been developed to support informal care, for instance through legislation (Department of Health, 2000, 2005) for the protection of carers' rights, and campaigning and support organisations such as Crossroads and the Princess Royal Trust for Carers.

At the societal and individual levels, therefore, we need to place a value on informal care: it is not a free resource, care-givers incur significant opportunity costs, and without their efforts there would need to be an increase in the availability of paid professional carers. Indeed, the importance of accounting for informal care in economic analysis has long been established. Writing more than 70 years ago, in her volume on the economics of household production, American economist Margaret Reid stated that aspects of household activity such as cooking, child care and gardening all constitute ‘work’, since others could be paid to perform these tasks while the benefit still accrued to the person who paid for it (Reid, 1934).

Yet despite the economic impact of informal care it is often excluded from economic analysis by health technology assessment bodies. The National Institute for Health and Clinical Excellence (NICE) in England and Wales is perhaps one of the best-known proponents of the use of economic evaluation to inform decision-making. NICE adopts a narrow health and personal social services perspective in respect of health care technologies, albeit using a broader perspective in respect of public health interventions whose impacts can be felt beyond the health system. To date, however, while it has acknowledged that the impacts on informal care-givers can be documented as part of the economic appraisal process, they have not been formally included within the cost component of economic evaluations conducted for NICE.

This has been contentious in some areas, such as interventions for the treatment of individuals living with Alzheimer’s disease (Sharp, 2006), where the majority of costs are incurred by carers who are themselves at significant risk of poor physical and mental health. Any impact of treatment on the caring responsibilities and/or the nature of the relationship between an informal carer and their loved one may thus be critical to the cost-effectiveness of some interventions (Wimo et al., 2004). One of the reasons put forward for this omission of care-giver impacts in technology appraisal is the lack of consistency and uncertainty over methods of measurement and valuation. It is certainly the case that estimating time spent caring and then valuing that time is by no means straightforward.

Practical challenges in the measurement and valuation of informal care

Conventionally in economic evaluations, resources are valued at their opportunity cost: that is their next best alternative use (Drummond et al., 2005). As we have already noted, informal care is far from being a costless resource. In addition to the emotional and physical impacts it can have, coupled with any out-of-pocket costs for additional fuel, food or cleaning etc, there are the opportunity costs of time spent caring that could otherwise have been spent engaged in other activities, including paid employment, voluntary work, education and training, household production, leisure activities or even sleeping.

There are several practical and methodological challenges associated with informal care (McDaid, 2001). One key challenge is to accurately measure the amount of time actually spent caring: for example, if an individual has always been responsible for cooking and cleaning in a household, how then does one measure any additional time spent on these tasks as a direct results of caring? It is also very difficult to ask someone to distinguish between the informal care they provide due to health or social welfare needs and care provided because of their relationship with the recipient.

A second challenge concerns the consequences of time spent caring. In some cases, the level of intensity in caring may be modest, which thus allows an individual to engage simultaneously in other activities. For instance, in the home environment, carers could conceivably ‘multi-task’: they could be supervising their loved one, the service user, while at the same time pursuing leisure activities such as reading or performing regular household chores such as cooking or cleaning. In this sense it might be said that there is no lost opportunity because the carer is doing an alternative activity at the same time as providing care.

It may also be important to identify the care-giving time not only of primary carers, such as spouses, but also secondary carers including children and family friends. One recent study suggested that informal caring time for people with dementia may be underestimated by 14 per cent if the contributions of secondary carers are not included (Neubauer, 2008).

Yet even if time spent caring can be accurately measured, a third major challenge concerns the valuation of that time. A fundamental question is whether the value should reflect the opportunity costs of time to individuals or the costs of any replacement care that would be necessary if informal care was no longer available.

