

WORK IN PROGRESS – PLEASE DO NOT QUOTE

Primary study to estimate the informal care costs of visiting patients in an adult Intensive care unit

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Summary

Visitation and proximity needs are consistently rated as very important by families of critically ill patients. However, the costs to families of their involvement in providing support to patients in intensive care units have received little attention. This study, investigated the financial and personal costs to caregivers (families, relatives and friends) visiting critically ill patients in an intensive care unit. The purpose of the study was: (1) to test the feasibility of collecting cost and time data from caregivers visiting an intensive care unit and (2) to estimate the financial and non-financial costs experienced by caregivers during these visits. Data was collected over a two-week period on out-of-pocket expenses and time foregone using a questionnaire developed for this purpose. The major variables investigated were: age and sex of respondents; employment status; lost wages; distance travelled; total time foregone; time spent with patient and out-of-pocket expenses.

Results: 54 caregivers participated in the study (response 50%). 48% of respondents were male and 52% female; the age range was 18-76 years. 35% completed the questionnaire in the ICU, 37% took the questionnaire home to complete, and the remaining 28% either could not be asked to participate in the study, were excluded or refused to participate. 59% of participants were in paid employment and 16% lost wages as a result of the visit. The average lost wages was £50.72. The average cost of time foregone was £46.21 and average out-of-pocket expenses £29.30. Caregivers on average travelled 46.5 miles (one-way); range (1.5 – 600 miles).

Conclusion: The study shows the feasibility of collecting data on expenses and time foregone from caregivers visiting the ICU. The average out-of-pocket expenses and cost of time foregone associated with visiting patients in the ICU are considerable.

Introduction

Informal care refers to services rendered by family, friends and others for which no payment is made, but for which there is an alternative use that is of value to those providing care. The motivation to provide care may depend on many factors including a sense of obligation, love, satisfaction from the caring process, and access to formal alternatives (McDaid & Sassi, 2001).

Informal caregiving lies outside the market economy, is socially and politically invisible, and hence its economic value is generally not acknowledged. However, Arno et al (1999) estimated the economic value of informal care in the United States in 1997 to be \$196 billion, which represented 18% of the total national health care expenditure in the United States. In the UK, using the General Household Survey data, the value of informal care has been estimated to be between £11.5 and £15.2 billion (Quoted in Glendinning, 1992) which represents 29%* of the total. *calculated using expenditure figures published by ONS

Studies show that informal caregivers provide a wide variety of assistance such as emotional, financial, physical and social support, with emotional support often cited as the most common activity (Tennstedt, 1999). Although most of the caregiving responsibilities involve long-term

commitments, shorter hospital stays account for some of the caregiving burden that families' face. Most acute situations require care provision at potentially high levels for time-limited periods. Sometimes, those providing assistance do not even define these situations as caregiving because of its short duration. As a result, research on informal caregiving has mainly focussed on long-term informal care provided to those living in the community, overlooking the care provided to hospitalised patients.

The resource inputs incurred by caregivers when visiting hospitalised patients can be captured if economic evaluations of health care incorporate a societal perspective. A societal perspective would ensure that all resource costs are included in an analysis, even when shifted between hospitals, insurers, patients, caregivers or any other parties.

However, most economic evaluations of health care interventions do not look beyond the perspective or viewpoint of the health service. It is often found that, even when the full range of paid medical services and other resource use are included in a study, neither the costs nor the benefits of unpaid caregiving are usually measured. Widening the perspective of costing studies to include caregiver costs would introduce a societal perspective and could become important in contributing to internal policy within hospitals.

This pilot study therefore aimed to investigate the costs of hospital visiting in order to gain a greater insight and understanding of the caregiver burden associated with hospital admissions.

Background

Admission to an ICU is associated with considerable distress and anxiety for both patients and their families. A factor, which is consistently rated as very important by families of critically ill patients, is the ability to visit them as often as possible (Halm & Titler, 1990; Stillwell, 1984).

Before the 1960s, hospital-visiting policies restricted the presence of family members at the bedside. Policies changed during the 1960s and 1970s when health care professionals recognised that both parents and children benefited when parents stayed with their hospitalised children. This later extended to include family members staying with adult patients (Carr & Fogarty 1999). Most ICUs now adopt a policy of unrestricted family visiting, with the result that families play an increasing role in the unit. In the UK, the participation of parents in the care of hospitalised children is actively promoted by government policy (Department of Health 1991). The policy advises health care providers to encourage and assist parents to be with their children at all times and to provide parents with suitable overnight accommodation if needed.

