Estimating Orphaning Prevalence and Incidence before and after Antiretroviral Treatment (ART) rollout in rural South Africa, 2000-2013

Gabriela Mejia-Pailles[1,2], Victoria Hosegood[1,2,3], Ann Berrington[1,3]

[1] ESRC Centre for Population Change, University of Southampton

[2] Africa Centre for Health & Population Studies, University of KwaZulu-Natal

[3] Department of Social Statistics and Demography, School of Social Sciences, University of Southampton

First draft – please do not cite without permission of the authors

Extended Abstract

Background: In the context of HIV treatment in sub-Saharan Africa, reliable data on the levels and trends of orphaning are needed to understand the impact of improved survival of HIV-infected parents.

Objective: First, we quantify paternal, maternal and double orphaning prevalence and incidence in rural South Africa between 2000-2013. This period includes observations before and after public HIV treatment was scaled-up in 2004-5. Second, we explore the causes of paternal and maternal deaths throughout the period of study to see whether AIDS related orphanhood is in decline but being replaced by orphanhood from other causes such as injury and non-communicable diseases.

Data and Method: Using the Africa Centre Demographic Information System (ACDIS), an ongoing longitudinal demographic surveillance system in rural KwaZulu Natal containing 11,000 households and a population of approximately 90,000 household members, we estimate trends in the incidence and prevalence of orphanhood. Orphaning prevalence at a given point in time reflects a combination of past and present orphaning, whereas incidence identifies new orphans. Both estimates provide an indirect measurement of the effectiveness of treatment affecting the survival of HIV-infected parents.

Results: Paternal and double orphaning prevalence was steadily increasing in the period before ART roll-out but started to decline around 2008-9. However prevalence appears to have stabilised from 2011. The prevalence of maternal orphaning has not changed significantly since the roll-out of ART. However, the incidence of both paternal and maternal orphanhood has declined since 2007-8 reflecting a more immediate impact of ART roll-out. In the study area, there is an increasing adult HIV prevalence and stable HIV incidence since roll-out, and our analyses show that the proportions of HIV-related maternal and paternal deaths are decreasing.

Conclusion: The effectiveness of ART rollout in the community is reflected in the decrease in the prevalence (of paternal and double orphaning) and incidence of orphanhood in the immediate period after the 2004-5 roll-out. Increasing survival of HIV-infected adults has resulted in a rise in HIV prevalence among parents, but a drop in the proportion of deaths attributable to HIV. This said, the incidence of orphanhood remains tragically high in this community as a result of high rates of adult (particularly male) mortality from both AIDS and non-AIDS related causes, especially injuries and non-communicable diseases.

Introduction

During the past two decades, South Africa has experienced one of the highest HIV prevalence in the world (UNAIDS 2010). In particular, rural communities in KwaZulu-Natal, South Africa, have been affected by a rapid and severe HIV epidemic. In 2007, it was estimated that 27% of adult females and 13.5% of adult males residing in the area were HIV infected (Welz et al. 2007), with HIV/AIDS constituting the leading cause of death (Hosegood *et al.*, 2004; Herbst et al. 2009). The consequences of premature death among young adults include the increase in the levels of children that have lost one or both parents to the epidemic (Hosegood et al. 2007, Hill et al. 2008).

In the context of HIV treatment in Southern Africa, reliable data on the levels and trends of orphaning are needed to understand the impact of improved survival of HIV-infected parents and changes in HIV incidence (Barnighausen et al. 2009) and prevalence (Zaidi et al 2012). In addition, these data are also needed to monitor the effectiveness of intervention programmes and policies directly or indirectly targeting orphans (Madhavan et al 2014). Orphaning during childhood has been found to be disadvantageously associated with numerous health and welfare outcomes including education (Guo & Sherr 2012), mental health (Cluver et al, 2012; Atwine et al, 2005), and early sexual debut (Operario et al 2011).

The main aim of this paper is to provide up to date estimates of maternal, paternal and dual orphanhood prevalence (Hosegood et al. 2007; Hill et al. 2008) in rural communities in KwaZuluNatal South Africa to cover the years 2000-2013. This period includes reports and observations before and after public HIV treatment was introduced (2004-05) and scaled-up (2006-07) in the area. Moreover, we are interested in estimating maternal and paternal orphaning incidence before and after HIV treatment rollout in the community. Orphaning prevalence at a given point in time reflects a combination of past and present orphaning, whereas incidence is an effective measure to identify new orphans, as well as the risk of becoming one. Both estimates work as an indirect measurement of the effectiveness of treatment affecting the survival of HIV-infected parents. Therefore, a second aim of the paper is to explore the causes of paternal and maternal deaths throughout the period of study to trace changes over time with the potential to distinguish between HIV-related orphans and non HIV-related orphans.

