REPORT OF THE SCIENTIFIC MEETING ON THE EMPIRICAL EVIDENCE FOR THE DEMOGRAPHIC AND SOCIO-ECONOMIC IMPACT OF AIDS.

26-28th March, 2003
Tropicana Hotel
Durban, South Africa

Hosted by
the
Health Economics and HIV/AIDS Research Division (HEARD)
University of Natal

Funded by

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INTRODUCTION

'A lot of projections, but little data', is a common complaint amongst HIV/AIDS researchers and policy makers in Africa. One response was the ***'Scientific Meeting on Empirical Evidence for the Demographic and Socio-Economic Impacts of HIV/AIDS'.*** This meeting was the culmination of an initiative begun two years ago, which recognised that interventions must be based on sound information about the medium and long-term demographic, social and economic consequences of HIV/AIDS. This initiative involved the London School of Hygiene and Tropical Medicine (LSHTM), the National Institute of Public Health in Mexico, the University of North Carolina (UNC) and HEARD.

The outcome was the 3-day conference where scientists could present and hear papers based on rigorous empirical research. Forty four presentations were scheduled around nine thematic sessions (*Adult Mortality, studies with HIV serology; Adult Mortality, evidence from national statistics; Family Welfare; Family and household structure; Empirical Evidence for Impact in the Public Sector; Empirical evidence of impacts in the private sector; Child mortality; Fertility effects of HIV; Testing the accuracy of projections*). Each session included a period for a discussant to review the presentations and there was a period for an overview of the day's debates.

The programme began with a keynote address by Professor Roy Anderson of the Imperial College, London. This was followed by plenary sessions for demographic research on Adult Mortality, on the grounds that this is the fundamental impact of the AIDS epidemic and why HIV is such a threat to society. Plenary sessions for demographic and socio-economic research on Family and Household Welfare followed on the second day of the meeting. The rationale here was that the effects of HIV/AIDS are felt initially and harshly amongst the general population. Parallel sessions were scheduled on the morning of the third day to address the extended impacts of HIV/AIDS. A final plenary session in the afternoon was held for critiques of HIV/AIDS models and projections, on the grounds that previous presentations would inform debate about this field of HIV/AIDS research, and allow the meeting to come to some conclusions about the veracity of projections in the light of empirical research.

In the event, 3 invited speakers could not participate as a result of the global repercussions of the Iraq War and the 'SARS' outbreak. There were more individuals who wanted to attend than could be accommodated at the venue. Approximately 80 interested scientists, government professional staff and journalists came to hear the presentations.

This report is a summary of the presentations, debates and conclusions at the meeting. It consists essentially of two parts: a summary, in point form, of discussions at each presentation and a short summation of the main threads in the debates and conclusions. We recommend readers to obtain fuller details of the presentations from HEARD's website (www.HEARD.org.za) where the 'Abstract' booklet and the collection of papers that have been submitted are posted, and from individual researchers via the 'Contact list' that is appended to this report. Furthermore, a special issue of the journal, AIDS, to be published in 2004, will include substantive review articles on the research presented at the meeting.

KEYNOTE ADDRESS

Roy Anderson, Professor, and Head of the Department of Infectious Disease Epidemiology, Imperial College, University of London, delivered the keynote address.[2]

MAIN POINTS

General Comments
- There is a need of an early assessment of demographic impact.
- There is the potential for community-based care to reduce demographic impact.
- Interventions targeted at commercial sex workers tend to be effective in the first 5 years of an epidemic, but, thereafter, community-based prevention is more effective.
- Aggressive sex education targeted at young people (11-13 years) is necessary because average age of sexual debut is declining.
- Historically, other major epidemics have shaped societies and shaped our genetic code. Recent studies show our genomes reflect our past experiences of major epidemics.
- Need to bear in mind commercial realities and keep pharmaceutical companies interested in developing vaccines and drugs.

Demographic Impact
- What makes AIDS different and more life threatening than past epidemics is the potential to influence human demography.
  - ✓ Case (infection)-related death rate is 90-100% of those infected in the absence of treatment. Plague was 30-40% in young and elderly.
  - ✓ Vertical transmission rate can be 30% and child mortality has disproportionate effect on life expectancy.
  - ✓ Biology: targets host cells that influence resistance to other infections.
  - ✓ Sexually transmitted: can persist in low-density population unlike many common respiratory infections (influenza).
  - ✓ Virus evolves very rapidly: in one AIDS patient with 10^{10} viral particles, every mutation across entire genome possible everyday. That mutation will take place is certain the timing is what is uncertain.
  - ✓ Women are infected at an earlier age than men.
  - ✓ Long incubation period and symptoms not apparent until late.
- HIV is moderately transmissible over a period of time.
  - ✓ USAID (2001) projection that by 2003, Botswana, South Africa and Zimbabwe will be experiencing negative population growth brings into question the accuracy of projections.
  - ✓ Need to monitor and evaluate interventions in communities.
  - ✓ Even small changes induced by interventions can greatly alleviate the impact of the epidemic.
  - ✓ Targeting core groups like sex workers and male clients can result in 75% reduction in transmission, but will take a very long time for the effect to show.
- HIV vaccines:
  - ✓ Currently 24 HIV-1 vaccine trials; Vax Gen (North America, 2003) - unmeasurable efficacy but has 78% efficacy among 'black' volunteers though sample was very small.

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[2] His previous positions include the Linacre Professorship and Head of Zoology, University of Oxford (1993-1998), Professor of Parasite Epidemiology and Head of Biology, Imperial College (1984-1993) and Director of the Wellcome Trust Centre for Infectious Disease Epidemiology, University of Oxford (1995-2000). He is also a Fellow of the Royal Society and a Foreign Associate Member of the Institute of Medicine at the US National Academy of Sciences. He has published over 400 scientific papers on the epidemiology, population biology, evolution and control of a wide variety of infectious disease agents, including HIV, BSE, Foot and Mouth Virus, vCJD, dengue virus, parasitic helminths and protozoa, and respiratory tract viral and bacterial infections.

- ✓ Vaccine development not that attractive to funders because of length of time and money for trials. Most stop at phase II but Phase III trials are more important because they measure the efficacy of community-based transmission potential.
- ✓ Trials of other drugs more attractive (except for cancer drugs) because they do not exceed 3 years compared to 10 years for HIV vaccine. Already many drug companies have stopped funding trials.
- Therefore, case for use of 'imperfect vaccines' recognizing this is a contentious issue
  - ✓ Vaccinated individuals acquire infection, but show slower progression to AIDS.
  - ✓ Slower progression is linked to lower viral loads-especially in the primary HIV-1 infection phase.
  - ✓ Lower viral load is linked to lower infectiousness to susceptible sexual partners.
  - ✓ Viral load related to probability of transmission; so reduction in viral load reduces probability of transmission. Vaccine will have impact on mortality and transmission.

CONCLUSIONS

- AIDS is having considerable demographic impact in most afflicted regions.
- Imperfect vaccines can have significant impact on community level transmission.
- Crucial need is to encourage industry to continue, and to increase investment in this field.
- Licensing an imperfect vaccine will present many problems, but analysis of potential impact can assist in this task. It would be almost impossible to license (if FDA does not license African countries may not do so).

PLENARY SESSION
ADULT MORTALITY, STUDIES WITH HIV SEROLOGY

Dr. Ties Boerma chaired this session. There were five presentations of research that used HIV serology to measure adult mortality due to HIV/AIDS and to estimate survival time post-infection. Presentations covered research done in Masaka, Uganda, Mwanza, Tanzania, Pointe Noire, Congo and Addis Ababa, Ethiopia. Dr Kholoud Porter was the discussant .

1. **J. Whitworth, L. Shafer C. Mahe and L. Van der Paal:** Survival since infection and its relation to background mortality in Masaka general population.
2. **M. Urassa, R. Isingo, G. Mwaluko, T. Boerma and B. Zaba:** Mortality of HIV prevalent and incident cases in the Kisesa cohort study.
3. **J. Todd:** Age Patterns and trends in HIV positive and HIV Negative mortality rate ratios**.**
4. **S. Le Coeur** HIV status and AIDS mortality in Pointe-Noire, Congo
5. **T. Araya, G. Renniers, A. Schaap, D. Kebede, A. Kumie, N. Nagelkerke, R. Coutinho and E. Sanders:** Monitoring HIV/AIDS mortality in Addis Ababa: lay diagnosis of death, verbal autopsies and health facility records.

