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#### **Original papers**

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## **Economic valuation** of informal care

## An overview of methods and applications

nformal care plays a substantial role in the total care provided, especially for care of persons with chronic and terminal diseases. To give an indication, in The Netherlands it was estimated that around 10% of the population of 16 million inhabitants provide informal care [1]. Because informal care is a less visible part of total care in terms of costs and effects it has often been ignored in economic evaluations and (subsequent) policymaking. At present the attention for informal care seems growing. There is increased insight in the amount of informal care provided (in various disease areas) and the tasks that caregivers provide [1]. Moreover there is growing evidence that informal care has adverse effects on informal caregivers in terms of, for example, opportunity costs and quality of life [2]. At the same time informal care is increasingly being considered as a valuable substitute and complement of expensive formal care. Therefore policy makers have increased their attention for the position of informal caregivers. This increased attention for informal care is especially important since the demand for informal care is likely to increase in the future, due to the aging of the population, the wish to be cared for at home by relatives and friends, and the rationing of formal care in many countries.

Changes in treatment patterns of care recipients, in particular substitution from inpatient to home care, may have a substantial effect on the amount and nature of informal care provided, as well as increased possibilities for monetary compensation of informal caregivers.

Parallel, economic evaluations of health care are more and more often used to inform decision makers on the relative efficiency of the programs in terms of benefits and costs [3]. Despite the increasing popularity of these economic evaluations, there is a lack on consensus and uniformity of the methodology used in these evaluations. This can lead to differences in which elements are considered to be a necessary part of the analysis and how these elements should be valued. Of course such discrepancies in what to incorporate in the analysis and how to incorporate this, can lead to problems in the interpretation of results and in comparison of results of different studies. Moreover, it can lead to miscalculations and wrong policy recommendations. In this context it is argued that economic evaluations should preferably take the societal perspective [4, 5]. This means that everyone affected by an intervention under study should be considered and all significant (health) outcomes and costs that flow from the intervention should be counted regardless of who experiences the outcomes and costs. This to prevent undesirable shifts in costs within the health care sector and between the health care sector and other sectors including the informal economy. The societal perspective also has implications for the way costs and outcomes should be measured, i.e., they should be measured in such a way that the full impact on affected members is captured without double counting.

When the societal perspective is adopted, informal care needs to be incorporated in economic evaluations, as has been recognized [5, 6]. However, presently the costs and outcomes of informal care are often ignored in economic evaluations [7]. This sometimes is related to the fact that the societal perspective is not adhered to (e.g., [8]), but, for instance, a health care budget perspective. More importantly probably, the methods available to measure and value informal care tend to be quite crude and the incorporation of informal care by no means uniform. More standardization as well as improved methods appear needed, while recognizing the fact that the proposed methods should be compatible with the common types of economic evaluation in health care: costbenefit analysis (CBA), cost-utility analysis (CUA), and cost-effectiveness analysis (CEA). The availability, development, and use of such methods is a prerequisite for the incorporation of informal care in eco-

nomic evaluations.

This contribution discusses available methods. As the costs of informal care are to a large extent related to time inputs by informal caregivers (see Netten [9] for an overview and discussion of other costs related to informal care), identification and valuation of informal caregivers time inputs are an important focus of this study. The time investment may lead to impacts normally referred to as costs, for example, opportunity costs due to forgone paid work and to impacts on health-related quality of life (morbidity and mortality risks) or well-being. We discuss the incorporation of these different impacts in economic evaluations. (The effects of receiving informal care on care recipients are not addressed here.)

The triad of definition, measurement, and valuation is crucial for the incorporation of informal care in economic evaluations. Therefore the structure of this paper is as follows. First, the heterogeneity of the commodity informal care is highlighted and a definition is proposed. Some measurement issues in correctly assessing the informal caregivers input are then considered. The different valuation methods are discussed next. Some of these methods aim at valuing the time inputs of informal caregivers, while others focus on assessing the impact of providing informal care on informal caregiver's health or burden. Finally, additional problems in the valuation and incorporation of informal care are highlighted.

## Informal care: a heterogeneous commodity

A clear definition of what informal care entails is a necessary condition for a proper measurement and subsequently for the valuation of informal care in economic evaluations. However, providing such a definition is not straightforward. One might agree on the fact that informal care at least involves care provided by someone from the social environment of the care recipient. On the basis of some prior relationship between carer and care re-

cipient therefore a caregiving situation evolves. Even though this is a good starting point, informal care is a rather heterogeneous commodity. Definitions of informal care therefore can vary greatly [10], even in applied work.

