

THE VALUATION OF INFORMAL CARE IN ECONOMIC APPRAISAL

A Consideration of Individual Choice and Societal Costs of Time

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Abstract

This article discusses the individual's choice to engage in informal care as an issue for economic evaluation. Traditional methods used in economic evaluation studies for valuing time spent on informal care are discussed and an alternative method is put forward that incorporates the quality of life of caregivers as an outcome measure to represent the effects on caregivers. The methodological issues concerning the valuation of informal caregivers' time are becoming more important as new drugs and other health care technologies are introduced for patients with diseases that are typically associated with informal care.

Keywords: Informal Care, Valuation, Cost-effectiveness Analysis

Informal care is a specific type of health care provided by nonprofessionals. Specifically, informal caregivers are defined here as family, friends, acquaintances, or neighbors of a patient providing care for which they do not have to be financially compensated (20;22). Informal caregivers give up normal activities because of the incidence of illness in their immediate social environment. An individual's choice to engage in providing informal care may not only be subject to an optimization process of his or her utility function. Many restrictions and difficulties may influence the outcome of the mix of formal and informal care.

The valuation of informal care in cost-effectiveness analysis is rather troublesome, since available methods aim at expressing all consequences for the informal

caregiver in monetary terms, and incorporate the results on the cost side of economic evaluations. This practice proves rather difficult for the valuation of informal care because these consequences include more intangible effects like fatigue, giving up leisure activities, and fewer social contacts. Research seems needed in order to find methods for valuing the time involved in informal care that are theoretically correct, yet practically applicable. To this point some suggestions are made in the literature, but these do not translate easily into guidelines for practical research. For instance, capturing the full opportunity costs of time by means of an adjusted wage rate will require research on how to adjust wages adequately for people who are engaged in home production or leisure (9).

Although difficult, the valuation of time of informal caregivers becomes more important now that drugs for patients with Alzheimer's disease and schizophrenia have become available. These conditions are typically associated with a considerable amount of informal care. Therefore, better methods for valuing informal care are called for to ensure a good estimation of the true societal impact of informal care. Moreover, in some countries there seems to be an increasing substitution of formal care with informal care, as formal care is increasingly being restricted.

This article discusses an individual's choice to engage in informal care, mainly focusing on the restrictions and difficulties that potential informal caregivers face. Then, we will discuss a preferred method of valuing informal care within the context of cost-effectiveness analysis, a method aimed at finding the societal opportunity costs and effects of informal care. It is different from other proposed methods in using quality-of-life measurement for informal caregivers to avoid arbitrary monetary valuations of such aspects of informal care as fatigue, giving up leisure or sleep, etc.

The individual's decision to engage in informal caregiving is considered in the next section. The third section discusses the societal valuation of the inputs of informal caregivers in economic evaluations. The conclusion indicates areas for future research.

THE INDIVIDUAL DECISION TO ENGAGE IN INFORMAL CARE

Basic Assumptions on Individual Choice

First, it is important to understand that the decision whether or not to become an informal caregiver is dependent on the incidence of illness in an individual's direct social environment. When and if illness sets in, one option is to continue normal activities and hire professional help to care for the patient. This formal help may take place at home or may involve institutionalization. One can also perform some or all caregiving activities oneself and give up activities that one was normally engaged in. Often, the decision is not all or nothing, but rather a decision to combine both formal and informal care.

Second, it may be argued that when a relative or friend falls ill and is in need of care, both formal and informal care yield utility for the potential informal caregiver. The alternative is to leave the patient with insufficient care, or in the worst case without care, which will be associated with a large disutility. As the well-being of the patient is assumed to be incorporated in the utility function of a relative or friend, any improvement in the patient's condition will have a positive impact on his or her utility. If, for instance, a patient has a very strong preference to stay at home, the disutility from institutionalization will be relatively high, both for the patient and the potential informal caregiver. The interaction between utility of

patients and informal caregivers is an interesting and challenging subject. The amount of utility from informal care and formal care is bound to differ for both the patient and the informal caregiver, since both involve a different time input of the caregiver, different financial costs, and a different process utility for the caregiver.