FINDINGS

Survival time from sero-conversion
Survival time from sero-conversion varies from 6-10 years.
- 8.6 years (Whitworth *et al*).
- 6-10 years (Todd).

Mortality rates
- HIV/AIDS dramatically increases mortality among infected. HIV/AIDS death in adult population varies around 68% (Araya *et al*).
- Overall rate was 11.6/1000 for persons between 15 and 50; 3/1000 for currently HIV negative persons; 37.3/1000 for HIV infected; 23.9/1000 for those not tested [7-year data record, Mwanza, Tanzania] (Urasa *et al*).
- 61/1000 person years mortality rate for HIV positives compared to 9.3/1000 person years for HIV negatives in Uganda (Whitworth *et al*).
- AIDS is leading cause of death (Le Coeur) and slightly higher impact of HIV/AIDS on mortality (5%) than estimated by epidemiological projections for Addis Ababa (Araya *et al*).
  - ✓ Deaths are greater in HIV positive than negatives (Urassa *et al*)
  - ✓ Mortality rates in HIV positive adults are 15 times that of HIV negative (Todd)
  - ✓ Higher for males than females (Urassa *et al*)
  - ✓ Mortality in adults is doubled by AIDS (Le Coeur)
- HIV contribution to death greater especially in oldest age group (Whitworth *et al*)
  - ✓ Mortality rate ratios are highest between 25 and 40 years (Todd)
  - ✓ Mortality rate highest in 35-39 age group for both sexes (Urassa *et al*)
  - ✓ Mortality rate ratios highest in 25-40 years (Todd)

CONCLUSIONS

- Calculating HIV net-mortality is feasible.
- Methods to account for other causes of mortality need to be explored to enable appropriate comparison of rates (Whitworth).
- There is an urgent need for more data [e.g. further follow up and analysis of sero-prevalence data] (Todd).

- The use of autopsy and hospital files for measuring AIDS mortality provides a direct, rapid, low cost, reliable and replicable measure of AIDS contribution to mortality relative to other causes (Le Coeur).
- The combined use of lay diagnosis (collected, for example, at burial sites) with verbal autopsies and/or hospital records is useful for monitoring population-based and cause-specific mortality patterns, especially in settings with poor data collection systems (Araya et al).

KEY POINTS FROM SESSION DISCUSSION

- Authors are not sure yet how the results compare with non-African countries.
- Adult and child progression rates are not similar (children progress faster).
- The small number of HIV positive people in cohort studies was attributed to low budgets for serological studies.
- The need to push vaccine trials with greater budgets was stressed.

DISCUSSANT'S REMARKS

- Age is a factor in mortality rate.
- An infected person has 15 times greater risk of dying than uninfected.
- This risk is greater for women than men.
- Survival from HIV sero-conversion is about 8 years.
- Mortality rates variable for both infected and uninfected.
- Differences largely driven by maturity of epidemic
- Relative contribution of HIV to mortality is highest in persons in 20s and 30s (49-86%) and in women.

PLENARY SESSION
ADULT MORTALITY: EVIDENCE FROM NATIONAL STATISTICS

Dr Basia Zaba chaired this session. Four papers were presented on research that used national statistical records to estimate the impact of HV/AIDS on adult mortality. Dr. John Blacker was the discussant.

1. **I. Timaeus and D. Bradshaw and M. Jasseh:** Adult Mortality in Sub-Saharan Africa: Evidence from the Demographic and Health Surveys
2. *D. Bradshaw and R. Dorrington:* The use of South African vital registration. Data to estimate the contribution of HIV to changing trends in mortality.
3. **W. Im-em:** Mortality trends and levels to verify the AIDS epidemic in Thailand: Analysis from death registration statistics, 1984-1997.
4. **S. Clark:** An exploratory analysis of Adult AIDS/TB Mortality Patterns from Community Surveillance in East and Southern Africa.

FINDINGS

Mortality Trends and Patterns
- 16 of 18 sub-Saharan African countries showed a significant increase in adult mortality, about 4 years after each country developed a generalised AIDS epidemic (fastest in South Africa, Zimbabwe, Zambia, Uganda, Guinea and Cameroon) (Timaeus *et al*).

- Explosive rise during the second decade of epidemic (Timaeus *et al*).
- DHS data suggest that more men than women are dying of AIDS in Africa (Timaeus *et al*).
- Tanzania and South Africa 'INDEPTH' data showed seven distinct patterns, two of which may be due to excess mortality from HIV/AIDS and are substantially different from patterns produced by Coale and Demeny and the United Nations, indicating uniqueness to Africa (Clark).
- Change in the age pattern of adult deaths in South Africa largely due to HIV/AIDS (Bradshaw and Dorrington).
- As epidemic matures, excess mortality more concentrated in young adults (Timaeus *et al*).
- Greatest increase in mortality occurs among women aged 25-44 and men aged 35-49 (Timaeus *et al*).

Mortality rates
- 40% of adult deaths, in age range 15-59 years, due to HIV/AIDS in South Africa (Bradshaw and Dorrington).
- Death rates in Thailand increased substantially among men aged 25-29 in last three years of study period while that of women in same age group show little change over time (Im-em).
- In Thailand, registered death rates and selected AIDS statistics are highly correlated (beginning 1990) and stronger in men than women.
- The death rate of men aged 25-29 is the strongest indicator for the presence of AIDS deaths in Thailand (Im-em).

CONCLUSIONS

- A sharp increase in adult mortality has occurred in Africa since HIV has become prevalent (Timaeus *et al*).
- Size and speed of rise in mortality in different countries and evolving age pattern of mortality impact are broadly in line with predictions from epidemiological data and models (Timaeus *et al*).
- Time for a systematic attempt to reconcile the demographic and epidemiological evidence concerning AIDS in Africa (Timaeus *et al*).
- Significant change in the pattern of deaths is largely consistent with, but lower than anticipated by some models (Bradshaw and Dorrington).
- Death registration statistics can be used as a simple indicator to monitor the AIDS epidemic at the national level, but vital registration on death statistics needs to be strengthened to make it reliable source of data to monitor the AIDS epidemic (Im-em).
- HIV and TB are leading causes behind mortality patterns in Tanzania and South Africa (Clark).
- Observed mortality patterns in Tanzania and South Africa are largely unique to Africa (Clark).

KEY POINTS FROM SESSION DISCUSSION

- Stated cause of death data at face value is not good for estimating HIV/AIDS death; assessed total cause of death is more useful.
- With regard to the use of death registration statistics to monitor mortality trends due to AIDS, it would be useful to compare different years in addition to analysing trends over a number of years.

DISCUSSANT'S REMARKS

Comments on Sources
What evidence do we have that mortality is rising in countries affected by HIV/AIDS?
1. *Census data*
   - Age distribution
   - Intercensal survival
   - Changes in Age Structure.

- Orphanhood.
2. ***Sample Surveys – Demographic Health Surveys (DHS)***
- Sibling survival
- Orphanhood-children under 15
3. ***Demographic Health Census***
4. ***Demographic Surveillance systems.***
- Verbal autopsies
- Age patterns of mortality.

Orphanhood
- Census data - an indirect method (not liked by DHS).
- Susceptible to several types of bias (e.g. 'Adoption effect'; Vulnerable to use of unsuitable models)
- Use of "hypothetic cohorts"

Demographic Health Survey
1. Sibling data
- Timaeus and Basia are the results "for real"?
- Comparison of results for overlapping data sets.

2. Orphanhood data
- Restricted to 5-9 and 10-14 age groups
- Not much use for establishing trends.

3. Registration
- Papers by Im-Em and by Bradshaw
- Extrapolation of trends: How much can we conclude?
- Important to measure AIDS mortality and subtract it from total mortality to give non-AIDS mortality.

4. Demographic surveillance
- The INDEPTH studies: How representative are these studies?
- They can only be pointers.
- Is all-cause mortality in Tanzania decreasing?
- The INDEPTH model life tables
    - Seven Patterns
    - The AIDS "add on"
- Is adult mortality rising in countries seriously affected by AIDS?
- How much of the rise is due to AIDS? How do we know?

General Comments
- Focus on deaths in the last 12 months/2 years; subject to biases, but useful tool
- Survival post infection: age pattern of infection incidence.
- General reluctance to link demography to epidemiological data.
- Different kinds of impact in different parts of the world should be explained by the (general) 6 years difference in onset of epidemic.