The heterogeneity of informal care is not only related to differences in time investment and duration of care, which of course is an important first source of diversity. It is also related to the (number of) care tasks provided, since informal care can be divided into different components, such as (a) housework, for instance cleaning and cooking, (b) personal care, including dressing, (c) support with mobility, (d) administrative tasks, and (e) socializing, for example, comforting a care recipient [11]. Not all of these tasks need to be performed by one informal caregiver or needed in all caring situations. Moreover, to make it even more complicated, not all of these tasks are necessarily informal care. For instance, housework may be normal for a housewife, but when her husband falls ill, she may have to increase the number of household tasks provided, the number of hours provided etc. Only the additional part of housework and administrative tasks due to the disease of the care receiver should be seen as informal care. If the informal caregiver already used to clean the house before the care recipient became ill it should not be considered informal care. And not all housework may necessarily be solely to the benefit of the care recipient. Economists make a distinction between household private and household public commodities in that context. Household private commodities are consumed by one individual solely, while all members of the same household consume household public commodities jointly and therefore benefit from increased activities in this area [12].

Another important issue is whether the caregiver and care recipient share the same household. This may have consequences, for example, in terms of time investment, travel time, and tasks provided. Moreover, sharing the same household may make it more difficult to separate informal care tasks from normal household activities (even for the informal caregiver). In addition, there may be differences in terms of the freedom of choice to be-

#### **Abstract**

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# Economic valuation of informal care. An overview of methods and applications

#### **Abstract**

Informal care makes up a significant part of the total amount of care provided to care recipients with chronic and terminal diseases. Still, informal care is often neglected in economic evaluations of health care programs. Probably this is related to the fact that the costs of informal care are to an important extent related to time inputs by relatives and friends of care recipients and time is not easy to value. Development of theoretically sound, yet easily applicable valuation methods is therefore important since ignoring the costs of informal care may lead to undesirable shifts between formal and informal care. Moreover, there is increasing evidence that providing informal care may lead to health problems for the caregiver, both in terms of morbidity and mortality. Until now these health effects have not been incorporated in economic evaluations. More attention for the identification and valuation of the full costs and (health) effects of informal care for the informal caregiver seems needed therefore. This contribution presents a critical evaluation of the available methods to incorporate informal care in economic evaluations.

#### **Keywords**

Informal care - Valuation methods - Economic evaluation

come an informal caregiver. It is conceivable that persons outside a household (e.g., neighbors and friends) enter a caregiving situation more voluntarily compared to persons sharing the care recipients' household. (This depends for an important part on the institutional context of a society. In some societies it is usual to demand inputs of family members before one could claim support from health care professionals, while other societies are less demanding on family members.) The latter may feel more obliged to care. Related to this point is the social relationship (e.g., spouse, parent, child, sister, neighbor or friend) between the care recipient and the informal caregiver. This can affect the way the provision of care is perceived, both by the care receiver and by the caregiver. Moreover, a person may care for a care recipient alone or together with other (informal) caregivers. Often a distinction is made between primary and other caregivers. The primary caregiver is likely to provide most hours of informal care and to coordinate the care provided by other (informal) caregivers.

An additional source of heterogeneity is the starting point and course of a caregiving episode. The starting point of caring may be obvious (e.g., with a stroke or heart attack) or slowly evolving (e.g., with rheumatoid arthritis or dementia). In the latter situation the caregiver grows in his or her role, gradually taking on more and more tasks, with no clear distinction between before and after becoming an informal caregiver and sometimes between normal and caregiving tasks. In the former situation, the caregiving situation arises abruptly and the forgone normal activities and additional informal care efforts are clearer. This issue has also implications for the measurement of informal care and is therefore also discussed be-

#### Towards a definition

On the basis of the discussed heterogeneity and the starting point that informal care involves we define informal care as: "a nonmarket composite commodity consisting of heterogeneous parts produced (paid or unpaid) by one or more members of the social environment of the care

recipient as a result of the care demands of the care recipient" [where "heterogeneous parts" include (a) home keeping (the additional part), (b) personal care, (c) support with mobility, (d) administrative tasks (the additional part), and (e) to some extent socializing]. In this definition we leave open the possibility for informal caregivers to be paid. It is often debated whether informal caregivers may receive some form of payment and still be considered informal caregivers. This question becomes increasingly relevant now that personal budgets become more popular, with which informal caregivers may be paid as well as formal caregivers. One possible answer is that as long as an informal caregiver does not receive a full market wage for all of his or her activities, they can be defined as informal care. Perhaps a better answer would be to say that only when the caregiver would not want to care for someone outside of his social environment for a similar wage, it is considered to be informal care. When the caregiver would care for anyone, regardless the social relationship, it is either a volunteer - (nearly) unpaid - or a professional carer - paid.

