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Economics of dementia: A review of methods

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Abstract
Given the expected increase in the number of people with dementia in the coming years, it is anticipated that the resources necessary to support those with dementia will significantly increase. There will therefore likely be increased emphasis on how best to use limited resources across a number of domains including prevention, diagnosis, treatment and supporting informal caregivers. There has been increasing use of economic methods in dementia in the past number of years, in particular, cost-of-illness analysis and economic evaluation. This paper reviews the aforementioned methods and identities a number of methodological issues that require development. Addressing these methodological issues will enhance the quality of economic analysis in dementia and provide some useful insights about the best use of limited resources for dementia.

Keywords
economic methods, cost-of-illness, economic evaluation, cost, valuing caregiving

Introduction

The consequences of dementia are wide-ranging. Prince et al. (2015) identify the impact of dementia on three inter-related levels: the individual with dementia, the family and friends of the person with dementia and wider society. The individual experiences impaired quality of life and reduced life expectancy. Family and friends, as well as dealing with the impact of the deterioration in the health of their loved one, often provide large amounts of informal care, while society as a whole incurs costs of providing health and social care to those with dementia as well the opportunity cost of lost productivity (Prince et al., 2015). The global cost of dementia was estimated to be US$818 billion in 2015 (Prince et al., 2015); approximately 40% of these costs were due to informal care, another 40% to direct social care and

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20% were attributable to direct medical costs. In Europe, the total cost of dementia disorders was found to be in the region of €160 billion, 56% of which was attributable to the costs of informal care (Wimo et al., 2011).

Given the expected increases in the number of people with dementia in the coming years (Ahmadi-Abhari et al., 2017), it is anticipated that the resources necessary to support those with dementia will significantly increase. Concerns are growing over the ability of often already resource-constrained formal and informal care infrastructures to cope with the expected increase in need (Gillespie & Connolly, 2015). Addressing these concerns, policy makers in many countries have developed, or are in the process of developing, national actions plans for dementia. These plans are generally informed by an evidence-based policy approach to determine what type of care is to be provided, where it is to be delivered and the personnel best suited to deliver it. Given the budget constraints facing health systems, economic analysis is playing an increasingly important role in informing decisions regarding services provision for people with dementia (Gillespie & Connolly, 2015).

Applying economic analysis to the study of dementia is a relatively new field of research, with the first comprehensive collection of literature presented in 1998 by Wimo, Jonsson, Karlsson, and Winblad. Since then, there has been a significant expansion of the discipline, with increasing number of studies published each year. Within this literature, two distinct economic methodologies are identified: (i) cost-of-illness analysis and (ii) economic evaluation. In brief, cost-of-illness techniques are used to express, in monetary terms, an estimate of the total cost of a particular disease to society, while economic evaluation methods are used to assess the costs and consequences of alternative interventions or technologies.

The aim of this paper is to provide an overview and assessment of the aforementioned economic methodologies in dementia research with a view to helping the reader interpret economic studies in dementia. The next section will provide an overview of cost-of-illness methodologies, while the following section will focus on economic evaluations and their role in dementia care. The final section will discuss the future role of economics in relation to dementia care.

Cost-of-illness studies

Overview

A number of methods have been developed by economists to calculate the economic burden of health problems including cost-of-illness, the value of lost output and the value of a statistical life. Here, the focus is on cost-of-illness, as it is the most commonly used method in dementia research and considered by many to be an intuitive way to measure the economic burden of ill-health (Bloom et al., 2011).