Data and Methods

This paper uses longitudinal demographic surveillance system data (DSS) collected since 2000 by the Africa Centre Demographic Information System (ACDIS) in 11,000 households and a population of approximately 100,000 household members. The demographic surveillance area (DSA) consists of a geographically contiguous area of 438km^2 in the Umkhanyakude district, northern KwaZulu-Natal, South Africa. The design of ACDIS has previously been described in detail (Tanser et al, 2008).

In this paper, our main variable of interest is whether the biological parents of a child are alive or dead. Furthermore, we are also interested to know the date and cause of parental deaths.

There are two ways to establish the survival status of a child's parent using existing ACDIS data. The first one is by examining any routine prospective observations made of those parents who themselves are a registered individual in the DSS and, for whom linkage with their children has been recorded. Linkages ae recorded when both a parent and a child are simultaneously registered members in the same household at some point during their life courses. For many children, this linkage with one or both biological parents will occur at the time they are registered as new births in the surveillance area. However, the linkage may also be made later in childhood for example, when a child migrates to join a parent who has been living in a different household in the DSA.

In case the linkage is not recorded, the way of establishing a child's parent survival status is from answers given by a household respondent to a direct question about whether a child's biological parent is currently alive (Hosegood, et al 2007). This question has been asked about each child during the routine household visit since 2004. This data permits the estimation of orphaning for all children regardless of whether the parent is registered or not. However, the use of these repeated observations has challenges. These include missing observations; where the respondent reports not knowing whether the child's parent is alive or dead; and implausible sequences of status observations such that a parent previously reported to have died is later reported to be alive. We explored these inconsistencies (Mejia-Pailles, et al 2014) and estimated parental survival status for unlinked parents using a series of assumptions based on the longitudinal reported information.

Orphaning prevalence levels is the result of both past and recent paternal and maternal mortality. In contrast, orphaning incidence provides a useful insight to identify new cases of orphans and the early and acute implications (Watts et al. 2005). With the data collected by ACDIS, we were able to estimate yearly maternal and paternal orphaning incidence rates as the number of maternal or paternal deaths per 1,000 person years among children 0-17 years

old whose mothers and father were alive at the start of the follow-up period, respectively. For children whose parents died during the observation time, the exposure time was estimated as the time between the start of follow-up and the date of death of the parent. We included in the analysis children that died, migrated outside the DSA or ended their household membership before the observation period[1]. The time of exposure for these children was censored at the time where there were last observed.

Levels and trends in orphanhood prevalence

In Figure 1, we present annual estimates of orphanhood prevalence between 2000-2013. For these estimates, we have used UNAIDS definition of orphan types[2]. The prevalence of maternal orphanhood has been stable since 2004. Although the prevalence of HIV in women has increased since the advent of HIV treatment (Zaidi et al 2012), the stable level of maternal orphaning may reflect a compensatory improvement in survival of HIV-infected mothers. In contrast, the considerably higher prevalence of paternal orphanhood continued to increase up until 2008-9 before declining. Paternal prevalence appears to have stabilised from 2011.

In this population, the proportion of paternal orphans at each age is expected to be higher than that of maternal orphans given that fathers are often older than mothers and that men have a higher rate of premature mortality than women, for example, from injuries and accidents (Anupam et al., 2011). The relative delay before mortality of fathers that appeared to decline may reflect the slower gains in survival of HIV-infected men compared to women in the community (Reniers et al. 2014).

Estimating Maternal and Paternal Orphaning Incidence

Since we need precise timing at death to estimate exposure times, in this section we only focused on children and parents that were ever members in the same household. Figure 2 shows the incidence of both maternal and paternal orphanhood estimated from ACDIS data for children under 18 years of age and their ever member paretns. The orphaning incidence shows an increasing trend in the risk of becoming an orphan in the pre-ART era, with

[1] For those children with intermittent period of household membership during the beginning and end of the observation time, we considered them as being continuously present. We are aware of the adjustment still needed to be made to consider accurate exposure time for these children.

[2] UNAIDS defines maternal orphans are children whose mothers have died or whose survival status is unknown, and whose father is alive; while paternal orphans have the opposite characteristics. Double orphans are those who have lost both parents or whose survival status is unknown.

maternal orphaning incidence reaching its peak in between 2002-2003, and paternal orphaning incidence reaching its peak during 2004-2005. Maternal orphaning incidence increased from 15.9 per 1000s person-years observed (PYO) (95% CI: 15.0-16.9) in 2000-01 to 19.1 per 1000s PYO (95% CI: 18.0-20.2) in 2002-03, whereas paternal orphaning incidence raised from 27.5 per 1000s PYO (95% CI: 25.9-29.2) in 2000-01 to 30.9 per 1000s PYO (95% CI: 29.1-32.9) in 2004-05.

