PharmacoEconomics (2013) 31:1105–1119
DOI 10.1007/s40273-013-0104-z

PRACTICAL APPLICATION

How to Include Informal Care in Economic Evaluations

Renske J. Hoefman · Job van Exel · Werner Brouwer

Published online: 12 November 2013

Abstract Economic evaluations of health interventions aim to support decision making in healthcare. To effectively do so, evaluations need to include all relevant costs and effects of an intervention. Informal care provided by family or friends is an important element of care for many patients, but can have a profound impact on the health and well-being of carers. Therefore, informal care should be considered in economic evaluations of health interventions. Different methods to do so exist. This paper provides an overview of state-of-the-art methods available for this purpose, illustrated with practical examples. Since the choice of measurement and valuation technique depends on the type and perspective of the economic evaluation, this paper supports researchers in choosing the appropriate techniques to include informal care in their economic evaluation of a health intervention. We discuss the different approaches to measuring and valuing informal care, covering both partial and full valuation methods, allowing inclusion as costs or effects.

Key Points for Decision Makers

- The impact of providing informal care can be profound and should therefore be considered in economic evaluations of health interventions.
- Instruments for this purpose are available: the choice of measurement and valuation technique depends on the type and perspective of the economic evaluation.
- This paper supports researchers in choosing the appropriate techniques to include informal care in their economic evaluation of a health intervention.

1 Introduction

Economic evaluations of new healthcare technologies, especially pharmaceuticals, are increasingly used to support policy decisions in healthcare [1–3]. To be useful for that purpose, such evaluations need to include all relevant costs and effects in an appropriate way. While this may seem straightforward, in practice it is not. Appropriately measuring, valuing, and including all different costs and effects in an economic evaluation can prove a difficult task. This is already true for aspects such as medical costs and measuring health benefits, but especially holds for costs and effects that are less central in common economic evaluations.

R. J. Hoefman (✉) · J. van Exel · W. Brouwer
Institute of Health Policy and Management,
Erasmus University Rotterdam,
P.O. Box 1738, 3000 DR Rotterdam,
The Netherlands
e-mail: hoefman@bmg.eur.nl

Informal care[1] is an important example. Informal care constitutes a substantial part of the total care received by (especially chronically ill) patients and elderly in many countries [4, 5]. Informal care can complement and substitute the formal care patients receive. It can complement formal care, for example, when informal caregivers assist patients with the management of their disease or medication. This improves the overall quality of care for patients who are not fully independent (e.g., in the context of aging, dementia, mental illness) [6, 7]. Informal care can also substitute formal care by supporting patients to stay at home longer or to be discharged from formal care sooner [8–10].

The impact of informal care on patients and carers can be profound [11–17]. Therefore, it is important to consider informal care in economic evaluations. This obviously holds for evaluations adopting a societal perspective. From this perspective, all relevant societal costs and effects of an intervention need to be included in an evaluation, regardless of where they fall [18–22]. Nonetheless, informal care is also relevant when a narrower perspective is adopted. For instance, in England and Wales where the National Institute for Health and Clinical Excellence (NICE) currently prescribes the healthcare perspective [23], in which only costs that fall within the healthcare budget and only effects on health or health-related quality of life (HR-QOL) should be considered. Then, policy makers interested in optimizing health from a given budget are likely to be interested in health changes in carers as well. Such health changes in carers have been demonstrated to exist and may have two distinct sources. First, they may be related to caregiving activities (the 'caregiving effect'). These activities can be physically and mentally straining [11–17]. Second, the health status of patients can directly affect their carers. This is labeled the 'family effect' [16, 24, 25].

Informal care is relevant in many care situations and, hence, for economic evaluations of health interventions. Although the interest in effects on carers appears to be increasing (which this paper underlines), until some years ago economic evaluations often ignored informal care [26]. Common explanations for disregarding informal care include the methodological difficulties of measuring and valuing the impact of informal care [26–28]. However, numerous measurement and valuation methods of informal care have become available in recent years [29, 30], thus facilitating the inclusion of informal care in economic evaluations.

Ignoring informal care is problematic, because it may result in biased calculations of cost effectiveness and, hence, in wrong policy information and decisions. Krol and colleagues [31], for instance, highlight the large impact that ignoring productivity costs can have on the outcomes of evaluations, which could imply the difference being considered cost effective or not. Ignoring the costs and effects of informal care may have similar impacts, especially in the context of disease areas where informal care is relatively important, such as in the case of Alzheimer's disease (e.g. Brouwer et al. [32, 33] and Goodrich et al. [32, 33]) or rheumatoid arthritis [41]. Whether informal care is important in the context of any specific intervention, and hence needs to be included, should be an important consideration for researchers when designing their study.

This paper aims to guide researchers in measuring and valuing the impact of informal care, in very practical terms. To this end, we summarize common methods to include informal care in economic evaluations of health interventions and present practical examples of how to apply these methods. To remain practical, we do not provide an exhaustive, systematic review of methods and instruments, but largely draw on experience built up in the course of developing the iMTA Valuation of Informal Care Questionnaire (iVICQ) and its accompanying manual [30]. Furthermore, we point out to researchers how to select the appropriate methods for their own research. We discuss which valuation methods are suitable per type of economic evaluation and perspective. In doing so, we primarily focus on a commonly used type of economic evaluations: cost-utility analysis (CUA). Given the similarities of techniques, we discuss CUA and cost-effectiveness analysis (CEA) simultaneously. We will also pay some attention to the applicability of methods in cost-benefit analysis (CBA) and multi-criteria analysis (MCA). Finally, in the following sections the primary focus is on including caregiving effects in economic evaluations of patient-oriented interventions, in terms of time investment, health, or well-being effects. However, some of the methods discussed can also be used when evaluating support interventions aimed directly at informal carers. Moreover, they may be used to measure and value the family effects carers (and other non-caring family members) may experience.

2 How Can Informal Care Be Measured?

Informal care can be included in the numerator or denominator of an incremental cost-effectiveness ratio (ICER). In other words, informal care can be captured on the cost-side or on the effect-side of an economic evaluation.

[1] An informal carer is defined here as a person who provides care and support to a family member, friend, or acquaintance with a chronic illness, disability, or other long-lasting care need due to ill health or aging. Informal care is typically provided on a voluntary basis, arising from a prior social relationship, and without financial compensation or specific training. This definition combines several aspects from descriptions of informal care in the literature (e.g., Colombo et al. [4, Hoefman et al. 30, and Al-Janabi et al. 101], Hoefman et al. [4, 30, 101], and Al-Janabi et al. [4, 30, 101]).

2.1 Measurement of the Costs of Informal Care

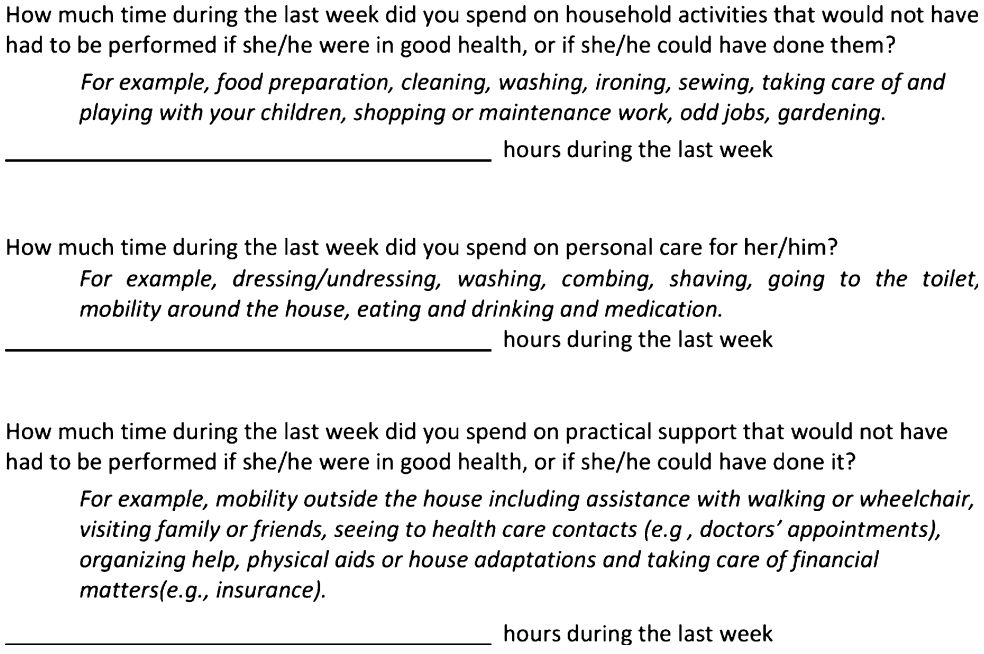
Two main types of costs of informal care can be distinguished: (1) out-of-pocket expenses, such as travel expenses; and (2) time input of carers, also called the objective burden of caregiving. Out-of-pocket expenses can be measured by directly asking carers about expenses for informal care. Time input by carers typically is more important. Researchers can use different methods to *measure* time input, such as the diary method and the recall method [34, 35]. The diary method is often considered to be the preferred method for recording time use of individuals. However, registering all activities performed in a specific timeframe is very time consuming. Moreover, this method can be straining for respondents and, hence, may not always be feasible [34]. With the recall method, researchers retrospectively ask about the number of hours spent on care tasks during the last week, such as in, for example, Hoefman et al. [36]. An example of such a question is shown in Fig. 1. This method provides a valid measure of time input as compared to the diary method [34].

