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ORIGINAL ARTICLE

The Reliability of Data Collection Periods of Personal Costs Associated with Vision Impairment

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ABSTRACT *Purpose*: To determine the reliability of vision-related personal costs collected over 1, 3 and 6 months (extrapolated to 12 months) compared to one-year data. *Methods*: Participants of any age, with a presenting visual acuity of <20/40 in the better eye and an ability to converse in English, were recruited. Monthly cost diaries, in large print and electronic copies with instructions available in audio and Braille, were used prospectively to collect personal costs. The personal expenses were grouped under four categories, namely: (a) medicines, products and equipment, (b) health and community services, (c) informal care and support and (d) other expenses. Sociodemographic and clinical data were also collected. *Results*: 104 participants (59 females) with a mean age of 64 years completed the 12-months diaries. Almost 40% of the participants had severe visual impairment (<20/200) in the better eye and the most common cause of vision loss was AMD (n = 40; 38%). The mean total personal costs collected from the 12-months diaries were AUS$ 3,330 ± 2,887. There were no significant differences between the 12-months data and extrapolated 1, 3 and 6-months diaries (t-tests; p = 0.17, 0.89 and 0.73, respectively). However, the 1-month variation was substantially larger (SD ± 5860) compared to the 3-month and 6-month variances (SD ± 3037 and 3030, respectively) for total costs. Also, compared to the 12-months diaries, the 1-month data consistently recorded the weakest correlation coefficients for all cost categories compared to the other time intervals. *Conclusions*: Given that diary completion can be particularly challenging for individuals with impaired vision, a minimum 3-months data collection period can provide reliable estimates of annual costs associated with vision impairment.

KEYWORDS Vision impairment; personal costs; data collection reliability; diaries

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INTRODUCTION

There are very good data on the causes and prevalence of vision impairment (low vision and blindness)[1,2] and recent research has described its psychosocial

impact.[3,4] To gain a complete picture of the economic impact of health care, both direct and indirect costs need to be measured. The economic impact of vision impairment has been costed at the global level using loss of productivity.[5]

Cost effectiveness analysis using costs and outcomes of eye care, especially for age-related macular degeneration (AMD) have been conducted recently.[6] In their cost effectiveness analysis of photodynamic therapy for AMD, Smith et al.[7] calculated costs from the government perspective, not just healthcare costs but including rehabilitation, welfare and community care. Costs from the perspective of a person with impaired vision are usually not included in the direct and indirect cost components. One of the reasons related to the omission of personal costs is that they are difficult to measure.

The Royal National Institute for the Blind identified the nature of additional expenditures related to vision impairment using focus groups but they did not measure the costs.[8] Costs can be incurred on a regular basis, such as assistance for household tasks, shopping, communication and transport. Large one-off expenditures are also necessary for adaptive equipment for the household, education or work, and low vision devices and computer hardware and software for alternative format material such as large print, audio or Braille.

Data on personal costs can be obtained retrospectively from structured or semi-structured questionnaires,[9] or prospectively using diaries.[10] Diaries have been used in other areas of healthcare such as back pain.[11] One of the issues associated with prospective data collection is the length of time needed to obtain reliable data. One alternative would be to collect data over relatively short periods of time, which could then be extrapolated to yearly expenditure. Goossens et al.,[11] for example, found no significant statistical differences between time intervals but recorded low correlation coefficients between collection periods and 12-month data.

As personal costs for people with impaired vision include regular and one-off costs, we compared the periods of data collection using cost diaries over 1, 3, 6 and 12 months to assess the time interval needed to obtain reliable results.

METHODS

Participants

The eligibility criteria for participants of any age were (a) presenting visual acuity of <20/40 in the better eye, or >20/40 with restricted visual fields, (b) an ability to converse in English, and (c) consented to participate. Eligible children under the age of 18 participated with the support and consent of a parent or guardian. Informed consent was obtained from all participants prior to the start of the study. Participants were recruited across Australia although the majority was from the local state of Victoria. The recruitment centres included The Royal Victorian Eye and Ear Hospital (RVEEH), private eye clinics, and vision rehabilitation organizations, namely Vision Australia, Glaucoma Australia, Retina Australia, and the Macular Vision Loss Support Society of Australia. Child participants were recruited from the Education Vision Assessment. The RVEEH Human Research and Ethics Committee granted the study ethical approval.