Third, the choice between formal and informal care as discussed here is relevant for only that part of formal care that may be substituted by informal care. It is obvious that some care activities are too complex to be performed by a nonprofessional.

Finally, a difference can be observed between members of the same household acting as an informal caregiver and someone else acting as an informal caregiver. Some of the costs associated with informal and formal care will have to be paid by the patient and thus may be expected to be of interest to members of the same household in case of a shared budget. Other informal caregivers may consider only the costs and effects that they will incur themselves. These two groups will not be consequently disentangled in the following discussion, but it is assumed to be obvious for the reader when to make this distinction.

The Choice Between Formal and Informal Care

If a person decides to become an informal caregiver, it is clear from a revealed preference viewpoint that, given the circumstances, this is the utility maximizing solution, because otherwise he would have chosen differently. This means that if informal care is provided, the positive and negative sides of informal care together yield more utility than the positive and negative aspects of the alternative formal care, and both yield more utility than no care at all. This will be the starting point for the discussion, but later we will concentrate on the fact that real-world circumstances often limit opportunities. From the starting point of the incidence of illness onward, both formal and informal care yield utility because the alternative is no care at all. Formal and informal care may then be viewed as two distinct types of care by both patients and caregivers. Both types of care and any combination of them are associated with different time input, financial costs, and process utility (providing care). An individual is supposed to be influenced by these aspects of informal and formal care when striving toward an optimal formal–informal care mix. Without trying to be complete, some of these positive and negative sides of formal and informal care are discussed below.

Informal care may involve hiring or buying certain attributes, such as buying special beds and adapting one's home, in order to facilitate the provision of informal care (8). Travel costs may be important when an informal caregiver does not live nearby. Hiring formal care may be costly as well, since the related costs may often not be entirely refunded by social or private insurance. Travel costs can also be of importance for formal care, for instance when visiting an institutionalized patient.

A major input in the treatment of the patient of an informal caregiver is time. The time allocated to informal care may otherwise have been invested in paid or unpaid work and/or leisure. The opportunity costs of time invested in informal care are equal to the valuation of alternative activities during that time, because it is the time use that is valued by persons, not time as such (15). The opportunity costs of this time input are expected to differ between formal and informal care, since the amount of time invested by informal caregivers in either case is bound to differ. The valuation of this time input in a cost-effectiveness analysis is discussed later.

Providing informal care may affect the well-being of the informal caregiver since it involves all kinds of pleasant and unpleasant activities. Cleaning up after

the patient has been sick, waking up in the middle of the night because the patient needs attention etc., may have negative effects on the caregiver’s utility. Positive effects are derived from being close to the patient, being able to take care of him or her, enjoying certain caregiving activities, etc. These positive and negative sides to informal care have been discussed extensively by Wright (22). These effects are closely related to the caregiving activities that replace normal activities, as we discuss later.

There will also be direct effects of formal care on the well-being of the relative or friend. When institutionalization is the alternative of informal care, the absence of the patient may have great impact on the well-being of the potential caregiver. This impact becomes even greater when the patient prefers to be cared for at home, since the well-being of the patient is assumed to be incorporated in the utility function of the relative or friend. When formal care can be provided in the patient’s home, and the caregiver is part of the same household, considerations of privacy and discomfort of having a strange caregiver in the house may also influence the exact mix of formal and informal care.

Individual Choice under Ideal Circumstances

In choosing between formal and informal care, the numerous aspects mentioned above may all enter the utility function of the potential caregiver and may all be considered to influence the final decision. The approach chosen here is to compare the utility from provision of informal care as such to that of hiring formal care. The total costs and benefits attached to formal and informal care may be considered. By taking into account all costs and effects of both types of care, the optimal mix of formal and informal care may be found.