Some critics have questioned the benefit of having caregivers in the intensive care setting (Frederickson, 1989) and whether caregivers participate in any caregiving activities. However, studies have described the caregiving provided by family members when their relatives are hospitalised (Astedt-Kurki et al 1997; Kelly et al 1999) and the beneficial effects of visiting on patients and their families (Kirchhoff et al, 1993; Simon et al, 1997; Hupcey, 2000). Astedt-Kurki et al (1999) found that two-thirds of family members visited their hospitalised relatives daily, and that they participated in their relative's care in several ways such as helping the patient to eat or get to the toilet, applying cream to the skin, help with shaving, cutting patient's hair and nails, reading, massaging etc. Hammond (1995) found that relatives wanted more participation in the physical care of their family member in intensive care.

In addition, studies have also been conducted to determine (1) how participation from relatives of hospitalised patients can be improved (Laitinen, 1992) and (2) the effect of this increased participation on caregivers and patients (Hammond, 1995; Laitinen 1993). In such a climate where participation by relatives in caring for hospitalised patients is a reality, and where increased participation is encouraged, more effort is needed to determine how this participation affects caregivers.

There is, currently, a great deal of interest in the social policies that should be adopted towards caregivers and care receivers which has led to a number of new policy initiatives on informal caregivers. In one such initiative, a key element is the provision of special funds to enable carers to take short-term breaks from caring (A National Strategy for Carers, 1999). However, this provision is for carers involved in long-term care activities. The caregiving role provided to hospital inpatients, though limited, is important as it provides vital emotional and social support to the patient whilst providing great satisfaction to the caregiver..

Link to National study

This study is complementary to a national multi-centre trial called CESAR (Convention Ventilation or ECMO for Severe Adult Respiratory Failure) that is currently in progress. The CESAR trial aims to assess the cost effectiveness of Extra Corporeal Membrane Oxygenation (ECMO) compared to conventional management for adult patients suffering from acute respiratory failure. It is anticipated that patients in the trial will spend a good proportion of their treatment time in intensive care, which may give rise to substantial visiting costs for caregivers. An economic evaluation planned alongside the CESAR trial would collect data on all health care resource use and direct patient costs (trial entry to 6 months). However, due to the lack of a well-

developed methodology, the collection of caregiver visiting costs was not included in the trial. It is hoped that the results from this study will enable a sub-study of caregivers' costs in the CESAR trial. This may help policymakers in their decision on the optimal allocation of ECMO treatment centres, if ECMO is proved to be effective.

Evidence

A review of literature revealed that four studies had looked at visiting costs. However, these were costs incurred by parents while visiting their hospitalised children (Callery, 1997; Smith & Baum, 1983; Giacoia et al, 1985; McLoughin et al, 1993). No study was found that had estimated the wide range of costs associated with visiting hospitalised adults. It is also not known whether it is possible to collect such data from visitors in the midst of stressful situations.

Methodology

The aims of the study were to:

1. To design and pilot a method for measuring the costs of visiting that fall upon the caregivers of adult patients admitted to an ICU.
2. To estimate the financial and non-financial costs of visiting that fall upon caregivers of adult ICU patients.

The study focussed on visitors of adult ICU patients as the secondary aim of the study was to provide guidance for collecting visitors' costs in the national CESAR Trial, which aimed to investigate the cost-effectiveness of ECMO for adult patients.

Visitors to the ICU incur two types of costs: time and out-of-pocket expenses. Those who are waged may also incur loss of wages. Both waged and unwaged caregivers will have costs in terms of having to forgo normal household duties, such as looking after children, as well as having to reduce or forgo any voluntary activities in which they may be involved. In addition, all caregivers may have to give up some of their leisure time (McDaid & Murray, 2001). Table 1 shows the full range of costs that may be incurred during such visits.

Table 1: Range of costs associated with ICU visiting

Costs related to:

1. Travel
2. Subsistence
3. Child care
4. Care for other dependent relatives
5. Time foregone (leisure or work)
6. Lost wages
7. Home help if needed

To collect the above mentioned costs, different options were considered and a decision was taken to collect data through questionnaires given to all visitors on the day of the visit in order to minimise recall bias.

A questionnaire was then designed incorporating all the items listed in table 1. For this purpose, the questionnaires identified during literature search. (ie those developed by Bricker et al (2000), Thompson & Wordsworth (2001) & Dr J Beecham (Beecham, 1995) were used as well as some additional questions.

As data had to be gathered from relatives visiting patients in the ICU the following problems were anticipated and steps were taken to overcome these problems.

- High refusal rate from visitors as they would have to give up valuable time to read an information leaflet, sign a consent form and complete a questionnaire at a time when they had come to visit a critically ill patient.
- Non-acceptability of questions about personal costs.
- The probability that some visitors would be missed as the ICU had a 24-hour open visiting policy.