PLENARY SESSION
FAMILY WELFARE

There were two plenary sessions on family welfare: the first covered presentations on demographic impacts; the second covered socio-economic impacts. Dr. Vicky Hosegood chaired the first session at which four papers were presented. Dr. Frederick Booysen chaired the second session at which three papers were presented. Prof. Tony Barnett was the discussant for both sessions.

1. **T. Yamano and T. S. Jayne:** Measuring the Impacts of Prime-Age Adult Death on Rural Households in Kenya.
2. **P. Gertler, D. Levine, S. Martinez, S. Bertozzi:** The presence and presents of parents: do parents matter for more than their money
3. **P. Mushati, S. Gregson, M. Mlilo, J. Lewis, and C. Zvidzai:** Adult mortality and erosion of households viability in towns, estates and villages in eastern Zimbabwe
4. **F. Booysen:** Poverty dynamics and HIV/AIDS-related morbidity and mortality in South Africa
5. **R. Monasch and N.Snoad:** The situation of orphans in a region affected by HIV/AIDS
6. **M. Daniel:** Children without parents in Botswana: the safety net and beyond
7. **J. Knodel and W. Im-em** The Economic Consequences for Parents of Losing an Adult Child to AIDS: Evidence from Thailand

FINDINGS

Demographic Impact
- Much higher incidence of morbidity and mortality in affected households than non-affected (Booysen).
- Households suffering the death of the head of household or spouse incurred a greater-than-one person loss in household size [older daughters commonly leaving the household after the death of a male head, while younger children were more likely to leave the household after the death of a female head/spouse] (Yamano and Jayne).
- Households experiencing the death of other adult household members often gained new adult members and these households tend to incur less of an economic shock (consistent with World Bank study) (Yamano and Jayne).
- More urban households function normally after death of member, but those in villages were less likely to have stayed in their locations and households on (tea) estates more likely to dissolve than the others (Mushati *et al*).

Socio-Economic Impact
- Incidence of deaths, sicknesses and poverty higher in affected than unaffected households. Many of the affected households live below the R220 per capita poverty line in South Africa (Booysen).
  - ✓ Parents of AIDS patients frequently paid for their children's funeral costs; funeral society memberships and customary contributions from those attending substantially reducing these costs to parents (Knodel and Im-em).
- Average on health care cost was $US 80 dollars (Mushati *et al*).
  - ✓ No significant difference between HIV costs and other care costs
  - ✓ Cost for memorial services met mainly by deceased or spouse's kin
  - ✓ Costs of funerals met mainly by broader circle of kin and affines
  - ✓ Memorial costs tend to be higher than funeral costs
- Mean income for affected households lower than that of unaffected households (Booysen).
  - ✓ Death of a male household head is associated with a 68% reduction in the net value of the household's crop production; much less severe effects were found in the case of death of other household members (Yamano and Jayne)
  - ✓ 9% reduction in household consumption in case of death of male household head, but no difference in the death of other adult females and males (Gertler et al)

- Most deceased children had contributed financially to the parental household before becoming ill, but with a minority acting as main finance providers. Poorer parents, however, were far more likely than better off parents to lose a main provider and to experience severe financial hardship because of this loss (Knodel and Im-em)
- Income differentiation is increasing (Booysen).
  - Female head-of-household or spouse mortality causes a greater decline in cereal and tuber area cultivated, while cash crops such as coffee, tea, and sugarcane are most adversely affected in households incurring the death of a prime-age male head (Yamano and Jayne)
  - One third of the widows received widows' pension from their employers (Mushati *et al*)
  - Parents of AIDS patients were frequently and substantially involved in paying for their children's care and treatment costs, but government health insurance and, to a lesser extent, welfare services helped alleviate these expenses (Knodel and Im-em)
- Income mobility more pronounced in affected households (Booysen).
  - Off-farm income is significantly affected by the death of the male head of household, but not in the case of other adult members (Yamano and Jayne)
  - Many parents borrowed to pay for expenses of daily living including medical services, though most repaid debt (Knodel and Im-em)
  - Although poorer AIDS parents spent much less than their better off counterparts on expenses related to the illness and death of their children, they were burdened to a greater extent by these expenses (Knodel and Im-em)
  - Parental care giving often involved disruption of economic activity, but the generally short duration of care giving lessened the extent of opportunity cost changes in household activities (Knodel and Im-em)
- Interruption of economic activities more for main caregivers and this caused hardship. (Knodel and Im-em).

Impact on Orphans
- More orphans in female-headed households than male-headed households; 20% of all households have at least one orphan (Monasch and Snoad).
- Parental deaths affect education, health and survival of children (Gertler *et al*).
- In Thailand children who have lost both parents often end up living with their grandparents; very few children who have lost a parent stay with the surviving parent (Knodel and Im Em).
- Orphans less likely to attend school; Boys and girls are affected in various ways in various countries and within countries (Monasch and Snoad).
- More orphans than non-orphans are involved in child labour though difference is not significant (Monasch and Snoad).
- Some families in Botswana are refusing to access food parcels because of stigma (Daniel).
- Evidence in Botswana that orphans are physically abused and used as a means of accessing government support for households already under stress (Daniel).

CONCLUSIONS

- Morbidity and mortality are important determinants of income mobility and chronic poverty.
- Substantial erosion of economic viability of households.
  - Affected households likely to experience variation in income levels and transient poverty.
  - Incidence, depth and severity of poverty are relatively worse among affected households that have experienced illness or death
  - Contrasting effects of HIV in locations of greater economic activity
  - Contrasting effects between better richer and poorer and less developed households
- The effects of adult death are highly sensitive to gender and position of the deceased family member in the household.
  - Death of female head/spouse less dramatic than death of male head but still have negative effects
  - Old age pensions can be used as security for households

- Need to improve the tools and sampling methodologies for measuring impact.
- Parents matter more as parents than their money.
- Programmes that provide emotional support, monitoring, tutoring and other services may complement scholarships and financial aid for disadvantaged orphans.
- Introduction of a broad-based social security system offering minimal benefits rather than specifically targeted welfare programmes may be important in mitigating the impact of HIV/AIDS.
- 'Home-based' economic safety net approaches must be combined with programmes for effective orphan-strengthening (caregiver guidance and education; promotion of orphan-and caregiver-targeted, small-scale, income generating opportunities to optimise 'safety net' performance).
- Need programmes that recognize and address the plight of older persons who lose a child to AIDS. These programmes must take into account the considerable range of vulnerability that exists and target those who are most susceptible to resulting economic hardship.

KEY POINTS FROM SESSION

Needs
- Need to know the characteristics of the individuals that are being affected in order to design intervention programmes. For example most of the males who die in Kenya are in the higher income groups, therefore may need to target education and prevention among high-income population.
- Need to keep orphan children within the families and also document best practices.
- Need to do extended studies on the impact of orphans refusing government support.

Questions
- The issue of people not accessing grants was discussed and stigma suggested as the major reason for this phenomenon.
- The issue of orphaned children turning to substance abuse was identified. Further studies needed to assess the circumstantial evidence.
- What happens to the non-orphans when orphans are brought into households?
- Is there a correlation between the education level of parents and the educational attainment of orphans?
- Problems with household definition and determination of when households have changed or dissolved suggest importance of inter-disciplinary studies (to address methodological and research design issues).

DISCUSSANT'S REMARKS

T. Yamano and T. S. Jayne's Paper
- Since 1989, various studies in East and Southern Africa
- This is the most quantitative and time series study from 1997 and 2000
- Shows consistency with previous findings

Questions/challenges
- Slow recovery- any recovery by affected families?
- Are families coping?
- Is there a rise of new destitute class?
- Is the study generalizable? (see Heaton and Stanecki paper).
- Need to look for regionally and national differentiated accounts.
- In some places the demographic 'chimney effect' is not apparent- for example in Kenya.

P. Gertler, et al. Paper
- Focus on the effects of parent death on investment in child human capital

Questions/challenges
- Emphasis that parent is more than material resource (What is the cost of a cuddle? i.e. the value to society (public good) of parental love and mentoring of children).
- Need for economists to take a broader view of the notions of 'impact' and 'cost'.
- More non-economic social scientists to engage with the researching difficult to measure 'costs' to society of parental deaths.

P. Mushati, et al. Paper
- HIV-associated death more likely to result in relocation or dispersal of affected households.
- The epidemic is undermining economic viability of households in east Zimbabwe.
- Relocation plus indigenous illness and death are deepening rural poverty.

Questions/challenges
- Evidence of development of 'new destitute' class.

