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SYSTEMIC REVIEWS

The Inclusion of Informal Care in Applied Economic Evaluation: A Review

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A B S T R A C T

Objective: Theory and guidelines advocating the inclusion of informal care in economic evaluation have, in recent years, been accompanied by developments in the methods for capturing the costs and outcomes related to informal care. The objective of this study was to review applied economic evaluations to identify the methods used for, and implications of, including informal care in practice. **Methods:** Searches of key databases were conducted to identify all full economic evaluations incorporating costs or outcomes relating to informal care. Information was extracted by using a standard template from all studies meeting the inclusion criteria. **Results:** Thirty economic evaluations were identified that included informal care. Twenty-five of these studies costed carers' time input and 17 measured outcomes for carers. The reported cost-effectiveness of interventions was altered by including informal care, in some cases changing the key conclusions for health care

funding. **Conclusions:** Theory and methods development around informal care are yet to significantly permeate the applied literature; however, the results suggest that some funding priorities may change if they were to do so. The development of 1) a reference case for including informal care; 2) sensitivity analysis for contentious issues; and 3) a statement for the reason for excluding informal care, if this is deemed appropriate, may help to improve the way that informal care is included in economic evaluations in the future.

Keywords: economic evaluation, indirect costs, informal care, outcome measurement, review.

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Introduction

Informal carers have an important, yet ambiguous, role in economic evaluation [1]. The time spent providing informal care (such as personal care and household tasks) is a resource that is used up as a result of an illness, and so carers should arguably be considered as a cost in economic evaluation. The carer's quality of life, however, may also be affected by a patient's illness, the caring tasks, or health care intervention, and so outcomes for carers may also be relevant in an economic evaluation. If a health care intervention improves the quality of life of the carer or reduces the time the carer need to spend caring, then economic evaluations that ignore informal care will underestimate the value of the intervention. When the economic evaluation is designed to inform decisions on the amount of health care funding, then ignoring informal care will lead to an underinvestment in health care. Conversely, if the economic evaluation is designed to inform resource allocation decisions within a fixed budget for health care, then ignoring informal care will lead to a relative underinvestment in those interventions that benefit carers [2].

For certain conditions, carers' time input may be substantial [3,4]. In economic evaluations where individuals' time use is considered an important resource (usually those evaluations that take a "societal perspective"), time needs to be measured and valued. Measurement and valuation of time is a contentious issue. Carers

may engage in joint production [5]; for example, they may use their time to carry out additional housework resulting from a patient's illness (which may be considered informal care), while engaging in leisure, for example, watching television. There is also debate as to whether foregone work time represents a significant loss in "value" to society. Proponents of the friction cost view of productivity losses argue that someone else who is not currently employed is likely to take up the job of an individual when he or she leaves the labor market. As a consequence, the net social loss of foregone employment, due to disease or caring, for example, is smaller than would be assumed under a human capital approach [6]. This is especially the case when unemployment and/or labor market flexibility is high. Because informal care, by definition, does not normally involve monetarily compensated tasks, non-market techniques are required to value the time spent on informal care. The two main methods use the price of an equivalent service (the proxy good method) or the value of the carer's foregone activity (the opportunity cost method) [7]. Valuations derived by using a single proxy good or opportunity cost may mask individual differences in the value different carers place on their time and ignore the value of the relationship between carer and recipient. As a result, a series of studies have also used stated preference techniques, such as contingent valuation and discrete choice experiments, to understand how much carers would need to be compensated to provide more care in specific situations [8–11].

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There is growing evidence demonstrating that the provision of informal care can affect the quality of life of carers. Caring has been associated with an increased risk of mortality [12], psychiatric morbidity [13], and complex well-being effects, both positive and negative [14–17]. The quality-of-life impacts on carers arise both from the anxiety over a loved one's health and the potentially fulfilling, but often stressful, nature of providing care. A broad array of outcome measures designed for use with carers are available [18]. These measures typically comprise items to measure problems in health, family life, and social life, but for economic evaluation, some measure of the value of change on the measures is required and this is rarely incorporated. The diverse quality-of-life impacts on carers can potentially be captured for economic evaluations by using generic health-related quality-of-life measures [19,20] or preference-based "care-related" quality-of-life measures [21,22]. Double counting may be a concern when informal care is incorporated as both an outcome and cost [23,24], as carers may, in theory, consider time sacrifices when expressing changes in their quality of life.