With the introduction of ART in 2004-05 and full roll-out since 2007, our results showed that both paternal and maternal orphaning incidence rates have declined, with an overall paternal orphaning incidence being higher than maternal orphaning incidence. Given its higher levels, overall paternal orphaning incidence starts to show a slightly more pronounced decrease over time than overall maternal orphaning incidence. The incidence of maternal orphanhood for children 0-17 years old decreased to 11.1 per 1000s PYO (95% CI: 10.2-11.9) in 2012-13, and paternal to 13.2 per 1000s PYO (95% CI: 11.8-14.8).

Young adult mortality peaked in the region in the mid-2000s (Reniers et al 2014), and so did both orphaning prevalence (Figure 1) and orphaning incidence (Figure 2) in the community.

Cause of Maternal and Paternal Deaths

When a parent is a registered member of ACDIS and has been linked to his/her children through simultaneous co-membership in the same household, it is possible to know the cause of death from data recorded from reports of verbal autopsies (Khan 2000). The cause of death was only possible to be assigned to those mothers and fathers that were ever members of the same household as the child, as not only the linkage with their children was produced, but they are also registered individuals of ACDIS themselves.

At the beginning of 2000, the HIV epidemic was not yet stable (Hosegood et al 2007). Hence, most causes of adult death were attributed to AIDS/TB, with a peak around early 2000s. However, with full ART roll out in the community, our results showed important decreases in the proportion of maternal and paternal AIDS related deaths for linked mother and fathers (Figure 3). Our results show that in 2000, nearly 80% of maternal orphans had lost their mothers to AIDS/TB. In the post-treatment roll out era, 50%-60% of maternal deaths were associated to AIDS/TB.

The reductions in maternal HIV related deaths seen since its peak in 2002-2003 are being replaced by increases in the proportion of deaths caused by non-communicable diseases

and undetermined causes of death in recent years. In 2000, non-communicable diseases accounted for less than 10% of maternal deaths, slightly increasing to nearly 15% in 2012. However, undetermined causes of death constituted less than 5% of maternal deaths pre-ART era, increasing to nearly 20% in 2013.

In a pre- and post-treatment era, a slightly slower proportion of children had lost their fathers to HIV (62% in 2000-2003 compared with 44% in 2013) than to mothers. For fathers, both causes of death associated to non-communicable diseases and injuries showed important proportion among paternal deaths. Although the proportion of deaths caused by injuries fall shortly behind deaths by non-communicable disease, adult male mortality related to injuries plays a very important role among the leading causes of death in the community (Hosegood et al. 2004; Herbst et al. 2009) The leading cause of morality among adults 25-49 year old continues to be HIV (Herbst et al 2009).

In a post-treatment era, non communicable diseases account for a considerable proportion of paternal deaths, reaching levels of around 20% of the deaths among fathers. Injuries account for a considerable proportion of paternal deaths, but not maternal deaths. Injuries have kept a stable trend over time, accounting for nearly 15%-20% of paternal deaths.

Our results showed an important decline in the proportion of cause of death due to HIV for both mothers and fathers (Figure 3). Hence, in the paper we seek to explore in further detail the orphaning prevalence and incidence due to AIDS and non-AIDS related maternal and paternal mortality.

Concluding notes

The effectiveness of ART rollout in the community is reflected in the decrease in the prevalence (of paternal and double orphaning) and incidence and in the immediate period after full ART roll-out. Increasing survival of HIV-infected adults has resulted in a rise in HIV prevalence among parents, but a drop in the proportion of deaths attributable to HIV. This said, the incidence of orphanhood remains tragically high in this community as a result of high rates of adult (particularly male) mortality from both AIDS and non-AIDS related causes, especially injuries and non-communicable diseases.

In further work we will seek to explore the linkage between HIV-infected parents in relation to their stage in treatment, i.e. whether they have been diagnosed after infection or are already eligible for treatment to understand the implications of treatment in reducing future HIV-related orphaning prevalence and HIV-related orphaning incidence.

References

Anupam, G., A. J. Herbst, V Hosegood & ML Newell "Injury mortality in rural South Africa 2000–2007: rates and associated factors*." *Tropical Medicine & International Health* 16.4 (2011): 439-446.

Atwine B, Cantor-Graae E, Bujunirwe F. (2005). Psychological Distress among AIDS Orphans in Rural Uganda. *Science & Medicine.* 61 (3): 555-564.

Barnighausen T, Tanser F, Newell ML: Lack of a decline in HIV incidence in a rural community with high HIV prevalence in South Africa, 2003–2007. AIDS Res Hum Retroviruses 2009, 25:405–409.