If desired, more detailed questions focusing on specific activities are available (for examples, see previous publications [16, 24, 37–41]). These questions provide more insight into the specific activities performed by carers. Furthermore, the number of tasks performed shows the complexity of caregiving situations, which can be an important determinant of the experienced subjective burden of caregiving [42].

Accurate time registration in the context of informal care often is problematic. Measurement bias may arise for instance from joint production, e.g., doing two things at the same time, such as surveillance while doing normal household work. Bias may also arise from difficulties in separating time spent on normal tasks and informal care tasks, e.g., carers that took over household tasks from the patient years ago may now see this as normal time use rather than informal care [34]. Moreover, sometimes respondents indicate that they spend 24 h per day on caring, for 7 days a week. This obviously is not realistic, because carers also need time for personal care and sleep. Such an answer therefore seems an expression of strain and involvement rather than an accurate registration of sacrificed time use. In such cases, previous studies have, for example, set a limit of 18 h per day (or 126 h per week) for the total number of hours caregiving (for examples, see previous publications [11, 36, 43]). Carers are then still assumed to spend most of their time on care activities, like they indicate themselves, but also to have an average of 6 h per day for their own basic needs. The validity of registered time inputs should always be considered carefully. Since a golden standard is lacking, this could be done by within-study checks (e.g., by linking number of hours to patient status) and by across-study comparison, preferably with studies using a similar patient/caregiver population and a comparable institutional context. It would also be helpful if more review studies became available in this area, like those reported for dementia [44, 45].

2.2 Measurement of the Effects of Informal Care

The impact of informal care can be quantified as an effect by *measuring* carers' (1) subjective burden, (2) health, or (3) well-being.


How much time during the last week did you spend on household activities that would not have had to be performed if she/he were in good health, or if she/he could have done them?

For example, food preparation, cleaning, washing, ironing, sewing, taking care of and playing with your children, shopping or maintenance work, odd jobs, gardening.

_____ hours during the last week

How much time during the last week did you spend on personal care for her/him?

For example, dressing/undressing, washing, combing, shaving, going to the toilet, mobility around the house, eating and drinking and medication.

_____ hours during the last week

How much time during the last week did you spend on practical support that would not have had to be performed if she/he were in good health, or if she/he could have done it?

For example, mobility outside the house including assistance with walking or wheelchair, visiting family or friends, seeing to health care contacts (e.g , doctors' appointments), organizing help, physical aids or house adaptations and taking care of financial matters(e.g., insurance).

_____ hours during the last week

Fig. 1 Example of recall method for measuring time input by informal carers [30]

Subjective burden is the strain of caregiving as perceived by carers. This subjective burden is not necessarily strongly related to the objective burden of caregiving [22, 28, 42]. Put differently, some carers perform many care tasks but do not feel strained, while others perform just a few tasks and consider this to be very straining.

A variety of subjective burden instruments exist. Most provide a detailed description of the impact of caregiving on things like mental health, physical health, and social and financial problems [29, 46, 47]. Some instruments implicitly or explicitly include positive aspects of caring, such as fulfillment from caring, e.g., the Self-Rated Burden (SRB) scale [22, 47] and Caregiver Strain Index plus (CSI+) [48, 49]. It is important to note that subjective burden instruments do not provide an economic valuation of informal care. Therefore, these instruments are unsuited to include informal care in the most common types of economic evaluations. This is also the case for some instruments that have been developed to measure caregiver quality of life (see, for example, Deeken et al. [29]), but lack an aggregate utility score. How the information such instruments provide can be used in the context of economic evaluations is highlighted Sect. 4.

The effect of providing informal care on carers' health can be expressed in changes in *health-related quality of life* (Table 1) [16, 22, 24, 41, 50] and measured in terms of quality-adjusted life-years (QALYs; Table 1) (e.g., Drummond et al. [19]). In the context of an economic evaluation, this can best be assessed directly by measuring changes in carers' health due to the intervention. In other words, measuring differences in health of carers between treatment arms. If this is not feasible, one can fall back on indirect evidence. For instance, by investigating the influence of informal care hours on health [16]. Alternatively, researchers can compare health of carers to the health of the population at large [41, 51]. It needs noting, however, that health effects may originate not only from the strain of caregiving, but also from the mere fact that a loved one has a serious illness or condition. This family effect can occur in a broader range of significant others than just the carer(s) [16, 24].

Informal care can have an impact on different life domains, also beyond health. Therefore, one may also consider measuring well-being, or general quality of life, of carers. One way of doing so is by measuring happiness of carers. Happiness, in general terms, is the judgment of an individual of the quality of their life as a whole [52]. As such, it can be seen as an expression of (experienced) utility or welfare, relevant in economic decision making. Important to note here is that changes in happiness may have different underlying sources. For example, caregiving can influence happiness of carers, but the knowledge that a direct family member suffers from a serious illness or condition can also have an impact, i.e., the family effect. Therefore, as with health effects, relevant changes in well-being can occur in a wider range of significant others, e.g., non-caring family members [24].

3 How Can Informal Care Be Valued?

Inclusion of informal care in economic evaluations requires a *valuation* in economic terms of the measured inputs or effects. Different options are available for the valuation of informal care [26–28]. The principal differences relate not only to *what* is valued, but also to *how* the valuation is performed.

A first important choice is whether one wishes to incorporate informal care in the numerator or the denominator of the ICER. In other words, researchers need to choose whether they will capture informal care on the cost or effect side of an economic evaluation. *Monetary valuation methods* value informal care costs, *non-monetary valuation methods* value carer effects. Moreover, methods differ in the range of consequences of informal care they consider in the valuation. Valuation methods can provide either a *partial* or a *full valuation* of informal care. A *partial valuation* focuses only on a selection of consequences of caregiving, such as time investment. *Full valuation methods of informal care* include all consequences of caring.

In general, from a welfare economic viewpoint, full valuations of informal care are preferred in economic evaluations. However, when an evaluation uses a narrower perspective, partial valuation methods may be required.

3.1 Monetary Valuation of Informal Care

Monetary valuation methods express the value of informal care in monetary terms. This value is multiplied with the

Table 1 Overview of non-monetary valuation methods of informal care

Concept	Valuation method
Health-related quality of life	Quality-Adjusted Life Year caregiver (QALY cg)
Care-related quality of life	Carer Experience Scale (CES)
	Care-related Quality of Life-7 Dimensions (CarerQol-7D)
Well-being	Care-related Quality of Life-Visual Analogue Scale (CarerQol-VAS)
	Process Utility (PU)

Table 2 Overview of monetary valuation methods of informal care

Concept	Valuation method
Revealed preference-based methods	
Time input caregiver	Opportunity cost method (OC)
	Proxy good method (PG)
Well-being caregiver	Well-being method (WB)
Stated preference methods	
Willingness to pay (WTP)/ willingness to accept (WTA)	Contingent valuation (CV)
	Conjoint analysis (CA)

number of care hours and included on the cost side of an economic evaluation. Normally, one derives a monetary value of a product or service from its market value. In other words, by using the observed prices. However, informal care is not traded on a normal market. Therefore, one cannot directly observe market prices for informal care [22, 28, 32, 46, 53, 54]. Hence, estimating the value of an hour of informal care requires other methods. Several of these methods exist: the opportunity cost (OC), proxy good (PG), well-being (WB), contingent valuation (CV), and conjoint analysis (CA) methods (Table 2). These methods differ in the way to derive values. This is explained in Sect. 5.

