An annotated cost questionnaire for patients: Results of piloting

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1. Introduction

Economic evaluation provides a framework to help inform the decision making process.[1] When a societal approach is adopted, the collection of data on patient costs is an important requirement in comparing health care interventions.[1-4] However, lack of funding and time constraints associated with developing a patient cost questionnaire can make this process cumbersome. Also, in the absence of a standardised tool for collecting such information researchers can spend a significant amount of time attempting to create an appropriate questionnaire.

The United Kingdom (UK) Working Party on Patient Costs was formed in 1999 with the specific remit of producing a standard "patient" cost questionnaire for use in evaluating health care interventions. The aim of the project was to produce a questionnaire for measuring inputs into the health production function that relate directly to patients and informal care-givers, where patients could be used as a source of information. It was anticipated that such a questionnaire could avoid unnecessary duplication and facilitate comparisons between the results of different researchers. The resultant "Annoted cost questionnaire for completion by patients" (hereafter referred to as the Patient Cost Questionnaire, or PCQ) comprises a "menu" of questions from which researchers are able to choose those relevant to their particular research project. The resultant "derived" questionnaire is then administered to patients. The PCQ questionnaire includes sections on visits to a single as well as to multiple health care facilities. The questionnaire also includes questions on domicillary care costs, productivity losses, payment for medication and medical supplies and payment for private consultations with health professionals.

An earlier draft of the PCQ was presented at a previous HESG meeting in Aberdeen in 1999.[5] After further revisions to the questionnaire a final draft was approved by the group and is to be published shortly as a HERU discussion paper. The next stage in the development of the PCQ then is to pilot test the various sections. This paper reports the results of the piloting of the multiple visits to a health care facility section, applied to a chronic illness, in this case end-stage renal disease. The following section of the paper describes the methods employed for the piloting with the results presented in Section Three. The final sections of the paper consider more general methodological and policy questions that are raised when using a derived version of the cost questionnaire and make some overall conclusions.

2. Methods

The multiple visits section of the PCQ was used to create a derived questionnaire to assess costs to patients receiving dialysis therapy for end-stage renal disease. There are two main forms of dialysis therapy, haemeodialysis (HD) and peritoneal dialysis (PD). The former involves patients receiving dialysis usually on a hospital outpatient basis, three times per week for around four hours. PD is carried out on an ambulatory basis and involves four fluid exchanges per day in the patient's usual setting, with hospital visits limited to clinic appointments. For HD patients travel and time associated with treatment are particularly important, due to the regularity of treatment. It was therefore anticipated that such patients would be a particularly useful group on whom to test the multiple visits section of the PCQ.

The derived questionnaire produced for this pilot study was generated with relative ease. A draft was compiled and forwarded to the staff of the dialysis unit for comment, after which a few alterations were made. The entire process, including the

printing of the questionnaires, took around five hours. The questionnaire itself comprised five sections. The first focused on patient travel costs in terms of mode of transport to and from the dialysis unit, distance travelled (one-way) and any other travel costs incurred by patients such as parking fees. The next section of the questionnaire asked patients about their time spent receiving dialysis therapy. This included questions concerning treatment time as well as any time taken from usual activities, such as work and leisure. Section Three of the questionnaire asked about any travel and time costs incurred if a companion accompanied the patient to the dialysis unit. Section 4 enquired about costs incurred by patients when attending health care facilities other than the dialysis unit, and any additional costs incurred as a consequence of their dialysis therapy, such as reading materials and special clothing. Respondents were then asked 3 questions concerning the derived questionnaire itself, in order to evaluate ease of completion and validity with regard to distance travelled. Patients were asked to rate on a scale of 1 to 5, where 1 represented extremely easy and 5 very difficult, their ability to answer the questions asked. An additional question addressed how appropriate the patients felt the questionnaire was in terms of assessing their particular circumstances and whether any important cost items had been omitted from the questionnaire. Patients were also asked for any further comments about the questionnaire. Finally, the respondents' age and gender, the time taken to complete the questionnaire and the patients` home postcode were recorded. The purpose of recording the home postcode was to compare patient estimates of distance travelled to the dialysis unit with that which might be expected given the home address. This enabled us to perform a simple internal consistency check. Asking patients how long they were on dialysis on the particular day interviewed and then comparing this with the reading on the dialysis machine allowed a second test of internal consistency.