Plans taken to overcome some of the above problems were as follows:

- Links were set up prior to the commencement of the study with the ICU Department of the Trust. The lead ICU Consultant, Charge Nurse and a Research Nurse attached to the unit were visited separately and advice was sought on how to make the staff and visitors aware of the planned study and to increase participation.
- A presentation was given to the ICU nursing staff on the planned study and again advice was sought on how to approach visitors with sensitivity and how to ensure that all visitors would be invited to participate in the study.
- Staff were reassured that visitors would only be approached with their approval and that their nursing time will not be called upon unnecessarily for the study.

After this consultation process the following additional steps were taken to improve participation.

1. A poster informing visitors of the planned study was displayed in the visitors' rest room one week prior to the commencement of the study.
2. An information sheet explaining the study was displayed in the visitors' rest room and the main door of the ICU (where visitors had to wait before being allowed into the unit) during the entire period of the study.
3. A folder was kept by each patient's bedside to record all visitors who came to visit that patient (date, time & relationship to patient).

Study Design, Setting, Population and Sample size

This was a prospective, longitudinal, observational study over a two-week period. The setting was the adult ICU of Broomfield Hospital, Essex. The study population was all adults (18 and over) visiting the ICU during the study period. The study period was divided into two: (17th – 23rd December 2001 and (7th – 13th) January 2002 in order to obtain a more representative sample of visitors.

Exclusion criteria:

- Visitors who were unable to give informed consent and
- Visitors who were felt to be inappropriate for the study by duty staff for reasons such as stress, anxiety or severity of patient's condition.

Data collection procedure

Caregivers visiting patients in the ICU were informed of the study and given the information leaflet either by the nurse allocated to each patient or the researcher(MMT). Those who expressed interest were given a consent form to sign followed by the questionnaire. Participants were given a choice of either (1) completing the questionnaire on site or (2) taking the questionnaire home. A stamped, addressed envelope was provided to those opting to take the questionnaire home.

Valuation of caregiver time

Informal caregivers give up normal activities because of the incidence of illness in their immediate social environment. For informal caregivers, time spend providing care will have alternative uses either for work or leisure. The rationale for estimating time costs is that time, like all resources, is scarce and has an opportunity cost (RIS MRC CFAS, 1998; Brouwer et al, 1998). The caregiver's time input includes time spent in travel and in the provision of caring, nursing and housework for the patient (Posnett & Jan, 1996).

Several approaches are possible to value the time input of informal caregivers: the market price method, contingent valuation method and the opportunity cost method (Brouwer et al, 1999). Of these, the opportunity cost approach is often recommended to be used in economic evaluations of health care (Gold et al, 1996). This study used the opportunity cost method suggested by Posnett & Jan (1996) and caregiver time was valued according to the following 4 scenarios:

1. When time inputs involve working time and where output is replaced, opportunity cost is proxied by the net wage rate
2. Where output is not replaced for working time, the opportunity cost is best proxied by the full wage rate

- 3a. For those currently in employment the opportunity cost of non-work time can be proxied by the net wage rate
- b. For those not in paid employment, and where unpaid activities are replaced (at another time or by another person), the opportunity cost can be proxied by the average wage rate of a particular occupation.
4. For those not in paid employment and where unpaid housework is not replaced, a suitable proxy for opportunity cost is market wage rate of a housekeeper.

Sensitivity analyses of the results employed Netten (1990)'s method to value caregiver time.

Ethics Committee and Hospital Trust Approval

Approval was obtained from both The Mid-Essex Ethics Committee and the Mid-Essex NHS Trust in early December 2001. Written consent was obtained from all participants recruited to the study. Every effort was made to protect visitors from undue intrusion.

Study observations, Data analysis & Results

Study observations

The ICU unit had a 24-hour open visiting policy. However, the main visiting hours were 12-3pm and 4-6.30pm. Visitors were mainly close family members and relatives who came almost daily until the patient's discharge. Some made multiple visits at different times during the same day.

Relatives spent several hours by the bedside talking to patients, reading out letters/newspapers, showing photographs, and sometimes alerting the nurse to changes in the patient. Some helped with minor tasks like wiping patient's face, adjusting the blanket etc. Personal care such as body baths, changing bed sheets etc was done by nursing staff.

Feasibility of data collection

The average daily number of patients in the ICU was 10 (range 8-11). The daily average observed visits were 21 (range 13-31). The total number of visitors during the study period was 107.

The response rate was 64% (39/61) during the first week of the project (17th – 23rd December) and 33% (15/46) during the second week (7th – 13th January), representing a combined response rate of 50% (54/107). 7 visitors (7%) refused to participate and 2 visitors (2%) had to be excluded due to language problem. 37 visitors (35%) completed the questionnaire on site while 40 (37%) took the questionnaire home to complete. A summary of these responses is given in table 2.