The OC and PG methods provide a *partial valuation of informal care*. Both methods only consider the value of the time carers sacrifice. Moreover, the OC and PG method value all hours equally. However, the value may differ between hours. That is, people may value the first hour different than the 20th hour of care. Moreover, people may prefer performing specific care tasks over others. Such preferences are not reflected in these methods [27, 28, 46]. The WB, CV, and CA methods in principle[2] provide a *full valuation of the impact of informal care.*

An important advantage of valuing informal care in monetary terms is the straightforward and uncomplicated inclusion in economic evaluations. The derived costs (or savings) can simply be added to other costs. A downside is that adding of the costs of informal care to the stack of other cost items in economic evaluations gives less explicit attention for the consequences of a healthcare program on carers [40]. Non-monetary valuation of informal care, which is discussed in the next section, may provide more explicit insight in the exact consequences of informal care.

3.2 Non-Monetary Valuation of Informal Care

The consequences of informal care, which may be negative as well as positive, can be made more explicit in an economic evaluation by expressing it as an effect [32]. Moreover, doing so may be perceived to be consistent with the common division between costs and effects, at least for certain aspects of informal care (especially health effects). Existing non-monetary valuation methods (Table 1) value effects in terms of carers' HR-QOL (using QALYs), care-related quality of life, or well-being (happiness).

By focusing on a single dimension of quality of life, i.e., the health domain, QALYs comprise a *partial valuation of informal care* [28, 46]. Measures for deriving QALY changes are readily available from patient studies (e.g., EQ-5D, SF-36, etc.).

Care-related quality of life conceptually resembles HR-QOL valuations commonly used in economic evaluations (in terms of QALYs), but values a broader range of utility impacts than only health. The focus is typically on the most prominent impacts of informal care on general quality of life, both negative and positive. Care-related utility scores can be calculated for each possible care profile using tariffs. Hence, researchers can derive changes in care-related utility of carers.

Two care-related quality-of-life measures are currently available: the Carer Experience Scale (CES) [55] and the Care-related Quality of Life (CarerQol) instrument [36, 40, 56, 57] (see Sect. 6.3). These measures aim to provide a *full valuation of informal care*. They focus on capturing the effect of informal caregiving on well-being. Therefore, factors not directly related to caregiving, such as wealth, are less likely to influence such care-related quality-of-life scores.

The general well-being score is also increasingly used as an outcome measure in the field of (health) economics [58, 59]. The main advantage of this broad valuation measure is that all the different effects of informal care, such as health effects, financial problems, or fulfillment from caregiving, are taken into account through their impact on general well-being. Therefore, well-being scores can constitute a *full valuation of informal care*. However, effects outside the direct scope of caregiving, such as educational level, type of job, and family life, might influence well-being answers as well. Moreover, the same applies to coping of carers to their stressful situation [46]. Hence, the way in which one derives well-being estimates is important. This is emphasized by the fact that the causality of the relationship between caregiving and well-being effects is ambiguous [28].

Sections 5 and 6 provide more detailed information on the application of both the monetary and non-monetary valuation methods. First, however, we highlight how informal care can be included in different types of economic evaluations.

[2] These methods can also partially value informal care, depending on the valuation exercise, e.g., when a willingness-to-pay question specifically excludes health or labor participation effects, the valuation is clearly partial when such effects do occur.

4 How Can Informal Care Be Included in Cost-Effectiveness/-Utility Analysis?

4.1 Cost-Effectiveness and Cost-Utility Analysis

Whether and how informal care can be included in economic evaluations importantly depends on the type of economic evaluation that is conducted. In this section, we discuss which valuation methods can be used to include informal care in CEA or CUA. Moreover, we propose preferred options for including informal care in these types of economic evaluation.

CEA and CUA can be conducted from a healthcare or societal perspective. The perspective determines which costs and effects are relevant to include in the cost-effectiveness calculations. Consequently, this affects which valuation methods are appropriate.

A study conducted from a healthcare perspective can include health effects (QALYs) in carers on the effect side (Table 3). This health information of carers can easily be aggregated with patient QALYs at the effect side of the CEA/CUA. Important to note here is that this only applies if the measurement and valuation methods of health effects in patients and carers are similar. Hence, in such cases, we advise researchers to use the same generic health measure for the carer as used for the patient to increase comparability and possibility of aggregating effects in patients and carers. More research into the sensitivity of these instruments in caregivers remains important.

Costs falling on carers are commonly deemed irrelevant when adopting a healthcare perspective. Such costs occur, for example, due to sacrificed labor time of carers. Hence, besides health changes, typically no further valuation methods need to be applied when taking a healthcare perspective.

However, in a CEA/CUA conducted from a societal perspective all (sufficiently large) consequences of caregiving are relevant (Table 3). Hence, researchers can combine health effects measured in QALYs at the effect side with time input of carers measured with the OC or PG method on the cost side. Alternatively, the full impact of informal care can be included at the cost side, e.g., using the willingness-to-pay (WTP)/willingness-to-accept (WTA) method (Table 3). It is not possible to combine QALYs with the WTP/WTA method. In principle, the latter method provides a full valuation of informal care. Therefore, WTP/WTA should already value the health effects of carers. Hence, combining both methods could result in double counting of health effects.

Important to note here is that researchers in general need to be aware of the risk of double counting the impact of informal care in economic evaluations when using different valuation methods. That is, if a particular consequence of informal care is already included in the numerator, it should not also be included in the denominator. Likewise, important impacts should not go unnoticed. An extensive discussion of this topic can be found in the literature [22, 27, 28, 46].

It should be emphasized that the above pertains to economic evaluations of interventions aimed at patients, in which case informal carers invest time in care and experience—both negative and positive—effects from caregiving. On top of these effects, as discussed in Sect. 1, informal carers—and other non-caring family members—may experience family effects from the fact that their loved one is ill. The latter effects are rarely considered in economic evaluations. On the other hand, when evaluating interventions specifically aimed at informal carers, caregiver outcomes are central. This, for example, applies to comparative research of different types of support or respite programs for carers. In such cases, the overall impact of caring can be included at the effect side of a CEA/CUA using a care-related quality-of-life instrument. This provides a full valuation of the impact of informal care in effect terms.

Table 3 Preferred valuation method for including informal care in economic evaluations per type of economic evaluation

Economic evaluation	Perspective	Preferred valuation method
CEA/CUA	Healthcare	QALY cg
	Societal	PG/OC method + QALY cg
CBA	Healthcare	QALY cg[a]
	Societal	WTA/WTP
MCA	Healthcare	QALY cg
	Societal	Care related quality of life

CBA cost-benefit analysis, *CEA* cost-effectiveness analysis, *cg* caregiver, *CUA* cost-utility analysis, *MCA* multi-criteria analysis, *OC* opportunity costs, *PG* proxy good, *QALY* quality-adjusted life-year, *WTA* willingness to accept, *WTP* willingness to pay

[a] Expressed in monetary terms; use same value for health effects in caregivers as used in economic evaluation for patients' health effects

4.2 Other Types of Economic Evaluations: Cost-Benefit or Multi-Criteria Analysis

A CBA performed from a healthcare perspective can include informal care by measuring health effects in carers. Because CBA expresses all costs and effects exclusively in monetary value, these health effects should be valued in monetary terms. Arguably, the same monetary value as used for monetizing health effects in patients should be used (Table 3).

Researchers conducting a CBA from a societal perspective could opt to measure time input of carers and multiply this with a WTA/WTP estimate per hour of informal care (Table 3). If the underlying valuation exercise was sufficiently broad, this method values the full impact of informal care.

Table 4 Information needed for calculating monetary valuation of informal care

Method	Measurement of time spent on:	Valuation hour informal care based on:
OC	Paid work	Gross personal income caregiver
	Unpaid work	
	Leisure time	
PG	Household activities	Tariff market substitute household activities[a]
	Personal care	
	Practical support	
WB	Informal care	Conduct WB study among own sample
		Monetary value WB study[a]
WTP/WTA	Informal care	Elicit WTP/WTA in own sample with CV/CA experiment
		WTP/WTA from CV/CA study[a]

CA conjoint analysis, *CV* contingent valuation, *OC* opportunity costs, *PG* proxy good, *WB* well-being, *WTA* willingness to accept, *WTP* willingness to pay

[a] Use external references

MCA from a healthcare perspective can include informal care in its analysis by measuring QALYs of carers. In MCA from a societal perspective, researchers can pay explicit attention to the overall impact of a patient intervention on carers. This can be done by using care-related quality-of-life instruments, such as the CES or the CarerQol. The outcomes can then be presented next to other outcomes of interest. Important to note here is that researchers can also present information on the objective burden (i.e., number of hours of caregiving) or subjective burden (e.g. felt strain of caregiving) of caregiving in MCA. Different methods to measure these two types of burden are described in the iVICQ [30].