Time measurement

It is critical to adopt a standard approach to the measurement of care-giver time. Much of the variation in the valuations of informal care is due to a lack of consistency and wide variation in reported estimates of caring time (McDaid, 2001). There are two principal methods of time measurement. The most accurate way of doing this is to ask individuals to complete a time diary, for example over the period of a week or a month (Valimaki et al., 2007). Time diaries might take different forms, for instance requiring individuals to record the amount of time spent on activities of daily living (ADL), (e.g. washing, dressing, feeding) and instrumental activities of daily living (IADL) (e.g. cooking and financial affair management and supervision time). Alternatively, individuals may be asked to retrospectively recall the amount of time they have spent engaged in care-giving tasks. Questionnaires such as the Resource Utilisation in Dementia instrument might be used, which asks individuals to record time spent on ADL, IADL and supervision over a one-month period (Wimo, 1998).

While easier to administer than a diary, obtaining accurate estimates of care-giving time is more difficult to achieve using the recall method, with care-givers tending to overestimate the amount of time spent caring (van den Berg & Spauwen, 2006). Given that it may be difficult for individuals to estimate accurately the amount of *additional* time spent on informal care activities, one way to counter this may be to adjust any care-giving time estimates in relation to existing time surveys which indicate how the general population make use of their time. Examples include the UK 2001 and 2005 Time Use Surveys; these provide breakdowns of how individuals typically spend their time, including activities such as sleeping, watching television, doing housework, eating, washing and dressing, social life and paid employment (Short, 2001; Lader et al., 2006).

Valuing informal care time

A number of different methods have been put forward to value the costs of carer time, each with their own strengths and weaknesses. Theoretically the opportunity cost approach would be preferable as this reflects the value of the next best use of the carer's care-giving time. In many cases this can be represented by the wages they have forgone. Where data on individual lost time from employment are not known, proxy values such as average or minimum wage rates may be used. However, it is not always easy both to identify what types of opportunity have been forgone to provide care and then to find appropriate opportunity cost estimates for all these different types of time. For example, paid employment is not the only 'next best' use of time; there is also leisure time, lost sleeping time and the lost productivity of those who are not engaged in paid work such as the retired, those with home responsibilities, or school-aged children who also provide informal care to a loved one.

To help identify what opportunities have been forgone, individuals might be asked what they would prefer to be doing if they could give up caring, but there is some evidence to suggest that not all individuals fully understand these concepts: one might imagine that everyone would have some time for leisure activities, yet some informal carers would not allocate any time to leisure activities (van den Berg et al., 2005). An individual's wage rate may be used as a proxy for all types of opportunity forgone or, as in the case of this edition of the Unit Costs of Health and Social Care, the 'national age-adjusted minimum wage rate' can be used.

An alternative approach, which SCIE currently recommends, is to value time spent caring at the market price that would have to be paid if the care was undertaken by a formal care-giver, e.g. home care workers or cleaners. From a public purse perspective this may make sense as it can indicate to policy-makers the potential financial implications of any reduction in the availability of informal care. From a pragmatic perspective, it may also be easier to identify market wage rates for specific caring tasks, rather than trying to identify the opportunity costs to different carers, dependent on their socio-economic status and other characteristics. However, using replacement costs may undervalue informal care; although it can be physically and emotionally stressful, some aspects of care giving can also be positive and rewarding, and this should also be reflected in valuations (Murray & McDaid, 2001).

In recognition of these limitations, other methods for valuing informal care have been tested but their use remains limited. They include the use of contingent valuation and conjoint analysis techniques to elicit from individuals the monetary value that they would place on informal care. For instance, contingent valuation might involve asking informal care-givers and/or the general population what they would be willing to pay in return for no longer having to perform informal care activities. In conjoint analysis individuals might rank different care-giving scenarios which provides information on a number of different attributes of care including monetary impact. Again, these methods have limitations relating to validity and consistency.

Conclusions

The costs of informal care are substantial, particularly in social care. Their consideration can have a major bearing on whether an intervention appears cost-effective. Much methodological work has been undertaken to help improve the way in which informal care can be valued. None of these methods is perfect; ideally the opportunity costs of informal care would be best reflected by the values that individuals place on the alternative use of their time, such as wages forgone. Accurately identifying all of these opportunity costs may be challenging, and a pragmatic alternative recommended by SCIE is to value informal care relative to the professional services that would be required in its absence. Whatever method of valuation is used, however, it is critical that more emphasis is placed on identifying the incremental time spent caring over and above normal household activities, as well as identifying the time inputs of both primary and secondary care-givers.

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