#### Measurement issues

Since the costs of informal care are to an important extent related to the time inputs of informal caregivers, valid (timespecific) ways of measuring are necessary for the valuation of informal care. We discuss some major issues in the measurement of time spent on informal care, i.e., the choice of a measurement method, the distinction of informal care and normal housework, joint production, and several informal caregivers caring for one care recipient. (For excellent methodological overviews of the measurement of time see

Two frequently applied methods of collecting time budget data are the diary method and the recall method. (Other methods include the "buzzer" method and the "outsider" method.) The diary method is normally considered to be the gold standard [14]. Answers typically depend on the questions posed and the recall period used. ("When the interviewee is asked how much time he spent on certain activities, rather than what activities he engaged in during a certain time, the results are bound to be less accurate because there is no time constraint (e.g., daily activities usually do not add up to 24 hours" [15]). In general, however, estimates from the diary method tend to be lower than estimates from the recall method. This is especially true for housework [16]. Still, a disadvantage of the diary method compared to the recall method is that it is very time consuming, which can bias the results in favor of less busy respondents.

In addition to the applied method and recall period used, the assessment of time investment also entails the explicitness of questions posed. For example, one may ask: How many hours did you spend on informal care during the last week? Some respondents could consider certain tasks as informal care while other respondents could consider them as leisure or housework. To prevent this kind of bias, the analyst should preferably present the respondents a list of informal care tasks and ask them to indicate how much time they spent on those tasks during a certain period. Using such a list makes it necessary however, to make a distinction between normal housework and informal care. This is especially the case if the informal caregiver and care recipient share the same household or if informal care has been provided for several years. Only the additional part of housework due to the disease of the care recipient should be counted as informal care. One must be clear about this point in a survey. Still, it may be difficult for respondents, especially in cases where informal care has been provided for many years already, to distinguish between normal tasks (i.e., those also performed if the care recipient had not been ill) and informal care.

Joint production, defined as doing two or more activities at the same time by one person, is another complicating factor. The more "joint" activities are, the less accurate the results tend to be. The problem tends to be more complicated when, for example, leisure activities are combined with providing informal care, for example, watching television and supervising after a care recipient with Alzheimer disease. Recently, Van den Berg and Spauwen [50] developed a diary and a recall meth-

Valuation methods for informal care		
Revealed preference methods	Stated preference methods	Others
Opportunity costs	Contingent valuation	Objective burden
Proxy good	Conjoint analysis	Subjective burden
		Health-related quality of life
		Well-being

od to compare the reported time in the different methods informal caregivers indicate to spend on providing care. They conclude that there are differences on the level of various care tasks. On the aggregate level, however, both methods yield the same results. Moreover, the diary was also developed to deal with joint production. If one corrects for joint production both methods do no longer yield the same results. Spauwen [17] showed that there is a positive relationship between providing informal care household activities and normal household activities at the same time. Providing informal care was, however, not combined with other activities, for instance, leisure. The latter combination is often suggested in the literature but not supported by these data. Another point of attention is that diaries and the recall method often, although not necessarily, are related to one informal caregiver, while in many cases more informal caregivers are involved. This can lead to an underestimation of the total amount of provided informal care and the time involved in it. Finally, in developing the survey, one must keep in mind the discussed measurement problems and the preferred valuation method needs to be the starting point.

#### Valuation methods for informal care

Various methods for the valuation of informal care have been discussed in the literature and have been applied in previous research. In this section we present an overview of the different methods. They can be divided into three categories, including revealed preference and stated preference methods ( Table 1). This distinction is of importance since the "difference between [the revealed and stated preference method] comes down to using uncompensated (Marshallian) demand curves in case of revealed preference valuation methods, and estimating the income-compensated (Hicksian) demand curves in the case of the stated preference valuation methods" [18]. In addition there are other methods. Valuation methods for informal care thus include:

- Revealed preference methods: opportunity costs, proxy good
- Stated preference methods: contingent valuation (CVM), conjoint anal-
- Others: objective burden, subjective burden, health-related quality of life, well-being.

(It is worth nothing that objective and subjective burden are not valuation methods but merely an indication of the burden of caring. Moreover, the methods in the column "others" are more general concepts and involve many specific methods or instruments.)

The major problem in valuing informal care is that by definition no market prices exist. It is often argued that informal care in economic evaluations should be valued with the opportunity cost method [5, 19, 20]. As an alternative the proxy good method is also proposed [6]. However, there are some problems with both methods, as they will be discussed below. In addition, the pro's and con's of other available methods to value informal care are discussed below.

#### Revealed preference methods

Both the opportunity cost method and the proxy good method use real-life decision data to value informal care and may therefore be seen as revealed preference methods. This means that preferences of informal caregivers are deduced from informal caregivers' decisions or from decisions in the market for close substitutes of informal care. For the application of the two methods only the time forgone or spent on informal care must be measured and valued in different states of the world: without and with the intervention under study or reference case and intervention. The advantages and disadvantages of both methods are discussed below.