Data Collection Procedure

Costs Diaries

For the daily recording of vision-related personal expenses, a one-month cost diary was mailed to participants before the commencement of each month over one year. To facilitate self-completion, the cost diary was produced in alternative formats suitable for people with impaired vision. Formats were large print and electronic for the diaries, and instructions were available in audio and Braille formats. A family member was allowed to provide assistance to participants who could not fill in the diary independently. Otherwise, a volunteer from the vision rehabilitation agency or a member of the research team completed the diaries with the participant over the telephone or in person at the end of every week. The diary was in booklet form, with each section divided into rows to clearly represent each day of the month and columns outlining the information to be recorded. Reply-paid envelopes were enclosed with each diary for participants to return the completed diary at the end of every month.

Each costs diary had four sections, which represented categories of vision-related expenditure. Each section had a title page with descriptions and examples of costs

that could be recorded. Instructions on how to complete the costs diary were provided at the beginning and the investigator's contact details were printed on the back cover. The four main categories of personal costs were:

(a) Medicines, products and equipment: costs under this category included prescription and non-prescription medicines, low-vision devices, eye care products, specialised equipment and computer software.
(b) Health and community services: under this category, hospital, medical, personal care, social support services-related expenses, the location of the service provided (i.e., home), the service provider's details and subsidies received, if applicable, were recorded.
(c) Informal care and support: costs associated with this category included assistance provided by the caregiver, friend or volunteer. Participants included the types of care received such as home help, meal preparation, personal affairs including shopping and personal care such as dressing, and costs associated with transportation. The participants also identified the caregiver (i.e., daughter), lost production time (in hours from the caregivers) and costs associated with that care. The monetary value of unpaid help was calculated using the average Australian hourly rate.
(d) The 'other expenses' category included vision-related costs associated with public transport (i.e., taxi) and expenditures not covered in the other categories.

Questionnaires

An interviewer-administered baseline questionnaire obtained vision-related expenditures, sociodemographic and vision details. The participant informed about the frequency and cost of any vision-related assistance provided by family, friends, health and community services, as well as any vision-related subsidies received. Vision data were also obtained from the participants' medical files or from their eye care professional. In addition, a follow-up questionnaire was used to validate the completeness and accuracy of the costs diary.

Statistical Analysis

Descriptive analyses were used to examine the participants' sociodemographic and clinical characteristics. Mean costs calculated at 1, 3 and 6 months were extrapolated into annual figures by multiplying by 12, 4 and 2, respectively. The collection periods represented data for the first, three, six and twelve months from the start of the study for each participant. The collection started on 1 February 2003 and finished on 31 October 2004. The variables of interest were the mean cost for each expenditure category and total costs (calculated from the sum of the four expenditure categories). The diary collection periods were compared using the paired t-tests. Univariate analyses were conducted to identify variables that were significantly associated with total costs. Stepwise regression analyses were undertaken to determine the association between demographic and socioeconomic characteristics, health status and total expenditure. A p-value <0.05 was used as the criterion of significance.

RESULTS

The participants' sociodemographic and clinical characteristics are shown in Table 1. One hundred-and-four participants (59 females-57%) with a mean age of 64 years completed all the diaries over 12 months. Almost 40% of the participants ($n = 36$) had severe visual impairment (<20/200) in the better eye and the most common cause of vision loss was associated with AMD ($n = 40$). Seventy-five percent of the participants ($n = 79$) required no help to complete the diaries. There were no significant differences ($p > 0.05$) between those who self-completed the diaries and those who required help (the research team, vision agency or family member) on any of the sociodemographic and clinical variables and the costs categories.

