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Health and economic impact of HIV/AIDS on South African households: a cohort study

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Published: 1 April 2003

Received: 29 October 2002

BMC Public Health 2003, **3**:14

Accepted: 1 April 2003

This article is available from: <http://www.biomedcentral.com/1471-2458/3/14>

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Abstract

Background: South African households are severely affected by human immunodeficiency virus / acquired immunodeficiency syndrome (HIV/AIDS) but health and economic impacts have not been quantified in controlled cohort studies.

Methods: We compared households with an HIV-infected member, and unaffected neighbouring households, in one rural and one urban area in Free State province, South Africa. Interviews were conducted with one key informant in each household, at baseline and six months later. We studied 1913 members of 404 households, with 94% and 96% follow up, respectively. Household and individual level analyses were done.

Results: Members of affected households, compared to members of unaffected households, were independently more likely to be continuously ill (adjusted odds ratio (OR) 2.1, 95% CI 1.3–3.4 at follow up), and to die (adjusted OR 3.4, 95% CI 1.0–11), mainly due to infectious diseases. Government clinics and hospitals were the main sources of health care. Affected households were poorer than unaffected households at baseline (relative income per person 0.61, 95% CI 0.49–0.76). Over six months expenditure and income decreased more rapidly in affected than in unaffected households (baseline-adjusted relative expenditure 0.86, 95% CI 0.75–0.99 and income 0.89, 95% CI 0.75–1.05). Baseline morbidity was independently associated with lower income and expenditure at baseline but not with changes over six months.

Conclusions: HIV/AIDS affects the health and wealth of households as well as infected individuals, aggravating pre-existing poverty.

Background

HIV/AIDS is now the leading cause of death in South Africa. [1] The Free State province, in which this study was conducted, has a population of 2.7 million, and is fairly average among South African provinces with regard to general health and economic status.[2] In 2001 30% of pregnant women attending Free State government antena-

tal clinics were infected with HIV compared to 25% for all South African provinces.[3] In parallel with increasing HIV prevalence, tuberculosis incidence has increased dramatically in recent years, affecting especially the 20–40 year age band, and tuberculosis case fatality rates have increased rapidly, all presumably due to HIV. [2,4] Epidemiological models predict that HIV prevalence in South

Africa is currently near its plateau, but that most AIDS cases and deaths have still to occur. [1]

A cornerstone of the South African government's HIV/AIDS policy is to develop home based care.[5] But the ability of affected South African households to care for ill members is not well understood, and is likely to deteriorate with time, as members become ill, lose employment, use household resources and die. Financial and logistical planning of social support and health services for households affected by HIV/AIDS clearly needs to be based on valid epidemiological and economic information.

Internationally, studies estimating effects of HIV on households are often impaired by a lack of longitudinal data and of unaffected comparison populations.[6] Changes within households affected by HIV cannot necessarily be attributed to HIV itself but could reflect population-wide changes, especially during rapid political, demographic and economic change. It is thus necessary to compare households affected by HIV with appropriate control populations and followed over time.[6] The present study aimed to do this. The aims of the study were to compare the physical, logistic and economic burdens of illness between households affected by HIV and unaffected neighbouring households, and to compare changes in households' incomes and expenditures, in two poor urban and rural settings in South Africa.

Methods

The study had a controlled cohort design, with individual- and household-level data from households affected and unaffected by HIV, gathered at baseline and six months later. The study population comprised members of households affected by HIV and, for each household, the closest unaffected neighbouring household, in one urban and one rural area in the Free State province of South Africa. Affected households were defined as all residents (members) of a dwelling in which at least one member was known to have HIV at the start of the study, or to have HIV and to have died less than six months before the start of the study. Unaffected households were defined as neighbouring households where no-one was known to have HIV, tuberculosis or pneumonia. The urban area was Welkom / Thabong, a mining town including wealthy, middle income and poor residential areas. The rural area was Qwa Qwa, a former apartheid homeland, with relatively high rates of poverty and unemployment, high population density and poor service provision. Our sampling frame entailed that the study population comprised mainly low income African households.

