High AIDS-related mortality among young women in rural KwaZulu-Natal

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Objective. To establish mortality rates and cause of death in a rural community in KwaZulu-Natal. This study was conducted as part of a demographic and health survey to assess the impact of HIV infection in this community.

Methods. A cross-sectional survey was conducted between February and July 2004. The survey made use of structured questionnaires and verbal autopsies, which yielded detailed information at household level, including the demographic profile of residents, mortality rates and cause of mortality between February 2003 and February 2004.

Results. The overall mortality rate in this community was 2.9 deaths per 100 person-years (95% confidence interval (CI): 2.5 - 3.3 per 100 person-years). The highest mortality rate among women occurred in the 30 - 34-year age group, while among men it occurred in the 35 - 39 and > 60-year age groups. Of the 185 verbal autopsies reported, 77 deaths (42%) were attributable to AIDS. The survey revealed that women aged 20 - 24 and men aged 35 - 39 years were bearing a disproportionately large burden of AIDS-related mortality in this community.

Conclusion. AIDS-related mortality was found to be disproportionately high in young women in this small rural community, and the majority of deaths resulted from pulmonary tuberculosis. The need to strengthen prevention and treatment efforts in this and similar settings is highlighted.

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KwaZulu-Natal (KZN) is at the epicentre of the HIV epidemic in South Africa.[1] As the HIV/AIDS epidemic has matured there have been anecdotal accounts of an increase in AIDS-related deaths. However, few systematically collected data exist on cause or number of deaths, especially in rural communities. This information is an important planning tool in terms of prioritising resource allocation, identifying level of household vulnerability, and assessing impact of prevention and treatment programmes.

In South Africa, mortality data are generally unreliable; this problem is more pronounced in rural communities where the dead are frequently buried at home and death certificates and hospital records are often not accessible or do not exist. Additionally, AIDS-related deaths are frequently misclassified and attributed to other causes, in the belief that benefits such as pensions and life insurance payouts may be withheld if it is known that the cause of death was AIDS-related.[2] Therefore in many instances the opportunistic infection present at the time of death is more likely to be recorded as the cause of death.[2,3] According to a technical report prepared by the South African Medical Research Council,[4] death registration improved from 54% in 1990 to 89% in 2000, although underreporting persists in rural areas and with regard to patients without government-issued personal ID numbers.

An additional problem relates to major differences in mortality rates and cause of mortality being reported because of differences in classification of cause of death.[2] For example, the Medical Research Council report[4] estimated that between 17% and 25% of adult deaths in 1999/2000 were possibly AIDS-related. In contrast, data from Statistics South Africa showed that only 7 - 8% of deaths between 1999 and 2000 were recorded as AIDS-related.[5]

Use of verbal autopsies (VAs) has been one strategy adopted to establish cause of mortality, although validation of its use in adult populations remains limited.[6] Depending on the signs and symptoms of the illness preceding death, this method may yield under- or overestimates of the cause of death. The sensitivity of VAs in detecting AIDS deaths in other rural African settings, when administered by trained lay personnel, ranges from 42%[7] to a theoretical maximum of 100%.[6] Notwithstanding these limitations, it is probably the best tool currently available to assess cause of mortality.

The purpose of this study was to establish mortality rates and cause of death between February 2003 and February 2004 in a rural KZN community. The study was conducted as part of a demographic and health survey to assess the impact of HIV infection in this community.

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Methods

Study setting

Vulindlela is a rural community situated about 150 km west of Durban. The 8 primary health care (PHC) clinics are nurse-managed public-sector health centres providing comprehensive primary care. The clinics provide family planning (FP) services, including male condom distribution, syndromic treatment of sexually transmitted infections (STIs), antenatal care, early childhood services, treatment of opportunistic infections, and voluntary testing and counselling services. The PHC clinics are linked by ambulance to the regional referral hospitals, viz. Grey's Hospital (about 30 minutes away), and Edendale Hospital (about 20 minutes away). There are approximately 60 organisations in the area representing a variety of civic interests such as youth, women, religion, politics, and housing. Several non-governmental organisations are currently providing HIV prevention and home-based care services to this community. In contrast to other rural areas in KZN, employment opportunities exist within Vulindlela through extensive forestry projects. In addition, men seek employment in the nearby urban centres of Pietermaritzburg and Howick. These men usually commute daily or live in Pietermaritzburg during the week and return home over the weekend. Women are also employed by the forestry projects and engage in communal income-generating activities such as gardening and sewing.