The aim of cost-of-illness studies is to identify and measure all the costs of a particular disease (Byford, Torgerson, & Raftery, 2000). The output, expressed in monetary terms, is an estimate of the total burden of a particular illness to society (Rice, 1994). While numerous cost-of-illness studies have been completed across a range of diseases and disorders, including dementia, they have been the cause of much debate among economists (Behrens & Henke, 1988; Rice, 1994; Shiell, Gerard, & Donaldson, 1987), both in terms of their methodology (Drummond, 1992) and their usefulness (Byford et al., 2000; Currie, Kerfoot, Donaldson, & Macarthur, 2000). However, they are a valuable resource for determining not only the burden of a disease but also the distribution of costs across budgets and sectors

of the community. Cost-of-illness studies therefore can indicate the amount that would be saved if a particular disease were eradicated. In addition, they can help to inform research priorities by providing estimates of the economic burden of particular health problems (Luengo-Fernandez, Leal, & Gray, 2012). A 2006 UK governmental review, for example, investigating how public bodies should allocate medical research funding (Cooksey, 2006), recommended that the impact of diseases on the population and economy should be assessed to help determine society's health priorities and in turn inform research priorities.

However, cost-of-illness studies have limitations: they do not address issues of inefficiency or waste nor do they weigh up costs and benefits of interventions (Angelis, Tordrup, & Kanavos, 2015). Also, it may not be correct to assume that the cost-of-illness estimates would be potential savings if a disease were systematically targeted because not all conditions can be fully eradicated and some proportion of economic burden will remain despite effective interventions (Angelis et al., 2015). Further, a high-cost condition is not necessarily amenable to treatment by current medical technology, while a low-cost condition may be fully amenable to low-cost prevention (Byford et al., 2000).

Methodological considerations

Cost-of-illness studies use a wide range of different designs and methodologies, often limiting comparability and usefulness of results (Angelis et al., 2015). In addition to different regions with different health systems and different care arrangements, studies differ along a number of domains including:

- the perspective of the analysis;
- the subjects included;
- whether a bottom-up or top-down approach is used – the top-down methodology uses aggregated data and divides by the number of units produced, while the bottom-up methodology calculates the cost of care by directly measuring patient-specific resource utilisation, which is subsequently assigned a unit cost and
- the method used to value resources which includes consideration of how to value non-health service resources including productivity losses and informal care.

Akobundu, Ju, Blatt, and Mullins (2006) provide a useful overview of cost-illness methods; here, the focus is on the methodological considerations of most relevance to dementia research including the perspective of the analysis, what costs to include and valuing informal care.

The perspective. Cost-of-illness studies can be carried out from a variety of perspectives including the healthcare system, third-party payer and societal. A health system perspective would consider costs imposed on hospitals and other healthcare providers. Alternatively, the broadest perspective is societal, which incorporates all costs and all health effects regardless of who incurs the costs and who obtains the effects. In terms of dementia, a societal perspective would include not only healthcare costs but also those costs falling outside the healthcare sector, such as social care costs, the opportunity costs associated with unpaid (i.e. informal) care to patients or productivity losses associated with premature death or absence from work due to illness (Luengo-Fernandez, Leal, & Gray, 2010).

The choice of study perspective is an important methodological decision because it determines what costs to count. While the appropriate perspective depends on the objective of the study (Torrance, Siegel, & Luce, 1996); in general, the broader societal perspective is preferred because the impact of a condition is not solely on the individuals or organisations that are directly involved. This is particularly important in dementia where many of the costs fall outside the formal health sector, in particular on informal caregivers and therefore all unpaid care by informal carers should be given a monetary value (Wimo, 2010).

What costs. Somewhat related to the perspective adopted is the categories of costs to include in cost-of-illness studies. Three cost categories can be identified – direct, indirect and intangible costs. Direct costs include those for which payments are made and consist of healthcare costs and non-healthcare costs incurred by the health system, society, family and individual patient (Jo, 2014). Direct healthcare costs include, for example, primary and secondary care services, pharmaceutical and appliances and devices. Indirect costs are those for which resources are lost and include productivity losses due to morbidity and mortality, borne by the individual, family, society or the employer. A number of methods have been used to measure productivity losses (Krol & Brouwer, 2014). However, most cost-of-illness studies of dementia do not include indirect costs (Schaller, Mauskopf, Kriza, Wahlster, & Kolominsky-Rabas, 2015) probably because indirect costs are less relevant in dementia where most of the affected are older people who are retired (Alzheimer's Disease International, 2010). Intangible costs include costs of pain and suffering and are generally omitted from cost-of-illness studies because of the difficulty in accurately quantifying them in monetary terms.