Table 2: Summary of visits

| | 1 st Week | 2 nd Week | Total |
|---|----------------------|----------------------|-------------------|
| Number of patients | 17 | 10 | 28 |
| Number of visitors | 61 | 46 | 107 |
| Response rate (for visitors) | 39 (64%) | 15 (33%) | 54 (50%) |
| How questionnaires were completed | | | |
| Number of visitors | 61 (100%) | 46 (100%) | 107 (100%) |
| Completed on site | 28 (46%) | 9 (20 %) | 37 (35%) |
| Took home to complete | 21 (34%) | 19 (41%) | 40 (37%) |
| Refused | 6 (10%) | 1 (2%) | 7 (7%) |
| Not asked** | 6 (10%) | 15 (33%) | 21 (20%) |
| Excluded | 0 (0%) | 2 (4%) | 2 (2%) |
| Questionnaires taken home | | | |
| Number taken home | 21 (100%) | 19 (100%) | 40 (100%) |
| Number taken home and returned | 11 (52%) | 6 (32%) | 17 (43%) |
| Number not returned | 10 (48%) | 13 (68%) | 23 (58%) |
| ** Visitors who looked distressed or in tears; visitors considered not appropriate for study by staff & late-night or early-morning visitors. | | | |

The characteristics of study participants are summarised in Table 3.

Table 3: Visitor characteristics (n=54)

| | |
|--------------------------------|---------------|
| Gender | |
| Male | 26 (48%) |
| Female | 28 (52%) |
| Age | |
| Age (range) | 18 – 76 years |
| Mean | 50.5 years |
| Median | 51 years |
| Visitors aged < 65 | 41 (76%) |
| Visitors aged ≥ 65 (Retired) | 13 (24%) |
| Relationship to patient | |
| Family members | 39 (72%) |
| Relatives | 9 (17%) |
| Friends | 5 (9%) |
| Paid caregiver | 1 (2%) |

Three participants (3%) who visited daily completed the questionnaires every day. A further 12 (11%) who came daily gave permission to use their first completed questionnaire as a proxy for calculating their weekly costs.

Out-of-pocket expenses

The out-of-pocket expenses were those related to travel, car parking, childcare, accommodation and refreshments. This is shown in table 4.

Table 4: Out-of-pocket expenses

| N=54 | Numbers (%) | Range | Mean | Median |
|--|----------------|-------------------|---------|---------|
| Travel (return trip) | | | | |
| Own car (standing & running costs) | 38 (70%) | £2.18 - £100.13 | £15.23 | £7.98 |
| Shared car journey | 10 (19%) | - | - | - |
| Plane | 4 (7%) | £100.00 - £506.94 | £201.74 | £100.00 |
| Public transport* | 3 (6%) | £1.50 - £7.10 | £3.65 | £3.00 |
| Parking | | | | |
| Parking fees | 41 (76%) | £0.00 - £10.00 | £1.50 | £1.05 |
| Childcare | | | | |
| With relatives/friends | 7 (13%) | - | - | - |
| Accompanied visitor | 1 (2%) | - | - | - |
| Paid childcare | 1 (2%) | £5.00 | £5.00 | £5.00 |
| Total needing childcare | 9 (17%) | - | - | - |
| Accommodation | | | | |
| Hospital accommodation | 2 (4%) | - | - | - |
| With relatives | 2 (4%) | - | - | - |
| Hotel | 1 (2%) | £30.00 | £30.00 | £30.00 |
| Missing | 3 (6%) | - | - | - |
| Total needing overnight stay | 8 (15%) | - | - | - |
| Refreshments | | | | |
| Food & drinks purchased during the visit | 11 (20%) | £3.00 - £10.00 | £5.82 | £5.00 |

Travel: 70% of visitors travelled by own car, with a further 19% sharing a car with a friend/relative making the total people who travelled by car 48 (89%). 41 visitors (76%) paid parking fees. Three visitors (5%) used public transport and four (7%) travelled by plane (one from USA and three from Scotland). The descriptive statistics is given in Table 5.

Table 5: Distance travelled by visitors

| N=54 | Range | Mean | Median |
|---------------------------------------|--------------------|------------|------------|
| Distance between visitor's home & ICU | (1.5 – 600*) miles | 46.5 miles | 11.5 miles |

*excludes one visitor who came from the USA to visit her mother.

Costs for private car travel was calculated using published AA (Automobile Association) motoring costs. The estimate used for this study was 36.28p/mile which includes standing and running costs for a petrol car of (1101– 1549)cc, with annual mileage 15,000, and current cost of unleaded petrol at 69.9 pence/litre.

Childcare: 9 visitors (17%) had to arrange childcare. Of these one paid for childcare, one brought her children with her and the remaining made arrangements with relatives.