Study population

Precise data on population size, demographic characteristics of residents and number of households were not available. It was estimated that there were about 400 000 residents and about 61 500 households in the district.

For the purposes of this survey we restricted our activities to the Inadi ward, which is a subsection of the Vulindlela district, as this geographical area is closest to the Centre for the AIDS Programme of Research in South Africa (CAPRISA) Vulindlela Research Facility and would be the priority catchment area for proposed research to be undertaken by CAPRISA. As there were no clearly identifiable street addresses, the Department of Health statistics used for health planning purposes were used to estimate the number of households to be included in the survey. These statistics indicated that there were about 1 800 households and approximately 11 000 people living in this ward.

Establishing a sampling frame

Recent (2001) aerial maps of the area were utilised to demarcate the boundaries of the area to be included in this survey. These boundaries were confirmed by driving through the demarcated areas on the map with the fieldworkers and then creating 3 subsections for conducting the survey in a systematic way.

The 8 fieldworkers responsible for data collection visited every household in each subsection and generated a more precise map of the area; every household in the area was marked and the number of residents per household was recorded. The fieldworkers established that there were 1 686 households in this section of the Vulindlela district, with a total number of 10 986 residents. They also used this opportunity to inform households of the proposed survey, the purpose of the survey and the possibility that they may or may not be included in the survey depending on the final sampling method to be used.

The household data were subsequently used to draw a 50% sample of households to administer the household questionnaire. The first household was randomly selected and thereafter every alternate household was visited. The consenting head or most senior member of the household was interviewed. If there was no-one in the household over the age of 18 years or if the head of the household refused to participate in the survey this was noted, and the next household on the list was visited.

Study procedures

This cross-sectional study was conducted from February to July 2004. Data collection was undertaken using a modified version of the instruments used in the South African Demographic and Health Survey[8] and included closed and open-ended questions. The questionnaire was pre-tested before administration. The modifications took local language and knowledge of disease into account.

The questionnaire recorded data on number of occupants in the selected household, demographic characteristics of the occupants (including detailed information on children under 18 years of age), the type of dwelling, source of water, latrine facilities, number and types of appliances in the household, religious and social affiliations, general health status of occupants and mortality rates and cause of mortality in the past year.

The questionnaire was administered by trained fieldworkers. Initially 14 community health workers who had a thorough knowledge and understanding of the selected area were trained over a 14-day period. Training included role-playing and piloting of the instruments. Eight of these fieldworkers were selected to implement the study. The fieldworkers conducted the interviews at the household in pairs and visited the selected households in 2 groups of 4 each. Each team of 4 fieldworkers had a leader who took responsibility for resolving any queries in the field, recording the households visited from the sampling frame, checking the daily visit logs completed by the fieldworkers, and submitting weekly progress reports to the fieldwork supervisor.

The fieldworker introduced the study to the head of the household or most senior household member present. After providing written informed consent, the interview was conducted in privacy and in the language preferred by the interviewee (English or *isiZulu*).

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To prevent a skewed sample, the fieldworkers visited the households at different times and on different days of the week. However, as most interviews were conducted during the week, the sample may have been biased towards unemployed men and women. To ensure that the perceptions of employed people were included, 10% of interviews were conducted over weekends.

As part of the survey, respondents were asked if there had been any deaths in the household in the past 12 months. A brief structured VA questionnaire focusing on the AIDS-associated symptoms of the deceased was administered in the case of households where deaths had occurred. The questionnaire included specific questions on 11 different symptoms, and an unstructured section that allowed respondents to describe the deceased's illness in their own terms. This instrument was developed and pre-tested by one of the authors (MM).