Valuing informal care. Methodological challenges exist in measuring the costs of informal care for people with dementia both in the estimation of the amount of time spent caring and in how this time should be valued (Winblad et al., 2016). Estimating the amount of time spent caring requires a definition of informal care. Informal care can mean different things to different people. For example, general household activities such as cooking and cleaning may be regarded as informal care by some but not others. Similarly caregivers may be able to perform other activities while simultaneously providing care and therefore some caregivers may regard it as caregiving and others not. A second issue arises in how to collect data on the amount of informal care. Two common methods include the diary method – where details on caregiving are filled in on a semi-regular basis – and the recall method where caregivers are retrospectively asked about the amount of caregiving relating to a particular period of time. The diary method is generally considered to be superior (van den Berg & Spauwen, 2006) and tends to provide lower estimates than that from the recall method (van den Berg, Brouwer, & Koopmanschap, 2004), but it is very time-consuming which can bias the results in favour of less busy respondents.

Perhaps even more difficult is how to value informal care, given that such care is generally provided free of charge. A number of methods have been proposed and used, each with their own advantages and disadvantages. The *opportunity cost approach* is the standard economic approach where the caregiver would be asked to identify the opportunities foregone because of caregiving. Typically caregivers would be asked to identify the next best use of their caregiving time, which could then be valued using the wage rate, rate for contribution to household production or rate for leisure time (McDaid, 2001). While this is relatively straightforward if the wage rate can be used (to value what would have been work time),

it is less straightforward to reach a value for household production activities or leisure time. A further limitation is that it gives higher value to informal care provided by higher income groups even if performing the same tasks to the same quality. An alternative approach to valuing informal care is the replacement cost method. This method values caregiving time as the level of remuneration required to hire an equivalent professional to replace the caregiver, with the potential cost varying depending on the service provided. This method will be difficult if there are no close formal substitutes. In addition, it requires that informal care is broken down into different components which can be appropriately valued. A disadvantage is that it assumes that formal care and informal care are substitutes which may not be the case. A formal caregiver may have more training and experience and therefore be more efficient in carrying out caregiving tasks. Alternatively, the caregiver and the care recipient may have a preference for the care to be provided by a family or friend instead of a formal caregiver.

The different approaches will likely give different results about the value of informal care depending on the characteristics of caregivers (age and economic activity) if the opportunity cost approach is adopted and wage rates of health and social care professionals if the replacement method is adopted. A small number of studies have used both methods to value informal care (Chari, Engberg, Ray, & Mehrotra, 2015; Jakobsen, Poulsen, Reiche, Nissen, & Gundgaard, 2011; Moore, Zhu, & Clipp, 2001); however, they do not find that one method consistently provides higher or lower values of informal care than the other.

Most dementia cost-of-illness studies have used the replacement cost approach to value informal care (Schaller et al., 2015). In their analysis, Jakobsen et al. (2011) note that the replacement cost approach was adopted because the method provides the most pragmatic estimate, namely, an estimate of the costs that would be imposed on the health and social care sector if informal care was not provided by family and friends but had to be delivered by professional caregivers. Others have favoured the replacement cost approach because of difficulty in obtaining true opportunity cost data (Max, Webber, & Fox, 1995; Rice et al., 1993). For example, Rice et al. (1993) attempted to collect data on missed wages and job and lifestyle changes that resulted from caregiving responsibilities in order to use the opportunity cost approach to measure informal care. However, they found that most caregivers were unable to respond to these questions.

Cost-of-illness studies in dementia

A number of cost-of-illness studies relating to dementia have been completed both at a global level and national level (Coduras et al., 2010; Quentin, Riedel-Heller, Luppa, Rudolph, & König, 2010; Wimo et al., 2011). Such studies have used a variety of methods and techniques making comparisons across health systems difficult. However, two main findings consistently emerge: firstly that the costs of dementia are high relative to other disease groups and secondly that the burden falls disproportionally on the social care system and informal caregivers.