5 How Can Informal Care be Valued in Monetary Terms?

In this section, which follows on from Sect. 3.1, we provide detailed guidance on how to use different monetary valuation methods.

5.1 Opportunity Cost Method

The *number of hours of activities sacrificed* in order to be able to provide care are central in the OC method. The OC method calculates the value of informal care by multiplying these hours of sacrificed activities with a value per hour for each activity. A general typology of sacrificed activities includes paid work, unpaid work (i.e., voluntary work or housekeeping), and leisure time (Table 4).

To register the amount of time sacrificed per activity, recall methods can be used (Fig. 2). A difficulty of such retrospective questions is that respondents might find it hard to indicate how

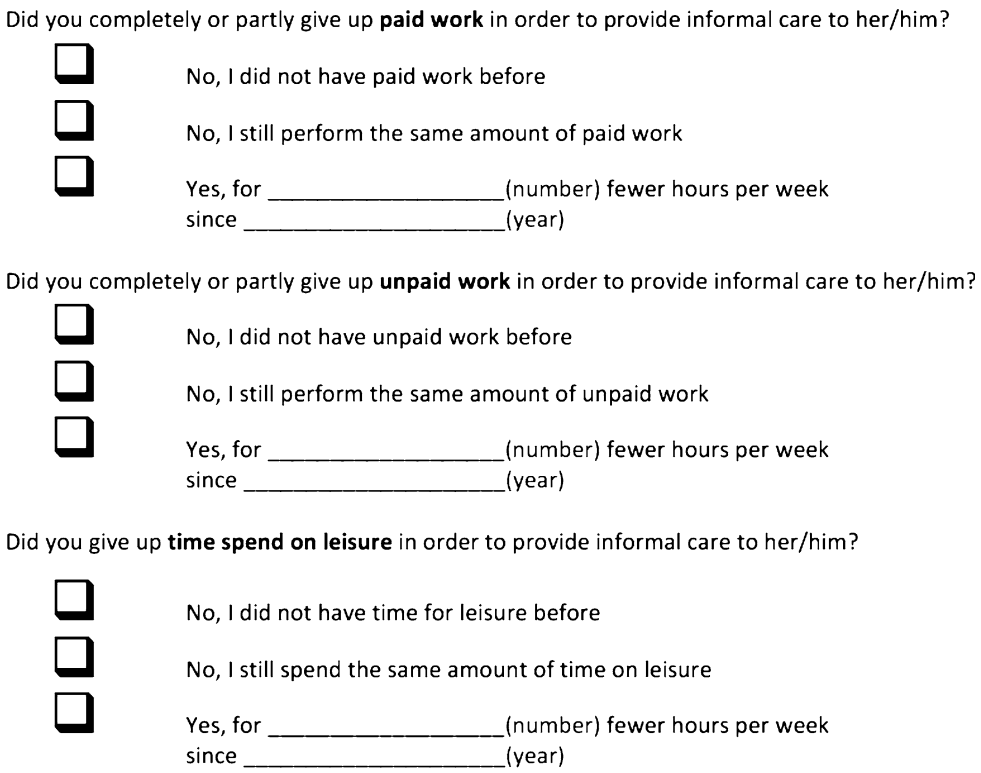


Fig. 2 Recall method: opportunity cost method [30]

Fig. 3 Hypothetical questions: opportunity cost method [30]

Suppose you did not have to provide informal care anymore. How would you spend this time: on paid work, unpaid work, or leisure?

- More paid work: ☐ No ☐ Yes: _____ hours per week
- More unpaid work: ☐ No ☐ Yes: _____ hours per week
- More leisure: ☐ No ☐ Yes: _____ hours per week

Fig. 4 Numerical example: opportunity cost method [30]

Suppose a respondent provides 12 hours of informal care per week, giving up the following to provide informal care:

- 1 hour paid work
- 3 hours unpaid work
- 8 hours leisure time

If the respondent's gross hourly wage rate is €30, the value of unpaid work and leisure time is set to the value of household activities of €12.50 per hour, then the monetary value of the time forgone to provide informal care of this person is (1 * 30) + (3 * 12.50) + (8 * 12.50) = €167.50.

much time they have sacrificed. Moreover, they might find it difficult to distinguish between 'normal time use' and informal care activities. This especially applies to carers who have been performing care for longer periods of time. In this situation, researchers can use hypothetical questions (Fig. 3). In these questions, respondents indicate which activities they *would* perform if informal care was not needed anymore.

Once the number of hours sacrificed per activity is known, these hours need to be valued. The value per hour for paid work, unpaid work, or leisure time can be set at different levels (Table 4). Often, the gross hourly wage of the respondent is used for paid work. However, many carers do not have a paid job, e.g., because they are the housekeeper or retired, and their wage rate is therefore unknown. For carers below retirement age, researchers can resort to an equivalent of the wage rate, such as the average hourly wage rate of persons of the same sex, age, and educational level. Another option is the reservation wage rate, which represents the hypothetical wage rate for which the unemployed carer would be willing to provide an hour of paid work. For carers who are retired, the activities sacrificed may be voluntary work or leisure time. If available, local tariffs from value of time studies can be applied. Otherwise, the PG method (see next section) may be the next nest alternative.

The use of wage rates in the valuation of informal care obviously may raise equity questions, because the (social) value of informal care is then related to the occupational position or educational level of the caregiver. Whether it is appropriate and fair that the value of an hour of informal care provided by a lawyer would be worth more than that of a waiter is open for debate.

Sometimes studies use the wage rate for all time components. Researchers can use an adapted gross hourly wage or a direct valuation to value household activities and leisure. However, both may prove difficult to obtain. Moreover, adjustments to the gross hourly wage rate tend to be relatively arbitrary.

For an example of the application of the OC method, see Fig. 4. More background information on the OC method can be found in the literature [27, 28, 46, 60]. Monetary values of studies using the OC method to value informal care range from €5 to €29 per hour[3] (for examples, see previous publications [60–75]).

[3] Values are in 2012 euros. Values in euros before 2012 can be converted to 2012 euros by multiplying with the annual average rates of change in harmonized indices of consumer prices (HICPs) [102]. Currencies other than euros were first converted with historical currency rates.

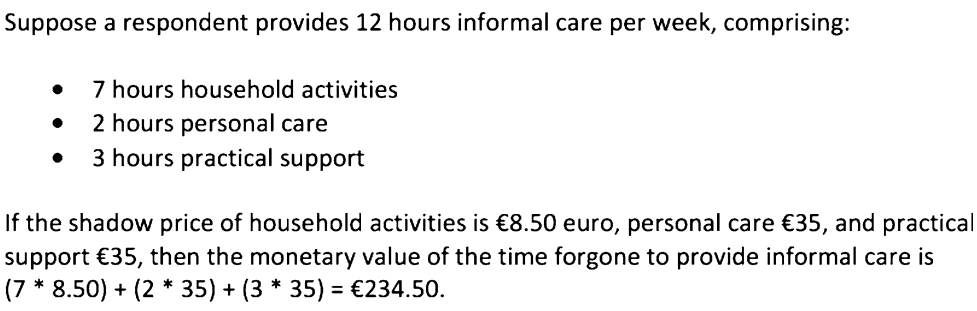


Fig. 5 Numerical example: proxy good method [30]

5.2 Proxy Good Method

The PG method calculates the value of informal care by multiplying *the number of hours spent on informal care* by a value per hour for each care task performed. Usually household activities, personal care, and practical support are distinguished (Table 4). In the PG method, the value per hour is based on the shadow price of a market substitute. Market prices can vary per task, because they are performed by care professionals earning different wages (Table 4). Several studies have applied the PG method. Values per hour spent on informal care in these studies range from €3 to €26[3] [60, 61, 69, 76–82]. For example, in The Netherlands the tariff for a market substitute for household activities is set to €12.50 [83].

The PG method uses wages earned by substitutes such as household helpers or specialized nurses. In doing so, the PG method provides insight into the costs of replacing informal care with formal care. An important, and probably unrealistic, assumption underlying this method is that formal and informal carers are perfect substitutes. This would imply that they can take over each other's tasks without efficiency or quality losses (or gains). For instance, by using the wage rate of a professional nurse, one implicitly assumes that a nurse spends the same amount of time on an activity as a carer. Contrary to the OC method, the PG method does not relate the value of informal care to the occupational position or educational level of the carer.