F. Booysen's Paper
- Affected households tend to remain poor or experience transitory poverty.

Questions/challenges
- Is it possible to talk about affected and unaffected households in these communities?
- Is the household framework appropriate (same question applies to Jayne and Yamano) might be a better but more difficult approach will be to look at livelihood network?
- Need more longer term studies (funding?).

R. Monasch and N. Snoad's Paper
- Multi-country review using indicators such as school attendance, nutritional status, child labour.
- Omits street children and child-headed households.
- Virtual orphans: 32% of single orphans living away from their surviving parent-(see Monk's Uganda study).
- The character of caretakers also affects orphan needs.

Questions/challenges
- War etc. may be as critical variable as HIV/AIDS
- Differential urban and rural over-representation of orphans emphasises need for context sensitive policies.
- Significance of Sudanese findings- is this low epidemic or relatively stronger unaffected family system?

M. Daniel's Paper
- Not a quantitative study but intense qualitative fieldwork in 4 communities (deals with individual and social wounds).
- Social denial of how orphans are treated and how tradition is failing to cope.
- Proposes a framework for understanding the ways that a society engages with its orphan: Involution, Institutionalisation, Distortion.

Questions/challenges
- How to assess full social cost, generalisability of response and role of government and NGO response?

J. Knodel and W. Im-Em's Paper
- Context of filial support and social reproduction.
- Quantitative and qualitative assessment.
- Considers various pathways to parental care giving.

Questions/challenges
- Need to develop new forms of analysis of social reproduction
- Do we need to distinguish between financial and non-financial and begin to quantify latter using non-money measures?
- Are there lessons from hedonic economics (happiness and trust) rather than from income *per se*?
- Loss of relational goods.

General comments
- What is the specificity of research work to context?
- How to integrate findings of research like that of Marguerite Daniel with the larger scale and quantitative studies (e.g. paper by Martinez *et al*.) and then feed into effective modelling.
- Relation between data and modelling
- Exposure of the degree of assumption in quantitative data.
- Studies on impacts of HIV/AIDS are dominated by economists and demographers; need for other social scientists to get their act together.

PLENARY SESSION
FAMILY AND HOUSEHOLD STRUCTURE

Dr. Jessica Nakiyingi chaired this session. Four papers were presented on research to assess the demographic effects of HIV/AIDS on family and household structures. Dr. Patrick Heuveline was the discussant.

1. **J. Busingye, J. Pickering and J.Whitworth:** Orphans in the HIV/AIDS era: A Study in Rural Uganda.
2. **S. Floyd, A. Crampin, J. Glynn, N. Madise, A. Nyondo, M. Khondowe, C. Njoka, H. Kanyongoloka, B. Ngwira, B. Zaba, P.Fine:** The Impact of HIV on households Structure in Rural Malawi
3. **V. Hosegood, K. Herbst and I. Timaeus:** The Impact of Adult AIDS Deaths on Household Structure and Living Arrangements in Rural South Africa.
4. **C. Nyamukapa, S. Gregson and M. Wambe:** Extended family child care and orphan education in eastern Zimbabwe

FINDINGS

Prevalence of HIV/AIDS and living arrangements among orphans
- Prevalence of orphans especially paternal orphans is higher than before in South Africa (Hosegood *et al*), but decreasing in Uganda (Busingye *et al*).
- Higher HIV prevalence among orphans, especially double orphans, than non-orphans (Busingye *et al*).
- Difference between orphans and non-orphans and paternal and maternal orphans were statistically significant (Nyamukapa *et al*).
- Mothers are making greater sacrifices and relatives are more likely to help widows (Nyamukapa *et al*).
- High rate of fostering in rural South Africa; 28% orphans are not resident with either parent (Hosegood *et al*).

HIV/AIDS and household structure
- Impact of HIV on household structure is substantial in Karonga, rural Malawi. Ten years after the baseline survey that identified HIV-positive and HIV-negative individuals, most children with a parent who was initially HIV-positive had lost one or both parents, and 36% of them were living apart from both parents (compared to 12% of children of initially HIV-negative individuals) (Floyd *et al*).
- HIV rates almost five times higher among surviving parents of orphans (Busingye *et al*).
- Almost no child-headed households exist in rural KwaZulu-Natal (Hosegood *et al*).

- Most marriages ended in widowhood (around 50%) and there was very little evidence of widow inheritance (Floyd *et al*).
- High prevalence of household headship (33%) among surviving wives of HIV-infected men, ten years after HIV infection was first recognized in their husband. Widowhood and separation increase vulnerability of surviving spouse (Floyd *et al*).
- HIV/AIDS impact mitigated by extended family: most children living apart from both parents were living with a close relative; no child-headed households (Floyd *et al*).

HIV/AIDS and migration in families/households
- Households that suffer an adult AIDS death experience a heightened risk of dissolving, but are unlikely to migrate as a unit (Hosegood *et al*).
- Children in households where an adult dies of AIDS are more likely to migrate than other children, especially if the deceased adult is their mother (Hosegood *et* al).

CONCLUSIONS

- Rural households may provide more conducive atmosphere for keeping children in school.
- Extended family system is still a key reference point for welfare support.
- Many children are living in potentially vulnerable situations.
- Institutional care of orphans by NGOs may not be suitable.
- Need for food aid to the vulnerable through school nutrition programmes.
- Need for agricultural starter packs.
- Need to support income-generating activities.
- Need to find other indicators for surveys.
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KEY POINTS FROM SESSION DISCUSSION

- There is a wealth of data that can be used from census for analysis on orphans. The use of this data is strongly recommended for future research efforts.
- Current AIDS impact represent incidence rate of about 10 years ago.
- AIDS deaths associated with an increase in household dissolution and child migration.

DISCUSSANT'S REMARKS

General Comments
- HIV/AIDS contributes to household dissolution in South Africa, but in northern Malawi household dissolution following widowhood did not depend on whether the death was of an HIV-positive or an HIV-negative individual (extant differences in household structures, e.g. 2- parent families).
- Replacement of household members in South Africa. Lower probability that wives of HIV-positive men remarry after widowhood/separation compared to wives of HIV-negative men, in northern Malawi.
- HIV prevalence in northern Malawi much higher now than ten years ago, implies an increasingly severe impact of the epidemic over time.
- Fostering already an important response (36% in northern Malawi 19% in south west Uganda, 21% in eastern Zimbabwe).
- Both increase and change in the nature of fostering arrangements.
- Clear differences in household wealth.
- Educational disadvantage.
- To date, less dramatic effects than anticipated.
- More important impact for maternal orphans whose prevalence will increase with the ageing of the epidemic.

Questions/challenges
- Lower dependency ratios? Selective entry into new households (need more ethnographic data on process) or post-fostering substitution within the recipient families?
- Evidence of strains to the system: what are the substitution effects?
- What does it mean to be ' not affected' by the epidemic in countries where prevalence may be as high as 30%?
- Do we really understand what researchers and communities mean by fostering, adoption, or household?
- Are households' current experiences of mortality the products of previous AIDS mortality experience?
- To see the full impact, we need to know more about the impact on the families that accommodate new members.
- Most social reproduction work is done by women; there is some research to value the work of women, but need to quantify more (e.g. measuring women's work time and how it is spent).
- Need to model secondary impacts of HIV/AIDS.
- HIV/AIDS is an epidemic of transition for societies.
- Need to look at strategies that will bring about locus of control to the individual. Need for more qualitative data, because of evidence of the fatalism in individuals.
- Need for more studies on community impact of death due to AIDS.
- Need for studies on timing and sequence of inter-related events
- Need to carry out event history analysis
- Need for studies on AIDS impact on inter-related households**.**
- Need to recognize that there are challenges to examining social impact of HIV/AIDS:
  - ✓ Multiple experiences of deaths;
  - ✓ Households responses may change as the contest alters in part due to rising aids mortality;
- Need to know the effects on surviving partner (e.g. survival and remarriage):
  - ✓ Effects on children (e.g. health, poverty and education);
  - ✓ Effects on children in foster families (substitution);
- Need to recognize empirical difficulties:
  - ✓ HIV clustering within kinship (double counting);
  - ✓ Benchmarking (before and after);
  - ✓ Selection biases.

PARALLEL SESSION
CHILD MORTALITY

Prof. Jimmy Whitworth chaired this session. Four papers were presented on research to assess the interrelationship between HIV/AIDS and child mortality. Prof. Marie-Louise Newell was the discussant.