Accommodation: Eight visitors (15%) needed overnight accommodation. The reasons for this were distance of ICU from home and severity of patient's condition. Of these only one paid for accommodation, two stayed in the hospital, two with relatives and three said "not applicable".

Refreshments: Eleven people purchased food or drinks. Of these 7 (13%) had spent more than 10 hours in the unit.

The average expenses and average travel costs of the 54 participants is shown in Table 6.

Table 6: Average costs per participant

| N=54 | | | | | |
|--------------------------------|---------------|----------|------------|-------------|--------------|
| | Range (£) | Mean (£) | Median (£) | Std dev (£) | 95% CI* (£) |
| Average out-of-pocket expenses | 0.00 - 509.54 | 29.30 | 9.39 | 73.42 | 9.25 - 49.34 |
| Average travel expenses | 0.00 - 509.54 | 27.04 | 7.58 | 72.40 | 7.28 - 46.80 |

**CI calculations were done assuming t-distribution as the standard deviation was estimated*

Activities foregone by visitors

Participants were asked about activities foregone for the visit and leave arrangements for those in paid employment. Of the 54 participants, 32 (59%) were in paid employment and the remaining 22 (41%) were either retired or houseparents. Of those in paid employment 7 came outside of work time, 8 took annual leave, 3 had obtained compassionate leave, and 4 intended to make the time up. Table 7 summarises these activities.

Table 7: Activities foregone & leave arrangements

| Category of Activities (n=54) | |
|-------------------------------|------------------|
| Working in paid employment | 32 (59%) |
| Housework | 11 (20%) |
| Leisure activities | 6 (11%) |
| Retired | 5 (9%) |
| Total | 54 (100%) |
| Leave arrangements (n=32) | |
| Took annual leave | 8 (25%) |
| Compassionate leave | 3 (9%) |
| Unpaid absence | 5 (16%) |
| Will make time up | 4 (13%) |
| Came outside of work time | 7 (22%) |
| Total | 32 (100%) |

Cost of time foregone

Table 8 shows the total time foregone by visitors for the visit and the actual time spent with the patient. Total time foregone was estimated as the difference between time of leaving home and the time expected to be back home (from questionnaire).

Table 8: Time forgone (n=54)

| | Range | Mean | Median |
|---|--------------------|-------------|---------------|
| Total time forgone for the visit | 1hr 15min – 24 hrs | 6hr 49min | 3hr 38min |
| Time spent with patient | 30min – 16hrs | 3hr 12min | 1hr 50min |
| Time spent with patient as a % of total time foregone | 3% - 100% | 56% | 57% |

The opportunity cost of time was estimated using the mean gross weekly full-time wage rate for men and women in Great Britain at April 2000 which was £453.30* and £337.60* respectively. Minus tax and National Insurance (estimated at 25.9% of gross salary), and assuming a 38.7* hour week for men and 36.6* hours for women the net mean hourly rates were £8.68 and £6.84. These rates were used for all men and women in paid employment. For those who were not in paid employment the market wage rate of a housekeeper £4.03 was used. Five visitors lost pay and this was calculated separately using the net wage rate. Table 9 shows the estimated costs.

*Published by The Office of National Statistics in their “New Earnings Survey April 2000”.

Table 9: Average cost of time forgone & lost pay

| Daily costs | Range (£) | Mean (£) | Median (£) | Std dev (£) |
|------------------------------|------------------|-----------------|-------------------|--------------------|
| Lost pay (n=5)* | 17.36 - 65.10 | 50.72 | 54.72 | 19.64 |
| Cost of time foregone (n=54) | 5.04 - 208.32 | 46.21 | 24.06 | 52.38 |

As only 5 visitors lost pay, when lost wages is averaged over all the respondents it becomes equal to £4.70.

Results - Weekly costs

This was calculated using data from 3 visitors who completed questionnaires daily and 12 visitors who gave permission to use data from their first completed questionnaire for all their visits. Descriptive statistics for weekly costs are given in Table 10.

Table 10: Weekly costs incurred by visitors (n=15)

| Weekly costs* | Range (£) | Mean (£) | Median (£) | Std Dev (£) |
|------------------------|------------------|-----------------|-------------------|--------------------|
| Cost of time foregone | 56.42 - 1,032.92 | 334.81 | 203.49 | 327.59 |
| Out of pocket expenses | 0.00 - 250.00 | 71.48 | 37.48 | 75.24 |

Key Assumptions & Sensitivity analyses

The key assumptions made when estimating visitors' costs were:

1. That the average male and female wage rates were appropriate for this population. For those in paid employment, non-work time was valued by the net wage rate and work time also by the net wage rate assuming that output is replaced. The time forgone of those not in paid employment was valued by the market wage rate of a housekeeper.
2. That when estimating weekly costs, visitors who came daily had foregone the same amount of time everyday.
3. That all car travellers had a petrol fuelled engine of (1101 – 1549)cc, did an annual mileage of 15,000, and used unleaded petrol at 69.9 pence/litre

Sensitivity analyses

1. The detailed occupational information required to accurately estimate the costs to visitors was not collected. Therefore, average male and female wage rates were used. Also, there is no clear agreement on the best method to value time. The average daily cost of time foregone estimated using baseline assumptions was £46.21.