The PG method, and its pros and cons, are extensively discussed in previous publications [27, 28, 46, 60] and the method is applied by Van den Berg et al. [60]. Figure 5 presents an example of the PG method.

5.3 Well-Being Method

Central in the WB method is the change in well-being of the carer due to caregiving. The WB method calculates the monetary amount required to compensate a carer for her/his loss in well-being due to caregiving. The WB method multiplies this monetary value of an hour of caregiving with the *number of hours spent on informal care* (Table 4). For instance, suppose that the happiness of a carer drops from 8 to 7 on a scale from 0 to 10 due to straining caregiving tasks. Assuming that income positively influences well-being, the WB method can derive the increase in income that would exactly offset the drop in well-being caused by caregiving. In other words, the income increase leading to a 1-point increase in well-being. While obtaining well-being scores in population samples is possible [84], and is becoming more common, transforming these into a monetary valuation of informal care requires substantial research effort. In most cases, it will not be possible to perform this method *within* an economic evaluation.

Alternatively, it is possible to use previously obtained values. Researchers then multiply these values with the number of hours of informal care as measured within the economic evaluation. Depending on the availability in the literature, values could be differentiated according to the intensity of caregiving or tasks performed. Notes on the calculation of a monetary value of informal care using this method can be found in Van den Berg et al. [27]. Van den Berg and Ferrer-i-Carbonell [84] applied the WB method and reported an average monetary value of approximately €12[3] per hour of informal care.

5.4 Stated Preference Methods

5.4.1 Contingent Valuation and Conjoint Analysis

The CV and CA methods calculate the value of informal care by multiplying *the number of hours spent on informal care* by a value per hour (Table 4). CV derives this value by presenting respondents with a hypothetical caregiving situation and asking them to specify the minimum compensation they would require for providing an extra hour of informal care (Fig. 6)[4]. This is an example of the WTA approach. Using CV, one can also ask what the maximum amount is that respondents are willing to pay to reduce their informal care provision with 1 h (WTP). In the context of valuing informal care, WTA seems the more appropriate approach,

[4] In these experiments, only the number of hours per week change; all other things, such as the recipient's need for care, are assumed to remain equal in order to avoid contamination of values with other aspects (such as the health of the patient).

because the common (policy) perspective of valuation questions is one of increasing caregiving and thus giving up time on other activities. Following this perspective, asking respondents about the minimum compensation required to provide an additional hour of care seems conceptually most appropriate [85, 86]. Nonetheless, WTP is more commonly used in valuation studies, often with reference to recommendations of the authoritative NOAA (National Oceanic and Atmospheric Administration) Panel that advocated WTP as the preferred approach [87].

In CA, or a discrete choice experiment (DCE), the monetary value of an hour of informal care is derived from respondents in an indirect manner [88]. In these experiments, respondents choose between two or more hypothetical informal care situations. These situations are described by different characteristics, also called attributes. These are, for example, the number of hours of care per week and the type of care tasks. To derive a monetary value, one of the attributes should concern money. For instance, an hourly wage rate received for informal care or a certain tax refund from government can be used. By varying the levels of the attributes and having respondents make several choices, implicit preferences for attributes can be derived. Using this information, researchers can calculate the monetary value of all attributes.

Responses to stated preference methods such as CV and CA are known to be prone to different biases, including strategic answering, starting point-bias, and hypothetical bias. Moreover, in the case of CA, it can be quite difficult for respondents to compare different (hypothetical) scenarios. Finally, especially when using WTP/WTA techniques, one needs to be aware of the fact that some respondents may find it unethical to receive money to provide more informal care or pay money to reduce it [39, 46]. For a discussion of the various biases in CV, see Van Exel et al. [86].

Researchers can obtain monetary values in the study sample within the context of an economic evaluation. It is often more feasible for researchers to conduct CV than CA in an economic evaluation. That is, designing a CA study tends to be more complex and respondent burden is often higher. Below we provide an (incomplete) example of a WTA question, which can be used in this context. The complete WTA exercise is included in the iVICQ [30].

More information on informal care CV studies can be found in the literature [39, 86, 89, 90]. Practical applications of DCEs to the monetary value of informal care can be found elsewhere [55, 91–94]. When obtaining values is not feasible in a specific study, researchers can use values reported in the literature. Monetary values for an hour of informal care found in these studies range from €4 to €14[3] for CV experiments [39, 90, 95] and from €1 to €15[3] in CA studies [91–93].

6 How Can Informal Care be Valued in Non-Monetary Terms?

In this section, which follows on from Sect. 3.2, we provide more detailed guidance on how to use different non-monetary valuation methods.

6.1 Health of Caregiver

The health status of carers in terms of QALYs can be measured with validated health utility instruments such as the EQ-5D [96] or SF-6D [97] and valued using national tariffs [98, 99], as is usually done in economic evaluations (Table 5). Preferably, researchers use the same generic health measure for the carers as the patient. This will increase comparability and possibility of aggregating effects in patients and carers. Ideally, researchers observe health effects in the context of a randomized controlled trial (RCT).

We discourage using predefined algorithms assuming some stable relationship between the health of carers and patients. The relationship between carer health and patient health is unlikely to be stable [46]. Often, if the patient's health improves, the health of the carer will also improve through reduced informal care needs. However, this need not be the case. For example, when the health of the patient improves this could postpone institutionalization of the patient leading to prolonged informal care provision. Moreover, the relationship between patient and carer health does not need to be linear or symmetrical [46].

6.2 Well-Being of Caregiver

The CarerQol-Visual Analogue Scale (VAS) (Table 1) values informal care in terms of *well-being changes* in carers. The CarerQol-VAS is part of the CarerQol

Table 5 Information needed for calculating non-monetary valuation of informal care

Concept	Instrument to measure and value	
Health-related quality of life caregiver	Health utility instrument	Tariff to calculate QALYs[a]
Care-related quality of life	CES CarerQol-7D	Tariff to calculate care-related quality of life[a]
Well-being caregiver	CarerQol-VAS Process Utility	

CES Carer Experience Scale, *CarerQol* Care-related Quality of Life, *CarerQol-7D* CarerQoL-7 Dimensions, *CarerQol-VAS* CarerQoL-Visual Analogue Scale, *QALY* quality-adjusted life-year

[a] Use external references; CES tariff can be found in Al-Janabi et al. [55], tariff for the CarerQol-7D can be found in Hoefman et al. [30]

Fig. 6 Example of willingness-to-accept question for informal care (incomplete version) [30]

Imagine that she/he needs **one extra hour of informal care** per week and that government will pay you for lending this extra hour of informal care. Please look at the numbers below, from left to right, and tick the *highest* amount that you **would definitely not** be willing to forgo to provide an extra hour of informal care.

For example: if you are certain that you would not provide the extra hour of informal care for €20 from the government, but not certain that you would forgo €22,50, tick €20.

0	5	7,50	10	12,50	15	17,50	20	22,50	25	30	35	40	45	50	higher
❑	❑	❑	❑	❑	❑	❑	❑	❑	❑	❑	❑	❑	❑	❑	❑

instrument [40]. The CarerQol-VAS is a horizontal VAS ranging from completely unhappy (with the value 0) to completely happy (with the value 10). Researchers can observe differences in well-being in the context of the evaluation of some intervention by comparing the carers in the two (or more) arms of an RCT.

Researchers can use an additional question to the CarerQol-VAS to quantify the process utility (PU) from caring (Table 1). PU refers to the value attached to the process of lending informal care by carers [11]. PU provides insight in the desirability of other persons taking over (all) care tasks. To calculate PU, the difference in happiness between two situations is taken: the CarerQol-VAS score of the current situation minus the CarerQol-VAS score of a hypothetical situation. In this hypothetical situation, a person selected by the care recipient and caregiver would take over the care tasks, without changing the living situation of the care recipient and free of charge.

6.3 Care-Related Quality of Life

To date, two measures of care-related quality of life of carers that allow utility measurement are available. Both are highlighted in the following sections.

6.3.1 Carer Experience Scale

The CES contains six dimensions of caregiving: (1) activities outside caring; (2) support from family and friends; (3) assistance from organizations and the government; (4) fulfillment from caring; (5) control over the caring; and (6) getting on with the care recipient. Respondents score their care situation by indicating the level of problems on these six dimensions. Based on the profile indicated, a care-related utility value can be attached to the profile, using a tariff based on preferences of carers of elderly persons in the UK. This tariff ranges from 0 (worst caring state) to 100 (best caring state) (Table 4). Instructions for calculating the CES score and more general information on the use of the CES can be found in Al-Janabi et al. [55, 100] and Lamers et al. [55, 100].