In the most simple case, formal and informal care may be seen as perfect substitutes. Then, for a potential informal caregiver with paid work, in a Gronau household production model the optimal spending of time may be denoted as:

$$U = U(Z_i + Z_f, Z_c, Z_l) \tag{1}$$

in which U represents the utility of the potential informal caregiver, which is dependent on four end products: formal care (Z_f) purchased for one’s partner, informal care (Z_i), leisure (Z_l), and other consumption (Z_c). Note that the formal and informal care is used to care for the partner or friend of this person. The substitutability of formal and informal care is formulated by making utility dependent on the sum of Z_i and Z_f .

Further, we will assume informal care (Z_i) to be equal to time spent on informal care, t_i , thus:

$$Z_i = t_i, \tag{2}$$

formal care (Z_f) is equal to the amount of formal care, F, purchased:

$$Z_f = F, \tag{3}$$

leisure (Z_l) is equal to all time not spent on paid work or informal care (t_i):

$$Z_l = t_i, \tag{4}$$

and other consumption (Z_c) is equal to the amount of other goods, C , purchased:

$$Z_c = C. \tag{5}$$

All the available funds, partly earned by performing paid labor and partly other (nonlabor) income (Y_0), will be spent on formal care and other consumption, so the budget restriction is:

$$p_f F + p_c C = t_w W + Y_0 \tag{6}$$

in which p_f is the price of formal care per unit, p_c is the price per unit of other consumption goods, t_w is the amount of hours spent on work, and W is the wage rate. Furthermore, the total amount of time is restricted:

$$T = t_i + t_j + t_w \tag{7}$$

Equations 6 and 7 may be rewritten to the total income equation:

$$WT = p_f F + p_c C + Wt_i + Wt_j \tag{8}$$

Using a Lagrange function, optimal time spending holds when:

$$\text{Max } Z = U(F + t_i, C, t_j) + \mu [WT - p_f F - p_c C - Wt_i - Wt_j] \tag{9}$$

From this one may derive the substitution rate between informal and formal care:

$$\frac{\partial Z}{\partial t_i} = \frac{\partial U}{\partial t_i} + \mu W = 0 \tag{10}$$

$$\frac{\partial Z}{\partial F} = \frac{\partial U}{\partial F} + \mu p_f = 0 \tag{11}$$

Combining 10 and 11 leads to:

$$\frac{\frac{\partial U}{\partial t_i}}{\frac{\partial U}{\partial F}} = \frac{W}{p_f} \tag{12}$$

Marginal substitution rate between providing informal care and purchasing formal care should therefore be equal to the price relation.

Of course, even in a textbook situation, the point at which one substitutes informal care by formal care will differ among persons and illnesses. Informal care may almost always yield more utility for some persons, while for others hiring formal care will be preferable at almost every point. Especially when the potential caregiver has a paid job, it may be difficult to be absent for a longer period, and thus formal care may be preferred relatively soon. Note that if a higher educated (and higher paid) person provides substantial amounts of informal care, revealed preference may indicate that the productivity of this person is high not only in the

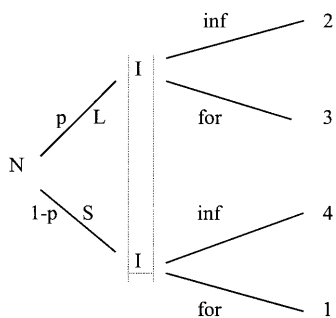


Figure 1. Example of a decision tree for an informal caregiver.

marketplace, but also at home. Empirical studies on the choice of informal caregivers are very scarce.

The amount of care a patient needs per day or week is of great importance. The utility derived from the two products, formal and informal care, may also shift over time. After having given informal care for several months, an informal caregiver might value formal care higher as compared to when he had just begun providing informal care (burn-out). This time effect on the formal–informal care decision would be extremely interesting to explore further in empirical work as well.