Data management

The data were captured using EpiData version 3.0 (the EpiData Association, Odense Denmark, 2003 - 2004). Data were entered manually by a trained data encoder using a single data entry method. Each record had a unique record number, corresponding with the study number allocated to the household where the interviews occurred.

Data from the questionnaires were captured after on-site and off-site quality assurance procedures had been done to ensure completeness and consistency of the information.

Quality control

A check file was written to ensure that responses would be restricted to the options in the questionnaires only so as to minimise transcription error. This occurred at the time of data entry. Any queries or comments by the data encoder were recorded using the note facility, which date stamps the entry and automatically enters the record number, variable name and unique patient study number.

Any encoder queries were discussed with the statistician, who worked closely with the study site to resolve queries if necessary, after which the database was updated accordingly. At predetermined intervals the database was exported to Intercooled STATA 9.0 (Stata Corp, College Station, Texas, USA) and data quality was checked. Frequency and cross tabulations were also generated by the statistician. Any inconsistencies in data were then checked against the original questionnaire or resolved in discussion with the fieldwork supervisor.

Statistical methods

Univariate analysis of the data was undertaken using Statistical Analysis Software (SAS) version 9.1.3 (SAS Institute, Cary, NC, USA) As HIV serostatus data were not available for any of the deaths, deaths were deemed to be HIV-related if they could be attributed to AIDS or an HIV-associated illness by the caregiver, or if at least 2 of the following symptoms were mentioned during the interview: peripheral neuropathy, oral

thrush, skin problems, prolonged fever or night sweats, weight loss, diarrhoea, pneumonia, dementia, vulvo-vaginal thrush or bedridden for more than 50% of the day in the month before death. A similar algorithm was found to have a reasonable sensitivity and specificity for predicting HIV serostatus of the deceased in a rural Tanzanian cohort.[7] For the purposes of the VA, deaths attributed to pulmonary tuberculosis (PTB) were considered to be HIV-related as there is high HIV prevalence among those who die of TB in South Africa.[3] Additionally, HIV-associated TB deaths are often attributed solely to TB by the individual or family because of the stigma associated with HIV infection, regardless of serostatus.[9] In this study deaths were attributed to violence or accident if either was mentioned as the cause of death during the unstructured part of the interview.

Age and gender-specific mortality rates were calculated using the maximum likelihood estimate by dividing the number of deaths in the given age and/or gender category by the number of persons in that age and/or gender category in the previous 12 months, with person-years of observation constituting the denominator. The normal approximation to the Poisson distribution was employed for calculating 95% confidence intervals (CIs).

Our data were compared with the demographic profile and mortality estimates for South African blacks extracted from the Actuarial Society of South Africa (ASSA) 2002 AIDS and demographic model without adjustments or recalibrations.[10] This model was designed to correct for gaps in census data before the 1996 census, and is based on results of the annual HIV seroprevalence surveys among antenatal clinic attendees, and annual adult death rates.[1,10]

Results

Initial household visits established that there were a total of 1 686 households in this ward. Although initially 843 households were to be visited, during the fieldwork stage an additional 126 households were interviewed because the head of household requested this. As these additional households were randomly included during the course of the study across all 3 subsections they were not excluded from the analysis. Thus a total of 969 household interviews were completed, constituting a 57% sample of households in this ward. Four households refused to participate in the survey.

Crude death rate

In the 12 months preceding this survey a total of 186 deaths were reported in the households interviewed, out of a total 6 349 people living in the households surveyed, yielding an overall mortality rate of 29 deaths per 1 000 person-years (95% (CI: 25 - 33 per 1 000 person-years). Data on gender were captured for 184 of these deaths and data on age for 177 deaths. The overall age- and gender-specific mortality rates are presented in Table I.

