THE ECONOMIC BURDEN OF INFORMAL CARE

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Abstract

Objectives: The great interest focused on home care technologies during the last decade resulted from its potential to cut costs. However, the reallocation of costs between healthcare providers and social welfare providers, and the indirect costs of informal care, are not as frequent topics of discussion. The aim of this paper is to discuss different models for estimating the costs of informal care in the home care setting in economic appraisals.
Methods: The outcome of using different models for estimating indirect costs was illustrated using empirical data regarding the time spent by informal caregivers in providing care in a group of home care patients (n = 59). The models used comprise different interpretations of the traditional human capital approach and the friction cost model.
Results and Conclusions: Informal care is an important component in home care. The inclusion of indirect costs of informal care in economic appraisals will have implications for the cost-effectiveness of home care, since it will raise costs depending on the model used for estimating indirect costs. In this study we have shown that indirect costs estimated by the friction cost model only amount to 18% to 44% of the cost when the human capital approach is used. The results indicate that, regardless of the method used to estimate indirect costs, the cost of informal care in evaluations of home care programs is often underestimated due to the exclusion of indirect costs.

Keywords: Indirect costs, Home care, Economic appraisal

The great interest focused on home care technologies during the last decade results from the combination of its potential to cut costs and financial cutbacks in the healthcare sector. However, scientific evaluations of the costs of home care and home rehabilitation are relatively few and are often not of high quality (19). The reallocation of costs between healthcare providers and social welfare providers with respect to home care have not (to our knowledge) been calculated earlier, and the inclusion of indirect costs of informal care has rarely been discussed in evaluations of home care technologies. Whether or not indirect costs should be included in economic appraisals, and if so, how, is still under debate, and guidelines that have thus far been presented are not in agreement (3;4). This paper focuses on valuation of the care provided by the informal caregiver in home care in health economic appraisals. This paper also addresses the question of how to estimate the indirect costs of informal care in advanced home care. We also analyze the outcome of using different

models for estimating the value of informal care in advanced home care using empirical data. In this study we do not consider costs related to healthcare providers or social welfare providers.

INDIRECT COSTS

Direct costs can be defined as costs that include actual changes in resource use that are directly attributable to a healthcare intervention. Indirect costs, on the other hand, reflect the value of indirect changes in health status and productivity that result from the health-care intervention (5). Indirect costs, calculated as individual loss of income due to disease, are often calculated as constituting a large proportion of the total cost of the disease in cost of illness studies. In the traditional human capital approach (7), indirect costs are defined as lost gross income during time absent from work due to mortality and/or mor-bidity. The method estimates the value of lost production due to disease up to the age of retirement. Indirect costs are to be valued by their opportunity cost. In a broader inter-pretation of the human capital approach, indirect costs are defined as the lost gross value during time absent from usual activities. This means that the value of activities other than labor should be included. Guidelines also recommend the inclusion of the value of other activities, like leisure time, in cost-effectiveness analyses (6). These indirect costs are some-times referred to as time costs. The more recent friction cost model defines indirect costs of disease as "the value of production lost to society due to illness with respect to paid labor as well as unpaid labor" (11). The costs of pain, suffering, and discomfort are ex-cluded, and are considered as effect variables (often described as decreased quality of life). In the friction cost model, the indirect costs for long-term absence mainly occur during the time it takes to replace a worker (the search for and training of a new employee), called the friction period. This results in a lower cost compared with the human capital approach.

In the friction cost model, the psychological gains (or losses) for the patient as a result of having a close relative as caregiver, or the gains and losses of being cared for by a close relative or friend, are considered as an effect rather than a cost and are therefore measured in terms of quality of life. Further, the indirect cost of informal care is barely mentioned in the friction cost method. Liljas (13) argues that, with an economic welfare perspective, the help given to a person with an illness or disease by family or close friends can be regarded as an indirect cost. Liljas defines indirect costs as follows:

• Reduced paid production due to the individual's disease;
• Reduced unpaid production due to the individual's disease; and
• Indirect costs accrued by the family and/or friends (which can occur both during paid and unpaid production time) for taking care of the individual due to his/her disease.