Real-Life Restrictions on Optimal Choice

The rational and unrestricted optimization behavior, as described above, will not be found in everyday circumstances. Here, we consider the importance of real-life restrictions on the optimal choice as described above. One complicating factor in real life is uncertainty. When deciding between formal and informal care, it may be unclear how long care is needed, and thus the decision whether or not to engage in informal care is made under uncertainty. Such a decision under uncertainty may perhaps be pictured better through a simple decision tree in which the potential informal caregiver is unaware of the length of the care period. In Figure 1 an example of a decision tree (or game tree) is provided for an informal caregiver. We will assume that the person in this example would prefer to provide informal care in case of a short period of illness and to hire formal care in case of a longer period of illness.

This decision tree has subjective, illustrative values that show the utility pay-off of each choice of the potential caregiver. The individual (I) has to decide whether or not to give informal care, without knowing whether the patient will be ill for a long (L) or a short period (S), which is decided by nature (N). The dotted lines indicate that the individual is unaware of his or her position in the decision tree. A lengthy illness has a chance of p , a short one a chance of $1 - p$. Depending on the length of the illness, informal care or formal care may be the best solution. A lengthy illness might cause considerable distress for the informal caregiver (for instance, reduced performance on paid work). However, a short period of informal care may be preferred over a short period of formal care, because of relational aspects, for instance. Under such conditions a person again will try to consider all costs and effects, and in this example the informal caregiver will perform informal care if he *believes* that the chance of long illness is less than 0.75.¹ Such decisions under uncertainty may occur frequently; therefore, observed behavior does not

have to be the result of optimization with perfect information, but based on beliefs of the informal caregiver.

Another problem is the substitution of formal care by informal care. Earlier we made the assumption that informal caregiving can be substituted with formal care at any point. However, this may not always be possible in reality, and the decision sometimes is more or less a “to care or not to care” decision (22). For instance, if the only reasonable alternative for extensive informal care involves institutionalization of a patient, the informal caregiver has to decide which alternative yields the highest utility or the lowest disutility. In general, discrete or “lumpy” decisions about the number of hours spent on informal care and/or formal care are common and may be modeled in a more formal analysis, which goes beyond the scope of this paper.

It may also be the case that only a limited amount of formal care can be hired, when insurance does not cover certain types of formal care and the household budget does not allow for it to be paid out of pocket. The decision not to use formal care may also stem from the supply side. When budgets are cut by governments, formal care may be rationed in order to provide a maximum amount of people with a minimum of care per patient. The remaining need for care will then have to be hired privately (if possible), or informal care has to be provided from that point onward.

Informal caregivers may not always be able to provide all the care they would want to. In that case, informal and formal care are complementary rather than substitutes. For instance, if an elderly woman takes care of her sick husband, she may be unable to perform physically demanding caregiving tasks, such as bathing her husband. This kind of caregiving task may then be performed by a formal caregiver, while she herself engages in the remaining caregiving activities.

Finally, the preferences of the patient can influence the decision of the caregiver. How does the patient’s utility interact with the caregiver’s utility? Often it is just assumed that patients’ utility is incorporated in the utility function of the informal caregiver (which may be correct); however, it would be interesting to see exactly how these two quantities interact.

It is recommended that all of the aspects mentioned above be investigated further empirically, since little empirical work on many of these issues is available.

Table 1 summarizes the main arguments affecting the caregivers’ utility function, and important restrictions are summarized.

SOCIETAL VALUATION OF TIME INVESTED IN INFORMAL CARE

Time: Amount and Valuation

Time spent on giving informal care is a resource invested by family and friends and should therefore be valued in an economic evaluation. Two main problems can be detected when trying to incorporate time costs into CEA: the amount and the value of time. The first problem is assessing the exact quantity of time spent on informal caregiving. During the time providing informal care, many normal activities often can continue as usual; thus, joint production occurs, as in the case of surveillance (5). It may also prove to be difficult to separate normal activities from caregiving activities. Preparing and serving a meal is often considered a normal task; however, helping someone to eat, in most cases, is not. These problems may be solved by using a structured interview or questionnaire asking specifically about loss of normal time use on paid work, unpaid work, and leisure (5).