#### Opportunity cost method

The opportunity costs of informal care are the informal caregiver's benefits forgone due to spending time on providing informal care. In general the forgone benefits are approximated by an individual's market wage rate. Thus the value of informal care equals the market wage rate of the informal caregiver multiplied with the hours of time forgone or the hours spend on informal care. In an optimal world this implies that from the perspective of the informal caregiver the value of all hours spent on informal care, including the last exceeds the caregiver's hourly market wage rate. Thus the opportunity cost method gives just a minimum of the value of informal care. However, informal caregiving often involves nonlabor market participation, for instance for full-time housewives or retired persons. As a solution to the nonlabor market participation, one can use a modified opportunity cost method to find out the reservation wage rate of the informal caregiver. This is the wage rate for which an individual is willing to supply at least 1 h on the labor market [21]. Another practical solution is the imputation of the known wage of similar persons (e.g., same sex, educational level and age). To make the valuation more complicated informal care is often at the cost of unpaid work or leisure time. The analyst needs to impute a valuation of these types of time forgone to obtain a value of informal care.

An advantage of the opportunity cost method compared to its close substitute, the proxy good method, is that it is not necessary to distinguish between different informal care tasks provided, which makes it easier to use. Still, distinguishing between the different types of normal time use sacrificed is necessary. As indicated, especially when informal care has been provided over longer periods of time, it may be difficult for respondents to indicate what time use has been sacrificed. An alternative approach, recently used by Van den Berg et al. [51] is to ask what persons would preferably want to do with their freed time if this had no longer to be spent on informal care.

Despite the recommendations to use the opportunity cost method to value informal care, the method has some important disadvantages. Using the opportunity cost method to value informal care instead of just to indicate informal caregiver's opportunity costs leads to different values of the same commodity informal care due to one's potential wages somewhere else in the economy. For instance, the same type and amount of informal care provided by a professor of health economics receives in the first case a higher value than informal care provided by a PhD student all other things equal (especially during paid work, but mostly valuation of leisure and unpaid activities are related to income as well, as microeconomic theory suggests). This is the socalled Hawrylyshyn paradox [15, 22]. An explanation for the Hawrylyshyn paradox is that providing informal care involves different direct utilities, sometimes also called process utility, for the professor and his PhD student. It is debatable whether this direct utility should be incorporated in economic evaluations while traditional measures of market output do not incorporate them. Moreover, the opportunity cost method is quite general with a focus on the valuation of time forgone due to informal caregiving instead off the valuation of the full impact of providing informal care for the informal caregiver.

Double counting of other, for example, care recipients' costs or outcomes, is not expected to pose a serious problem. The costs of informal care can be incorporated in the cost side of CBA, CUA, or CEA, as they are purely monetary. The method can also be used in combination with other methods to measure the full impact of informal care, such as health-related quality of life. In that case avoidance of doublecounting needs more attention as well as the appropriate way of incorporating the health effects of informal caregivers in economic evaluations. The latter issue is further discussed below. Examples of the

application of the opportunity cost method to value informal care are provided elsewhere [23, 24].

#### Proxy good method

The proxy good method or market cost method values time spent on informal care at the (labor) market prices of a close market substitute. This approach requires the availability of a market substitute for the nonmarket good, which is assumed to be almost perfect. The time spent on informal care is valued at the wage rate of a market substitute, which can differ for different tasks, for example, housework is valued at the market wage of a professional house worker and personal care is valued at the market wage of a professional nurse. [One can debate whether this should be the gross wage (the real opportunity costs to society) or the net wage (the wage rate for which the professional is willing to sacrifice leisure).]

This method is also rather simple and crude. Using a list of performed activities and the time spent on these activities, it is possible to calculate some kind of formal proxy value. However, the method has also some disadvantages. First, by using wage rates of, for example, health care professionals as the proxy value, one assumes that formal care and informal care are perfect substitutes. For instance, no differences in efficiency and quality are assumed to exist. It is also assumed that informal caregiving does not involve direct (dis)utility. This means that neither the care recipient nor the informal caregiver enjoys the fact that the latter provides the care. Another point of concern is the used wage rates. Due to collective agreements and regulation the wages of professionals in the health care sector do not necessarily represent real labor scarcity in society.

The proxy good method poses other measurement problems than the opportunity costs method, because the analyst does not need to know the different sources of time forgone. However, the distinction between "normal" tasks and informal care tasks as discussed above is crucial. For the practical application the availability of a close market substitute in the heavily regulated health care sector or the informal sector for household services is also crucial.