Liljas also argues that we should differentiate between paid and unpaid production. Absence from paid work due to disease, or in this case the disease of a close relative or friend, should be valued as lost gross income, while lost unpaid production (i.e., leisure time) should be valued as the individual's own valuation of leisure time. It would be theoretically correct to estimate the value of leisure time by using the individual's willingness to pay (WTP) (12). However, this method has some practical limitations and is often replaced by an estimate of the individual's marginal wage net of taxes. A fourth method for estimating indirect costs is the QALY approach. In this model the only indirect costs included are those incurred as a result of the patient's travel time to where the treatment is given, the time undergoing treatment, the cost for training a substitute, and in some cases the cost for a difference in productivity. Other costs estimated by the human capital approach and the

Table 1. Possible Ways of Becoming an Informal Caregiver

1. Relative or friend	Quits job	Becomes an informal caregiver
2. Relative or friend	Reduces work hours	Becomes an informal caregiver
3. Relative or friend	Unemployed	Becomes an informal caregiver
4. Relative or friend	Retired	Becomes an informal caregiver
5. Relative or friend	Uses leisure time	Becomes an informal caregiver

friction cost model are assumed to be included in the individual's estimation of quality of life and are thus expressed in quality-adjusted life-year (QALY) weights. However, since this study focuses on home care, and since travel time therefore is not an issue, the QALY method will not be discussed further.

INFORMAL CARE

Home care often depends on the efforts made by informal caregivers. Terminal or palliative care in the home is strongly dependent on the patient's family (1). Informal care is care provided by the patient's relatives or friends who are not paid for their services.

Table 1 illustrates different scenarios for possible changes in work patterns or social patterns as a result of an individual becoming an informal caregiver. The time spent in being an informal caregiver can naturally vary. In the first two alternatives, the relative or friend could be forced to quit his/her job or reduce his/her work hours to part-time, or could do so by choice, in order to become an informal caregiver. In alternatives 1 and 2, there is a potential production loss to society, according to the narrow interpretation of the human capital approach, up to age 65, as well as according to the friction cost approach. In alternatives 3–5, however, when the informal caregiver is unemployed, retired, or uses his/her leisure time, or if the absence is very short, there is no production loss to society according to the friction cost approach. If the broader interpretation of the human capital approach is used, there is a production loss in all alternatives.

METHOD

The empirical data were obtained from the County Council of Östergötland, Sweden. The data represent all patients registered in hospital-based home care at the University Hospital in Linköping, Sweden, during a 1-week period in November 1999. Data on 59 patients were collected using a standardized form. The data include background variables, length of the care episode, information regarding types of visits, visit frequencies, diagnosis, control of symptoms, procedures, and questions regarding informal care (primarily amount of time the informal caregiver provided care). The patients were enrolled in home care for less than 1 week, 1–2 weeks, 2–4 weeks, 1–2 months, 2–6 months, or more than 6 months. The informal caregiver "worked" 24 hours per day, either during the daytime or at night, 7 days/week, at least 1 day/night per week, or several times a month during the enrollment period.

Table 2 combines the time the informal caregiver spent providing care with the time that the patient was enrolled in home care. Of the 59 patients, 39 had an informal caregiver. In Table 2 all 39 patients are included, regardless of age. The data set was used for testing different models for estimating the value of informal care and thus shows an approximation of a cost often neglected in evaluations of home care.

Data Input and Demarcations
Data Input in the Models Based on the Friction Cost Model. In this section we will set up the data that are to be used in the friction cost model (10), although some

Table 2. Time Spent by the Informal Caregiver in Providing Care (n = 39)

Enrollment time	Time spent by the informal caregiver in providing care				
	24 hours/day	Daytime, 7 days/week	Nights, 7 days/week	At least one day/night per week	Several times per month
<1 week	1		1		
1–2 weeks	3				
2–4 weeks	5			1	
1–2 months	6	1	1	1	1
2–6 months	4	1		2	
>6 months	7	1			3

simplifications will be made. The data apply to the model of a specific economic evaluation using empirical patient data. We will calculate the indirect cost of informal care for one average care episode of home care for this patient group. We will use individual data on length of absence and number of hours worked. Loss of production was estimated to equal the average monthly labor costs of a full-time Swedish employee in 1999, including payroll taxes (17) (the average monthly labor cost is set at SEK 19,400 per month).