Affected households were defined by identifying HIV infected individuals obtaining care from the local AIDS Training and Information Centres, which are the main

community based HIV counselling and testing services in the province. Subjects known to have HIV were asked by Centre staff for informed verbal consent for their households to take part in the study, on condition that their HIV status was not disclosed to other household members. Eligible affected households were then visited, and the head of each household was asked for informed verbal consent to take part in the study. Unaffected households were then identified as a home physically near to each affected household, and were approached in the same way. To decrease the chance of misclassifying unaffected households, if anyone in the neighbouring household was currently being treated for tuberculosis, or had been admitted to hospital for pneumonia in the past month, then that household was excluded from the study and the next nearest household was approached instead.

Data were collected using interviewer-administered questionnaires. Each household had one informant, who was the person primarily responsible for household finances. The design of the instrument was informed by a literature review of household impact research methods, [6] focus group interviews with key informants, and piloting. The questionnaire included questions on the demographic, economic and health characteristics of a household and its individual members. Economic questions covered employment (11 items), income (22 items), expenditure (17 items), savings (7 items), debt (26 items), assets (16 items) and borrowing (5 items). These data were used to calculate monthly household income and expenditure. Income and expenditure were also calculated as per person and adult equivalent indices. Adult equivalent income was calculated as $(\text{household income}/n^{0.6})$, where n is the household population size, and accounts for the lower cost of children in a typical household.[7] Health questions included whether anyone in the household had been continuously ill during the past month or had died during the past six months. For each ill or dead individual, we asked about their diagnosis, severity of illness, source and cost of health care, impact on their income, nature of home care provided, and the logistical and financial burden of caring.

Questionnaires were drafted in English and translated into Sesotho and Xhosa. Ten interviewers were trained and issued with training and instruction manuals. Questionnaires were administered during mid-2001 and six months later. Data collection was supervised by a field work manager and a data editor at each site. If informants were not at home at the time of interview, or if questionnaires were returned with missing data, interviewers returned to the households up to five times.

Statistical analyses were conducted at household and individual levels with Stata software.[8] The demographic

Table 1: Demographic and economic characteristics of households at baseline

	Urban		Rural		Combined		P*
	Affected	Unaffected	Affected	Unaffected	Affected	Unaffected	
Household members	(n = 571)	(n = 455)	(n = 454)	(n = 429)	(n = 1029)	(n = 884)	
Age. (median (IQR) in years)	22 (10–37)	22 (12–37)	21 (11–35)	22 (11–39)	21 (11–36)	22 (12–39)	0.22
Females as % of members	57	54	60	60	58	57	0.55
Household composition	(n = 101)	(n = 100)	(n = 101)	(n = 104)	(n = 202)	(n = 204)	
Household size (mean)	5.6	4.6	4.5	4.1	5.1	4.3	0.002
Nuclear family as % of members (mean)	74	83	72	81	73	82	<0.001
Dependency* ratio (mean)	37	32	34	34	35	33	0.310
Percentage of household employed (median [IQR])	17 [0–29]	20 [5.6–47]	0 [0–20]	0 [0–25]	11 [0–25]	20 [0–33]	0.0025
Household monthly income and expenditure (South African Rands)	(n = 99)	(n = 100)	(n = 95)	(n = 99)	(n = 194)	(n = 199)	
Average income							
Per household (mean)	1630	2692	948	1596	1296	2147	0.001
Per person (mean)	335	741	232	417	285	580	<0.001
Per adult equivalent person (mean)	614	1211	397	694	508	954	<0.001
Average expenditure							
Per household (mean)	1178	1414	627	968	900	1187	0.035
Per person (mean)	244	373	157	266	200	319	<0.001
Per adult equivalent person (mean)	445	619	264	435	354	525	0.002

IQR Interquartile range. * Affected vs. unaffected with χ^2 or rank sum tests. ** Dependency ratio = proportion aged under 15 or aged 65 years and over

composition, health status and economic status of households and their members were compared between affected and unaffected households, and between baseline and follow up surveys, using χ^2 or exact tests for proportions, and the t test or rank sum test for continuous variables. Multiple regression was used to identify the independent effects on health status and on economic status of affected versus unaffected status, rural versus urban location, and other household and individual characteristics. Logistic regression was used for binary outcomes and linear regression was used for continuous outcomes. Income and expenditure had positively skewed distributions and were logarithmically transformed before linear regression. Changes in income and expenditure over 6 months were analysed in linear regression models using analysis of covariance, that is, with follow up values as outcomes and with the respective baseline values as explanatory variables.[9] The antilogs of the coefficients (and 95% confidence limits) from the latter models represent the ratios between affected and unaffected households. Regression analyses conducted at individual level were adjusted for intra-household clustering of outcomes, using Stata's "cluster" option.[8]