The monetary costs of informal care according to the proxy good method can be incorporated in the cost side of CBA, CUA, and CEA. Double counting with, for example, care recipient's outcomes or costs is not expected to be a serious problem because only the informal caregiver's perspective is used. The method can also be used in combination with other methods, like health-related quality of life, but again the threat of double-counting needs attention.

#### Stated preference methods

Next we discuss two stated preference methods for the valuation of informal care: the contingent valuation method (CVM) and conjoint analysis (CA). Stated preference methods are used to measure and value respondents' preferences mostly for nonmarket commodities through (oral or written) surveys. Often, the aim is to find a monetary valuation of a nonmarket commodity, such as informal care. This monetary valuation is used as a proxy for respondents' well-being because wellbeing is not direct measurable. However, an individual's preferences are not always a good indicator of an individual's wellbeing [25]. This may be the case (a) when the preferences of an individual are affected not only by his own welfare but also by his consideration for the welfare of others, (b) due to ignorance and/or imperfect foresight, and (c) when an individual exhibits irrational preferences. [As Ng [25] observes: "The preference of an individual is here defined irrational if he prefers x over y despite the fact that his welfare is higher in y than in x, and his preference is unaffected by considerations of the welfare of other individuals (any sentient creature can be an individual here), or by ignorance or imperfect foresight.") One must keep in mind those cases in the application of stated preference methods.

#### Contingent valuation method

Hicks [26] identified two methods to express the effect of an intervention on an individual's well-being in a money metric: compensating variation (CV) and equivalent variation (EV) (see also [27, 28]). These methods are commonly known as willingness to pay (WTP) and willingness to accept (WTA). One could apply CVM to value informal care, for example, by assessing the minimum amount of money an informal caregiver would need to receive to be willing to provide a certain or an additional amount of informal care.

Although the concepts of WTP and WTA are relative easy to grasp, the practical application of CVM could be troublesome in the context of informal care because informal caregivers often claim that money is at least low on their agenda [19]. This could imply that informal caregivers find it unseemly to indicate that they would need a monetary compensation in order to provide informal care to somebody in their social environment they love. Moreover, economists often reject CVM because the method conflicts with one of the central axioms in economics: revealed preference. They argue that it is just the intention of respondents that is measured in CVM instead of real behavior as required in the revealed preference axiom. In addition, on an applied level it is well known that CVM studies involve different types of bias. (For an extensive overview of these and other practical problems in assessing an individual's WTP or WTA see [29]). Finally, double counting could be a major problem in the application of CVM to value informal care since informal caregivers are assumed to take the preferences and perhaps the health of their care recipient into account.

An example of the application of the CVM method to a close nonmarket substitute of informal care is provided by Garbacz and Thayer [30]. They used an experiment in senior companion program services to value companionship with the CVM. In their design respondents were placed in a hypothetical market where the current level of their services was reduced with either 25% or 75%. Then, respondents were asked either to determine their maximum WTP to prevent the reduction or their minimum WTA to be compensated for the proposed reduction in services. Finally, these results were compared to the actual costs of the program to see whether the reduction in the service level could be justified on the basis of CBA.

Recently Van den Berg et al. [49] applied CVM to elicit informal caregivers

WTA in order to provide an additional hour of informal care. Their study shows that it is feasible to apply CVM to elicit informal caregivers' monetary compensation to provide additional informal care. Moreover, the study shows that informal caregivers' WTA seems to be sensitive to some of the informal caregiver's and his care recipient's real life circumstances, for instance, health-related quality of life.

#### Conjoint analysis

CA or Choice Experiments, also called Conjoint Measurement (CM), is a method for the analysis of respondents' preferences for a set of multiattribute alternatives. It can be linked to Lancaster's [31] attribute based utility theory. Lancaster's contribution was that he stressed that a commodity possesses more than one characteristic. For example, a meal has both nutritional and esthetic characteristics in different relative proportions for different individuals. Green and Srinivasan [32] define CA as: "any decompositional method that estimates the structure of a consumer's preferences ..., given his/her overall evaluations of a set of alternatives that are prespecified in terms of levels of different attributes."

Different CM techniques are available, such as ranking, rating and discrete choice or choice experiments. Respondents are asked, for instance, to rate different states of the world, often called vignettes, to reveal their preferences. The states of the world can differ according to dimensions, called attributes. If one attribute is a price, it is possible to derive implicit prices for the other attributes. Thus a value in monetary terms can be derived. One can also attain a utility outcome from the respondents' choices.