Cost of time was then re-calculated using Netten's (1990) method. Here, all non-work time (whether caregivers were waged or not) was valued by the domestic wage rate, work time (if caregivers lost pay) by the net wage rate, and work time (if caregivers did not lose pay) by "zero" wage rate as the loss is to the employer. The cost of time forgone then became £26.59.

When instead of an average rate by gender alone, average wage rates by age and gender were used, the average cost changed to £41.80.

Finally, when time not in paid employment and non-work time for those in paid employment was valued at "zero rate"; the average cost of time foregone became £8.05.

Table 11: Sensitivity analysis for cost of time (N=54)

| Cost of time forgone | Range | Mean | Median |
|--|-----------------|--------|--------|
| Baseline (Posnett & Jan) & wage rate by gender | £5.04 - £208.32 | £46.21 | £24.06 |
| (Netten, 1990)'s method | £0.00 - £147.56 | £26.59 | £12.62 |
| Wage rates by age & gender | £5.04 - £225.17 | £41.80 | £24.20 |
| Unwaged time at zero rate | £0.00 - £147.56 | £8.05 | £0.00 |

2. The average weekly cost calculated using the baseline method was £344.81 and £244.93 by Netten's method. Both these methods assumed that visitors spent the same amount of time

everyday. If the weekly time foregone is reduced by 50% under the worst scenario, the average weekly costs changed to £167.40.

Table 12: Sensitivity analysis of weekly time cost (n=15)

| Weekly cost of time foregone | Range | Mean | Median |
|---|--------------------|---------|---------|
| Baseline - Posnett & Jan's method | £56.42 - £1,032.92 | £334.81 | £203.49 |
| Netten's method | £36.54 - £1032.92 | £244.93 | £103.53 |
| Assuming total time foregone is half of that of baseline time | £28.21 - £516.46 | £167.40 | £101.75 |

- Detailed questions about type of car, engine capacity, mileage done etc were not asked in the questionnaire. Therefore it was felt that the baseline assumptions used for estimating motoring costs were appropriate for the study. However, sensitivity analyses was done with two further scenarios and costs were estimated (£21.27 & £18.73).

Table 13: Sensitivity analysis for motoring costs (N=38)

| Daily cost of travel by own car | Cost/mile | Range | Mean | Median |
|---|-----------|-----------------|--------|--------|
| (1101-1549)cc; 15,000 mileage; price of petrol 69.9p/litre | 36.28p | £2.18 - £100.13 | £15.23 | £7.98 |
| (1550-2000)cc; 10,000 mileage; price of petrol 71.9p/litre | 50.67p | £3.04 - £139.85 | £21.27 | £11.15 |
| (up to 1100 cc); 5,000 mileage; price of petrol 69.9p/litre | 44.63p | £2.68 - £123.18 | £18.73 | £9.82 |

Examination of Results & Discussion

The purpose of the study was to explore the feasibility of collecting data on out-of-pocket expenses and time foregone by visitors to the ICU and, if feasible, to obtain estimates of time forgone and total expenses incurred by visitors. The secondary aim was to provide guidance for implementing this method in the national CESAR Trial.

Feasibility of data collection

Visitors were on average willing to participate in the study with 54 (50%) completing the questionnaire. Only 7 visitors (7%) refused. As most visitors visited more than once, even those who were missed on a particular day could be invited to participate on another day. 35% of visitors completed the questionnaire on site while 37% preferred to take it home to complete. This was to enable them to spend most of their visiting time with the patient. However, of the questionnaires taken home only 43% were returned. To increase the response rate, therefore,

efforts need to be made to meet visitors outside the ICU either before, or after, their time with the patient.

There was an appreciable difference in the response rates between the two weeks: 64% for the first week as opposed to 33% during the second week. This could have been due to the variability between patients, visitors, severity of patients' illness or seasonal variation. 21 visitors (20%) were not asked to participate in the study for the following reasons.

1. Inability to meet all visitors during peak visiting hours and explain the study to them.
2. Inability to meet late night or early morning visitors.
3. Lack of understanding of the purpose of the study by ICU staff and hence the reluctance to mention the study to visitors.
4. Short duration of visit (< 15 minutes). The policy adopted was to allow visitors about 10-15 minutes with the patient before giving them details of the study.
5. Visitors who were visibly distressed or who were thought to be unsuitable for the study by ICU staff.