In the UK, the cost of dementia per patient was found to be £27,647 per annum (2007–2008) compared to a cost of £5999 for cancer, £4990 for stroke and £3455 for heart disease (Luengo-Fernandez et al., 2010). While a Spanish study found that of 19 brain disorders, dementia was the most costly given the relatively high prevalence rate (Pares-Badell et al., 2014). As well as being more costly, dementia is unusual in the distribution of costs in that direct non-medical costs are generally greater than healthcare costs. For example, Connolly,

Gillespie, O'Shea, Cahill, and Pierce (2014) found that in Ireland, 48% of the total cost of dementia was accounted for by informal care provided by family and friends, 43% due to residential long-stay care and 9% to formal health and social care costs. In the UK, among four conditions, dementia was estimated to have the lowest healthcare costs (£1.2 billion compared to £4.0 billion for cancer, £2.2 billion for coronary heart disease and £1.6 billion for stroke) but significantly higher social care costs (Luengo-Fernandez et al., 2012).

While cost-of-illness studies in dementia provide some common findings around the distribution of costs, the policy relevance of these studies is less clear. A systematic review assessing the policy making relevance of dementia cost-of-illness studies noted that the studies were typically not conducted for policy making purposes and did not commonly provide prescriptive policy options (Oremus & Aguilar, 2011). However, the authors of the review noted that there may be potential to use cost-of-illness studies to generate hypothesis for further policy-orientated research. For example, the common finding of a high cost burden on informal caregivers may point to the need for more policy-orientated research on the implications for the caregiver and patient of potential ways to mitigate the burden. In addition, cost-of-illness studies are important for planning and resource allocation especially in light of an increasing number of people with dementia. To further enhance the usefulness of future cost-of-illness studies in dementia, a consensus should be reached on how best to conduct cost-of-illness studies in dementia.

Economic evaluation

Overview

As the prevalence of dementia increases, those responsible for planning and financing services face the challenge of allocating increasingly scarce resources across areas such as early detection and diagnosis, preventative strategies, new medications, residential care, supportive care and meeting the needs of caregivers as well as patients (Shearer, Green, Ritchie, & Zajicek, 2012). As a result, healthcare funders in many health systems are increasingly looking for evidence on the value of new interventions through a comparison of benefits (in terms of health status) and costs relative to those of competing or existing practices (Shearer et al., 2012). Economic evaluation is a tool for assessing the costs and consequences of alternative healthcare interventions and is increasingly being used in the dementia field to make decisions about the allocation of scarce resources. For example, in the UK, the National Institute for Health and Care Excellence (NICE) makes recommendations about which interventions should be made available under the National Health Service for those with dementia.

There are a number of different types of economic evaluation including (but not limited to) cost–benefit analysis, cost-effectiveness analysis and cost–utility analysis. In short, all three types deal with costs in the same manner but differ in how they deal with consequences. In cost–benefit analysis, consequences are considered in monetary terms and can therefore be directly compared to costs. In cost-effectiveness analysis, consequences are usually clinically defined units appropriate to the area under study such as lives saved or change in blood pressure. Cost–utility analysis is generally regarded as a special form of cost-effectiveness analysis in which consequences are measured in quality-adjusted-life years (QALYs) – a composite measure of gains in life expectancy and health-related quality of life (discussed in more detail below).

The most common finding from economic evaluations is that an intervention is more effective and more costly than the alternative. In this case, the question arises as to whether the additional benefit is worth the cost (Holloway & Ringel, 2011). To make this decision, an incremental cost-effectiveness ratio (ICER) is required. The ICER is the incremental costs of implementing the intervention over the alternative divided by the incremental benefit and (in the case of cost–utility analysis) provides an indication of the cost per QALY gained. To make a decision about whether the additional benefit is worth the cost, the ICER can be compared to a cost-effectiveness threshold – an amount of money that society is willing to spend to gain one QALY. Unfortunately, however, in many countries, well-accepted thresholds of cost-effectiveness do not exist, though currently in the UK, the NICE use a threshold range of £20,000 to £30,000 per QALY gained (Claxton et al., 2013). Therefore, interventions with an ICER of less than £30,000 per QALY gained would be regarded as cost-effective and recommended for reimbursement within the UK National Health Service.