Within economic evaluation CA is of growing importance for the measurement of care recipient's preferences (for overviews see [33,34]). A Dutch study [35] used CA to investigate the extent to which persons wish to spend more or less time on providing informal care given their own circumstances and what determines their choice between hiring a professional caregiver and providing informal care. The design of this study makes a distinction between providing informal care for a partner, parent (in-law), family, or

friends and neighbors. In general, the researchers concluded among other things that the amount of time available and the amount of time necessary to spend on informal caregiving are important predictors of an individual's decision to be involved in the informal caregiving process as opposed to hiring another caregiver. The social relationship between informal caregiver and care recipient, however, makes the tradeoff more subtle. The closer the social relationship, the more willing an informal caregiver is to provide the care himself. The less close the social relationship, the more important other considerations become. Providing informal care for a parent (in-law) for instance is more likely to be preferred when it involves more than 1 h a day preferably 1 or 2 days a week. Moreover, it is in providing informal care to a parent (in-law) preferred if informal caregivers receive a small monetary compensation. This finding is contrary to the suggestion of Smith and Wright [19]. Advantages compared to CVM are CA's ability to elicit respondents' preferences for different detailed scenarios and respondents' ability to express their preferences for more than one scenario. CA's complexity, in other words respondents need to consider a number of attributes at the same time simultaneously, may be a problem. Double counting again can be a problem in the application of CA, as in CA the informal caregivers can also take the preferences of the care recipient into account.

#### Other methods for measuring the impact of informal care

This section presents other methods to capture the impact of informal care. First, we deal with the assessment of objective and subjective burden of informal care. Although these are no valuation methods from an economic point of view, much work has been carried out in this area by, for example, sociologists and psychologists. Next, we discuss health-related quality of life measurement in the context of informal caregiving. Finally, we discuss direct measurements of well-being. The central problem with these methods is that their results cannot easily be incorporated in economic evaluations. We discuss this issue after we have discussed the methods.

#### Objective burden assessment

Objective burden entails assessing the time invested in caregiving, the seriousness of the care recipients' illness, and the care tasks performed. Problems concomitant to the measurement of time were discussed before. Two examples to measure the time spent on caring for care recipients with Alzheimer disease are the Caregiver Activities Time Survey (CATS) [36] and the Caregiver Activity Survey (CAS) [37]. Both instruments were developed to incorporate informal care in economic evaluations. However, the underlying aim was to translate the results in monetary units with the proxy good method. The results of objective burden assessment can also be used as additional information for the decision maker. However, normally, the focus in an economic evaluation lies on monetary costs and health effects solely. Additional outcomes, such as the objective burden of informal care are hard to incorporate coherently and comparably in an economic evaluation. Still, due to the practical difficulties with deriving a monetary value of informal care one could argue that it is better to present an additional outcome measure in an economic evaluation than to neglect informal care or to attach an arbitrary monetary valuation to

#### Subjective burden assessment

There is abundant literature on the impact of providing informal care on informal caregivers (see, for example, [2, 38, 39, 40, 41, 42, 43]). Often a distinction is made between the physical, emotional, and social burden of informal caregiving. The assessment of subjective burden relates to the strain of care as experienced by the informal caregiver. Informal caregivers may, for example, be asked about lack of support of others and disruption of their schedule. Many subjective burden instruments are disease-specific and focus often on the negative aspects of caring (see, for example, the Caregiver Strain Index [CSI] [44]).

Three problems related to subjective burden are mentioned here. First, the concept of subjective burden is lacking a theoretical foundation leading to a lack of conceptual clarity [38,39,42]. This involves results in differences in the elements captured in terms of subjective burden and differences in the way these elements are made operational and measured. This makes the interpretation and comparison of the results rather troublesome. Second, the subjective burden assessment focuses mainly on the negative aspects of the caring process experienced by the informal caregivers. The positive aspects of caring are often neglected, and if not, the rationale behind the choice of the included positive aspects is hardly ever indicated. Finally, existing subjective burden instruments do not value the subjective burden but they "merely" register it on some scale.

Given the informational richness of burden assessments, it has been suggested to incorporate the results of these studies in economic evaluations [45]. Moreover, the results of subjective burden assessment could, as with the results of objective burden assessment, be used as a kind of additional natural units of information in CEA. However, Drummond et al. [45] are skeptical since subjective burden measures may not be very responsive to change while in economic evaluations it is exactly a change or difference that needs to be registered and valued. The measurement of subjective burden may lead to fewer problems than the measurement of objective burden. To indicate the amount of time spent on caring is perhaps more difficult for informal caregivers than to express their feelings about a list of items on a certain measurement scale as in subjective burden. Still, the interpretation of objective figures may be more straightforward than the interpretation of their subjective counterparts.

#### Health-related quality of life

It has been argued that the provision of informal care can lead to both mental and physical health problems [39] and even to higher mortality risks [2]. These are indications that informal caring is an independent risk factor for mortality and morbidity concerning some groups of informal caregivers, for example, elderly spousal caregivers [2]. In this sense healthrelated quality of life measurement may be used in order to assess the impact of providing informal care on informal caregivers' health, as the main goal of health care is to preserve or restore health [46].