Table 1. Summary of Individual Choice

Costs and Health/Welfare Effects
<p>Formal care: Costs: Travel costs if patient is institutionalized, costs of hiring formal care (if not totally refunded), time costs. Effects: Privacy, absence of patient in case of institutionalization, patient's utility (preferences).</p>
<p>Informal care: Costs: Travel costs, costs of home adaptations and consumer durables, time costs (giving up paid work, unpaid work, and/or leisure). Effects: Performing tasks that are unpleasant or at awkward times (e.g., at night), fatigue, patient's utility (preferences).</p>
Important Restrictions
<p>Formal care: Uncertainty (e.g., about length of illness), budget restrictions, external restrictions on amount of formal care, sometimes formal–informal mix not possible (e.g., when institutionalization is only alternative).</p>
<p>Informal care: Uncertainty (e.g., about length of illness, progression in care intensity), physical restrictions to perform all caregiving tasks, sometimes formal–informal mix not possible.</p>

The second problem is the valuation of the time input into informal care. Several approaches are possible: the market price method, the opportunity costs method, and contingent valuation.

In the market price method, the time input of informal caregivers is valued at its market price. This market price is equal to the costs of hiring a professional caregiver to perform the caregiving activities (19). This method can be seen as a valuation method of output rather than of input (18), since the output of informal care is valued at a price equal to that of formal care. The most important objection against valuing informal care with this practical method is that the value that is ultimately attached to informal care may have little or no relation to the amount and value of the inputs sacrificed in informal care (the opportunity costs of inputs).

The second way to value informal care is to look for the opportunity costs of the time spent on informal care, which involves the valuation of input (18). These opportunity costs are set equal to the value of the best alternative use of time by the informal caregiver. The best alternative use is assumed here to be the normal use of time, following a revealed preference viewpoint (which is questionable, but alternatives are not easy to find). This opportunity costs approach is often recommended to be used in economic evaluations (9). Generally, this valuation method considers lost working time by taking the wage rate. Although this valuation method is widely accepted, it should be noticed that it ignores any nonmonetary utility that may be derived from working. The valuation of time otherwise spent on leisure activities or unpaid work is more difficult (9;20). One method to value unpaid working time is to use the wage rate that a person receives when working for pay, or a similar person receives as wage (9;18). Wage rates serve here as a lower bound estimate of full opportunity costs (9). The reasoning behind this is that if full opportunity costs would be below the level of the wage rate, the person would have worked for pay instead of engaging in such unpaid activities as home production. However, exactly how the wage rate relates to the gain from unpaid activities is unclear. Although it is sometimes assumed to be close enough to the

real opportunity costs (9), the empirical evidence for this assumption is lacking, especially for people who are restricted in their choice by the labor market situation or by personal, institutional, or other factors.

Leisure time is sometimes completely ignored in economic evaluations. Although appealing, adjustment of wage rates to serve as a proxy for opportunity costs of leisure time is rather difficult. In transport appraisals, leisure time was valued at 40% and later at 24.7% of working time (20). One may argue that this seems an underestimation of the value of leisure time because a substantial proportion of the work force is engaged in parttime work, trading paid work for leisure. Also, if one bases the valuation on microeconomic models of time allocation, as Posnett and Jan (18) elegantly do, one would expect a valuation of leisure time equal to (or higher than) the marginal valuation of working time.

Although the opportunity cost method is theoretically the most appealing, its translation into practical guidelines necessarily seems to involve somewhat arbitrary and difficult decisions to find monetary values for time uses that cannot be expressed in monetary terms easily. An opportunity cost-based method is sought that would try to avoid an arbitrary monetary valuation of unpaid working time and leisure time, yet would give practical and applicable solutions.

