



## THE COST OF HOME-BASED TERMINAL CARE FOR PEOPLE WITH AIDS IN SOUTH AFRICA

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**Objectives.** To describe the costs of establishing and operating a home-based care (HBC) project providing palliative care for people with AIDS (PWA), and to project the full costs to the health care system of extending this care model.

**Design.** Data were collected from seven sites participating in the Hospice Association of South Africa integrated community home-based care (ICHC) model, using site records, interviews with personnel, a continuity of care survey of nursing staff supervising the sites, and time logs kept by community caregivers (CCGs). The seven sites were spread across five provinces, with a mix of rural, peri-urban and urban settings.

**Outcome measures.** Set-up (training, equipping and planning) costs per HBC site, HBC operating costs (total and average cost per patient), and average hospital inpatient, hospital outpatient and primary care clinic cost per participating patient. Estimates of scaling up this model of HBC to national roll-out are also provided.

**Results and conclusions.** Providing palliative HBC to PWAs in their last year of life using the ICHC model costs R2 840 per patient per year. Even with this level of HBC input, patients still incurred hospital costs of R2 522 and primary care clinic costs of R1 154 per patient per year. HBC costs are increased in rural areas where a vehicle is required for staff transport. HBC shows considerable potential to deal cost-effectively with growing palliative care needs in the face of the AIDS epidemic, but we need to understand better the true extent to which HBC can substitute for hospitalisation.

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With 4.2 million people infected with HIV/AIDS in South Africa in 2000,<sup>1</sup> local evidence increasingly shows that demand for care for AIDS-related conditions is already beginning to 'crowd out' other activities in hospitals in badly affected provinces.<sup>2</sup> Home-based care (HBC), which allows AIDS care activities to be delivered in the patient's home rather than in hospital, has increasingly been proposed as an affordable mechanism for achieving an acceptable level of coverage for AIDS care in high-prevalence, resource-constrained countries. However, experience with HBC remains relatively limited in southern Africa,<sup>3</sup> and the limited evidence on costs does not provide unqualified support for this model.<sup>4</sup>

In 1999 a study of seven South African sites offering home-based AIDS care was funded by the Department of Health. At all seven sites, members of the Hospice Association of South Africa (HASA) offered home-based AIDS care in partnership with local provincial clinics and hospitals. Their integrated community-based home care (ICHC) model aims to integrate all service providers in a community into a continuum of care for clients. The objective of the study was to identify the costs of the ICHC service model. Following the completion of our study, the Centre for Health Policy (CHP)<sup>5</sup> published the findings of its study of the costs of HBC at four South African sites. The CHP study includes data gathered at the South Coast Hospice Association, which is also one of the study sites reported on in this paper. There is thus some overlap between the two studies, although their final results are not directly comparable.

### DATA COLLECTION AND METHODS

The study took place at seven sites in five provinces. Two of the sites were rural, two peri-urban and three urban. All sites were in under-served areas. The costing was based on a range of data collection instruments, including staff interviews and record reviews at ICHC sites, hospitals and clinics; a 'continuity of care' survey of supervisory registered nurses (SRNs), documenting all contacts with health services by 10 clients per site over a period of 3 months; and a log kept by all community caregivers (CCGs) for 1 week to document their actual time spent on work activities.

The available data are presented to describe HBC costs from the perspective of the health care provider (HASA). Costs of care provided to ICHC patients in hospitals and primary health care clinics are also estimated, from the perspective of the public health system. All cost data are presented in South African Rands, in constant 2000 prices.

### THE COST OF SETTING UP AN ICHC PROGRAMME

A standard training curriculum lasting 3 months was employed at all seven sites, although direct teaching time per



site ranged between 132 and 384 hours (average 221 hours). An average of six CCGs were trained per site. Almost all the trainers were experienced professional nurses, and therefore the middle notch of the senior professional nurse category was used to calculate teaching costs (R89 737 per annum). At one site CCGs provided much of the training (salary R18 576 per annum). These salaries equate to hourly rates of R44.50 for nurse trainers, and R9.21 for CCG trainers. Site records were used to determine other training costs, including meals and travel costs, preparation and duplication of training materials, and sundry supplies.