Some of the above factors can be addressed with better planning leading to perhaps more support from staff. Observations made during the study period showed that support from staff plays an important part in securing visitor participation. This is because patients in ICU receive 24 hour one-to-one nursing enabling duty nurses' easy access to all visitors. It was found that visitors who had been informed about the study by staff were more willing to participate than those who were contacted by the researcher. Staff members who supported the study helped in many ways such as recording visits in the visitor's book, giving out questionnaires and information leaflets and obtaining consent.

Some senior nurses in the ICU gave the following suggestions to increase staff co-operation.

- 3-4 months of preparation time needed to make sure that the entire staff team understand the purpose of the study and their particular role in it.
- Several presentations of the planned study in order to reach all senior nurses (E, F and G Grade) because they work different shifts.

This study had set up links with the ICU during the planning stages such as meetings with the consultant, charge nurse and research nurse and a single presentation to staff. However, when data collection commenced it was found that some nursing staff lacked a clear understanding of the study while some others had not heard about it. This highlighted the necessity for better communication cascade if such a study is to be repeated in other settings.

Estimates of visitor's cost

The average out-of-pocket expenses for visitors was £29.30 (95% CI, £9.72 - £48.88) and the average cost of time forgone was £46.21 (95% CI, £31.91 -£60.51). The four visitors who used air travel to visit the ICU during the study period have contributed to the reasonably high average out-of-pocket expenses. More such studies are needed to determine how representative such visits are in an ICU. The average travel costs alone came to £27.05, which showed that travel was the main component of out-of-pocket expenses. The average time foregone for the visit was 6 hr 49 min, of which about 3hr 12 min (56% of total time) was spent with the patient. Time spent in travelling, resting, consuming food/drinks, and time spent in the waiting room while waiting to see the patient are some of the reasons for this difference. When calculating cost of time, the total time foregone was used because this was the amount of time given up by visitors for the visit.

Visitors on average travelled 47 miles (one-way) to the ICU; range (1.5 – 600) miles. This range excludes one visitor who travelled from the United States. 44% of visitors lived within 10 miles (one-way) of the ICU with 56% travelling more than 10 miles (one-way). 17% travelled more than 50 miles (one-way). Those who were furthest away from the hospital tended to spend longer hours in the unit.

Distance travelled was calculated using postcode data. 49 postcodes were correct enabling accurate distance calculation. 4 postcodes contained only the first three digits and one postcode was wrong. Question 5 had required respondents to give the distance of ICU from home. The importance of obtaining postcodes was highlighted because a comparison of distance estimated by respondents and distance calculated using postcodes found that the two did not match. Only 7 (13%) gave the exact mileage while 9 (17%) had given the round trip distance. The remaining 38 (70%) gave values between these two extremes.

Visitors' age ranged from 18 – 76 years. There was little difference in their gender, 48% being men and 52% women. 72% were family members and 17% relatives. Only 9% were friends. This could be due to the “2 only by the bedside” policy of the ICU. 41 (76%) visitors were of working age, of which 32 (78%) were in paid employment. Five visitors (16%) took unpaid leave and the average lost wage was £50.72. Averaged over all the study participants this becomes £4.70. Lost wages were calculated using time off from work and not the total time foregone for the visit. One visitor had given up work completely to care for her brother.

Nine visitors needed overnight accommodation. Of these eight had travelled more than 100 miles (one-way) for the visit. However, only one paid for accommodation. 11 visitors consumed food and drinks and the average amount was £5.82. There appeared to a reluctance to answer this question, as many visitors who had spent several hours in the unit had entered “not applicable” for this question. It must be noted that visitors are not served food or drinks in the ICU. They have

to buy refreshments from the hospital canteen/coffee shop. Visitors may have decided to spend their time with the patient rather than search for the canteen/coffee shop and lose valuable time.

The average weekly out-of-pocket expenses came to £71.48 and average weekly cost of time foregone to £334.81. Weekly costs were calculated only for visitors who had come daily for 7 days either during the 1st or 2nd week of data collection. The estimated weekly cost of time is an indication of the many hours spent by visitors at the patient's bedside providing emotional support. The estimated costs also show that for daily visitors the weekly cost of time is almost five times as much as the weekly out-of-pocket expenses.

Sensitivity analyses showed that cost estimates of time are sensitive to valuations of unpaid time.