Another possible option is contingent valuation. In such a method, one can ask informal caregivers or the general public to assess their willingness to pay for no longer having to perform informal care activities or their willingness to accept having to perform them. This would provide an overall estimation of the costs of informal care, but theoretically only time aspects can be focused on as well. Although this method is appealing, there are concerns about the validity and consistency of the valuations provided. Apart from concerns about the operationalization of such methods (information dissemination, type of question used, and framing bias), there are also concerns on the validity of the actual answer, even if operationalization were perfect. Would the willingness-to-pay amount actually be paid if the situation described occurred? There may be strategic behavior by the respondents, but also one might question whether people are capable of validly valuing something as complex as informal care.

If we look at two important publications on the methodology of cost-effectiveness analysis, i.e., that of Gold et al. (9) and that of Drummond et al. (7), both publications offer little practical guidance as to how informal care should be valued. Drummond and colleagues mention that “in general the valuation of this raises the same issues as the valuation of patients’ time” and they recommend for patient time the use of gross salary when absent from work and that “different assumptions can be made about the opportunity costs of leisure time” (7,86). These recommendations are very similar to those of the U.S. Panel on Cost-Effectiveness in Health and Medicine. They state that the time of informal caregivers can be valued by using “its market or reservation price, similar to the methods suggested for valuing time of housewives and househusbands” (9, 203). However, neither offers a method of adjusting wage rates for time spent on unpaid work or leisure.

Valuing Time Spent on Informal Care: An Alternative Approach

Here we will present an approach that was initially aimed at establishing time costs of patients; however, the approach can also be used to value time of informal caregivers (4). In three brief sections, valuation of paid work time, unpaid work time, and leisure are discussed.

Paid Work. When the caregiver gives up paid labor time, this time input can be valued with a method like the friction cost method (11;13;14). In the context of this paper, a thorough discussion of the friction cost method is not feasible. The friction cost method measures production losses due to absence from a societal viewpoint. It recognizes possibilities to replace a person who gives up paid work time in order to provide informal care. Lost utility because of lost role functioning in a paid job may be captured in terms of quality of life. Incorporating lost income in quality-of-life measurement is not considered a valid method, since the relationship between productivity, income, and quality of life is quite arbitrary (2;3;21).

Unpaid Work. Unpaid work is seen as yielding two types of utility: process utility and product utility. Product utility is utility gained from the output of home production, the produced items themselves (as may be produced by a professional housekeeper). The productive value (product utility) of home production may best be estimated by taking the wage rate of a professional housekeeper. Future research may be aimed at investigating the possibility of replacement of unpaid work. Process utility is the utility gained from the process of performing the tasks yourself. Especially since home production may involve aspects such as raising children, the production process may in itself yield a considerable amount of utility. A good estimation of the opportunity costs of this aspect of unpaid work seems essential. In our opinion this utility may best be measured in terms of quality of life. This should ensure a true estimation of the impact involved, and avoid the use of an arbitrary monetary estimation of the opportunity costs involved. For instance, in the EuroQol, a standard classification instrument, this aspect already has been captured, for patient time, albeit perhaps in not the most sophisticated manner. This shows that there seems to be some consensus that this part of home production is related to home role functioning and therefore should be captured in quality of life.

Leisure Time. Leisure time contributes positively to one's quality of life and may be valued highly by persons engaged in informal care. Leisure time may be sacrificed when elderly retired persons are involved in caregiving (22). However, to capture this loss in quality of life in a monetary amount seems difficult, if not impossible. Therefore, we propose to value lost leisure time through quality of life and not monetarily. Again, in many quality-of-life instruments (e.g. EuroQol), the ability to engage in leisure activities is already included as an aspect of quality of life. Johannesson also feels that it "seems reasonable to assume that individuals take into account the change in leisure in assessments of quality weights. . . ." (10)

Quality-of-life Effects of Caregiving Activities. When using a quality-of-life questionnaire, the quality of life of informal caregivers may be assessed while also considering the impact on quality of life of the caregiving activities they perform. It seems useful to incorporate these effects of informal care on quality of life of the informal caregiver in the analysis in terms of quality of life. Other valuation methods are dependent on an often arbitrary monetary valuation of these intangible effects, such as the disutility from having to perform activities that are unpleasant. It would be practical to combine all effects on quality of life in one measurement method, i.e., one questionnaire.