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Table I. Age- and gender-specific mortality rates for reported deaths in households, February 2003 - February 2004

Age (years)	Total				Male				Female				
	Deaths (N)	Total population (N)	Death rate/1 000 person-years	95% CI	Deaths (N)	Total population (N)	Death rate/1 000 person-years	95% CI	Deaths (N)	Population (N)	Death rate/1 000 person-years	95% CI	Male/female rate
0 - 4	9	493	18	6 - 30	2	255	8	0 - 19	7	238	29	8 - 51	0.3
5 - 9	4	650	6	0 - 12	3	322	9	0 - 20	1	328	3	0 - 9	3
10 - 14	1	723	1		1	380	3	0 - 8	0	342	0	0 - 0	Unknown
15 - 19	5	809	6	1 - 12	4	412	10	0 - 19	1	396	3	0 - 7	3.3
20 - 24	23	733	31	19 - 44	4	368	11	0 - 22	19	365	52	29 - 75	0.21
25 - 29	20	623	32	18 - 46	8	294	27	8 - 46	12	329	36	16 - 57	0.8
30 - 34	23	454	51	30 - 71	9	190	47	16 - 78	14	263	53	25 - 81	0.9
35 - 39	22	329	67	39 - 95	14	146	96	46 - 146	8	182	33	14 - 74	2.9
40 - 44	10	252	40	15 - 64	7	107	65	17 - 114	3	145	21	0 - 44	3.1
45 - 49	12	255	47	20 - 74	6	112	54	11 - 96	6	143	42	8 - 76	1.3
50 - 54	10	266	38	14 - 61	9	110	82	28 - 135	1	156	6	0 - 19	13.7
55 - 59	10	194	52	20 - 84	6	91	66	13 - 119	4	103	39	1 - 77	1.7
> 60	28	409	68	43 - 94	16	136	118	60 - 175	12	272	44	19 - 69	2.7
Missing	9*	149	47	12 - 82	4	66	61	1 - 120	3	83	36	0 - 77	1.7
Total	186	6 339	29	25 - 33	93	2 989	31	25 - 37	91	3 345	27	22 - 33	1.1

*Two deaths had neither age nor gender recorded.

Although the overall death rates were similar for both men and women, viz. 31 (25 - 37)/1 000 person-years for men and 27 (22 - 33)/1 000 person-years for women) there were sex- and age-specific differences (Table I). The highest overall mortality rates were reported in the 35 - 39-year and > 60 age groups. The highest mortality rate among women occurred in the 30 - 34-year age group, compared with that for men which occurred in the 35 - 39 and > 60-year age groups. Estimated death rates for those with missing age data were much higher for men than women (61 (1 - 120 per 1 000 person-years) for men and 36 (0 - 77 per 1 000 person years) for women).

Verbal autopsy

Of the 185 VAs reported, based on AIDS-defining criteria mentioned above, 77 deaths (42%) were attributable to AIDS, and 16 (9%) to violence or accident.

The most common AIDS-related symptom was PTB. This was reported in 44% of the AIDS-related deaths. Seven deaths were attributed to AIDS or HIV by the respondent; all of these met our criteria for AIDS-suspected death. In 86 (46%) of the VAs (including all of the deaths from violence or accident), none of the symptoms inquired about were reported to be associated with the cause of death. Four of the VA interviewees specifically mentioned HIV or AIDS as relating to the cause of death. Death certificates were not available for any of the deaths.

Table II shows the breakdown of deaths by age group and gender, and suspected cause of death, as determined by VA.

Fig. 1 shows actual male mortality rates in Vulindlela compared with estimates for 1985 and 2005, while Fig. 2 shows actual female mortality rates compared with estimates for the same period.

Excess mortality was attributed to AIDS and was calculated by subtracting the ASSA 2002 non-AIDS death rate estimates from the death rates for Vulindlela. This generated an AIDS-related mortality of 36/1 000 person-years for the 20 - 39 year age group and 20/1 000 person-years overall.

Using this method, 77 of 98 deaths (79%) in the 20 - 39-year age group and 127 of 186 deaths (68%) in the overall population were attributable to AIDS. This generates a theoretical maximum sensitivity for AIDS deaths using the VA technique of 65% in the 20 - 39-year age group and 60% overall.