Over three consecutive days, 2 health economists administered the questionnaire to all adult HD patients (n = 83) receiving dialysis on an outpatient basis from the dialysis unit at Aberdeen Royal Infirmary (ARI). Patients were given the questionnaire during their dialysis session. They were offered a choice of either reading and completing the questionnaire on their own and then discussing the questionnaire with the interviewer or the interviewer reading the questionnaire to the patient and completing the questionnaire on their behalf. This second option was necessary because patients had one arm occupied receiving dialysis and it was difficult for them to write themselves. To examine the test re-test reliability of the questionnaire, a random sample of 20 patients who had completed the first questionnaire were given the questionnaire again ten days after they were first interviewed. To date given time constraints for this paper, these results have only been checked for face validity.

3. Results

All 83 patients agreed to complete the derived dialysis patient cost questionnaire, the main results of which are presented in Table 1. Results presented here are largely descriptive statistics. Further analysis will be performed once the results from the PD patients piloting are collated. From the HD sample around 39.8% (n=33) of the patients were female and almost two-thirds (62.7%) were aged 65 years or above. Most patients (94.0%) completed the questionnaire in less than ten minutes and the majority of patients found the questionnaire very easy to complete (79.5%).

Travel costs

With respect to travel costs, the majority of patients travelled to the dialysis unit by patient transport (ambulance). Overall 68.7% (57) returned home using the same form of transport. Twenty-six respondents (31.3%) used a different mode of transport to

return home. This difference largely related to the patients who had travelled to the unit by ambulance for the afternoon dialysis session. If these patients were late starting dialysis, they were more likely to travel home by a taxi paid for by the dialysis unit, because the patient transport service closes at 5 p.m. Of those patients who travelled to the unit by ambulance, only 50% (n=22) returned home the same way. Of those who returned home using a different mode of transport, 18 returned home by a taxi paid for out of dialysis unit funds and the remainder were either collected by a relative or took a taxi which they paid for themselves.

Table 1. Costs relating to dialysis patients

Cost category	Cost options	(%) frequency
Travel costs		
Main mode of transport to dialysis unit *	Patient transport (ambulance)	53 (44)
	Hospital taxi	6 (5)
	Private car	31.3 (26)
	Bus	2.4 (2)
	Private taxi	1.2 (1)
Distance travelled one-way for dialysis (miles)	Mean 14.56	SD 15.32
Time costs		
Travelling to dialysis unit	Mean 35.93 minutes	SD 29.86 mins
Length of time receiving dialysis	277.95 minutes Range 240 – 360 (4 - 6 hours)	SD 32.15 mins
Total time at hospital	342.13 minutes Range 240 – 482 (4 - 8.03 hours)	SD 58.59 mins
Employment status	Retired	62.7 (52)
	Home maker	10.8 (9)
	Full-time work	9.6 (8)
	Certified disability	4.8 (4)
	Part-time work	3.6 (3)
	Sick leave	2.4 (2)
	Other	6.0 (5)
Other activities	Leisure activities	77.1 (64)
	Housework	9.6 (8)
	Sick leave	6 (5)
	Paid work	4.8 (4)
	Caring friend or relative/in education	2.4 (2)

* 5 patients are missing from this section because they were inpatients and therefore the questions regarding travel to and from the dialysis unit were irrelevant.

Time

When total time spent at the hospital was examined (treatment time and waiting to go on and off dialysis), if patients were late arriving at the unit, this had a follow on effect in terms of when their treatment started. It was found that patients receiving dialysis for 4.5 hours often spent as much time at the hospital as those receiving dialysis for longer periods, if they had to wait for a considerable length of time for their treatment. Therefore, whether or not patients arrived sufficiently early had a major impact of total time spent at the hospital.

Main activity and employment status

The majority of patients (77%) indicated that they would have been taking part in leisure activities if they had not been receiving dialysis at the time they were interviewed. With regard to employment status, 52 (62.7%) patients were retired, and 9 (10.8%) were homemakers.