1. **J. Nakiyingi, J. Whitworth, M. Crampin, S. Floyd, M. Urassa, G. Mwaluko, M. Marston and B. Zaba:** Impact of vertical transmission and parental survival – lessons from the UNICEF meta-analysis.
2. **H. Brahmbhatt and R. Gray:** Survival of infected and uninfected children of HIV positive mothers – evidence from Rakai.
3. **H. Coovadia:** Infant Mortality according to timing of transmission of HIV from Mother to Child.
4. **N.Walker and P. Ghys:** Proportion of child mortality attributable to HIV.

FINDINGS

Child Mortality
- 32% MTCT rate in countries where breastfeeding is prevalent (Walker and Ghys).
- Over 50% of children infected with HIV died by 24 months of age (Brahmbhatt and Gray).
- Children of positive teenage mothers were more likely to die (Nakinyingi et al).
- Child mortality increases in mothers with CD4 count of below 200, and with increasing maternal or infant plasma viral load (Brahmbhatt).
- Maternal and infant viral loads are predictors of child mortality in this population (Brahmbhatt).
- Children with the worst survival rates are those without mothers (Nakinyingi et al).
- Comparison of crude mortality rates suggest that infants infected through breastfeeding have lower mortality than those infected in utero or intra-partum, but analyses did not adequately allow for age at acquisition of infection.
- Lower mortality rates in countries where bottle-feeding is prevalent (Walker and Ghys).
- Proportion of under-five mortality is highly variable (Walker and Ghys).
- Under-five mortality rates have not peaked yet and vary between countries (Walker and Ghys).

CONCLUSIONS

- The mortality hazard faced by children of HIV positive mothers is high (Nakiyingi *et al*).
- Retrospective reports by surviving mothers underestimate the true levels of child mortality in AIDS affected populations (Nakiyingi *et al*).
- HIV/AIDS is an increasingly important cause of under-five mortality (Walker and Ghys).
- HIV infection in mother and infants were the most important predictors of child mortality in the Rakai, Uganda population (Brahmbhatt and Gray).
- Maternal and infant viral load levels and maternal CD4 counts <200 were important predictors of progression to death for HIV infected children (Brahmbatt and Gray).
- Study findings have implications for the debate on breastfeeding and infant milk (Coovadia).
- Age at acquisition of infection in children should be considered and mode of infant feeding and duration of breastfeeding exposure allowed for (Coovadia).
- Preventive efforts needed to continue to reduce HIV at birth and via breastfeeding. (Brahmbhatt).

KEY POINTS FROM SESSION DISCUSSION

- Need to check definitions of child – some research uses below age 5; others below age 2 years.
- Need for analysis of the more likely route of infection (in-utero, at birth or via breastfeeding) of children.
- UNAIDS adjusts figures from rural sites because, in some countries, some clinics in rural areas are based in semi-urban sites; therefore, figures may be higher than should be. Adjustment is done to control for this discrepancy.
- UNAIDS is willing to use any new available and useful data or information for making estimations.

DISCUSSANT'S REMARKS

General comments
J. Nakiyingi, *et al*. Paper
- 4% of mothers die within 5 years of giving birth.
- Impact of vertical transmission and parental survival-UNICEF meta analysis
- Overall child mortality rate 13/1000 person years.
- The timing of maternal death was significantly associated with infant and child mortality risk.

- Children born to an HIV infected mother have a 3-fold increased mortality risk compared to those of HIV uninfected mothers.
- Mother's death or terminal illness increases child mortality hazard 3-5 fold in the year preceding death of the mother and 4.9 fold in the year after death of the mother, an effect independent of maternal HIV status.
- 60-85% of children of infected mothers remain uninfected, but there is a greater risk of mortality for these children because of their mothers' health.

H. Brahmbhatt and R. Gray's Paper.
- Prospective community-based study.
- Antenatal HIV prevalence 20%.
- 2-year mortality rates in children of HIV-ve women was 128/1000, in HIV-ve children of HIV+ve mothers 165.5/1000 and in HIV+ve children 540.6/1000.
- Hazard of mortality was 2.04 if mother was HIV infected and 3.78 if child was infected.
- HIV RNA viral load was significantly associated with mortality risk.
- In resource-poor countries up to 50% of infected children will die before age 2 and few survive beyond 5 years.
- In Europe and USA an estimated 15% of children will have progressed to serious disease or death by age 1 and 50% by 10 yrs.

H. Coovadia's Paper
- Causes of infant mortality are multifactoral.
- Environmental factors play a major role and explain differences between studies.
- Preliminary analysis of a large data set from 6 trials in African breastfeeding populations suggests that infants who acquire HIV in utero or intrapartum are at substantial higher mortality risk than infants who acquire HIV through breastfeeding after 1-3 months of age.
- Children born with HIV are likely born to mothers advanced in infection and this affects the survival of children because of the state of health of the mother.

N.Walker and P. Ghys' Paper.
- 10 % of all deaths among children under 5 years in sub-saharan Africa are due to HIV infection.
- In demographic studies, the HIV infection status of the child is generally unknown; therefore, reliance on assumptions.
- Based on a number of assumptions, a model was constructed that showed that almost 10% of all deaths among children under-5 years in sub-Saharan Africa are HIV-related.
- Effect of HIV/AIDS differs widely between countries, reflecting antenatal HIV prevalence and background mortality.
- In the most affected countries, an estimated one-third of under-five mortality could be due to HIV infection in the child.
- There is a lack of data regarding the biology of MTCT.
- In the light of on-going PMTCT efforts, it is important to develop tools to monitor the effect not only on reducing the number of infected children but also in improving child survival.

Conclusions
- In demographic-oriented studies, HIV infection status of the child and/or mother is generally unknown.
- In epidemiological-oriented studies, the numbers studied are smaller and the estimates thus more unreliable; these studies are very costly and not sustainable, follow-up usually only to 2 years at the most.
- There is a lack of data regarding biological understanding of MTCT, and regarding details of age and cause of death in children born to HIV infected mothers.
- Efforts to model the epidemic or the contribution of HIV to overall child mortality need to be informed by up-to-date and reliable data.
- Policy implications:
  - ✓ It is important to improve interventions not just to prevent mother to child transmission.
  - ✓ Population level with each percentage point of HIV prevalence

PARALLEL SESSION
FERTILITY EFFECTS OF HIV

Prof. Rob Dorrington chaired this session. Four papers were presented on research to assess the relationship between HIV/AIDS, fertility and fertility intentions. Dr.Carinne Ronsmans was the discussant.

1. **J. Lewis, C. Donnelly, G. Garnet and S. Gregson:** Assessing the population impact of the interaction between HIV and fertility.
2. **A. Ross:** HIV progression and fertility in Uganda.
3. **L. Van der Paal:** Effect of pregnancy on HIV disease progression and survival among women in rural Uganda.
4. **A. Ezeh**: Fertility intentions in the era of AIDS.
5. **M. Garenne and J. Zwang**: Premarital fertility and HIV/AIDS in Africa.

FINDINGS

HIV progression, foetal loss and fertility
- Significant increase in foetal loss for HIV infected women (Lewis *et al*; Ross *et al*; Van der Paal).
- Increased risk of foetal loss in early stages of HIV infection (Ross *et al*).
- Fertility is reduced from the earliest asymptomatic stage resulting from both a reduced incidence of recognised pregnancy and increased foetal loss (Ross *et al).*
- The greatest reduction in fertility was observed following AIDS diagnosis when there were very few recognised pregnancies Ross *et al*).
- Women with two or more pregnancies after sero-conversion had higher CD4 count, a borderline significant longer survival, were healthier at onset, and had slower disease progression; thus, likely to be sexually active and to become pregnant ('healthy pregnant women effect') (Van der Paal).
- CD4 slope showed steeper decline after pregnancy: clinical significance?(Van der Paal).

HIV Prevalence, Fertility Intentions, Premarital Fertility and Sexual Behaviour
- At aggregate level of analysis, there was not a strong association between HIV prevalence and changes in fertility preferences or contraceptive (Ezeh).
- At individual level of analysis, women who perceive high risk of infection are more likely to desire to stop childbearing (Ezeh).
- Personal knowledge of HIV+ person, level of correct HIV knowledge and HIV test status has significant effects on fertility intentions and family planning, especially in countries with a more mature epidemic where HIV prevalence is declining.
- Some positive correlation between premarital fertility and HIV/AIDS prevalence (Garenne and Zwang).
- Permissiveness and lack of protection during intercourse related to premarital fertility (Garenne and Zwang).