6.3.2 CarerQol Instrument

The CarerQol instrument includes the CarerQol-VAS (discussed in Sect. 6.2) and the CarerQol-7 Dimensions (7D). The CarerQol-7D consists of five negative and two positive dimensions of informal care. Negative dimensions are (1) relational problems; (2) mental health problems; (3) problems combining daily activities with care; (4) financial problems; and (5) physical health problems. The positive dimensions are (6) fulfillment from caregiving; and (7) support with lending care. As shown in Fig. 7, respondents indicate whether an item applies to them with three possible responses: (1) no; (2) some; and (3) a lot. Answers on the negative dimensions of the CarerQol-7D receive a value of 0 (a lot), 1 (some), and 2 (no). Answers on the positive dimensions receive a value of 0 (no), 1 (some), and 2 (a lot). The CarerQol has been applied in several studies [36, 40, 43, 50, 56].

A care-related quality-of-life score can be derived from the CarerQol-7D profiles, using a tariff based on preferences from the general population in The Netherlands [30] (Table 5). These tariffs are reported in the iVICQ [30] and yield care-related utility scores ranging from 0 (worst informal care situation) to 100 (best informal care situation) (Fig. 8). In the iVICQ, syntax files for SPSS® and Stata® are provided to calculate CarerQol-7D scores.

7 Conclusion

Including informal care in economic evaluations of healthcare interventions poses important methodological questions. However, several options are available for researchers to include it in a suitable way. This paper has highlighted these options and highlighted methods that facilitate inclusion in a fairly straightforward way. We strongly encourage researchers to include informal care in

Fig. 7 Care-related Quality of Life (CarerQol) instrument [30]

We would like to form an impression of your caregiving situation. Please tick a box to indicate which description best fits your caregiving situation at the moment.

Please tick only one box per description: 'no', 'some' or 'a lot of'.

	no	some	a lot of	
I have	❑	❑	❑	fulfillment from carrying out my care tasks.
I have	❑	❑	❑	relational problems with the care receiver *(e.g., he/she is very demanding or behaves differently; we have communication problems).*
I have	❑	❑	❑	problems with my own mental health *(e.g., stress, fear, gloominess, depression, concern about the future).*
I have	❑	❑	❑	problems combining my care tasks with my own daily activities *(e.g. household activities, work, study, family, leisure activities).*
I have	❑	❑	❑	financial problems because of my care tasks.
I have	❑	❑	❑	support with carrying out my care tasks, when I need it *(e.g., from family,friends, neighbours, acquaintances)*.
I have	❑	❑	❑	problems with my own physical health *(e.g., more often sick, tiredness, physical stress).*

How happy do you feel at the moment? Please place a mark on the scale below that indicates how happy you feel at the moment.

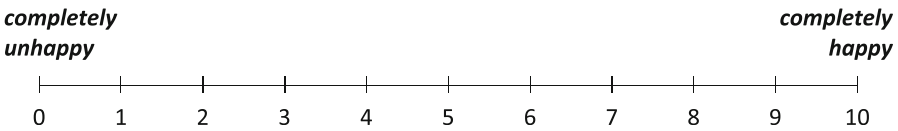


Fig. 8 Numerical example of the Care-related Quality of Life-7 Dimensions (CarerQol-7D) score [30]

Suppose that the answers of a respondent on the CarerQol-7D are:

- *some* fulfillment
- *a lot of* relational problems
- *no* mental health problems
- *some* problems combining daily activities
- *no* financial problems
- *a lot of* support
- *no* physical health problems

The CarerQol-7D score is: 13.6 + 0 + 13.3 + 6.4 + 14.3 + 6.5 + 15.1 + 6.6 = 75.8

It is important to keep in mind when calculating the CarerQol-7D score that respondents get a 'bonus' of 6.6 for having neither mental nor physical health problems.

economic evaluations. This will allow decision makers to be fully informed about the costs and consequences of healthcare interventions, not only in patients but also in their carers. Given the impact informal care can have on the lives of carers and its important role in the healthcare sector, providing information on this impact to policy makers is clearly important. Instruments such as the iVICQ [30] provide further guidance on how to do so. More research in this important field and increased consensus on how to value informal care in practice remains important.

Authors' contribution RH drafted the manuscript. JE and WB provided comments to draft versions of the manuscript. WB supervised the project. All authors read and approved the final manuscript.

Conflict of interest The authors declare that they have no competing interests.

References

1. Brazier J, Ratcliffe J, Salomon JA, Tsuchiya A. Measuring and valuing health benefits for economic evaluation. Oxford: Oxford University Press; 2007.
2. Brouselle A, Lessard C. Economic evaluation to inform health care decision-making: promise, pitfalls and a proposal for an alternative path. Soc Sci Med. 2011;72(6):832–9.
3. Stolk EA, de Bont A, van Halteren AR, Bijlmer RJ, Poley MJ. Role of health technology assessment in shaping the benefits package in The Netherlands. Expert Rev Pharmacoecon Outcomes Res. 2009;9(1):85–94.
4. Colombo F, Llena-Nozal A, Mercier J, Tjadens F. Help wanted? Providing and paying for long-term care. Paris: OECD Publishing; 2011.
5. Riedel M, Kraus M. Informal care provision in Europe: regulation and profile of providers. ENEPRI Research Report no. 96 (2011). http://www.ceps.be/book/informal-care-provision-europe-regulation-and-profile-providers. Accessed 30 Oct 2013.
6. Clark AM, Reid ME, Morrison CE, Capewell S, Murdoch DL, McMurray JJ. The complex nature of informal care in home-based heart failure management. J Adv Nursing. 2008;61(4):373–83.
7. Knowlton AR, Arnsten JH, Gourevitch MN, Eldred L, Wilkinson JD, Rose CD, et al. Microsocial environmental influences on highly active antiretroviral therapy outcomes among active injection drug users: The role of informal caregiving and household factors. JAIDS. 2007;46:S110–9.
8. Jiménez-Martín S, Prieto CV. The trade-off between formal and informal care in Spain. Eur J Health Econ. 2012;13(4):461–90.
9. Clark RE, Xie H, Adachi-Mejia AM, Sengupta A. Substitution between formal and informal care for persons with severe mental illness and substance use disorders. J Ment Health Policy Econ. 2001;4(3):123–132.
10. Weaver FM, Weaver BA. Does availability of informal care within the household impact hospitalisation? Health Econ Policy Law. Epub 2013 Apr 8:1–23.
11. Brouwer WB, Van Exel NJ, Van den Berg B, Van den Bos GA, Koopmanschap MA. Process utility from providing informal care: the benefit of caring. Health Policy. 2005;74(1):85–99.
12. Schulz R, Beach SR. Caregiving as a risk factor for mortality: the Caregiver Health Effects Study. JAMA. 1999;282(23):2215–9.
13. Wilson MR, Van Houtven CH, Stearns SC, Clipp EC. Depression and missed work among informal caregivers of older individuals with dementia. J Family Econ Issues. 2007;28(4):684–98.
14. Joling KJ, van Hout HPJ, Schellevis FG, van der Horst HE, Scheltens P, Knol DL, et al. Incidence of depression and anxiety in the spouses of patients with dementia: a naturalistic cohort study of recorded morbidity with a 6-year follow-up. Am J Geriatr Psychiatry. 2010;18(2):146.
15. Van Vliet D, De Vugt ME, Bakker C, Koopmans RTCM, Verhey FRJ. Impact of early onset dementia on caregivers: a review. Int J Geriatr Psychiatry. 2010;25(11):1091–100.
16. Bobinac A, van Exel N, Rutten FFH, Brouwer WBF. Health effects in significant others. Med Decis Making. 2011;31(2):292.
17. Tolkacheva N, Van Groenou MB, De Boer A, Van Tilburg T. The impact of informal care-giving networks on adult children's care-giver burden. Ageing Soc. 2011;31(1):34.
18. Gold MR, Siegel JE, Russell LB, Weinstein M. Cost-effectiveness in health and medicine. New York: Oxford University Press; 1996.
19. Drummond MF, Sculpher MJ, Torrance GW, O'Brien BJ, Stoddart GL. Methods for the economic evaluation of health care programmes. Oxford: Oxford University Press; 2005.
20. Jacobs P, Ohinmaa A, Brady B. Providing systematic guidance in pharmacoeconomic guidelines for analysing costs. Pharmacoeconomics. 2005;23(2):143–53.
21. Health Care Insurance Board. Guidelines for pharmaco-economic research; evaluation and actualisation [Richtlijnen voor farmaco-economisch onderzoek; evaluatie en actualisatie]; 2005.
22. Van Exel J, Bobinac A, Koopmanschap M, Brouwer W. The invisible hands made visible: recognizing the value of informal care in healthcare decision-making. Expert Rev Pharmacoecon Outcomes Res. 2008;8(6):557–61.
23. National Institute for Clinical Excellence. Guide to the methods of technology appraisal; 2008.
24. Bobinac A, Van Exel NJ, Rutten FF, Brouwer WB. Caring for and caring about: disentangling the caregiver effect and the family effect. J Health Econ. 2010;29(4):549–56.
25. Al-Janabi H, Flynn TN, Coast J. QALYs and carers. Pharmacoeconomics. 2011;29(12):1015–23.
26. Stone PW, Chapman RH, Sandberg EA, Liljas B, Neumann PJ. Measuring costs in cost–utility analyses. Variations in the literature. Int J Technol Assess Health Care. 2000;16(1):111–24.
27. Van den Berg B, Brouwer WB, Koopmanschap MA. Economic valuation of informal care. An overview of methods and applications. Eur J Health Econ. 2004;5(1):36–45.
28. Koopmanschap MA, Van Exel JN, Van den Berg B, Brouwer WB. An overview of methods and applications to value informal care in economic evaluations of healthcare. Pharmacoeconomics. 2008;26(4):269–80.
29. Deeken JF, Taylor KL, Mangan P, Yabroff KR, Ingham JM. Care for the caregivers: a review of self-report instruments developed to measure the burden, needs, and quality of life of informal caregivers. J Pain Symptom Manage. 2003;26(4):922–53.
30. Hoefman RJ, Van Exel NJA, Brouwer WBF. iVICQ. iMTA Valuation of Informal Care Questionnaire, Version 1.1; 2011.
31. Krol M, Papenburg J, Koopmanschap M, Brouwer W. Do productivity costs matter? The impact of including productivity costs on the incremental costs of interventions targeted at depressive disorders. Pharmacoeconomics. 2011;29(7):601–19.
32. Brouwer WBF, Van Exel NJA, Koopmanschap MA, Rutten FFH. The valuation of informal care in economic appraisal. Int J Technol Assess Health Care. 1999;15(1):147–60.