For those patients who were still working (n=11), they tended to work hours that complimented their treatment needs. Some patients were able to work a normal 35-40 hour week (n=8), while others were forced to reduce their paid work time because of their dialysis treatment (n=3). Six patients had withdrawn from paid work entirely because of their requiring dialysis treatment, 4 of which had taken early retirement and the remaining 2 were placed on indefinite sick leave. These individuals now considered leisure the most likely alternative use of their time. For the patients who withdrew from the formal work force, this came at a significant cost to the patient in terms of foregone wages. However, the cost to society in an environment where there is unemployment would be lower, and could be estimated using one of several methods.[6-12]

Companion costs

For the most part the section on companion costs was not relevant to this group of patients. Only six patients were accompanied to the hospital and only two had a companion stay with them during treatment. The alternative use of the companion's time was housework or leisure in every case. As such, this section of the questionnaire could probably be taken out for future use.

Other healthcare facilities and additional costs

Aside from the visits to the dialysis clinic for regular check-up appointments, few patients had contact with other health care facilities. This was surprising given the multifaceted nature of renal disease. However, it became clear from the section asking for further comments that patients believed that receiving dialysis so frequently enabled them to be seen regularly by health care professionals and they regarded the dialysis unit as a source of advice for all their renal-related illnesses. PD patients have less contact with the dialysis unit, therefore it is anticipated that the PD sample will provide us with more cases of visits to additional healthcare facilities. With regard to additional costs related to being on dialysis, most patients did not identify any costs, aside from six patients paying for the annual dialysis related drugs prescription themselves (most had an exemption certificate) and a handful mentioning books and magazines. The 6-month recall period for this question appeared not to be a problem in this case because patients often had regular appointments with health care professionals, for example, once every 2 months or once every 3 months.

Evaluation issues

The results of the two tests of internal consistency provided encouraging results. All patients reported their length of time on dialysis correctly when compared to the

machine reading and only two patients reported mileage from home that was very different from that implied by their postcode. With regard to whether patients felt that our questionnaire was relevant to their circumstances, only the 5 inpatients said that it was not entirely relevant (lack of travel costs). All the remaining outpatient dialysis patients felt that the questionnaire was relevant and that no important costs categories had been omitted. The results of the test-retest reliability demonstrated that patients provided very similar responses when completing the questionnaire again 10 days later. Of the 20 patients seen again, only 2 had changed their mode of travel, which also changed their times. However, when all other categories where examined (main activity, employment, visits to other healthcare facility, distance from home etc), little had changed. Ease of completion remained the same and there was a slight reduction in completion time.

4. Discussion and conclusions

This paper has demonstrated that the PCQ can be adapted, with minimal researcher effort, to estimate costs to patients for a specific health care intervention. This pilot study also produced encouraging results in terms of question acceptability and the ease with which the derived questionnaire could be completed. However, a number of issues remain to be addressed, as discussed below.

For the HD patient group, the opportunity to examine productivity losses in detail was limited because of the small number of patients who had taken time from work to attend treatment. Therefore, it could be important to examine the productivity loss aspect of the questionnaire on patients who had only recently commenced on dialysis and therefore are in the midst of changing work patterns. It would also be of

value to test the questions relating to productivity changes on a less chronically ill group of patients with a different illness.

A second issue that remains to be addressed relates to the fact that the derived questionnaires were completed by semi-structured interviews, because all patients preferred to have the interviewer write their responses down. While this enabled valuable feedback for the piloting, it does imply that we can say little at this stage about the potential for this questionnaire to be administered by postal survey. We aim to retest the same patients by postal survey in the near future.

If researchers were intending to use patient costs within an economic evaluation framework, then costs from a comparator intervention would be required. For dialysis therapy, costs relating to the PD patient group need to be examined, which is the focus of a current survey. Once this is completed, we will then be in a position to demonstrate how costs incurred by dialysis patients can be used in a decision-making context for policy makers.

In conclusion, this paper was concerned with estimating patient costs for dialysis therapy for end-stage renal disease, using a questionnaire derived from the PCQ. This pilot study has demonstrated that the section of the PCQ relating to multiple visits to medical facilities is acceptable to patients and provides accurate cost information for researchers. On this basis, we now encourage other researchers to experiment with the questions contained in the PCQ more generally. However, further piloting is necessary in order to examine other sections of the questionnaire such as those relating to visits to a single health care facility before the PCQ in entirety can be *recommended* for widespread use. As such we plan to adapt the dialysis questionnaire and test the product on patients

with a new diagnosis of end-stage renal disease and due to have a first appointment at the dialysis unit.

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