How to register possible health-related quality of life changes due to informal caregiving is controversial. Moreover, the causality of the relationship between providing informal care and health-related quality of life losses remains unclear. For example, does the strain of providing informal care lead to reductions in healthrelated quality of life, or do persons with health problems who become informal caregivers find this more straining? This causality is crucial if one wishes to incorporate informal caregivers' health losses in economic evaluations because the focus of an economic evaluation is on the health effects of an intervention. Moreover, some health-related quality of life reductions reported in informal caregivers (e.g., depression and anxiety) may be related more to the mere incidence of illness in ones social environment and less with the provision of informal care. In other words, reductions in health-related quality of life when a child falls ill may occur regardless of whether the parents provide informal care. This kind of health-related quality of life reductions should not be incorporated in economic evaluations.

Mohide et al. [46] developed a Caregiver Quality of Life Instrument (CQLI). They used Torrance's time trade-off (TTO) technique to obtain utility scores for three standardized caregiver situations and utility scores for the respondent's own state. The respondents were asked to choose between being in alternative states of the world for different periods of time. The alternative states of the world differed in five dimensions: two social dimensions, i.e., amount of time to socializse with family and friends, and quality of the relationship between the caregiver and the care recipient; two physical dimensions, for example, degree of physical wellness and energy, and adequacy of amount of sleep; and one emotional dimension, for example, degree of happiness and freedom from anxiety and frustration. The CQLI is used to obtain utility scores from informal caregivers. The results, however, must be interpreted carefully to avoid double counting. It would be incorrect to add the utility scores of informal caregivers and care recipients simply in economic evaluations because their utility functions are expected to be interdependent. If the informal caregiver takes into account the utility of the care recipient and the care recipient does vice versa, adding their utility scores will lead to a misperception of the total utility.

Disadvantages of the CQLI are its complexity and its high costs. The method is not easy to understand thereby limiting its application and introducing possible bias. It is also an expensive method because it requires face-to-face interviews by trained interviewers, which may not be feasible in many contexts.

#### Well-being

Psychologists and sociologists have carried out substantial research on the concept of well-being. A distinction is made between satisfaction with life as a whole and satisfaction with a specific domain. The main findings are that subjective variables explain individual satisfaction better than objective variables, and that domain-specific satisfaction is strongly correlated with well-being in terms of satisfaction with life as a whole [47]. In (health) economics this research is uncommon, partly because the objections of economists against the measurability and comparability of well-being and partly because of the focus on health rather than on well-being. Frijters [47] tries to remove the opposition from economist against the measurement of well-being.

We suggest that informal care could also be valued by registering changes in well-being of informal caregivers. An advantage of this method is that it allows economic and noneconomic factors affecting the preferences of an individual to be combined [48]. To our knowledge, no research has been done using this concept to value informal care. It would be interesting to measure informal caregiver's well-being to compare it with informal caregiver's health-related quality of life or with the well-being of the general population. Possible differences in reported well-being could be used as alternative measures to the so far discussed methods. Moreover, they could be incorporated in economic evaluations taking a societal perspective that is broader than a health perspective.

#### Some unresolved issues

We have discussed different methods for the valuation of informal care. It proves that not all of those methods can be incorporated in the main types of economic evaluation. The main reason is that CEA, CUA, and CBA require different kinds of information. Moreover, not all methods yield complete valuations of informal care. Finally, it is not always clear who should value informal care: the care recipient, the informal caregiver or the general public? In this section we discuss these matters somewhat further.

#### Incorporation

The issue of incorporation is connected with yielding monetary or nonmonetary results. All three types of economic evaluation can incorporate a monetary value of informal care on the cost side of an analysis. This implies that the valuation methods that yield monetary values can be used in all three evaluation contexts; CBA, CUA, and CEA. The opportunity cost method, the proxy good method, CVM, and CA. Since in CBA all information on costs and outcomes needs to be expressed in monetary terms, the mentioned valuation techniques are also the only ones that can be used in CBA. In principle, measurement of objective burden, subjective burden, health-related quality of life and wellbeing yields nonmonetary outcomes. However, it is worth noting that it is possible to translate the nonmonetary outcomes in money outcomes. In the context of a CUA, one needs valuation techniques yielding preference-based or utility-based outcome measures. Utility based healthrelated quality of life changes in informal caregivers could therefore in principle also be included in such an analysis. How to combine these changes with changes in health-related quality of life in care recipients is, however, unclear. Moreover, preference-based or utility-based CA or wellbeing measures may also considered to be suitable for incorporation in CUA, as they reflect preferences or utility of informal caregivers. Meaningfully combining these with quality of life changes of care recipients seems, however, impossible, leading such CUAs to become multicriteria analyses. Finally, in CEA, one may use the three mentioned techniques in case of CUA, as well as objective burden and subjective burden measures. The latter may be seen as a measure of the impact of informal care in "natural units" to be put on a balance sheet of pro's and con's.