We use three time episodes in this model: very short-term absence, short-term absence, and long-term absence. In this model very short-term absence is defined as less than 2 weeks, short-term absence as less than 3 months, and long-term absence as more than 3 months. Very short-term absence is not assumed to cause indirect costs. The elasticity of annual working time versus productivity is assumed to be 0.8, based on Dutch estimates (10). A 40-hour work week is used, 160 hours per month, which results in an hourly salary of SEK 121.25. Our data do not allow us to adjust the model for sex, disability, mortality, education level, or profession. The training cost for a new employee is estimated as one double monthly salary, and the training period is set at 1 month. We also make the assumption that there is unemployment and therefore no extra cost for recruiting labor. This demarcation is made since this cost is assumed to vary considerably from one case to another and must therefore be considered on a case-to-case basis. It is also important to note that we do not calculate indirect costs due directly to disease but rather due indirectly to disease, since the informal caregiver is not the one who is ill.

Data Input in the Models Based on the Human Capital Approach. In the human capital approach we will use the same data on absence and wages, with the only difference being the friction period. We will also base our calculations on the broader interpretation of the human capital approach as suggested by Liljas (13) and include the gross value of time absent from usual activities. The model can thus be extended and can include all informal caregivers regardless of age.

RESULTS

The background data on the 59 patients show that 52.5% were men, and 76% were registered in palliative home care and 24% in acute home care. Sixty-six percent of the patients had an informal caregiver, most of them for 24 hours every day, and 10 (17%) were younger than 65 years of age. Sixty-three percent had cancer or some other tumor disease, and 13% had coronary disease. As regards the informal caregivers, we only have data on length of time and amount of time per day spent providing care (Table 2).

Models 1–3 estimate the indirect costs (IC) using the friction cost model for different lengths of time absent from work, since time is a central factor in the friction cost model.

The first alternative using the friction cost model illustrates very short-term absence (i.e., less than 2 weeks), model 2 illustrates short-term absence, and model 3, long-term absence.

$$\text{Model 1:} \quad IC = 0$$

The indirect cost is set at zero or close to zero since the model assumes that a worker can make up for lost work when he/she returns to work or the work is done by a coworker. In the latter case there might be a cost for overstaffing or maintaining a reserve of labor to keep up production.

The second alternative illustrates short-term absence (i.e., less than 3 months), and the friction period is set at 3 months (i.e., the time of absence is less than the friction period), which means that the IC is 80% of the value during the time of absence.

$$\text{Model 2:} \quad IC = ((\text{lost gross income} * \text{reduced productivity}) * 8 \text{ hours}) * \text{number of days absent from work}$$

In the third alternative absence is set at more than 3 months and the friction period is set at 3 months (i.e., the time of absence is longer than the friction period and IC equals the cost of the friction period).

$$\text{Model 3:} \quad IC = \text{cost of the friction period (FP), where,}$$
$$FP = ((\text{lost gross income} * \text{reduced productivity}) * 8 \text{ hours}) * \text{days before replacement} + \text{training cost for new worker}$$

In the friction cost model it is stated that the length of the friction period is positively related to the length of education. We are also advised to take into consideration the time that passes before a decision is made about a replacement and before the new worker's first working day. However, this is not possible in this simplified model.