Drummond et al. (6) and Mohide et al. (16) have already performed some work in this area. Drummond and colleagues evaluated a support program for caregivers of demented elderly. The fact that relatively large changes in the quality of life of caregivers were found in their study provokes the question of why caregiver quality of life is not measured as a normal part of cost-effectiveness analysis when

informal care is significantly present. This would give explicit attention to significant quality-of-life changes of caregivers rather than making them a part of total costs. The above-described method would make such a shift from costs of informal care to effects on caregivers possible without double-counting. Mohide et al. (16) used the time trade-off technique to assess well being of family caregivers. They found that this method, normally used to assess patient quality of life, appeared to be feasible, reliable, valid, and responsive to change. Therefore, the quality of life of caregivers seems to change due to caregiving and it seems possible to measure this change in a valid way.

Incorporation of Results in the Analysis

The change in quality of life of caregivers due to the caregiving activities should in principle be measured in an economic evaluation such as a cost-effectiveness analysis. One might argue that the incorporation of informal caregivers' effects in an analysis in terms of quality of life is closer to the concept of taking the societal perspective than to force these effects into the cost-side of the analysis. The U.S. Panel on Cost-Effectiveness in Health and Medicine also mentions that the "societal perspective prescribes that consequences for all affected persons should be included in the analysis" and encourages analysts "to think broadly about the people affected by the intervention and begin to include health-related quality-of-life effects of significant others in sensitivity analyses when they are important" (9,67). Of course, the U.S. Panel seems to refer to family effects, i.e., effects of the outcomes of an intervention on family and friends, rather than to the effects on family and friends providing inputs in the intervention itself.

However, since the efforts of informal caregivers can be seen as inputs to the intervention itself, it seems even more appropriate to incorporate their quality-of-life changes in the analysis. Nonetheless, the distinction between effects from such input and those from the disease or the intervention should be noted. Here, only the effects from providing informal care are discussed. Parker, for instance, states:

I have tried to raise in readers' minds some doubts about the advisability of measuring the quality of life of any single individual, without also taking into account the quality of life of those who support and care for him or her. (17,127)

Parker seems to imply that she wants to measure both family effects and informal care effects in terms of quality of life, which is a broader view of caregiver quality of life than the one discussed here. Similarly, Baldwin and Gerard (1) indicate that in families caring for mentally handicapped children, the costs attached to this care "are significant and diverse, potentially affecting the quality of life of all members of the family" (1, 145). And "in order fully to evaluate the effects of respite care it is necessary to face up to the difficult task of trading off gains and losses in the quality of life of different family members" (1, 146).

In some instances, such as informal care for a patient with Alzheimers' disease who already has significant cognitive deterioration, one might consider the caregivers' quality of life to be just as or even more important as that of the patient. Incorporating these effects in terms of quality of life ensures that the impact on caregivers will receive explicit attention. By incorporating these effects in monetary terms, this attention will probably be less explicit and the estimations of the impact may be less accurate. From a societal perspective, it is unclear why a quality-of-life change of a caregiver should have less explicit attention than that of a patient.

As mentioned earlier, caregivers' quality of life has been measured in earlier studies and used for a cost-effectiveness analysis (6), but according to our knowledge never combined with patient quality of life. This should not be surprising, since the denominator of the cost-effectiveness (C/E) ratio is exclusively reserved for health-related quality of life, whereas caregivers' quality-of-life change can be considered to be care-related.