The study protocol was approved by the University of the Free State's Research Ethics Committee. Informed consent was obtained from the person known to have HIV in each affected household, and from the questionnaire respondent in each household. Confidentiality of households'

and individuals' identities was maintained. Each participating household was issued with a food voucher worth 300 Rand (about US\$30) after the second interview.

Results

We obtained baseline information from 202 affected households with 1029 members, and from 202 unaffected households with 884 members (Table 1). Of the 404 baseline households, 387 (96%) were followed up, providing repeated measure data on 94% (1805/1913) of baseline individuals. Affected and rural households tended to be larger and poorer and to have lower employment rates than unaffected and urban households. Affected households' incomes per person were about half of, and their expenditures per person were about a third lower than, unaffected households. Affected households were 10% more likely to have members from outside the nuclear family, but did not differ in age or gender composition.

Table 2 shows the prevalence of continuous illness during the past month, and of deaths during the past 6 months, among households and individuals. Affected households, and their members, were more likely to experience any illness, infectious disease, hospital admission and death. The biggest differences were in illness due to serious infectious disease (defined here as HIV/AIDS, tuberculosis, meningitis or pneumonia), and in deaths. Both affected status and rural location were associated with morbidity and mortality, but did not interact. Morbidity and death

Table 2: Period prevalence of illness and death among households and individuals, at baseline and after 6 months

	Urban		Rural		All		P*
	Affected n/N (%)	Not affected n/N (%)	Affected n/N (%)	Not affected n/N (%)	Affected n/N (%)	Not affected n/N (%)	
Continuously ill in the last month							
Households							
Baseline	61/79 (77)	18/89 (20)	82/114 (72)	19/103 (18)	143/194 (74)	37/194 (19)	<0.001
Follow up	46/79 (58)	12/92 (13)	57/114 (50)	17/100 (17)	103/194 (53)	29/193 (15)	<0.002
Individuals							
Baseline	54/571 (9.5)	21/455 (4.6)	63/454 (14)	11/429 (2.6)	205/1022 (20)	55/884 (6.2)	<0.001
Follow up	96/565 (17)	23/460 (5.0)	108/450 (24)	3/443 (0.7)	117/1064 (11)	32/889 (3.6)	<0.001
Continuously ill with HIV/AIDS, TB, meningitis or pneumonia in last month							
Individuals							
Baseline	36/671 (6.3)	1/455 (0.22)	51/454 (11)	2/429 (0.47)	87/1032 (8.4)	3/885 (0.34)	<0.001
Follow up	29/571 (5.1)	2/455 (0.44)	48/454 (11)	4/429 (0.93)	81/1032 (7.9)	7/885 (0.79)	<0.001
Severity of illness if ill (at follow up)							
Admitted to hospital	16/56 (29)	1/21 (4.8)	20/67 (30)	1/12 (8.3)	36/123 (29)	2/33 (6.1)	0.006
Unable to perform daily tasks	17/54 (32)	4/21 (19)	22/67 (33)	3/12 (25)	39/123 (32)	7/33 (21)	0.24
Not recovered	50/56 (89)	20/21 (95)	63/67 (94)	9/12 (75)	113/123 (92)	29/33 (98)	0.48
Died in the last 6 months							
Households							
Baseline	10/79 (13)	1/89 (1.1)	29/114 (25)	1/103 (1.0)	39/194 (20)	2/192 (1.0)	<0.001
Follow up	8/79 (10)	1/89 (1.1)	16/114 (16)	2/103 (2.0)	24/194 (12)	3/192 (1.6)	<0.001
Individuals							
Follow up**	13/571 (2.3)	2/455 (0.44)	13/454 (2.9)	3/429 (0.70)	26/1025 (2.5)	5/884 (0.57)	0.001

* All affected vs. all not affected using χ^2 test for morbidity and exact test for mortality. ** Individuals' risk of death not calculated at baseline because deceased were not part of denominator

were less frequent at follow up than at baseline, but the prevalence of serious infectious disease among members of affected households did not change, from 87 (8.4%) at baseline to 81 (7.9%) at follow up. Thirty nine affected households had experienced a death during the 6 months before the baseline survey, and another 26 in the subsequent 6 months.