In the first alternative in the human capital approach, we show the most extreme case in which the indirect cost for 1 week could be calculated as follows, using the extended human capital approach, where the indirect cost is calculated for time absent from usual activities and where all time over and above working time is regarded as leisure time.

$$\text{Model 4:} \quad IC = ((\text{hourly gross wages} * 8 \text{ hours}) * 5 \text{ days})$$
$$+ ((\text{marginal wage net of taxes} * 16 \text{ hours}) * 5 \text{ days})$$
$$+ ((\text{marginal wage net of taxes} * 24 \text{ hours}) * 2 \text{ weekend-days})$$

Model 4 also calculates the indirect cost for 1 week and assumes a normal working day of 8 hours, 5 days a week, and that the informal caregiver gets paid to be on call 24 hours per day, allowing for no personal time. However, leisure time is assigned a lower value (marginal wage net of taxes, i.e., gross wages reduced by payroll taxes, 30%) compared with working time in order to distinguish between paid and unpaid time. This model is, of course, too extreme to be realistic. The value of production may be less when working at home caring for a relative than when working in the labor market. This is also dependent on the caregiver's level of education and occupation. Some of the time working at home may also be used to carry out normal household chores. Leisure time should also be less than 16 hours per working day and less than 24 hours per weekend day, since some of the time is spent on activities such as sleeping and is not to be referred to as leisure time. A more realistic model for calculating the indirect cost for 1 week, where time for sleep (8 hours/day) has been excluded, would be:

$$\text{Model 5:} \quad IC = ((\text{hourly gross wages} * 8 \text{ hours}) * 5 \text{ days})$$
$$+ ((\text{marginal wage net of taxes} * 8 \text{ hours}) * 5 \text{ days})$$
$$+ ((\text{marginal wage net of taxes} * 16 \text{ hours}) * 2 \text{ weekend days})$$

Table 3. Cost of Care Provided by Informal Caregiver Using Different Models (n = 39 in all models)

	Time spent by the informal caregiver in providing care				
	24 hours/day	Daytime, 7 days/week	Nights, 7 days/week	At least one day/ night per week	A few times per month
Models 1-3, based on the friction cost model					
1 week	0	-	0	-	-
2 weeks	0	-	-	-	-
4 weeks	77,600	-	-	0	-
2 months	186,200	31,000	0[a]	0	0
4 months	192,400	48,100	-	0	-
6 months	336,800	48,100	-	-	0
Total cost					920,200
Model 4, based on the human capital approach					
1 week	15,700	-	4,800	-	-
2 weeks	94,300	-	-	-	-
4 weeks	314,300	-	-	3,900	-
2 months	754,300	49,700	38,000	7,800	1,900
4 months	1,005,700	99,300	-	31,000	-
6 months	2,640,100	149,000	-	-	5,800
Total cost					5,215,600
Model 5, based on the human capital approach					
1 week	11,000	-	4,800	-	-
2 weeks	65,800	-	-	-	-
4 weeks	219,200	-	-	3,900	-
2 months	526,100	49,700	38,000	7,800	1,900
4 months	701,500	99,300	-	31,000	-
6 months	1,841,500	149,000	-	-	5,800
Total cost					3,756,300
Model 6, based on the human capital approach					
1 week	4,800	-	3,400	-	-
2 weeks	29,100	-	-	-	-
4 weeks	97,000	-	-	19,400	-
2 months	232,800	38,800	27,200	77,600	1,900
4 months	310,400	77,600	-	232,800	-
6 months	814,800	116,400	-	-	5,800
Total cost					2,089,800

[a] The reason this was set at zero is that in the friction cost model, only indirect costs due to absence from work are calculated. In this model we used the simplification that work only includes daytime work and nights are considered leisure time. In models 1–3, it is assumed that an absence shorter than 2 weeks does not cause indirect costs.

The model can be restricted even further so as not to include leisure time at all:

$$\text{Model 6}: \quad \text{IC} = ((\text{hourly gross wages} * 8 \text{ hours}) * 5 \text{ days})$$

In Table 3 we use the data from Table 1 and the models described earlier to calculate the cost of informal care for this group. Models 1–3 represent the friction cost model and models 4–6 represent the human capital approach. Model 1 is used for very short-term absence, i.e., less than 2 weeks in the friction cost model.

DISCUSSION

Studies of dementia have shown that unpaid informal care forms a major part of the total costs of care (18;20). In a study by Neumann et al. (16), it is stated that time costs should include the unpaid provision of care by family members. Our study shows that the frequent

exclusion of costs of informal care in advanced home care and home rehabilitation can result in an underestimation of the total cost.