This issue is somewhat dependent on the questionnaire used. For instance, if only a EuroQol questionnaire were used, with the explicit notion that the respondent should incorporate changes due to providing informal care, one might conclude that only health-related quality-of-life changes are measured, since that is the aim of the EuroQol instrument. Influences on the mental and physical health of the caregiver and on his or her social activities may then be considered as changes in health-related quality-of-life and balanced with that of the patient. However, this health-related quality-of-life change of the caregiver is not normally incorporated in a cost-effectiveness analysis.

On the other hand, by specifically considering informal care activities, one might argue that the quality-of-life impact registered then is care-related rather than health-related. The obvious advantage is that such instruments may be more sensitive. To combine patient and caregiver effects in the C/E ratio when quality-of-life measurement is more care-related will ultimately lead to optimization of health-related and care-related quality of life. Though this may have certain advantages, it is unclear whether such a change is to be considered an improvement or a degradation of cost-effectiveness analysis. To use multicriteria analysis for studies in which informal care plays a significant role seems a compromise between ignoring caregiver effects and just combining them with health-related patient quality of life. Also, using the pro-memory informal caregiver quality-of-life change in the sensitivity analysis as suggested by the U.S. Panel may be considered a useful method of incorporating the results in the analysis. Aggregation of caregiver and patient quality of life, especially when measured with different instruments, undoubtedly raises numerous questions of how this should be operationalized in a valid manner.

At this point, measuring informal caregivers' quality of life, and developing and validating questionnaires to do so, is recommended here. It seems an appropriate tool to use in studies in which informal care plays an important role. Future research may also be aimed at finding ways to balance caregiver and patient quality of life.

DISCUSSION

More empirical research on the individual's decision to engage in informal care is needed to increase our knowledge on this subject. In such research, not only actual informal caregivers should be interviewed but also potential informal caregivers who have decided to hire formal care. In this way, we can attempt to estimate the utility functions underlying their decisions, taking into account real-life restrictions and perhaps designing support programs that would reduce the strain on informal caregivers. This would ensure the maximum use of the possibilities for substituting expensive institutional care for home care, which may reduce costs and improve the quality of life both for informal caregivers and patients.

Volunteers, people engaged in caregiving in their leisure time, form a specific group of informal caregivers. They have incorporated caregiving willingly and freely

into their normal activities. Therefore, in a revealed preference framework, one may argue that they do not give up a better activity for caregiving from their individual perspective, but choose to perform care tasks as the best possible use for part of their leisure time. In that respect, no *individual* opportunity costs from caregiving may be incurred. However, one might claim that volunteers who would not care for these patients would free resources, i.e., time, for other alternative uses (like caring for other patients), and thus volunteer care does lead to opportunity costs from a societal perspective. Which of these approaches is considered most appropriate remains unclear.

The societal valuation of informal care proves a difficult subject. The alternative method presented here is believed to be a first step toward a reliable estimation of the total opportunity costs involved. This method should be developed further by constructing internationally applicable questionnaires or techniques in which all aspects mentioned can be incorporated. Existing questionnaires, such as the caregiver quality-of-life instrument used by Drummond et al. (6), the time trade-off technique used by Mohide et al. (16), the caregiver hassle scale (12), and the burden interview (23), should be examined for their appropriateness to use together with the costing principles discussed. Further research may also be conducted in order to investigate the desirability to incorporate caregivers' quality of life into the effect side of the C/E ratio. Until better solutions are available, a multicriteria approach or incorporating results in the sensitivity analysis seems most appropriate for studies in which informal care is important. Especially now that drugs are becoming available for patients with diseases often associated with a considerable amount of informal care, such as Alzheimer's disease and schizophrenia, the valuation of time of informal caregivers becomes more important. Therefore, it seems useful to further investigate the proposal discussed in this paper in order to ensure a good estimation of the true societal impact of informal care.

NOTE

¹ Expected utility from choosing informal care: $2p + 4(1 - p)$.

Expected utility from choosing formal care: $3p + (1 - p)$.

Indifference when $2p + 4 - 4p = 3p + 1 - p$

→ $-2p + 4 = 2p + 1$

→ $-4p = -3$, thus $p = .75$.

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