Discussion

AIDS-related mortality was found to be impacting significantly on this small rural community. Young women between the ages of 20 and 34 and young men between the ages of 25 and 44 years were the groups with the highest rate of AIDS-related deaths. This is not surprising given the HIV prevalence in this community[11] and the natural history of infection where morbidity and mortality occur 9 - 10 years post-infection.[12,13]

Table II. Cause of death determined by verbal autopsy, by age and gender

Age (years)	Male			Female			Total		
	Total	HIV/AIDS	Violence/accident	Total	HIV/AIDS	Violence/accident	Total	HIV/AIDS	Violence/accident
0 - 4	2	0	0	7	2	0	9	2	0
5 - 9	3	0	0	1	0	0	4	0	0
10 -14	1	0	1	0	0	0	1	0	1
15 -19	4	1	1	1	1	0	5	2	1
20 – 24	4	2	0	19	10	0	23	12	0
25 – 29	8	5	1	12	9	1	20	14	2
30 – 34	9	3	1	14	11	1	23	14	2
35 – 39	14	7	1	8	3	1	22	10	2
40 – 44	7	5	1	3	2	0	10	7	1
45 – 49	6	2	1	6	3	1	12	5	2
50 – 54	9	2	0	1	1	0	10	3	0
55 – 59	6	0	0	4	1	0	10	1	0
60+	16	4	3	12	1	0	28	5	3
Unkown	4	2	0	3	0	1	7	2	2
Total	93	33	10	91	44	5	184	77	16

Note: age and gender data were missing for 2 patients, 1 of whom died as a result of violence/accident.
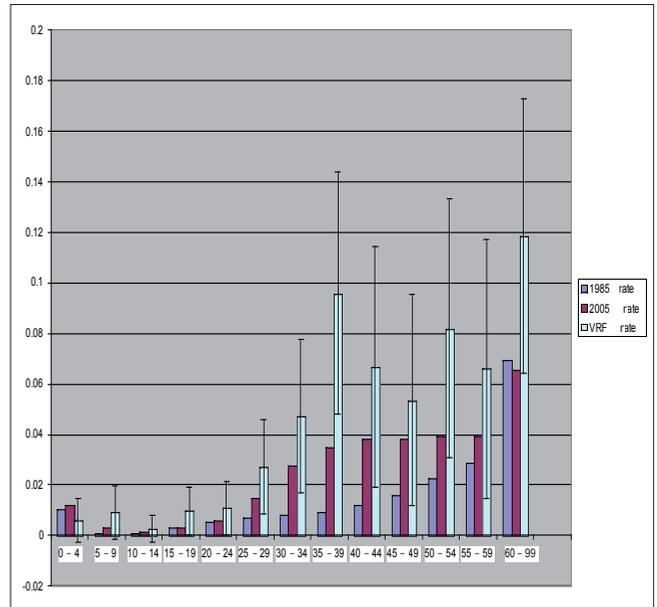
Fig. 1. Male mortality rates by age in Vulindlela compared with ASSA 2002 estimates for black South African mortality in 1985 and 2005. Error bars indicate 95% CI (with updated data 25/4/05). VRF = Vulindlela Research Facility.

There are several reasons why the AIDS-related mortality as determined by VA may be lower in this study than other estimates. It should be noted that the responses given on the free-text portion of the VA often belied the responses given with regard to inquiries about specific symptoms, suggesting an underreporting of symptoms. This may be the result of either survey fatigue on the part of the respondents, insufficient training of personnel administering the survey, and/or disinclination to report AIDS-associated symptoms because of AIDS-related stigma. Using verbal autopsy one study[9] found that 86% of reported TB deaths in a rural South African population were HIV-associated. A smaller study done in Vulindlela,[14] with the verbal autopsy carried out by a clinician, rendered a 72% HIV-related mortality for the area.