The odds of illness were around 4 to 13 times higher for affected than for unaffected households, and were about 2 to 5 times higher among members of affected households (Table 3). For serious infectious disease the odds ratios ranged from 11 to 72. The odds ratio for death ranged from 3 to 21. Odds ratios were generally higher for household-level than for individual-level analyses. Affected:unaffected odds ratios were similar at baseline and at follow up. For illness due to serious infectious disease, however, odds ratios decreased markedly at follow up, partly because households with tuberculosis or pneumonia were excluded from the unaffected sample at baseline.

Statistical adjustment for age, sex, household income, rural versus urban location and household population size

either increased or did not affect the magnitude of odds ratios (Table 3). Further adjustment for the presence at baseline of the respective morbidity or mortality outcome tended to decrease the odds ratios for illness and death. Baseline illness was more strongly associated with illness at follow up in affected than in unaffected households (likelihood ratio P value for interaction term = 0.049). Among affected household the odds ratio for illness at follow up, comparing those ill to those not ill at baseline, was 18 (95% CI 11–28). Among unaffected households this odds ratio was 7.1 (3.0–16). The period prevalences of illness and death were similar in urban and rural areas, except that serious infectious disease was about twice as likely among rural than urban household members in all of the models shown in Table 3.

The diagnostic mix among people who were ill or died did not change between baseline and follow up. Of the 240 episodes of illness in affected households during the 12 months of observation, 166 (74%) were attributed to HIV/AIDS, tuberculosis, pneumonia or meningitis. The corresponding prevalence in unaffected households was 10/85 (12%). Of the 70 deaths in affected households

Table 3: Increased odds of illness and death in affected and unaffected households: logistic regression models

Outcome	Unit of analysis	Crude odds ratio	(95% CI)	Adjusted odds ratio**	(95% CI)	Baseline-adjusted odds ratio***	(95% CI)	P
Ill (baseline)	Household	6.1	(4.0 – 9.3)	13	(7.6 – 22)	NA		
Ill (follow up)	Household	6.4	(3.9 – 10)	6.3	(3.7 – 10)	3.8	(2.1 – 6.8)	<0.001
Ill (baseline)	Individual*	3.4	(2.2 – 5.3)	3.8	(2.4 – 5.9)	NA		
Ill (follow up)	Individual*	3.8	(2.6 – 5.6)	4.9	(3.2 – 7.5)	2.1	(1.3 – 3.4)	0.003
Ill with HIV/AIDS, TB, meningitis or pneumonia (baseline)	Individual*	27	(8.5 – 86)	72	(9.9 – 534)	NA		
Ill with HIV/AIDS, TB, meningitis or pneumonia (follow – up)	Individual*	11	(4.5 – 25)	11	(4.4 – 28)	21	(12 – 36)	<0.001
Died (baseline)	Household	4.7	(2.5 – 9.1)	21	(4.9 – 92)	NA		
Died (follow up)	Household	8.9	(2.6 – 30)	8.3	(2.3 – 30)	8.3	(2.2 – 31)	0.002
Died (follow up)	Individual*	4.6	(1.5 – 14)	5.0	(1.4 – 18)	3.4	(1.0 – 11)	0.04

* For individual level analyses, P values and 95% confidence intervals adjusted for intra-household clustering of outcomes ** Adjusted for age, sex, baseline household income, rural vs. urban location and, for household level analyses, household population size ***For follow up data, also adjusted for baseline value of outcome variable, i.e. individuals' previous illness or previous death in their household. NA Not Applicable

during all 12 months covered by the study, 24 (34%) were attributed to HIV/AIDS, 16 (23%) to tuberculosis, 10 (14%) to pneumonia and 4 (6%) to meningitis and 16 (23%) to other or unknown causes. Five people died in unaffected households during the 12 months covered.