Economic evaluation provides a systematic method for guiding decision on the allocation of scarce resources. In particular, it can identify which intervention or course of action can provide the greatest benefit for a given level of resources. It has therefore advantages over other methods of deciding on the allocation of scarce resources such as allocating based on allocations in previous years or allocating resources on a lottery basis that lack an evidence base. However, economic evaluation is rarely the sole basis for making decision on allocations. Decision-making in the real world is complicated and will include considerations outside of economic evaluation such as fairness and justice, feasibility issues and total budgets.

Methodological considerations

While there has been increasing use of economic evaluation over the past 20 years, it is a relatively new discipline whose methods are continually being updated. A number of authors have provided a detailed account of the methods of economic evaluation in general (Drummond, Sculpher, Torrance, O'Brien, & Stoddart, 2005) and in relation to dementia (Jones, Edwards, & Knapp, 2016). Here, a very brief overview of the methods of economic evaluation is provided, but the main focus is on issues which are of particular relevance to economic evaluations in dementia including measuring outcomes and the related issue of the inclusion of people with dementia.

Measuring outcomes. As noted above, QALYs are the most common outcome measure in cost–utility analysis. QALYs capture the impact of a particular intervention on length and quality of life and can be used for interventions which impact on quality of life even if they have little impact on length of life. One QALY corresponds to one year in perfect health; years spent in less than perfect health are assigned a weight (sometimes known as a health utility), calculated on the basis of preferences for the health state (Winblad et al., 2016). Therefore, in order to calculate QALYs, quality of life needs to be expressed in terms of preferences that people have for particular health outcomes or health states. While many studies have explored quality of life in dementia, most have not reported outcomes in terms of preference-based units and therefore cannot inform economic evaluation (Shearer et al., 2012).

Shearer et al. (2012), having completed a systematic review of health state values for use in the economic evaluation of treatments for Alzheimer's disease (AD), identified 12 studies that reported utility values associated with health states in AD, almost all of which were based on two generic measures of quality of life: the EQ-5D and the health Utility Index mark 2/3. They did not identify any health state values from disease-specific measures of quality of life. The most common, the EQ-5D is a patient-reported generic measure of health status that consists of five dimensions: mobility, self-care, usual activities, pain/discomfort and anxiety/depression. Each dimension has three levels – no problem, moderate problem, severe problem – producing 243 possible health states (Brooks, 1996). Sets of values for each possible health state have been estimated using preferences elicited from various groups including members of the UK general population. Health utility weights (in which 1 equals perfect health and 0 is equivalent to death) have been estimated as ranging from 0.69 in mild disease to 0.33 in severe disease using the EQ-5D (Jonsson et al., 2006).

While generic instruments such as the EQ-5D are regularly recommended as they facilitate comparison across different health conditions and diseases (Drummond, Sculpher, Claxton, Stoddart, & Torrance, 2015), they may lack the coverage to detect changes in important aspects of certain conditions (Comans et al., 2018). For example, the EQ-5D lacks attributes to meaningfully capture cognition (Hounsome, Orrell, & Edwards, 2011). As a result, there has been increasing interest in the use of dementia-specific measure such as DEMQoL (Mulhern et al., 2013) and the Quality of Life in AD (Comans et al., 2018) in dementia-related economic evaluations. However, these disease-specific measures have not yet been widely applied in economic evaluation studies.

Inclusion of people with dementia. There is increasing recognition of the need to include people with dementia in research (Wilkinson, 2002) as proxies cannot provide as complete a perspective on what is important to a person with dementia as can a person living with the syndrome (Slaughter, Cole, Jennings, & Reimer, 2007). However, the inclusion of people with dementia raises a number of potential issues including their cognitive ability to meaningfully consent and participate.