Mortality/age distribution

AIDS exacts a high toll on the population of South Africa, with estimates for AIDS-related adult deaths (age 15+) ranging from 40% in 2000[15] to 70% in 2004.[10] In KZN, estimates tend to be higher – Hosegood et al.[3] found that AIDS caused 48.2% of deaths in rural KZN in 2000, reflecting the greater prevalence of HIV in KZN compared with other provinces in the country.

The data collected in Vulindlela suggest a heavy mortality burden in the 20 - 39-year-old age group exceeding that of estimates by ASSA for South African blacks (Figs 1 and 2). Our data point to two significant differences between the study population and the ASSA 2002 estimates for black South Africans in 2005, viz. the increased death rates among women aged 20 - 24 and men aged 35 - 39. The increased death rate
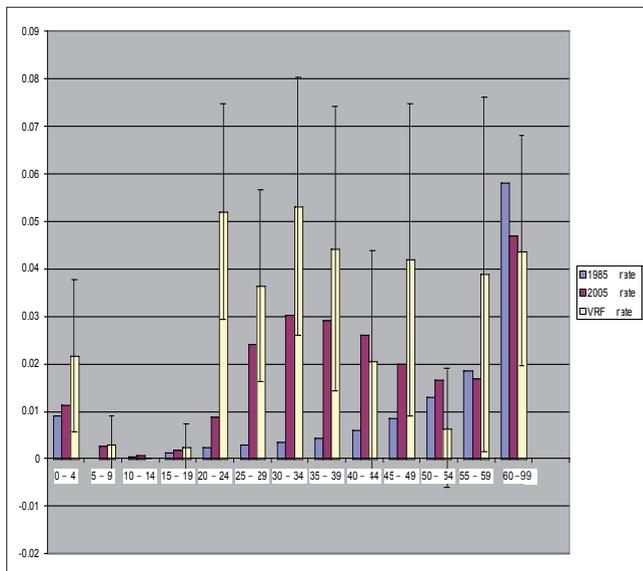
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Fig. 2. Female mortality rates by age in Vulindlela compared with ASSA 2002 estimates for black South African mortality in 1985 and 2005. Error bars indicate 95% CIs (with updated data 25/4/05).

among 20 - 24-year-old women is consistent with previously collected incidence and prevalence data from the Vulindlela area, which show a higher incidence of HIV seroconversion for women in this age range (13.9% per person-year) compared with women in the 25 - 29-year-old age group (4.4% per person-year).[11] The roughly equal prevalence for the two age groups (45.8% and 42.9%) implies a high level of mortality in the 20 - 24-year-old group to offset the high incidence.

Time from infection to death has been generally estimated at 9 - 10 years for adults,[12,13] suggesting that the women in the 20 - 24-year-old age group were infected in their early teens, and/or that they represent faster disease progressors having been infected at 15 - 19 years. This may explain the difference in mortality between this age group and the ASSA 2002 model, which assumes that children under 14 years old are not sexually active.[13]

Fewer data are available to explain why the mortality rate among 35 - 39-year-old men in Vulindlela is higher than the ASSA 2002 estimates for South African blacks; however, the rate is consistent with the higher HIV prevalence in KZN compared with South Africa.[16]

As the survey achieved a high rate of participation from households in the community, the results are unlikely to be the consequence of sampling bias. However, as a retrospective survey it is prone to recall bias, and it is possible that deaths that occurred in the earlier portion of the evaluated 12-month period were not recorded. This would be more likely to have altered the mortality statistics for the general population, rather than the age or gender distribution of the deaths, as age of the deceased is unlikely to have been misattributed by the respondents. Additionally, the levels of mortality revealed in

this study are consistent with the high levels of HIV infection in young adults in KZN.

This study strongly suggests that HIV-associated mortality in the South African HIV epidemic is significantly higher in rural KZN than in the country as a whole, and that women aged 20 - 24 and men aged 35 - 39 years bear a proportionately larger burden of mortality in this area than in South Africa as a whole. The survey underscores the importance of making antiretroviral treatment available to those living in rural areas to lessen the extremely high mortality levels found here among young adults. This is already under way in this community and the evidence to support this recommendation is growing.

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