The main sources of health care among 325 ill individuals in affected households, at baseline or follow up, were government clinics (45%), government hospitals (29%), and private doctors (16%). The main sources of health care among 64 individuals in affected households who died, at baseline or follow up, were government hospitals (59%), government clinics (20%), traditional healers (13%) and private doctors (11%). Ill members of affected households were three times as likely to use hospitals as ill members of unaffected households (29% vs. 10% of visits), indicating more severe illness

Ill members of affected households required more caring support from their households than did ill members of unaffected households. At follow up, 35% (71/202) of affected households had needed someone to accompany an ill member to a health service, compared to 6.4% (13/202) of unaffected households (P < 0.001). Among households with ill members, the median number of hours that home carers spent with ill people was 5 hours (interquartile range 4–7) per day for affected households, and 3.5 (3–5) for unaffected households (P = 0.06). The corresponding figures for people who died were 5 (5–7.5) and 6.5 (6–10.5) hours per day (P = 0.18).

Table 4 shows the relationships between economic indicators and households' affected status. Affected house-

holds had significantly lower incomes and expenditures at baseline. At follow up, baseline-adjusted incomes and expenditures were also lower in affected households, indicating more rapid decreases over six months. Although the latter relative incomes were not statistically significant, they were of similar magnitudes to relative expenditures. Addition of morbidity and mortality to these models reduced the relative differences and made them statistically non-significant. Depending on the indicator, affected households' incomes and expenditures were between 12% and 29% lower than unaffected households at baseline, and 9% to 19% lower at follow up, independent of their members' age, sex, and employment or urban or rural location.

Households with any ill members during the previous 6 months had incomes and expenditures that were independently 14% – 26% lower than households with none (Table 5). Baseline morbidity and mortality were however not independently associated with income or expenditure at follow up. Affected status did not significantly modify the effect of illness on income (that is, there was no significant interaction). Baseline income and expenditure were significantly lower in rural than in urban households in all regression models. To examine possible sampling biases caused by our exclusion of houses experiencing tuberculosis or pneumonia at baseline, we repeated these analyses excluding all households with either illness at baseline. This very slightly increased the income and expenditure ratios between affected and unaffected households, but did not render significant differences non-significant, nor vice versa.

Table 4: Ratios between affected and unaffected households' income and expenditure: linear regression models

Outcome	Crude model			Adjusted for household demography and employment*			Adjusted for household demography, employment, morbidity and mortality**		
	Ratio Affected: Unaffected	(95% CI)	P	Ratio Affected: Unaffected	(95% CI)	P	Ratio Affected: Unaffected	(95% CI)	P
Baseline									
Household income	0.71	(0.57 – 0.88)	0.002	0.80	(0.65 – 0.97)	0.024	0.84	(0.65 – 2.09)	0.17
Income per person	0.61	(0.49 – 0.76)	<0.001	0.75	(0.62 – 0.89)	0.002	0.85	(0.68 – 0.48)	0.18
Adult equivalent income per person	0.65	(0.52 – 0.80)	<0.001	0.77	(0.64 – 0.92)	0.004	0.85	(0.67 – 1.07)	0.16
Household expenditure	0.78	(0.64 – 0.95)	0.013	0.82	(0.68 – 0.99)	0.036	0.89	(0.70 – 1.14)	0.31
Expenditure per person	0.68	(0.56 – 0.83)	<0.001	0.78	(0.66 – 0.47)	0.05	0.92	(0.74 – 1.12)	0.42
Expenditure per adult equivalent	0.72	(0.59 – 0.87)	0.001	0.80	(0.67 – 0.94)	0.009	0.90	(0.73 – 1.14)	0.36
Follow up#									
Household income	0.92	(0.77 – 2.50)	0.35	0.91	(0.77 – 1.07)	0.25	0.94	(0.75 – 1.17)	0.56
Income per person	0.90	(0.76 – 1.07)	0.24	0.89	(0.75 – 1.05)	0.17	0.95	(0.76 – 1.19)	0.68
Adult equivalent income	0.90	(0.76 – 1.07)	0.24	0.89	(0.76 – 1.05)	0.16	0.94	(0.76 – 1.18)	0.61
Household expenditure	0.85	(0.74 – 0.97)	0.02	0.85	(0.75 – 0.98)	0.02	0.88	(0.73 – 1.05)	0.16
Expenditure per person	0.85	(0.74 – 0.98)	0.03	0.86	(0.75 – 0.99)	0.04	0.92	(0.77 – 1.11)	0.38
Expenditure per adult equivalent	0.85	(0.74 – 0.97)	0.02	0.85	(0.75 – 0.98)	0.02	0.90	(0.76 – 1.08)	0.26