ICHC teams require basic nursing care equipment, which should be available on loan. Essential equipment includes bedpans, urinals, sheepskins, special mattresses, commodes, and various smaller items. The cost per site of this list was R10 379.

Detailed records of time spent on the initial planning of the project had been kept at one site. ICHC personnel had spent 76 person hours on planning and organisational issues, at a cost of R3 382. Assuming similar inputs from local hospital and clinic staff, the total human resource cost would be R10 146, plus travel costs of approximately R2 000.

The average setting-up costs per ICHC site were therefore: (i) training R7 145; (ii) equipment R10 379; (iii) planning R12 146; and (iv) total R29 670.

## RUNNING COSTS OF AN ICHC PROGRAMME

### Hospital cost

#### Hospitalisation

Hospital utilisation was estimated by documenting all health service contacts for 10 clients at each site seen by CCGs over a period of 3 months. Recent cost studies<sup>8,9</sup> were used to generate average estimates of public hospital and primary health care (PHC) clinic costs, giving values of R385 for a regional hospital bed day, and R331 for a district hospital bed day (average R358 per patient per day). Seventy-five per cent of ICHC patients in the survey were not hospitalised; the 25% who were had an average stay of 10 days. Therefore, with an average overall length of stay of 2.6 days, the average inpatient cost per ICHC patient was R931 per annum.

#### Outpatient care

Many PWAs enrolled in ICHC attend hospital outpatient clinics, generally for tuberculosis (TB) care, and prophylaxis or treatment of opportunistic infections. To calculate the cost of such care the last three visits of 10 clients at each outpatient service were surveyed. The cost included diagnostic tests, medication, and sundry disposables such as syringes, gloves and lotions. For 16% of the visits surveyed, data on one or more items were missing; the survey could be conducted at five of the seven study sites only.

The survey recorded 29 hospital outpatient visits by 40 clients. Average utilisation was 2.7 visits per person every 3 months. This would mean that 11 visits per annum should be seen as the average for planning. Combining survey data on costs of medication, consumables and tests with standard average costs for an outpatient visit (R118.50), the average cost per visit was R144.22, and the annual outpatient cost for PWAs would be R1 586.42 per patient.

#### Programme activities

Hospital staff generally attended the monthly co-ordination meeting for 1 hour. The cost of this would therefore be R44.50 per month, or R534 per annum. Since the average number of ICHC patients served per hospital was 114, the cost per patient of such activities would be R4.68.

#### Total hospital costs

The average hospital cost per patient is therefore: (i) hospitalisation R931.00; (ii) outpatient care R1 586.42; (iii) programme activities R4.68; and (iv) total R2 522.10.

### PHC clinic cost

The continuity of care survey indicated that ICHC patients presented to PHC clinics for an average of 3.4 visits in the 3 months surveyed, implying an average of 14 clinic visits per patient per year. Medication and disposables dispensed at clinic level cost, on average, R21.27 per visit. These costs were added to standardised PHC cost estimates of R56.50 per clinic visit, yielding a cost per visit of R77.77. This implies an annual average PHC cost per PWA of R1 088.78.

The involvement of PHC staff with the ICHC programme varies from site to site, but the average is about 7 hours per month, including training, case discussions and general support. The cost is therefore R312 per month, and R3 744 per year, or R65.68 per patient per year.

#### PHC clinic cost for one patient for 1 year

The average PHC cost is therefore: (i) visits R1 088.78; (ii) programme R65.68; and (iii) total R1 154.46.