Informed consent involves being able to decide whether or not to take part in the research, in order to give informed consent, a person must have enough information about the research, be able to understand the information and have the power of free choice so that they can voluntarily consent or decline (Higgins, 2013). The symptoms of dementia, such as short-term memory problems and difficulty with concentration and understanding, raise questions as to whether they can give informed consent. As a result, consent (or assent) of caregivers is generally sought, though this can give rise to further difficulties, not least of which is that proxies will often have different views and provide different data than people with dementia.

While proxy-administered EQ-5D ratings have been found to be valid and reliable in dementia (Coucill, Bryan, Bentham, Buckley, & Laight, 2001; Karlawish et al., 2008b; Naglie et al., 2006), there is less certainty around the validity and reliability of patient administered ratings (Ankri et al., 2003; Coucill et al., 2001; Karlawish et al., 2008b). Shearer et al. (2012), for example, identified a small number of studies which provided health state values based on both caregiver and patient reports and found poor correlation between ratings, particularly for patients who had moderate-to-severe cognitive impairment. Patients often rated their ability to perform activities of daily living more highly than proxies did (Karlawish et al., 2008a). Karlawish et al. (2008b) having looked at the feasibility,

reliability and validity of use of caregivers ratings concluded that caregivers assessment of quality of life were at least as reliable as those of the people with dementia based on test–retest reliability. They also found that the reliability of patient reports may have been affected by large proportions of patients who did not perceive or acknowledge any disability. While standard practice often involves relying on proxy reports from caregivers, this raises other issues including whether a proxy can full appreciate a patients' health-related quality of life, the influence of a proxy's own subjective state of mind and the associated impact of caregiver burden on ratings (Shearer et al., 2012).

An ongoing challenge for economic research in dementia (and indeed all research in dementia) is to identify ways to meaningfully involve people with dementia in research while protecting the rights and interests of individuals with dementia who participate in this research (Slaughter et al., 2007).

Economic evaluation studies in dementia

The use of economic evaluation in dementia is increasing. While initial work was largely in the area of pharmacological interventions, more recently economic evaluation is also being used to assess the costs and outcomes of psycho-social interventions in dementia. Knapp, Lemmi, and Romeo (2013), reviewing the evidence on the cost-effectiveness of prevention, care and treatment strategies in relation to dementia, identified three areas – pharmacological interventions, non-pharmacological interventions for individuals with dementia and interventions targeted on caregivers. They found that the majority of economic evidence was on pharmacological interventions, in particular focusing on drugs for AD. For example, reviewing the evidence on treatments for mild-to-moderate AD, a 2011 study by NICE noted that donepezil, rivastigmine and galantamine were cost-effective treatments from a health and social care perspective. However, the authors note that more work may be required in this area, given the relatively small number of studies and that many of the studies were conducted by the manufacturers of the medications with the potential for a conflict of interest (Knapp et al., 2013).

A small but increasing number of studies have examined the cost-effectiveness of non-pharmacological interventions in dementia. Knapp et al. (2006), for example, examined the effectiveness and cost-effectiveness of cognitive stimulation therapy (CST) for people with mild-to-moderate dementia and concluded that CST had the potential to be more cost-effective than usual care. However, caution is needed in interpreting the results given the relatively small sample size and the short period of follow-up (Knapp et al., 2013). A later study with a longer period of follow-up and a higher number of participants conducted as part of a randomised controlled trial found that while gains from long-term CST were modest over a six-month period, long-term CST appeared to be cost-effective (D'Amico et al., 2015).

While initial research on the cost-effectiveness of non-pharmacological interventions is favourable (D'Amico et al., 2015; Knapp et al., 2006), research is in this area is in its infancy and more work is required to examine which interventions are cost-effective, for whom and in what format. For example, a recent study found that the joint reminiscence groups (between patient and caregiver) were unlikely to be cost-effective, as the potential beneficial effects for people with dementia who attend sessions were offset by raised anxiety and stress in their caregivers (Woods et al., 2016).