33. Goodrich K, Kaambwa B, Al-Janabi H. The inclusion of informal care in applied economic evaluation: a review. Value Health. 2012;15(6):975–81.
34. Van den Berg B, Spauwen P. Measurement of informal care: an empirical study into the valid measurement of time spent on informal caregiving. Health Econ. 2006;15(5):447–60.
35. Wimo A, Gustavsson A, Jönsson L, Winblad B, Hsu M, Gannon B. Application of resource utilization in dementia (RUD) instrument in a global setting. Alzheimers Dement. 2012;9:429–35.e17.
36. Hoefman RJ, van Exel NJA, Foets M, Brouwer WBF. Sustained informal care: the feasibility, construct validity and test–retest reliability of the CarerQol-instrument to measure the impact of informal care in long-term care. Aging Mental Health. 2011;15(8):1018–27.
37. Van Exel NJA, Van den Berg B, Koopmanschap MA, van den Bos GAM, Brouwer WBF. Informal care in the Netherlands: a situational sketch of informal care-providers reached via Informal Care Centres. Institute of Medical Technology Assessment Report 02.58b. Rotterdam: Erasmus MC, 2002.
38. Van Exel NJ, Koopmanschap MA, Van den Berg B, Brouwer WB, Van den Bos GA. Burden of informal caregiving for stroke patients. Identification of caregivers at risk of adverse health effects. Cerebrovasc Dis. 2005;19(1):11–7.
39. Van den Berg B, Brouwer W, Van Exel J, Koopmanschap M. Economic valuation of informal care: the contingent valuation method applied to informal caregiving. Health Econ. 2005;14(2):169–83.
40. Brouwer WB, Van Exel NJ, Van Gorp B, Redekop WK. The CarerQol instrument: a new instrument to measure care-related quality of life of informal caregivers for use in economic evaluations. Qual Life Res. 2006;15(6):1005–21.
41. Brouwer WB, Van Exel NJ, Van de Berg B, Dinant HJ, Koopmanschap MA, Van den Bos GA. Burden of caregiving: evidence of objective burden, subjective burden, and quality of life impacts on informal caregivers of patients with rheumatoid arthritis. Arthritis Rheum. 2004;51(4):570–7.
42. Van Exel NJ, Brouwer WB, Van den Berg B, Koopmanschap MA, Van den Bos GA. What really matters: an inquiry into the relative importance of dimensions of informal caregiver burden. Clin Rehabil. 2004;18(6):683–93.
43. Van Exel J, de Graaf G, Brouwer W. Give me a break! Informal caregiver attitudes towards respite care. Health Policy. 2008;88(1):73–87.
44. Wimo A, Reed CC, Dodel R, Belger M, Jones RW, Happich M, et al. The GERAS study: a prospective observational study of costs and resource use in community dwellers with Alzheimer's disease in three European countries–study design and baseline findings. J Alzheimers Dis. 2013;36:385–99.
45. Gustavsson A, Jonsson L, Rapp T, Reynish E, Ousset P, Andrieu S, et al. Differences in resource use and costs of dementia care between European countries: baseline data from the ICTUS study. J Nutr Health Aging. 2010;14(8):648–54.
46. Brouwer WBF, Van Exel NJA, Tilford MJ. Incorporating caregiver and family effects in economic evaluations of child health. In: Ungar WJ, editor. Economic evaluation in child health. Oxford: Oxford University Press; 2010.
47. Van Exel NJ, Scholte op Reimer WJ, Brouwer WB, Van den Berg B, Koopmanschap MA, Van den Bos GA. Instruments for assessing the burden of informal caregiving for stroke patients in clinical practice: a comparison of CSI, CRA, SCQ and self-rated burden. Clin Rehabil. 2004;18(2):203–14.
48. Robinson BC. Validation of a caregiver strain index. J Gerontol. 1983;38(3):344–8.
49. Al-Janabi H, Frew E, Brouwer W, Rappange D, Van Exel J. The inclusion of positive aspects of caring in the Caregiver Strain Index: tests of feasibility and validity. Int J Nursing Studies. 2010;47(8):984–93.
50. Payakachat N, Tilford JM, Brouwer WBF, van Exel NJ, Grosse SD. Measuring health and well-being effects in family caregivers of children with craniofacial malformations. Qual Life Res. 2011;20(9):1485–95.
51. Poley MJ, Brouwer WB, Van Exel NJ, Tibboel D. Assessing health-related quality-of-life changes in informal caregivers: an evaluation in parents of children with major congenital anomalies. Qual Life Res. 2012;21(5):849–61.
52. Veenhoven R. Conditions of happiness. Dordrecht: Kluwer Academic; 1984.
53. Francis J, McDaid D. SCIE's work on economics and the importance of informal care. In: Cutis L, editor. Unit costs of health and social care 2009. Canterbury: University of Kent; 2009. p. 27–33.
54. Faria R, Weatherly H, van den Berg B. A review of approaches to measure and monetarily value informal care. In: Curtis L, editor. Unit Costs of Health and Social Care 2012. Kent: PSSRU; 2012. p. 22–31.
55. Al-Janabi H, Flynn TN, Coast J. Estimation of a preference-based carer experience scale. Med Decis Making. 2011;3:458–68.
56. Hoefman RJ, Van Exel NJA, Redekop WK, Looren-de Jong S, Brouwer WBF. A new test of the validity of the CarerQol instrument: measuring 'care-related quality of life' of informal caregivers for use in economic evaluations. Qual Life Res. 2011;20(6):875–87.
57. Hoefman RJ, Van Exel NJA, Rose JM, Lawerman-van de Wetering EJ, Brouwer WBF. A discrete choice experiment to obtain a tariff for valuing informal care situations measured with the CarerQol instrument. Med Decis Making. Epub 2013 Jun 14.
58. Ferrer-i-Carbonell A, Frijters P. How important is methodology for the estimates of the determinants of happiness? Econ J. 2004;114:641–59.
59. Frey BS, Stutzer A. What can economists learn from happiness research? J Econ Lit. 2002;40:402–35.
60. Van den Berg B, Brouwer W, Van Exel J, Koopmanschap M, Van den Bos GA, Rutten F. Economic valuation of informal care: lessons from the application of the opportunity costs and proxy good methods. Soc Sci Med. 2006;62(4):835–45.
61. Maniadakis N, Gray A. The economic burden of back pain in the UK. Pain. 2000;84(1):95–103.
62. Patel A, Knapp M, Evans A, Perez I, Kalra L. Training care givers of stroke patients: economic evaluation. BMJ. 2004;328(7448):1102.
63. Leal J, Luengo-Fernández R, Gray A, Petersen S, Rayner M. Economic burden of cardiovascular diseases in the enlarged European Union. Eur Heart J. 2006;27(13):1610–9.
64. McCrone P, Darbishire L, Ridsdale L, Seed P. The economic cost of chronic fatigue and chronic fatigue syndrome in UK primary care. Psychol Med. 2003;33(2):253–61.
65. Kobelt G, Berg J, Lindgren P, Fredrikson S, Jönsson B. Costs and quality of life of patients with multiple sclerosis in Europe. J Neurol Neurosurg Psychiatry. 2006;77(8):918–26.
66. Romeo R, Knapp M, Scott S. Economic cost of severe antisocial behaviour in children–and who pays it. Br J Psychiatry. 2006;188(6):547–53.
67. Mihalopoulos C, Cadilhac DA, Moodie ML, Dewey HM, Thrift AG, Donnan GA, et al. Development and application of Model of Resource Utilization, Costs, and Outcomes for Stroke (MORUCOS): An Australian economic model for stroke. Int J Technol Assess Health Care. 2005;21(4):499–505.
68. Thalanany MM, Mugford M, Mitchell-Inwang C. Visiting adult patients in intensive care: the importance of relatives' travel and time costs. Intensive Crit Care Nursing. 2006;22(1):40–8.