Adjusted for the respective baseline income or expenditure variable in all follow up models * Adjusted for urban or rural location, age and gender composition and percentage of household members employed. ** Adjusted further for baseline morbidity and mortality and, for follow up analyses, mortality and morbidity at follow up

The regression models shown in Table 4 accounted for up to 38% of the variances in the logs of baseline incomes and expenditures. For these analyses, R² values ranged from 1.5% to 5% for crude models, and from 16% – 37% for age-, sex- and employment-adjusted models; further adjustment for baseline morbidity or mortality increased R² values by about another 1%. The percentage of household members in employment accounted for 13% – 25% of the variances in baseline income and expenditure in these models.

To elucidate the mechanisms of the economic effects of HIV/AIDS, we examined relationships between health, employment, income and expenditure over time. Employment rates among members of affected and unaffected households aged over 15 years were, respectively, 21% and 31% at baseline, and 21% and 29% at follow up, accounting for much of the differences in income and expenditure. Changes in the number or percentage of individuals employed per household were however not associated with morbidity or mortality, nor with affected status at baseline or at follow up, and accounted for only 0.5% of the variance in household income at follow up. Baseline income was associated with morbidity at follow up (relative income 0.70 (95%CI 0.56–0.89), P = 0.003, R² = 2.3%) to a similar extent as was baseline morbidity associated with income at follow up (relative income 0.77

(95%CI 0.62–0.96), P = 0.02, R² = 1.4%), suggesting that the influence of income on morbidity is of a similar order of magnitude as the influence of morbidity on income.

Discussion

The study quantifies the higher morbidity and mortality among selected South African households affected by HIV, and their impact on household economies. It is to our knowledge the only such evidence from a South African controlled cohort study. The study shows that affected households, compared to their neighbours, tended to be larger, poorer, and to have lower employment rates. It should be stressed that the term "unaffected household", used in this study for convenience, does not entail that neighbours were not at all affected with HIV, which clearly has pervasive effects throughout the population. Illness within households at baseline was independently associated with lower baseline income and expenditure. Over six months household expenditure decreased significantly more rapidly in affected than in unaffected household (Table 4). Income also declined more rapidly, although this was marginally non-significant. Some economic effects of HIV are likely to take longer than a year to occur, and so we intend to follow these households for at least another two years.

Table 5: Ratio of baseline income and expenditure between households with and without any ill members at baseline: linear regression models*

Outcome	Ratio	(95%CI)	P
Household income	0.84	(0.67 – 1.05)	0.12
Income per capita	0.74	(0.58 – 0.93)	0.009
Adult equivalent income per capita	0.78	(0.62 – 0.97)	0.024
Household expenditure	0.81	(0.66 – 1.00)	0.052
Expenditure per capita	0.70	(0.57 – 0.87)	0.001
Adult equivalent expenditure per capita	0.74	(0.61 – 0.91)	0.005

* Adjusted for age, gender, employment, affected/unaffected and urban/rural, as in Table 4.

The results are consistent with results of similar HIV impact studies in Africa and Asia. The morbidity pattern is similar to that reported in other South African case series.[4] Decreased household income following deaths due to AIDS has been shown in Zambian [10] and Thai [11] studies. Other studies have generally not examined decreased income resulting from illness, rather than from death, except for a Zambian study.[10] Our finding that per capita incomes in households with at least one ill member were independently 26% lower than in households with none (Table 5), thus provides original evidence of the economic impact of morbidity on households. Like studies in Tanzania,[12] Uganda [12] and Thailand,[11] however, we did find a higher dependency ratio in affected households, although this was not statistically significant.

HIV appeared to affect income more than expenditure, presumably because HIV imposes additional costs on households, most important of which are health care and funeral costs. The importance of these costs has previously been shown in Rwanda,[13] Ivory Coast,[12] Uganda,[12] Ethiopia[14] and Tanzania,[14]. Few other studies have precisely quantified household costs of health care, however, an exception being a Rwandan study.[13] A striking finding in our study was the high cost of funerals compared to the low cost of free government health services.