The mean total personal costs associated with vision impairment collected from 12-months diaries were AUS$ 3,330 $\pm$ 2887, of which informal care and support costs accounted for more than half of the total costs (55.9%, AUS$ 1862 $\pm$ 2338; Table 2). The costs for medicines, products and equipment; health and community services; informal care and support; other expenses and total costs at 1, 3 and 6 months extrapolated to 12 months are shown in Table 2. There were no significant differences when the 12-months diaries for total costs were compared to extrapolated 1, 3 and 6-months diaries (t-tests; $p = 0.17$, 0.89 and 0.73, respectively). However, while the variances for 3, 6 and 12 months were similar (AUS$ 3037, 3030 and 2887, respectively), the 1-month variation was substantially larger for total costs (AUS$ 5860). This pattern was also

TABLE 1 **The Sociodemographic and Clinical Characteristics of the 104 Study Participants**

Age (yr) (mean ± SD)	63.8 ± 20.3
Duration of vision impairment (yr) (mean ± SD)	16.9 ± 18.7
Gender	
Males	45 (43.3%)
Females	59 (56.7%)
Presenting visual acuity*	
20/40 or better	21 (20.2%)
<20/40-20/60	8 (7.7%)
<20/60-20/200	35 (33.7%)
<20/200	36 (36.5%)
Main cause of vision impairment	
Age-related macular degeneration	40 (38.5%)
Glaucoma	11 (10.6%)
Other Retinopathy	34 (32.7%)
Other	19 (18.3%)
Other comorbidity[a]	
No	27 (26%)
Yes	76 (73.1%)
How much other comorbidity interferes with daily living?	
Not at all	33 (43.4%)
A little	19 (25.0%)
A great deal	24 (31.6%)
Accommodation[a]	
House/retirement village	96 (92.3%)
Boarding house/hostel	3 (2.9%)
Other	4 (3.8%)
Living arrangement	
Alone	41 (39.4%)
Spouse	35 (33.7%)
Other	28 (26.9%)
Member of social group[a]	
No	28 (26.9%)
Yes	75 (72.1%)
Employment status	
Full time/part-time	9 (8.7%)
Retired	36 (34.6%)
Unemployed	4 (3.8%)
Pension	55 (52.9%)
Subsidy	
No	32 (30.8%)
Yes	72 (69.2%)
Private health coverage[a]	
No	54 (51.9%)
Yes	49 (47.1%)

*Four participants did not have presenting visual acuity data as they were blind. [a]Data for one participant are not available.

evident for three of the four costs categories, namely medicines, products and equipment; informal care and support; and other expenses. Furthermore, while the one year-extrapolated total costs for 1, 3 and 6 months were significantly associated ($p < 0.001$ for all) with the 12-months data (Table 3), the association was substantially weaker when the one-month data were compared to the 12-month diaries. A similar result was found for the specific costs categories (Table 3).

Only four variables were significantly associated with total costs. Females spent more than males ($p = 0.04$), those with worse visual acuity spent more than those with better vision ($p = 0.04$), those receiving subsidies had greater expenditure than those who did not ($p < 0.001$), and those who were privately insured spent more than those with no insurance cover ($p = 0.02$). When those significant univariate variables were entered into stepwise linear regression models, only subsidy and private health cover were identified as significant predictors of total costs and explained 17.2% of the variance in the model, suggesting a greater ability to spend (Table 4).

DISCUSSION

In order to obtain comprehensive costs data associated with visual impairment and to perform cost-effectiveness studies evaluating treatment, it is essential to obtain information from participants as to personal costs. By using a prospective diary method, this study was able to provide reliable cost information independent of momentary recall associated with retrospective questionnaires. One potential disadvantage of the diary record method is that it could result in a relatively low compliance rate in completing the diaries over a long period of time. This shortcoming, however, could potentially be solved with short periods of data collection, which could then be extrapolated to annual costs. Our analysis of the effect of different periods of data collection for personal costs associated with visual impairment found no significant differences between the three alternatives (1, 3 and 6 months) and one-year data for total costs and four costs categories. However, the one-month data generated a substantially larger variance of the estimate when compared to the other two alternatives and produced the weakest association with total costs. These results seem to suggest that the 3- and 6-months data collection periods could be the two most reliable and accurate estimates of annual costs for personal expenditure related to visual impairment.