CONCLUSIONS

- Women who want to become pregnant should do so in earlier stage of HIV infection because has less health consequences for the child and mother.
- Further research needed on how stage of infection influences intention and use of family planning.
- If data on premarital fertility can be considered reliable, much doubt about data on HIV sero-prevalence (e.g. South African ANC data).
- There is a pattern linking premarital fertility and prevalence of HIV/AIDS.
- Need for studies to take account of the strong dynamic component of premarital fertility and HIV prevalence. A better understanding of these complex dynamics would require more extensive and

better quality data on HIV sero-prevalence, and the possibility of crossing these epidemiological data with other cultural and behavioural factors.

KEY POINT FROM SESSION DISCUSSIONS

- Further research should include the analysis of the relationship between fertility intentions and presence of adopted children.

DISCUSSANT'S REMARKS
General
- Session sought to show the interaction between HIV and pregnancy.
- Focus on the following research questions:
    - ✓ Does HIV affect fertility in the general population? If so how?
    - ✓ Does HIV affect pregnancy outcome? If so, how much?
- Session is of public health relevance.
- HIV does affect fertility.
    - ✓ Illness causes reduced coital frequency and amenorrhoea
    - ✓ Increased foetal loss.
    - ✓ Increase risk of STDs (sub fecundity)
    - ✓ Increase partner illness, mortality, divorce, separation, and decreased production of spermatozoa.
- Aggregate level: no strong association between HIV prevalence and changes in reproductive preference.
- Little change over time in the percentage of women who want to stop child bearing.
- No clear pattern on the individual level (Findings vary between countries; need to look more closely at what is happening in each of these countries).

Questions/challenges
- Effects of pregnancy on HIV.
    - ✓ Need to counsel HIV + women about pregnancy
    - ✓ Need to understand trends in maternal mortality
- Need to have studies that will adjust for the following factors.
    - ✓ Look at net effect of adjusting for these factors so that we know the contribution of each factor:
    - ✓ Impact of HIV on fertility HIV negative or all women?
    - ✓ Delayed age at start of sex activity
    - ✓ Reduced partnership re-entry rates
    - ✓ Condom use by non-contraceptors
- Ecological study has a number of limitations highlighted by the authors.
- What is the effect of pregnancies on HIV disease progression?
- Do early pregnancies matter?
    - ✓ Are there cumulative effects from one pregnancy to the next?
    - ✓ HIV negative women should be compared with the positive women.
    - ✓ CD4 count can be used to classify the women when trying to control for the effect of HIV.

Conclusions
- We need modelling to understand these relationships better.
- Major effect of HIV on fertility in settings with low contraceptive use and limited knowledge of HIV status.
- Need research that differentiates fertility issues between HIV positive and negative women.

PARALLEL SESSION
EMPIRICAL EVIDENCE OF IMPACTS IN THE PRIVATE SECTOR

Prof. Alan Whiteside chaired this session. Four papers were presented on research on companies. Dr. Greener was the discussant. Please note that there was no rapporteur at this session; thus the discussant's remarks only are presented below.

1. **D. Muirhead:** Economic Impact of HIV/AIDS in the Mining Sector – The Anglo American example.
2. **S. Rosen:** Investing in the epidemic: the value to the South African employers of HIV/AIDS prevention and treatment.
3. **J. Simon:** The impact of HIV/AIDS on labour productivity in Kenya
4. **C. Evian:** Comparison of results from an HIV prevalence survey among a large agricultural/ manufacturing workforce in eastern Swaziland with local ante-natal HIV data.

DISCUSSANT'S REMARKS

General Comments
- Information is sensitive in the private sector.
- Private sector is the driving force of the economy in most countries.
  - ✓ Produces the goods and service;
  - ✓ Main sources of employment
  - ✓ Engine of economic growth
  - ✓ Source of innovation and research
  - ✓ Generates the revenue for the public health sector
- All macro-economic impact channels are relevant to the private sector.
- Important to understand what is happening to the working population.

Evidence from the presentations
- Loss of experience and skills.
- Morbidity a critical issue.
- Medical insurance or medical costs an important component to consider.
- Lower productivity absenteeism and sick leave.
- Experience of large companies.
  - ✓ The law of large numbers ensures impact
  - ✓ Less likely to be in denial
  - ✓ Can adopt flexible strategies:
  - ✓ Succession planning capacity
  - ✓ Multi tasking capacity
  - ✓ Benefit restructuring medical care (sometimes on site)
  - ✓ Can do long term planning
- Experience of small companies.
  - ✓ Impacts likely to be 'lumpy'
  - ✓ More likely to be in denial
  - ✓ Living hand to mouth (short term planning)
  - ✓ Unable to be flexible
- ARV is not usually cost effective at current prices.
- Effectiveness of prevention expenditure is not known.
- Cost-benefit of impacts is very different for different grades of employees.
- HIV prevalence in Swaziland study: A rare example of release to the public domain.
- Prevalence higher for lower grades of employee.

- Private sector assessment of HIV impact do not usually incorporate public cost and benefit (The 'benefit of a cuddle' is not measured; The private sector has to think in terms of cost-benefit, but many of the benefits are public goods).
- If intervention is not cost effective for companies, what is the public responsibility?
- The Mining sector:
  - ✓ good example of what is possible within a large organisation, and has detailed information on relationship between prevalence and impact;
  - ✓ should be able to give valuable and generalisable information about the relationship between costs and interventions
- Information sensitivities: Aggregate results from several companies can be published
- Potential value in comparing large workforce data with predictions based on ANC data
- Potential value in cross-sectoral/industry comparative analysis.

PARALLEL SESSION
EMPIRICAL EVIDENCE FOR IMPACT IN THE PUBLIC SECTOR

Mr. Gavin George chaired this session. Three papers were presented on research covering effects of HIV/AIDS in the public sector. Please note that there was no rapporteur at this session; thus the discussant's remarks only are presented below. Alison Hickey was the discussant.

1. **M-H. Boily:** The Impact of HIV/AIDS on the social Sectors: The case of Health Care and Education, Burkina Faso
2. **P. Badcock-Walters:** Educator Mortality in KwaZulu-Natal: A Consolidated Study of Impact and Trends
3. **J. Glynn:** HIV and pulmonary tuberculosis: the impact goes beyond those infected with HIV
4. **S. Forsythe:** Goals modelling in Kenya: Using Kenya's resource envelope to achieve its HIV/AIDS strategic objectives

DISCUSSANT'S REMARKS:

General
- HIV/AIDS directly impacts on government's ability to deliver regular services at the same time that it requires that government deliver more services.
- Impact on demand:
  - ✓ Education: school enrolments; teacher mortality and attrition rates
  - ✓ Health: Increase demand for services
  - ✓ Increase demand for supplies/medicines
  - ✓ Change in services demanded (disease burden)
- Impact on supply:
  - ✓ Health: Impact on medical practitioners (mortality, morbidity, moral)
  - ✓ Crowding out effect (rationing in the public service leads to poorer services)
  - ✓ Education: Increased need for staff training and recruitment (e.g. projected 60, 000 new teachers needed in KwaZulu-Natal by 2010)
- AIDS is exacerbating existing operations and structural problems in the government systems.

Questions/challenges
- Difficulties in assessing indirect impact of HIV/AIDS on health expenditure.

- ✓ Methodological difficulties (e.g. assumptions of 100% take up rate of services; that rationing does not occur)
- ✓ Field researchers encounter confidentiality and stigma issues
- Need to consider government departments' ability to spend (general capacity to deliver).
- Need to recognise that cost-effectiveness is not (and should not be) the sole determinant of the budget. Other factors in national resource allocation are: Previous budget; policy priorities (political); constitutional obligations/legal framework; rights/moral choices; need (e.g. prevalence rates); cost of programmes; equity; capacity to spend.
- Need to consider impact of HIV/AIDS on revenue (macro economic growth).
- Need to further investigate the link between revenue and the expenditure sides of the budget (tax expenditure).
- Need for tax analysis from HIV/AIDS, pro-poor perspective.
- (Responses):
  - ✓ Need operation systems to allow amendments to spending procedures to accommodate changes in demands for services.
  - ✓ Need to consider policy priorities (political)
  - ✓ Need programmes with sound consideration of constitutional obligations/legal framework;
  - ✓ rights/moral choices.
  - ✓ Need programmes for which costs have been researched.

PLENARY SESSION
TESTING THE ACCURACY OF PROJECTIONS

Dr. Debbie Bradshaw chaired this session. There were four presentations on research to assess the accuracy of modelled projections of HIV/AIDS impacts. Dr. John Stover was the discussant.