Alternatives to economic evaluation in dementia research

A potential limitation of economic evaluation in dementia care is that there are potentially 'soft' outcomes such as increased participation and confidence which may be important to those with dementia and their caregivers but are not easily captured within the methodology and in particular within the QALY framework. There is therefore increasing interest in the use of alternative methodologies which may better identify and capture outcomes which individuals themselves consider important for their well-being. Examples of such methodologies include social return on investment (SROI) analysis and discrete choice experiments (DCE).

While a detailed description of SROI is beyond the scope of this paper (and can be found in the report by the SROI network; Nicholls, Lawlor, Neitzert, & Goodspeed, 2012), in short, SROI is a method of measuring impact, outcomes and value created by interventions or organisations (Willis, Semple, & de Waal, 2018). The key difference between economic evaluation and SROI is that SROI explicitly attempts to involve stakeholders at every stage of the analysis through assessing how much stakeholders value a particular service or intervention (Millar & Hall, 2013). DCEs are a quantitative technique for eliciting preferences (Mangham, Hanson, & McPake, 2009). In DCEs, study participants are presented with descriptions of hypothetical goods and services based on a combination of characteristics and asked to select their preferred option. It is assumed that individuals will consider all information provided and then select the alternative which they perceive to have the highest value (Ryan, Gerard, & Amaya-Amaya, 2008).

There are a small number of studies which have used SROI and DCE in dementia research. Willis et al. (2018), for example, used the SROI approach to quantify the benefits of peer support for people with dementia, while Chester et al. (2018) used a DCE survey to assess people with dementia and carer preferences for home support services in early-stage dementia. A strength of both instruments is the ability to include outcomes which may not be easily incorporated into a standard economic evaluation; however, the measures are not without their issues. For example, a potential limitation of DCEs for people with dementia is that it may be cognitively demanding. Chester et al., for example, found that feedback from a small number of carers and people with early stage dementia completing a DCE was mixed with some suggesting that the survey was challenging to complete and others seeming to enjoy the task. Therefore, while such alternative methodologies offer potential advantages over standard economic evaluation in dementia research, more work is required in developing and streamlining the methodologies.

Discussion

It is anticipated that the number of people with dementia and the demand for health and social care services will increase in the coming years. Coupled with a potential decrease in the availability of informal caregivers due to changing population demographics, it is likely that economic analysis will play an increasingly important role in informing decisions regarding services provision for people with dementia. The application of economic methods to dementia is a relatively new development and while there have been a number of cost-of-illness studies and economic evaluations (particularly for pharmacological interventions) in dementia, differences in the quality and methods of the studies highlight the need for additional research in the area.

In addition to the general issues associated with research in dementia, two areas of potential concern when applying economic methods to dementia are (1) how to value informal caregivers' time and (2) what health outcomes to include. The distribution of costs in dementia is different to many other conditions given that the bulk of costs often fall on social care services and informal caregivers. Failure to include these costs in economic analysis will give a skewed picture about the costs of dementia and in the potential value of new treatments. Winblad et al. (2016) note that treatment options with the potential to change the long-term course of dementia often require substantial upfront investments and that full benefits could take years or decades to be realised. Failure to quantify the impact on informal caregiving in economic evaluations could underestimate the costs associated with informal caregiving if the intervention led to a reduction in the need for such care or alternatively could result in an underestimate of the costs if the intervention increased the need for informal care.

Another area of potential concern relevant for economic evaluations is the identification and measurement of appropriate outcomes. While QALYs have formed the outcome measure for a number of economic evaluations in relation to dementia care, more recent research has sought to identify and quantify alternative measures which go beyond a focus on length and quality of life to incorporate alternative outcomes which may be more relevant to those with dementia and their caregivers.

While there is a growing body of research applying economic methods to dementia care, in general, economic analysis has not yet played a significant role in influencing public policy in the area. There are a number of potential reasons for this including a scarcity of studies and methodological limitations in existing studies (Knapp et al., 2013), as well as a failure of researchers to consider the potential policy implications of their work. Addressing existing methodological issues as well as increased discussion between researchers, policy makers and people with dementia and their caregivers will help realise the potential of economic analysis in addressing difficult questions around the care for people with dementia.

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