Methodological limitations must be considered. HIV infected individuals within households could not be identified, because of confidentiality concerns. Although index cases gave consent for their households to be approached for interview, several did not wish the interviewee to be informed that they had HIV, presumably to avoid stigma within the home. Interview data did not permit linkage with identities of index cases. However illness or death due to HIV/AIDS, tuberculosis, pneumonia or meningitis, which were often specified in affected households, pro-

vided good indicators of AIDS. Food vouchers were only offered to interviewees once they had consented to participate in the baseline study, and were not offered to index cases, so this offer would not have biased the sample by selectively including the poorest households. The sampling frame, based in one service organisation, meant that the results cannot be automatically generalised to other populations. Because of limited HIV testing, and confidentiality requirements for HIV screening, a comprehensive sampling frame was not available. Instead we aimed to maximise internal validity by comparing affected households with their neighbours. The substantial disease burden and economic changes among unaffected households highlight the need for comparison populations in HIV impact studies. Index cases were identified among clients seeking help from an AIDS Training and Information Centre. They were thus more likely already to have symptoms than were all HIV infected individuals, as reflected in the frequency of illness and death. Thus this study probably largely reflects the experience of households affected by symptomatic HIV infection, which would be more severe than that of households in which someone was infected but still asymptomatic. Unfortunately, the number and characteristics of all potential index cases who were invited to take part in the study were not recorded, so the extent of response bias could not be determined. "Unaffected" households may have, without our knowledge, included members with HIV. Misclassification of affected households as unaffected would have reduced the strength of association between affected status and health or economic variables. Conversely, by excluding potentially unaffected households experiencing tuberculosis or pneumonia at baseline, we may have exaggerated the morbidity difference between affected and unaffected households. Secondary analysis provided reassurance that such bias, if present, would have been slight. Finally, the short duration of follow up precluded identification of longer-term trends which future survey rounds are intended to detect.

What are the mechanisms by which HIV causes poverty, and by which poverty causes HIV infection? We did not find unemployment mediating between HIV infection and poverty but this may be because the unemployment rate in affected households at baseline (79%) was already so high. Longitudinal studies can potentially distinguish causes from effects by examining their sequence, but we did not clearly show a dominant temporal direction of effect between poverty and illness. By continuing the study with six-monthly follow up for a total of three years we aim to elucidate these puzzles. We suggest that future similar studies should sample a higher proportion of middle income households, in order to detect possible changes in employment and income that were undetectable in this very poor population.

The study has several implications for health and social policies. It quantifies poverty among affected households, and the compounding effects of illness. This raises questions about how social welfare policies can target the most vulnerable households – the study suggests that health services may be an appropriate starting point for many. The study shows the importance of free government clinics and hospitals in providing care, and in avoiding poverty or barriers to access caused by user fees. These services should be protected. It shows that households already provide a substantial amount of home-based care for ill members. The high unemployment rate meant that caring for ill members rarely led to lost income among carers. The government policy of supporting home-based care by training and employing lay carers from low income communities, currently being implemented in South Africa, could simultaneously introduce government money into poor communities, and provide an appropriate level of palliative care.

Conclusions

In one poor rural and one poor urban area of the Free State, South Africa, households affected by HIV had a higher burden of illness and were substantially poorer than their neighbours. Affected households' income and expenditure declined more rapidly during 6 months of follow up. Government hospitals and clinics, and members of affected households, are all important providers of essential care and so their support should be a priority.

Competing interests

None declared.

Authors' contributions

Both MOB and FLRB were centrally involved in the design, analysis, interpretation and writing up of the study. FLRB calculated the economic indices and MOB conducted the regression analyses. Both authors have read and approved the final manuscript.

Acknowledgements

We are grateful to the United States Agency for International Development for financial support and to HCJ van Rensburg, M Engelbrecht, F Steyn and K Meyer for assistance with instrument design and data collection. The authors are responsible for this report.

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Pre-publication history

The pre-publication history for this paper can be accessed here:

<http://www.biomedcentral.com/1471-2458/3/14/prepub>

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