1. **T. Buettner, C. Sawyer and H. Zlotnik:** Assessing the adequacy of AIDS modelling in the estimation of population trends
2. **R. Dorrington:** ASSA2001: Can we reconcile the population size and structure with the deaths with the antenatal prevalence levels with the prevalence levels from the national household survey in South Africa?
3. **J. Blacker, P. Kizito and B. Obonyo:** Projecting Kenya's Mortality: Using *Spectrum* to Project the AIDS and non-AIDS Components
4. **N. Grassly, N. Walker, M. Mahy and I. Timaeus:** Comparison of survey and model-based estimates of mortality and orphan numbers in sub-Saharan Africa

FINDINGS

- Use of new UNDP epidemiological model shows evidence of demographic impact of HIV/AIDS (Buettner *et al*).
- Evidence of rising mortality of infant and under fives in Kenya (Blacker *et al*).
- There is evidence of stabilising or even a falling of prevalence in 15-19 year age group which can be reproduced by the model assuming a change in behaviour (Dorrington).
- Official analysis of the 1998 census in Malawi, Kenya and Botswana suggests that mortality is probably due to AIDS (Buettner *et al*).
- AIDS has introduced new biases into both the direct and indirect mortality rates derived from the DHS's and the 1999 census in Kenya; life tables become difficult to use with large AIDS elements (Blacker *et al*).
- Survey data suggest that UNAIDS projections consistently over-estimate the numbers of orphans. Over-estimation is worse in countries with low prevalence (Grassly *et al*).

- Fertility is not likely to be systematically overestimated and in fact more accurate than estimates of child mortality (Grassly *et al*).
- The retrospective population projections prove a consistent accounting framework that can help to construct a plausible population trend even in the presence of missing inaccurate and defective data (Buettner *et al*).
- Integrate all elements of population change and plausibility checks to assess accuracy of projections (Buettner *et al*).
- There is need to make adjustment while calculating the indices for calculating mortality because child mortality has been distorted by HIV (Blacker *et al*).
- Spectrum model is not flexible enough (Blacker *et al*).
- Prevalence levels are high in South Africa (Dorrington).
- However the pattern of projection of all cause from the model differs from that derived from the cause of death (Dorrington).

CONCLUSIONS

- Current evidence suggests incorrect assumptions about mortality for causes other than AIDS is major reason for a discrepancy between projected and survey estimates of mortality and orphans numbers; Also possible that children die earlier so they can't be enumerated in surveys.
- Cannot assume that the background mortality has remained the same since the pandemic began. Malaria and poor and deteriorating health services may be significant factors.

(No key points from the discussion recorded).

DISCUSSANT'S REMARKS
General Comments
- Projections are important advocacy tool.
- Consistency more important than accuracy. If resources are not adequate, accuracy is less important but more important when coverage is high.
- Buettner *et al* assessment worked well for Malawi not so much for Botswana.
- Inputs are getting better (Accuracy of estimates depends on quality of inputs).
- Information presented will help improve data projection.

Questions/challenges
- Tracking the AIDS cases to statistical data problematic (e.g. in Honduras showed that many did not get into the records).
- Accuracy of estimates depends on quality of inputs; Non-AIDS death appears to be a critical variable.
- More of these projections should be done to see the discrepancies, particularly that model estimates are within the range that the data suggests.

SUMMATION

The 41 presentations provided a wealth of information; certainly much more than this report can do justice to. Here, we pick up what was revealed about the state of scientific knowledge on HIV/AIDS. We summarise this information, using three themes (impacts; data needs; methodological issues) that flowed through the meeting's deliberations.

Impacts

The principal result was emphatic illustration of the profound, diverse and tragic effects of HIV/AIDS on society. This states the obvious; something that millions of people already know through experience. However, it needs to be stated in view of persistent denial of these effects in many quarters of society and, equally, to affirm the efforts of many agencies to contain the pandemic. To emphasise this point reflects African sensitivities perhaps, but the notorious record of ambivalence about HIV/AIDS within the national executive of the South African government is testimony to the importance of re-stating the obvious and more.

The meeting showed that AIDS is affecting the demographic composition of many countries. A comparison by Prof. Anderson in his keynote address captured the point. The pandemic's general mortality rate of 90-100% to date, notably amongst mature adults, is in stark contrast to the world's other notable pandemic, the Plague, which led to the death of 30% of populations, primarily amongst the aged and young.

The demographic ramifications of HIV/AIDS were captured in some general and specific conclusions of the meeting's presentations and discussion:
- Survival from HIV sero-conversion is about 8 years;
- The risk of infection is greater for women than men (prevalence of 'maternal orphans' will increase with the ageing of the epidemic);
- HIV has substantive effects on fertility in settings with low contraceptive use and limited knowledge of HIV status.

Notable nuances in the conclusions were:
1) Age is a significant factor:
    - Empirical evidence on mortality generally and evolving age pattern is in line with predictions from epidemiological data and models, but lower than anticipated by some models;
2) Different mortality rates (and other demographic and socio-economic impacts) in different parts of the world, are due largely to variation in maturity of each national epidemic:
    - Current AIDS impacts represent incidence rate of about 10 years ago.
    - Assumptions about mortality due to causes other than AIDS is major reason for a discrepancy between modelled projections and survey estimates of mortality and orphans numbers;
3) Surveys in Tanzania and South Africa suggest mortality patterns that are unique to Africa.

The meeting's deliberations were formally divided into sessions on demographic and socio-economic impacts, but the linkages between biological, demographic and socio-economic effects of HIV/AIDS reverberated throughout each session. Notable illustrations include:
1) Morbidity and mortality are important determinants of socio-economic impacts and variation within the latter upon families and households:
    - Substantial changes to household economic viability, income, consumption patterns of households;
    - Affected households experience greater variation than non-affected households in income levels, poverty conditions and are more likely to suffer severe poverty;
    - AIDS deaths are associated with an increase in household dissolution and child migration.
2) Gender and the position of the deceased family member in the household are significant indicators of HIV/AIDS effect on household economic and social viability:

- Illness and death of mother an indicator of child mortality
- HIV/AIDS is an increasingly important cause of under-five mortality;
- Maternal and infant viral load levels are predictors of progression to death for HIV infected children;
- Mortality rates amongst children infected in pregnancy or during childbirth are higher than those who are infected during breastfeeding.

3) Extended effects of HIV/AIDS are highlighted in the impacts on organisations:
- Loss of experience and skills
- Lower productivity; higher absenteeism and leave rates
- Differential impacts between large and small companies
- ARV is not usually cost effective at current prices (in South Africa).
- HIV undermines government capacity to deliver services
- HIV/AIDS exacerbates existing problems in government structures and operations

People have responded, of course, to the pandemic in many different ways. How people respond is an important consideration and much research presented at the meeting highlighted this point. In particular, the extended family's role as a social welfare mechanism was revealed. This was in part due to a general focus on AIDS in developing countries and amongst the poorer (majority) section of populations, where the lack of formal welfare services is often very evident. Predictably, the extended family was shown still to be a vital feature of people's responses; for instance:
- Parents matter more as parents than their money;
- Increase in fostering and change in the nature of the arrangements;
- HIV affects fertility, but little change over time in the percentage of women who want to stop child bearing;
- Many children are living in potentially vulnerable situations.

However, the important qualification was that empirical research is showing that the nature and form of both direct consequences and popular responses in a country change as the epidemic matures.

In sum, empirical research has progressed beyond simply finding out what is happening, to drawing out the complex relationships between the bio-physical and social conditions that drive the pandemic and the responses. Scientific attention has turned inevitably to the question of what is required to improve this knowledge of human ecology. Answers at the meeting revolved around what information was needed and the analytical challenges now facing researchers.

Data Needs and analytical challenges
There is an ever expanding and rapidly increasing body of rigorous research on HIV/AIDS, but the meeting also highlighted researchers' acknowledgement of the limitations. Three principal concerns were the need for:
1) More comprehensive data, because the capacity for scientific prediction depends on the quality of data;
2) 'Background' data on morbidity and mortality from causes other than HIV/AIDS, in order to measure accurately the contribution of the pandemic to demographic and socio-economic developments;
3) Data on the secondary, extended impacts of HIV/AIDS in order to allow modelled projections to be refined.