Liljas' conclusion that the indirect costs of informal caregivers should be estimated in studies using an economic welfare perspective seems logical. If the informal caregiver is absent from work during the time he/she cares for the patient, the absence, and thus the production loss, is no different from that of the patient's. Since a great deal of home care requires the help of informal caregivers, the cost of informal care should be estimated in evaluations of home care technologies. However, questions remain concerning what model should be used and whose time should be valuated:

- Should we include only those informal caregivers who are younger than retirement age and thus part of the labor force, thereby discriminating against others?
- Should we use a 40-hour work week for the estimation, regardless of time spent providing care (model 6), or should we use the individual caregiver's normal working hours for the estimate?
- Should we include leisure time (at a reduced cost) as well as normal working hours, and if so, to what extent (model 5)?
- Should we include 24 hours per day (model 4) if the informal caregiver feels "tied-down" during the whole 24-hour period, even though he/she does things other than providing care during this time?
- Should we use friction periods, and if so, how long should they be?
- If the friction cost model is utilized, what elasticity should be used?
- If the friction cost model is used, do we need to consider the informal caregiver's level of education, normal occupation, unemployment rates, etc?

If the estimation of indirect costs is to reflect the value of lost production, we tend to lean toward model 6. However, in the case of home care, where many of the informal caregivers are retired, absence from normal activities as described by Liljas seems more relevant, and model 5 would therefore be a more reasonable alternative. In model 5 it is also reasonable to use a reduction in productivity if the informal caregiver is retired, and thus less productive, and use a lower hourly gross wage. In this study we did not have the opportunity to adjust the time costs according to the informal caregivers' normal occupation or give consideration to the informal caregivers' own valuation of the time spent caring. Had this been possible, it would have been preferable.

Table 3 shows the monetary value of time for absence from work or usual activities (depending on the model) when a person provides informal care. The human capital approach leads to a higher value of lost production to society compared with the friction cost method. In Table 2 we can see that indirect costs estimated by the friction cost model only amount to 18% to 44% of the cost as compared with the human capital approach. Figures mentioned by Johannesson and Karlsson (8) indicate that in 1993 labor costs accounted for 66% of the value added in the whole economy for labor cost in healthcare programs. It should be noted that the friction cost approach and the QALY approach have been criticized in favor of the human capital approach, and it has been argued that they are not consistent with economic theory (8;13). The assumption that people can make up for lost production when they return to work may be valid for some types of employment, but not all. Liukkonen (14) has shown that short-term absence from work actually causes the highest costs for employers. Therefore, the assumption by Koopmanschap and coauthors (10;11) that short-term absence does not lead to indirect costs may be incorrect.

McDaid (15) brings forward several important issues regarding difficulties in defining and measuring informal care. Attention should be paid to the fact that the time spent caring could be mixed with ordinary household chores or normal family socializing, i.e., joint

production. In this study the informal caregivers were asked to estimate the time they spent on caring on a five-grade scale. However, we did not have the opportunity to study the contents of the care in greater detail. A more detailed documentation, such as a diary, could be very informative in future studies.

We believe that indirect costs in the case of advanced home care should be calculated as a production loss for the informal caregiver as well as the patient. The results in this study indicate that, regardless of the method used to estimate indirect costs, the cost of informal care in evaluations of home care programs is often underestimated due to the exclusion of indirect costs.

POLICY IMPLICATIONS

The objective of this study, i.e., to establish the economic burden of informal care, is important since the increasing number of the elderly generates a parallel increase in several chronic diseases. Informal care is therefore an issue for home care and care of the elderly. In the care of the elderly in Sweden, informal care is two-thirds of that given by professional caregivers in the home (9). Also, new drugs have become available for Alzheimer's disease, which may have a great impact on informal care (2;15). Since informal caregivers often are substantial contributors to advanced home care, the cost of informal care should be included in economic evaluations. Otherwise the costs of home care programs will be underestimated.

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