#### Partial or complete valuation

Complete valuation methods focus on all aspects of informal care, while partial valuation methods focus only on some aspects of informal care. Especially burden measures and health-related quality of life measurement can be used to indicate only some aspects of informal care. Ideally, they should be complemented with other valuation methods, avoiding double counting. CVM and CA are normally used to create a total valuation of informal care. However, it often depends on the questions asked and the tasks considered whether such a complete valuation is reached. In CA, for instance, complete valuation would entail specifying all aspects of informal care in a vignette. This could be troublesome in practice. All the other methods do not yield a total valuation of informal care. Therefore methods could be combined, for example, complementing the opportunity cost method with health-related quality of life measures.

#### Who to ask

Finally, who should value informal care? This is a complicated issue in the context of the valuation of informal care. A first response could be to use actual informal caregivers as source of valuation. However, this source may come up with biased or strategic answers, just as in health state valuations. To avoid such problems one may measure the preferences of the general public as potential, actual or former care recipients or informal caregivers. Just as for the valuation of health-related quality of life, the general public may be used as a "more objective" although less informed source of valuation therefore.

In addition to this problem, there is also the problem of whether the producer of informal care or the consumer of informal care should value this nonmarket commodity. Should an additional hour of informal care be valued by the producer, for example, the value this additional hour has for the informal caregiver or rather by the consumer, for example, the value of the additional hour to the care recipient. The answer to this question is a matter of perspective probably (e.g., do we wish to determine the impact of informal care on the (health or well-being of the) care recipient, or do we wish to determine the impact of providing informal care on the caregiver), but also has implications for the methods chosen in the economic evaluation. In the opportunity cost method, for instance, the informal caregiver is central to the valuation of informal care. His time investment and his wage rate are used. In the case of the proxy good method some kind of societal replacement value is calculated on the basis of, for instance, formal caregivers' wage rates. For CVM, CA as well as well-being it is, however, more difficult to grasp who should be central to valuation. As long as the informal caregiver enters a caregiving situation voluntarily and given the focus on health outcomes in relation to costs, it appears that the valuation of informal care should be caregiver centered. Yet, this point and the interdependencies between preferences of caregivers and care recipients should receive more attention in future research.

#### **Conclusions and recommendations**

Despite its contribution to the care for chronic and terminally ill care recipients, informal care is often neglected in economic evaluations of health care programs. The incorporation of informal care in economic evaluations is, however, crucial to prevent undesirable policy recommendations. Informal care should not be treated as "free" in economic evaluations, as this may lead to cost-ineffective care strategies from a societal perspective and even to health damage in the population at large. It is therefore crucial to incorporate the full impact of providing informal care on informal caregivers as well as on the care recipient. We have discussed different methods available to value and register the impact of informal caregiving on the informal caregiver.

The main message of this contribution is that to preserve undesirable shifts due to new policies on the account of informal caregivers a full valuation method of the costs and effects of providing informal care for the informal caregivers is necessary. In theory CVM and CA are such methods. However, this must be confirmed in practice. For instance, it must be substantiated that the application of CVM and CA yields reliable results and that respondents indeed can incorporate all aspects of informal care in their valuation of it. A clear advantage of both methods is that they yield monetary results and can therefore easily be incorporated on the cost side of all types of economic evaluations.

As long as no valid empirical applications of CVM and CA exist, the opportunity cost and proxy good methods can be used to incorporate informal care in economic evaluations. However, neither the opportunity cost method nor the proxy good method covers the full costs and effects of informal care. Therefore, they should be complemented by other methods such as health-related quality of life measurement in informal caregiving, be it at the price of a more complex interpretation of the results of economic evaluations. Moreover, more empirical evidence is necessary to ensure that health-related quality of life methods are sensitive enough to measure changes in the healthrelated quality of life of informal caregivers due to the provision of informal care. It is also worth noting that a combination of, for example, the opportunity cost method and health-related quality of life measurement does also not necessarily cover the full impact of informal caregiving because, for instance, the direct utility of the informal caregiver is neglected.

More research is needed and it is recommended to combine different methods in ongoing research to detect the full impact of informal caregiving as well as gathering more information on the performance of different methods. We should get more serious about valuing something valuable as informal care.

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#### Erratum

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### An exponential representation of health state utility

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Unfortunately there were errors in some equations. In print, the derivative signs have been omitted throughout the text. The correct version is shown below.

The measure of constant absolute risk posture is

$$-\frac{U''(y)}{U'(y)}$$
 instead of  $-\frac{U(y)}{U(y)}$ .

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