Illustrations of where data (and research) was needed included:
1) Community impact of death due to AIDS, including changes to and strains upon extended family support networks (the 'traditional' social welfare mechanism in much of Africa);
2) Timing and sequence of inter-related events (e.g. event history analyses);
3) AIDS impact on inter-related households;
4) Effects of AIDS-death of spouse on surviving partner (e.g. survival and remarriage);
5) Indirect effects (e.g. health, poverty and education) of HIV/AIDS on children generally (e.g. children in foster care; orphans and non-orphans in same households);

6) The inter-connections between health status of an HIV infected person(s), individual and family responses (e.g. effects of pregnancies on HIV disease progression?; how stage of infection influences intention and use of family planning, in view of range in research results in different countries);

7) In MTCT the biological association between the infection of the child and disease progression;

8) With regard to research on organisations, incorporation of medical insurance or medical costs into measurements of HIV/AIDS impact; and more research on the effectiveness of prevention and treatment programmes.

Nonetheless, the meeting recognised and drew attention of researchers to the value and potential in various large-scale data sources; notably:

1) Death registration records as a useful, simple means to monitor the progression of national epidemics, though vital information on death certificates need to be improved;

2) Censuses as a source of wide range of data for use in orphan research.

Furthermore, there was consideration of the analytical challenges emerging as a result of experience. Notable considerations were:

1) The need now for scientists to link, and reconcile discrepancies between demographic and epidemiological data; for instance, if data on premarital fertility can be considered reliable then there is reason to doubt aggregate HIV sero-prevalence data (e.g. South African ANC survey data);

2) The need for studies that examine the effects of pregnancy on HIV progression to recognise the inter-play of a range of factors and adjust analyses accordingly in order to know their relative contribution;

3) The need for researchers on private sector impacts (and companies themselves) to incorporate assessments of the costs (of not intervening) and benefits (of interventions) to the 'public good'.

4) The need for researchers on public sector impacts to provide more comprehensive data in order to improve assessments of macro-economic consequences of HIV/AIDS (e.g. cost and cost effectiveness of budget allocations; impact of HIV/AIDS on revenue).

5) The need for modelling work to investigate discrepancies between estimates and empirical data, and to ensure that model estimates are within a valid range suggested by the data.

These considerations were inter-woven with broader points about methods and methodologies.

Methods and methodology

The interest in methods and methodologies was not surprising. Research on HIV/AIDS is driven by the scientific injunction for objectivity and rigour on the one hand, and, on the other, by intent to contain the pandemic and improve the quality of life of people infected and affected by HIV/AIDS. In other words, researchers attempt to combine, either overtly or implicitly, 'pure' and 'applied' research agenda. Research designs can be confounded by these agenda, however, for they presume different methodologies; hence, at some point in their work, researchers must confront the limitations of, and constraints on research, and find ways around them.

Method innovation:

One of the conclusions from the meeting provides an apt example of the inter-weaving of pure and applied research agenda. The conclusion was that:

'verbal autopsies, hospital records, lay diagnosis, and peer clinician assessment support, are useful for measuring AIDS mortality especially in settings with poor data collection systems'.

The lack of reliable data and the difficulty of obtaining coherent data sets are frequent problems that pose, in turn, difficulties for designing empirical research studies. However, the problem is less significant from an applied research perspective. If the emphasis is on providing adequate information as efficiently and quickly as possible, to enable decision-making on the need for intervention and what interventions are necessary, then a greater margin for *potential* error in data reliability is acceptable

and accepted. A focus on the main or general indicators of HIV/AIDS presence and/or impact, for example, can be adequate.

Consequently, methods such as verbal autopsies and lay diagnosis have been recognised as useful tools. The risk of false reporting, the inability to measure that risk precisely, and the reliance largely on the researcher's experience and judgment to 'adjust' data for error, are often outweighed by the opportunity to obtain relatively sound information. Nonetheless, the value of the methods must still be defended; decision-makers are concerned as much about the adequacy of the information in a researcher's report as academic peers are about the validity of research results. For the researcher, therefore, there is still the imperative to minimise the potential for error; thus, innovations such as peer clinician assessments of records and lay reports in the case of research on causes of illness and death.

Innovations in methods may appear on the surface as practical solutions to problems encountered in the field. They are informed, of course, by a deeper interest to obtain a thorough understanding of HIV/AIDS. That interest was voiced in various ways that are captured, albeit somewhat loosely, in the frequent references to the need for researchers to test assumptions in the body of empirical research to date.

Testing assumptions:
An indication of this concern was the frequent re-iteration of the need for 'background' data – bio-physical (i.e. other diseases) and socio-economic (e.g. social differentiation) 'causes' of morbidity and mortality - in order to assess relative effects of HIV/AIDS. To date, much research has been based on evidence of the 'unnatural' occurrence of morbidity and death (e.g. amongst 15-40 year old adults), and the absence of credible, alternative explanations (e.g. 'poverty'). An indication of the progress in demographic and socio-economic research was the attention paid at the meeting to the question of how to do more thorough studies.

On the one hand, appropriate caveats were voiced; for example:
a) Demographic studies cannot assume that the background mortality has remained static (e.g malaria; poor/ deteriorating health services may be significant factors);
b) Socio-economic studies on public health systems cannot assume that HIV/AIDS prevalence matches demand for services; that '100%' demand indicates service capacity constraints; that rationing of service delivery does not occur;
c) The numerous sampling and recording pitfalls such as selection biases; double counting when HIV is clustered within a group of interacting kin and the problems for analysis without 'benchmarking' research.

On the other hand, the importance of qualitative research was recognised:
a) To expose the nature and extent of assumptions in quantitative data and analyses;
b) To amplify meaning in quantitative data;
c) To identify significant indicators of HIV/AIDS impact for use in design of future empirical studies (e.g. inclusion of psycho-social variables such as 'parents matter more as parents than their money');

Such reflection included other caveats for the design of studies in the future. For instance, the importance of longitudinal studies was a point well taken, but conducting them has brought into question common methodological concepts and analytical categories. Examples include:
1) Household: a problematic unit of study in the light of evidence that it cannot capture complex social dynamics (e.g. re-emphasis of 'traditional' social structures such as the extended family as a safety net/social welfare mechanism, amidst changes to these structures under the stress of the cumulative consequences of HIV/AIDS). There is also the practical research design problem of maintaining samples amidst dissolution, relocation and/or new forms of 'households' in the wake of AIDS deaths.
2) Categories of 'affected' and ' not affected' people in places where prevalence may be as high as 30%; in view of extended, secondary impacts and responses (e.g. family planning) and, in

socio-economic studies, in view of the concept of vulnerability being a longstanding foundation for research.

3) Orphan: deviation from the standard definition of loss of both parents (e.g. 'maternal'; 'double'; 'social' orphans) in order to accommodate social context is confounded often by:
   - variable and context-specific 'fostering' practices (e.g. fostering while one or both parents are alive being a normal and longstanding response to difficult socio-economic conditions in many societies];
   - implicit focus on the 'child' and the general vulnerability of children *per se*, particularly for studies seeking to identify need for interventions.

This questioning does not disavow these concepts and categories; their utility depends on the purpose of a study. Rather, the questioning drew attention to the importance of clarifying the purpose of studies. The inference was, to make explicit 'pure' and 'applied' research agenda in order to provide a basis for deciding what concepts and units of study are appropriate. There is, indeed, a further inference: longitudinal studies by their nature reveal original design limitations and indicate areas where sub-projects could provide valuable insights, all the while having the foundation of regular, systematically obtained 'baseline' data; in short, they have the potential to evolve. This inference was not openly voiced at the meeting, but is discernable from the general interest in developing a more comprehensive understanding of the complex bio-physical and social dynamics of HIV/AIDS via multi- and inter-disciplinary research.

Multi- and inter-disciplinary research:
The case for co-ordinated, collaborative research between different disciplines did not have to be made; it is an axiom of the social sciences today. Nonetheless, in re-iterating this axiom, the meeting highlighted again the methodological challenges for researchers. To use one example: empirical research on fertility has indicated a complex relationship between pre-marital fertility and HIV prevalence and one conclusion is that improved understanding of that relationship depends on 'extensive and high quality data on HIV sero-prevalence, and the means to analyse epidemiological data with other cultural and behavioural factors'.

The point that we wish to end on, nonetheless, is that the meeting clearly encouraged methodological innovation. In other words, there is scope for experimentation, be it with linking and reconciling epidemiological and demographic data, comparing large workforce and ANC survey data, or conveying the significance of 'the cost of a cuddle'.

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