A similar result was obtained by Goossens et al.[11] who found no significant differences between one-year data, costs for the first two weeks of each second month

TABLE 2 **Mean ± SD Costs at 1, 3 and 6 Months (Extrapolated to One Year) and 12 Months for Medicines, Products and Equipment; Health and Community Services; Informal Care and Support; Other Expenses and Total Costs for the 104 Study Participants**

Costs	1 month*	3 months*	6 months*	12 months
Medicines, products and equipment	1236 ± 5084	606 ± 1741	534 ± 1125	419 ± 702
Health and community services	362 ± 750	383 ± 758	418 ± 846	457 ± 886
Informal care and support	1781 ± 2739	1717 ± 2115	1828 ± 2359	1862 ± 2338
Other expenses	682 ± 1279	599 ± 846	513 ± 702	592 ± 772
Total Costs	4061 ± 5860	3305 ± 3037	3293 ± 3030	3330 ± 2887

*Costs extrapolated to one year.

and costs based on months 1, 6 and 16 in patients with fibromyalgia and low back pain. We, however, recorded substantially stronger correlation coefficients between our alternatives and the one-year data (r = 0.57–0.96) compared to those reported by Goossens et al. (r = 0.17–0.32). This discrepancy could be related to the nature of the diseases (fibromyalgia or low back pain), which require unexpected visits (and expenditure) to physiotherapists and specialist care during occasions of unexpected flaring up. Conversely, the deterioration in vision is more gradual and the largest proportion of our participants had AMD, which requires an annual or biennial visit to an eye care specialist. These factors may have contributed to a more consistent pattern of expenditure in our participants.

It was anticipated that one-off large expenditures such as the purchase of expensive low vision devices, specialist electronic equipment or software would have contributed to unstable patterns of expenditure, which may have contributed to significant differences between the time intervals. Although there was no statistical evidence supporting this expectation, the difference between the variance of the estimates at one month compared to the other alternatives was the highest for medicines, products and equipment-related costs, suggesting this category to be the most volatile of all the types of personal costs. This observation further supports the overall conclusion that one-month data extrapolated to 12 months may not be the most accurate and reliable alternative to keeping the diary for a whole year.

While the main aim of this paper was to determine the influence of different periods of data collection, it is worth mentioning that the mean annual total personal costs associated with vision impairment are substantial (AUS$ 3330). Of critical importance, however, is the finding that more than half of this mean value is related to costs associated with informal care and support. This form of expenditure is often not included when computing the overall costs of visual impairment in the community and should be given further significance in future estimates of the economic impact of vision impairment.[12]

An interesting finding of the study was that the only two independent predictors of total personal costs associated with vision impairment were private health cover and subsidy. Those who receive a subsidy contributed most to the regression model (12.8%), with those participants with private health cover adding a further 4.4%. The finding implies either that a great number of purchases are covered by those who have the economic means or that those participants are able to purchase

TABLE 3 **The Relationship between Yearly Costs and 1, 3 and 6-Months Costs Extrapolated to One Year for Medicines, Products and Equipment; Health and Community Services; Informal Care and Support; Other Expenses and Total Costs for the 104 Study Participants (Pearson Correlation Coefficients; $p < 0.001$ for all)**

Costs	1 month*	3 months*	6 months*
Medicines, products and equipment	0.57	0.71	0.87
Health and community services	0.59	0.77	0.86
Informal care and support	0.79	0.91	0.96
Other expenses	0.69	0.84	0.88
Total Costs	0.69	0.87	0.95

*Costs extrapolated to one year.

TABLE 4 **Annual Total Costs: Stepwise Linear Regression Model Summary including Standardised β-Coefficients and Adjusted R^2 after Controlling for Age, Duration of Visual Impairment and Degree of Vision Loss**

Predictor	Standardised β	Adjusted R^2
Subsidy	0.34**	0.13
Private health cover	0.21*	0.17

*$p < 0.05$ and **$p < 0.01$. Variables entered: gender (male and female), presenting visual acuity (20/40 or better, <20/40–20/60, <20/60–20/200 and <20/200).

more. Conversely, this result may also imply that those without the financial capacity are unable to meet those personal costs associated with visual impairment or that they are able to buy less.

In conclusion, this study found that a reliable estimate of annual personal costs associated with visual impairment could be obtained by collecting data over short time intervals, namely 3 and 6 months. Considering that completing diaries can be challenging for older adults, especially those with vision impairment, this finding is important for future economic evaluations. Given that most eye diseases are relatively stable, we propose that a short data collection period (3–6 months), as opposed to 12 months, would be able to provide reliable costs data associated with vision impairment.

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