### HBC cost

The single largest cost of HBC is CCG salaries, which have been calculated for two CCGs per team, working 8 hours per day (Table I). The continuity of care survey showed that the average monthly number of visits to a patient ranged from 3 visits at one site to 15 at another, with an average of 7. The average number of home visits during the first 4 months of this project was 164. This means that on average every CCG looked after 23 patients per month, but at two sites they were actually dealing with many more ( $N = 53$ ). A realistic number may be 30 patients per CCG, and this estimate will be used to calculate the cost per patient of the CCG's contribution to the model.

While many of the disposable items used by the hospices for HBC were donated, their cost was calculated using current

**Table I. Average monthly costs (R) of HBC by component**

Community caregivers (all sites)	3 146
Disposables (all sites)	889
Clerical support (all sites)	401
Professional staff (all sites)	2 489
Travel	
Sites without vehicle	801
Site with vehicle	4 000
Total cost per month	
Sites without vehicle	7 098
Site with vehicle	10 995

market prices. These items include soap, toilet paper, tissues, linen-savers, nappies, gloves, creams and disinfectants.

Clerical support for HBC varied from 2 hours to 16 hours per month across sites, costed at the salary of a middle-level administrative officer (R68 069) per annum. Professional staff provide supervision and training, and at certain sites professional social workers who support HBC clients.

Travel costs vary considerably depending on the type of transport used, which ranged from CCGs using a dedicated vehicle (with a monthly running cost of R4 000) to one site which provided care only for those clients who could be reached on foot with virtually no use of public transport (at a monthly cost of R34). Obviously, cost must be balanced against accessibility, and in many rural areas significant travel costs must be expected.

To these monthly costs must be added the replacement cost (R151 806) of a new 4 x 4 vehicle (where applicable), which can be depreciated over a 5-year life.

Based on a 'typical' caseload of 30 patients per team, the average cost per patient per year of the ICHC HBC model is as follows: (i) site with vehicle R5 060; and (ii) site without vehicle R2 840.

#### Summary of full health system costs

The total cost per patient per year for providing palliative care for PWAs using the ICHC HBC model is therefore as follows: (i) hospital costs R2 522 (39%); (ii) PHC clinic costs R1 154 (18%); (iii) ICHC HBC costs R2 840 (43%); and (iv) total costs R6 516.

Where a vehicle is provided for CCGs, the total cost per patient increases to R8 011.

#### PROJECTED COSTS FOR THE COUNTRY

As the AIDS epidemic increases in magnitude, the need for affordable terminal care services will inevitably expand greatly. A simple model of the likely costs to the State of expanding the ICHC model of palliative care to meet these needs is presented here. The model illustrates the costs of providing palliative care for the last month of life only for PWAs. The model therefore

reflects a highly restricted use of HBC for end-stage terminal care, and does not attempt to model broader applications of HBC, e.g. for the management of opportunistic infections. However, many PWAs die without receiving even basic palliative care, so that the limited application of HBC modelled here would still represent a major improvement on current service provision.

#### Epidemiological data and scenarios

It is not our purpose to enter the ongoing debate on approaches to forecasting HIV and AIDS cases. Rather we use one such projection to illustrate the possible costs of the ICHC model, acknowledging the uncertainty inherent in any projection of the future. We have used Kinghorn and Steinberg's<sup>9</sup> projection of AIDS deaths from 1998 to 2010, which estimates an increase in number of deaths from 127 077 to 591 106 over that period.

These estimates are combined with the cost data already presented on the ICHC model in three scenarios, which indicate the likely costs of using the model to provide terminal care for the last month of life for all PWAs in South Africa. In all scenarios, the model reflects set-up costs falling in the year 2000, with teams becoming operational in 2001.

#### Scenario 1 — comprehensive

In this scenario ICHC care is provided for every PWA for the last month of life. One team provides care for 30 patients for 1 month each, i.e. 360 patients per year. Ten per cent of teams in the most remote rural areas are provided with a vehicle, while all other teams operate on foot. Vehicle costs are included as set-up costs, and vehicles are assumed to operate for 5 years, after which time they need to be replaced (incorporated in the model at year 6).