Finally, an analysis of the comments given by participants showed some dissatisfaction with car parking charges. Nine participants (17%) mentioned parking charges. While some daily visitors were worried about the costs involved (£1.05 for 4 hrs) others felt that finding the right change was a problem and a cause of additional stress to them. Some felt that it was unfair to charge relatives visiting severely ill patients. A few commented that visitors could also have financial problems amongst others. One pensioner mentioned that since her husband's hospital admission she had spent more than £100.00 in parking charges alone.

Limitation of the study:

This study only estimated the costs of visiting but not the benefits. The measurement of satisfaction and utility from time given is complex and was beyond the scope of this study.

Cost estimates were also limited to the duration of the two-week study period. The data required for estimating the full visiting costs associated with a patient's entire stay in the ICU is prohibitive and was beyond the scope of this study. The study acknowledges that daily or weekly costs may vary during a patient's stay. The extrapolation of the two-week cost data may require some further modelling, validation or bigger sample size.

The full range of informal care costs that would constitute a full societal perspective of a patient's stay in ICU was not done as this too was beyond the scope of this pilot study. A full societal perspective would include the costs that fall upon the NHS (accommodation costs, medical and nursing time spent with visitors and handling of patient related telephone enquiries), and costs that fall upon others such as relatives/friends taking on duties of childcare, overnight accommodation, and helping out with household duties in patient's home etc.

Discussion

The largest part of the resource cost of care in the United Kingdom tends to fall on the health service. However, informal care provided by relatives and friends is an important element of the

total care provided to patients including those admitted to the ICU. Informal care, as with any other activity, implicitly involves a consideration of the personal costs and benefits by the individuals concerned. From an economic perspective it is important to assess the deployment of informal care resources, to ensure the maximisation of the social benefits generated by these scarce resources. The costs and benefits of informal care will vary according to the context of the economic appraisal.

People engaged in the caregiving of ICU patients, form a specific group of caregivers. They have incorporated caregiving willingly and freely into their normal activities. Therefore, 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 time. In this 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 (time), for other alternative uses (such as working in the community) and thus volunteer caregiving does lead to opportunity costs from a societal perspective. Which of these arguments should be applied is a value judgement.

In the context of ICU patients, it must be said that the support provided by caregivers does not replace the care provided by medical and nursing staff but rather enhances it. This is because the caregivers' concern for the patient usually over-rides financial, social and personal considerations and they choose to become involved in the support of their hospitalised relatives/friends irrespective of the care provided within the ICU. For example, the distance of a patient's home from the ICU may vary, being influenced by the provision of adult intensive care services in the region and intensive care bed availability. Regardless of this, caregivers may travel long distances, sometimes staying overnight in order to be able to visit their relatives frequently. This type of care provision is, therefore, unique as it is not possible to either replace it or substitute it with formal care and even the thought of not visiting would be unacceptable to caregivers. Most visitors might not perceive time spent as a cost or related expenses as a burden. Nevertheless such costs could be an important proportion of household resources. Hence, the costs estimated in this study can be used to estimate the overall cost burden associated with critically ill patients admitted to intensive care.

Implementation of the study

This pilot study has shown that it is feasible to collect data on expenses and time foregone from visitors to the ICU and that visitors are willing to participate in such studies. Results appear to be generalisable to other settings and several of such studies carried out in different settings would provide average costs of visiting ICU patients in the United Kingdom. Data appears to be reliable, but has to be compared against results from other settings. The 54 returned questionnaires had complete data with no missing values. This is an indication that questions were worded with sensitivity and ease of understanding. Refusal was less than expected and only 2 visitors (1.9%) had to be excluded.

Suggestions are now being drawn up to plan a sub-study of visitor's costs in the national multi-centre CESAR Trial. A presentation of the study will be made available to the CESAR Project Management Group in the very near future.

Implication for policy and practice

At present the costs borne by caregivers in providing emotional support to relatives/friends in the ICU are largely hidden and are consequently overlooked in the design of services.

The results of this study draw attention to the considerable costs of “visiting” that fall upon relatives and friends. The findings of this study have implications for the organisation of hospital care. Service purchasers and providers could start by limiting the financial burden of parking costs for daily/frequent visitors, for example by ensuring that frequent visitors are given discounted rates.

An important point to mention here is that the Hospital Trust where the study took place had a policy to limit parking charges for daily visitors where one could purchase 7 days of 24 hour parking for £7.00. A large number of visitors, however, were unaware of this. Perhaps the ICU could do more in making this information available to all visitors. In some special cases such as those on low income a further discount from this amount could be considered.

Future research

Cost estimates, especially of time, are sensitive to assumptions about the valuation of unpaid work. There is scope for further investigation of the values visitors attach to their own time.

More empirical work is required to elicit information on both the positive and negative satisfaction associated with care-giving and to incorporate this into valuations of the costs related to informal care. Similarly more research is needed to assess and address all areas of concern to relatives/friends of critically ill patients.

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