69. Dewey HM, Thrift A, Mihalopoulos C, Carter R, Macdonell R, McNeil J, et al. Informal care for stroke survivors results from the North East Melbourne Stroke Incidence Study (NEMESIS). Stroke. 2002;33(4):1028–33.
70. Smith CA, Frick KD. Cost–utility analysis of high-vs. low-intensity home-and community-based service interventions. Soc Work Public Health. 2008;23(6):75–98.
71. Wilson E, Thalanany M, Shepstone L, Charlesworth G, Poland F, Harvey I, et al. Befriending carers of people with dementia: a cost utility analysis. Int J Geriatr psychiatry. 2009;24(6):610–23.
72. Agha Z, Lofgren RP, VanRuiswyk JV. Is antibiotic prophylaxis for bacterial endocarditis cost-effective? Med Decis Making. 2005;25(3):308–20.
73. Andersson F, Kjellman M, Forsberg G, Möller C, Arheden L. Comparison of the cost-effectiveness of budesonide and sodium cromoglycate in the management of childhood asthma in everyday clinical practice. Ann Allergy Asthma Immunol. 2001;86(5):537–44.
74. Duff P, Dolphin C. Cost-benefit analysis of assistive technology to support independence for people with dementia—Part 2: results from employing the ENABLE cost–benefit model in practice. Technol Disability. 2007;19(2):79–90.
75. Getsios D, Blume S, Ishak KJ, Maclaine GD. Cost effectiveness of donepezil in the treatment of mild to moderate Alzheimer's disease. Pharmacoeconomics. 2010;28(5):411–27.
76. Graff MJ, Adang EM, Vernooij-Dassen MJ, Dekker J, Jönsson L, Thijssen M, et al. Community occupational therapy for older patients with dementia and their care givers: cost effectiveness study. BMJ. 2008;336(7636):134–8.
77. Schneider J, Hallam A, Islam MK, Murray J, Foley B, Atkins L, et al. Formal and informal care for people with dementia: variations in costs over time. Ageing Soc. 2003;23(3):303–26.
78. Hollander J, Liu G, Chappell N. Who cares and how much. Healthcare Q. 2009;12(2):42–9.
79. Gaugler JE, Zarit SH, Townsend A, Parris Stephens M, Greene R. Evaluating community-based programs for dementia caregivers: the cost implications of adult day services. J Appl Gerontol. 2003;22(1):118–33.
80. Gitlin LN, Hodgson N, Jutkowitz E, Pizzi L. The cost-effectiveness of a nonpharmacologic intervention for individuals with dementia and family caregivers: the tailored activity program. Am J Geriatr Psychiatry. 2010;18(6):510.
81. Nichols LO, Chang C, Lummus A, Burns R, Martindale-Adams J, Graney MJ, et al. The cost-effectiveness of a behavior intervention with caregivers of patients with Alzheimer's disease. J Am Geriatr Soc. 2007;56(3):413–20.
82. van Helvoort-Postulart D, Dirksen CD, Nelemans PJ, Kroon AA, Kessels AG, de Leeuw PW, et al. Renal artery stenosis: cost-effectiveness of diagnosis and treatment. Radiology. 2007;244(2):505–13.
83. Hakkaart-van Roijen L, Tan SS, Bouwmans CAM. Handleiding voor kostenonderzoek, methoden en standaard kostprijzen voor economische evaluaties in de gezondheidszorg. Geactualiseerde versie; 2010.
84. Van den Berg B, Ferrer-i-Carbonell A. Monetary valuation of informal care: the well-being valuation method. Health Econ. 2007;16(11):1227–44.
85. Bromley DW. Property rights and natural resource damage assessments. Ecol Econ. 1995;14(2):129–35.
86. Van Exel NJA, Brouwer WBF, Van den Berg B, Koopmanschap MA. With a little help from an anchor: discussion and evidence of anchoring effects in contingent valuation. J Socio Econ. 2006;35(5):836–53.
87. Arrow K, Solow R. Report of the NOAA panel on contingent valuation; 1993.
88. Louviere J, Flynn T, Carson R. Discrete choice experiments are not conjoint analysis. J Choice Model. 2010;3(3):57–72.
89. Van den Berg B, Bleichrodt H, Eeckhoudt L. The economic value of informal care: a study of informal caregivers' and patients' willingness to pay and willingness to accept for informal care. Health Econ. 2005;14(4):363–76.
90. De Meijer C, Brouwer W, Koopmanschap M, Van den Berg B, Van Exel J. The value of informal care—a further investigation of the feasibility of contingent valuation in informal caregivers. Health Econ. 2010;19(7):755–71.
91. Van den Berg B, Al M, Brouwer W, Van Exel J, Koopmanschap M. Economic valuation of informal care: the conjoint measurement method applied to informal caregiving. Soc Sci Med. 2005;61(6):1342–55.
92. Van den Berg B, Al M, Van Exel J, Koopmanschap M, Brouwer W. Economic valuation of informal care: conjoint analysis applied in a heterogeneous population of informal caregivers. Value Health. 2008;11(7):1041–50.
93. Mentzakis E, Ryan M, McNamee P. Using discrete choice experiments to value informal care tasks: exploring preference heterogeneity. Health Econ. 2011;20:331–47.
94. De Groot AWM, Van Praag BMS, Velthuijsen JW, Zijderveld CE. Wie dan zorgt… De zorgtijd voor kinderen en ouderen onderzocht:zelf zorgen of hulp inhuren? In: Hazeu CA, Eggelte JJA, den Butter FAG, editors. Naar een vrijwel volledige arbeidsparticipatie. The Hague: WRR; 2000.
95. Gustavsson A, Jonsson L, McShane R, Boada M, Wimo A, Zbrozek AS. Willingness-to-pay for reductions in care need: estimating the value of informal care in Alzheimer's disease. Int J Geriatr Psychiatry. 2010;25(6):622–32.
96. EuroQol Group. EuroQol—a new facility for the measurement of health-related quality of life. Health Policy. 1990;16(3):199–208.
97. Brazier J, Roberts J, Deverill M. The estimation of a preference-based measure of health from the SF-36. J Health Econ. 2002;21(2):271–92.
98. Dolan P. Modeling valuations for EuroQol health states. Med Care. 1997;35(11):1095–108.
99. Lamers LM, McDonnell J, Stalmeier PF, Krabbe PF, Busschbach JJ. The Dutch tariff: results and arguments for an effective design for national EQ-5D valuation studies. Health Econ. 2006;15(10):1121–32.
100. Al-Janabi H, Coast J, Flynn TN. What do people value when they provide unpaid care for an older person? A meta-ethnography with interview follow-up. Soc Sci Med. 2008;67(1):111–21.
101. Saltman RB, Dubois HF, Chawla M. The impact of aging on long-term care in Europe and some potential policy responses. Int J Health Services. 2006;36(4):719–46.
102. Eurostat. Harmonized Indices of Consumer Prices (HICP); 2013. http://epp.eurostat.ec.europa.eu/portal/page/portal/hicp/data/main_tables. Accessed 15 Feb 2013.