#### Scenario 2 — hospitalisation instead of vehicle

This scenario is the same as scenario 1, except that no vehicles are provided in the most rural areas. For the 10% of patients in these areas, ICHC is not provided, but patients are assumed to be hospitalised for 1 week only in a district or regional hospital.

#### Scenario 3 — volunteer CCGs

This scenario is the same as scenario 2, but it assumes that CCGs are not paid in order to show the impact of remuneration on costs.

#### Model results

In scenario 1, following set-up costs of R24 million in the year 2000, government would face an additional cost of R65.7 million to operate ICHC model home-based terminal care in 2001, rising to R141 million by 2010 as the workload increases. In scenario 2, eliminating vehicles (and assuming that 10% of PWAs will therefore not be able to access HBC) has a relatively limited impact on costs, decreasing initial set-up costs to R15.5 million and 2001 operating costs to R57.8 million (rising to



R126 million by 2010). The assumption in scenario 3 that CCGs receive no pay reduces the costs of HBC significantly, but even if CCGs were unpaid volunteers, it would still cost the government R37 million to operate such a scheme in 2001, rising to R77 million in 2010 (Fig. 1).

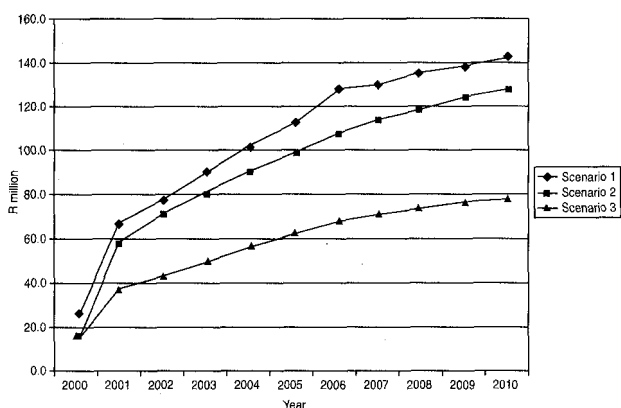


Fig. 1. Home-based care costs only.

When hospital and PHC clinic costs are incorporated, including the assumption that the 10% of patients who cannot access ICHC care in scenarios 2 and 3 are hospitalised for 1 week, a different picture emerges (Fig. 2). In scenario 1, the combined cost of hospital, clinic and HBC rises from R146 million in 2001 to R345 million in 2010. In contrast, combined health care costs rise in scenario 2 from R197 million in 2001 to R446 million in 2010 because of the extra hospitalisation resulting from incomplete coverage by HBC. Indeed, extra hospitalisation costs more than offset the 'savings' from using unpaid CCGs in scenario 3. Thus scenario 1 emerges as the cheapest option for providing terminal care to all PWAs when total health system costs are considered.

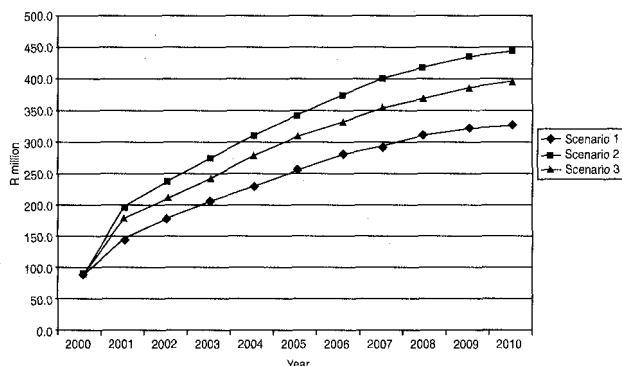


Fig. 2. Combined hospital, clinic and ICHC costs.

LIMITATIONS

Particular limitations in our data need to be pointed out:

1. The HBC component had only functioned for an average of 4 months at the time data were collected. HBC was therefore still in its implementation phase, and the data might not reflect the utilisation rates which one could expect from fully matured services.
2. The CCG data do not differentiate levels of illness or care needs within the client caseload, making it difficult to extrapolate with certainty from the workload data collected in this study.
3. Many of the cost calculations are based on average figures from one area, and not on national data.