Alongside methodological development in techniques to incorporate informal care in economic evaluation, policymakers are beginning to acknowledge the importance, and the need, to consider informal care in policy decisions [25]. A growing number of countries are adopting economic evaluation as a method to inform funding decisions, with around half recommending a societal perspective in economic evaluation and three quarter a health care perspective [26]. Notably, both the influential US panel on cost-effectiveness and the UK National Institute for Health and Clinical Excellence advise analysts to consider health impacts on family members and carers [27,28].

Given the calls for informal care to be given prominence in economic evaluations, it is pertinent to examine whether these calls have been heeded. The aim of this study was to investigate three related research questions to inform this issue: 1) To what extent has informal care been included in applied economic evaluation? 2) How consistent are the methods for including informal care? and 3) To what degree does including informal care make a difference to the inferences drawn from the economic evaluation?

Methods

A review of applied economic evaluations was conducted to explore the three research questions stated in the previous section. Inclusion criteria was set in advance, with studies being included only if they 1) were full economic evaluations; 2) incorporated costs and/or outcomes related to informal care, describing the methods for doing so; and 3) were written in English.

Search Strategy

MEDLINE (OVID), EMBASE (OVID), NHSEED (CRD), CINAHL (EBSCO), ERIC (PROQUEST), PsycInfo (OVID), EconLit (EBSCO), and Web of Science (ISI) were searched for studies between 1950 and 2010. ERIC covered both published and nonpublished literature. A Boolean strategy was used for the search in which a keyword relating to informal care was combined with a keyword relating to economic evaluations (Table 1). Where appropriate, an asterisk was used to capture all possible variations of the stem word. All possible combinations were used in each database, with the exception of NHSEED (because NHSEED contains only health-related economic evaluations, keywords relating only to informal care were used). The search was expanded to include all areas of the article, including the full text, because it was possible that an economic evaluation incorporated informal care despite not describing that fact in the keywords or the abstract. The list of study titles was also supplemented with potentially relevant economic evaluations already known to the study authors.

Table 1 – Keywords used in the search.

Keywords relating to informal care	Keywords relating to economic evaluations
Caregive*	Cost-benefit analysis
Carer	Cost-effectiveness analysis
Family carer	Cost-utility analysis
Home carer	Economic evaluation
Informal care*	
Informal caregiver*	
Unpaid care*	

Note. Search in MEDLINE.

[caregive* OR carer OR family carer OR home carer OR Informal care* OR Informal caregiver* OR unpaid care*] AND [cost-benefit analysis OR cost-effectiveness analysis OR cost-utility analysis OR economic evaluation].

Study Selection

Following deletion of duplicates, the study selection occurred in two phases, first based on the titles and abstracts and then based on the full texts. In the first phase of the study selection, studies were excluded as not relevant if they were not published in English, descriptive studies (not full economic evaluations), and/or studies in which the costs and outcomes were detailed in the abstract and clearly did not include informal care. Where there was ambiguity, the study was retained. Full articles were then obtained for the second phase of study selection, and studies were excluded at this stage if they did not incorporate informal care as a cost or outcome, did not differentiate between formal and informal care, or provided no details as to how informal costs and/or outcomes were incorporated in the economic evaluation. Country of origin, disease area, perspective, and type of economic evaluation were not, however, used as exclusion criteria.

To investigate reliability of the study selection, selection was performed by all three authors on a random sample of 5% of the studies by using the exclusion criteria described above. The overall agreement was then calculated by using Cohen's kappa statistic [59].

Data Extraction

A data extraction form was developed to extract the relevant information from the studies selected. To identify the characteristics of studies incorporating informal care, information was extracted from all studies on the publication year, study country, disease area, intervention, perspective, type of economic evaluation, use of sensitivity analysis, and the impact of incorporating informal care on the results of the economic evaluation.

Results

Study Selection

The review was performed in June 2010. In total, 5967 potential studies were identified (5849 were derived from the database search, 106 from hand-searching the references and citations of key articles, and 12 from the study authors). Following the removal of duplicates, 2282 studies remained. All three study authors reviewed a subsample of 114 randomly selected abstracts. The chance-corrected agreement between the abstracts selected by the primary author and the two coauthors was in the range of 0.79 and 0.9, or "almost perfect" [60]. Discrepancies were resolved through discussion between the authors as to how the study characteristics of the disputed studies related to the inclusion criteria. Disagreement occurred only on a tiny fraction of abstracts. The

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