The model presented above considers the provision of terminal care in the last month of life only, which is a highly restricted case. It therefore cannot directly answer questions on the wider application of HBC in providing treatment for opportunistic infections, substituting for hospital admission for symptomatic care, or the use of HBC to ensure compliance with long-term drug regimens, such as TB DOTS (directly observed therapy short course), or antiretroviral therapy.<sup>10</sup> Reliance on a single projection of AIDS mortality, and the use of only three scenarios also clearly limit the model's reliability. More importantly, though, our lack of data on the care actually available to PWAs in the absence of HBC is a major limitation on our understanding of this issue.

CONCLUSION AND RECOMMENDATIONS

Our simple model indicates how sensitive health system costs are to the assumption that HBC can avoid hospitalisation. Simply assuming that 10% of PWAs could not be given home care, and were therefore hospitalised, translated apparently cost-saving measures (i.e. withholding vehicles, not paying CCG salaries) into major extra costs. Care must therefore be taken in planning further implementation — restricting coverage could, if it leads to hospitalisation, possibly increase rather than reduce costs. If PWAs are not hospitalised in the absence of HBC, however, health system costs would be quite different, underscoring the considerable importance of determining exactly what care PWAs actually receive in different settings around the country.

Nonetheless, important questions remain. Scenario 1 would require an additional R66 million to implement in 2001 — less than 0.3% of current national and provincial spending, and therefore apparently quite affordable. Yet one must ask whether providing only 1 month of terminal care is really acceptable in quality terms — certainly, the ICHC sites provide care of significantly longer duration to their current clients. Indeed, the model of HBC being developed by government at present places a substantially wider range of tasks within the



remit of HBC. Not only does the government model incorporate longer-term treatment and care for opportunistic infections, but also several important social welfare functions (e.g. assisting with access to social welfare benefits, supporting carers, identifying children at risk of becoming orphans, supporting child-headed households). This wider range of tasks requires a substantially more expensive HBC team, but one that delivers greater benefits to clients.

The Centre for Health Policy's study found the South Coast ICHC programme to be relatively expensive when compared with other organisational models for HBC. This probably reflects both the relatively 'formal' nature of hospice services, with significant professional nurse input and high training levels among CCGs, and the relatively higher intensity of care required in the last weeks of life. Across the ICHC sites, data showed that on average the utilisation of services over 3 months per patient was as follows: 2.6 days in hospital, 2.7 hospital outpatient visits, 3.4 clinic visits, and 21 home visits. This shows a pleasing downward trend towards greater use of more economical services. However, 43% of patients died in hospital even with the model in place, indicating that hospitalisation can be limited but not eliminated. Projections showed that even a modest increase in hospital utilisation increases costs dramatically. It is impossible to say whether the model limits hospitalisation significantly, since no comparative data are available.

A number of conceptual problems pose particular difficulties in researching community-based alternatives to hospital,<sup>11</sup> especially relating to the choice of appropriate comparators and the specific context in which HBC schemes are being promoted. While highly suggestive of an important role for HBC in relation to AIDS in South Africa, neither our results nor those of the Centre for Health Policy provide a comprehensive answer to the questions of precisely when and where HBC can most cost-effectively substitute for hospital services. As HBC services develop in more sites nationwide, it will be essential that researchers explore the following:

1. Comparison of the utilisation of services at sites where the model has and has not been implemented, and of the actual impact of HBC on hospitalisation.
2. Comparison of clinic and hospital costs at sites where HBC does and does not exist, in order to provide firmer estimates of the additional costs and/or savings associated with HBC.
3. The feasibility and desirability of integrating HBC with other activities of community health workers, such as DOTS.
4. Longitudinal studies to establish the duration and utilisation of HBC for the average client. This has not been possible over the short period of this study (10 months). Without knowing how long a person needs HBC, it is difficult to calculate cost realistically.

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