Cluver L, Orkin M, Boyes ME, Gardner F. (2012). AIDS-orphanhood and caregiver AIDS-sickness-status: Effects on psychological symptoms in South African youth. *Journal of Pediatric Psychology*. DOI: 10.1093/jpegsy/jss004. (IF 2.943) .

Guo Y, Sherr L. (2012). The impact of HIV/AIDS on children's educational outcome: A critical review of global literature. *AIDS Care.* Apr 23 Epub ahead of print.

Hill, C., V. Hosegood, et al. (2008). "Children's care and living arrangements in a high HIV prevalence area in rural South Africa." Vulnerable Children and Youth Studies **3**(1): 65-77.

Herbst, Abraham J., et al. "Adult mortality and antiretroviral treatment roll-out in rural KwaZulu-Natal, South Africa." *Bulletin of the World Health Organization*87.10 (2009): 754-762.

Hosegood, Victoria, et al. "The impact of adult mortality on household dissolution and migration in rural South Africa." *Aids* 18.11 (2004): 1585-1590.

Hosegood, V., Floyd, S., Marston, M., Hill, C., McGrath, N., Isingo, R., Crampin, A., & Zaba, B. (2007). Growing up in rural Africa: orphanhood and living arrangements of children in high HIV prevalence populations in Malawi, Tanzania and South Africa. *Population Studies, 61*(3).

Kahn, Kathleen, et al. "Validation and application of verbal autopsies in a rural area of South Africa." *Tropical Medicine & International Health* 5.11 (2000): 824-831.

Madhavan, S., T. Moultrie, V. Adjiwanou (2014), Fathers, 'Dead' Fathers and 'Absent' Fathers – An Analysis of Reporting on Survival Status of Fathers in South Africa , seminar presented at the Centre for Actuarial Research, University of Cape Town, March 2014, Cape Town, South Africa.

Mejia-Pailles, G., V. Hosegood, A. Berrington (2014). "Exploring factors associated with completeness of parental survival data in a longitudinal surveillance system in rural South Africa". British Society for Population Studies Annual Conference, Winchester, September 2014.

Operario D, Underhill K, Chuong C, Cluver L. (2011). HIV Infection and Sexual Risk Behavior Among Youth who have Experienced Orphanhood: Systematic Review and Meta-Analysis. *International Aids Society.* 14:25.

Reniers G., E. Slaymaker and B. Zaba (2014), "Adult mortality in East and Southern Africa in the era of antiretroviral therapy", PAA, Boston, MA, April 2014.

Tanser F., et al. "Cohort Profile: Africa centre demographic information system (ACDIS) and population-based HIV survey." *International Journal of Epidemiology* 37.5 (2008): 956-962.

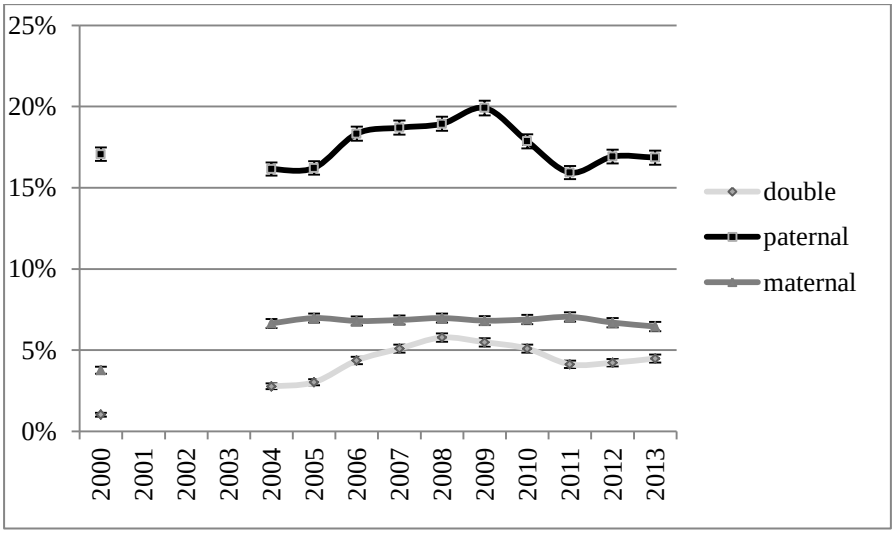
UNAIDS. 2010 Report on the Global AIDS Epidemic. Geneva: Joint United Nations Programme on HIV/AIDS; 20010

Watts, Helen, et al. "Rising incidence and prevalence of orphanhood in Manicaland, Zimbabwe, 1998 to 2003." *Aids* 19.7 (2005): 717-725.

Welz T, Hosegood V, Jaffar S, Batzing-Feigenbaum J, Herbst K, Newell ML: Continued very high prevalence of HIV infection in rural KwaZulu-Natal, South Africa: a population-based longitudinal study. AIDS 2007, 21:1467–1472.

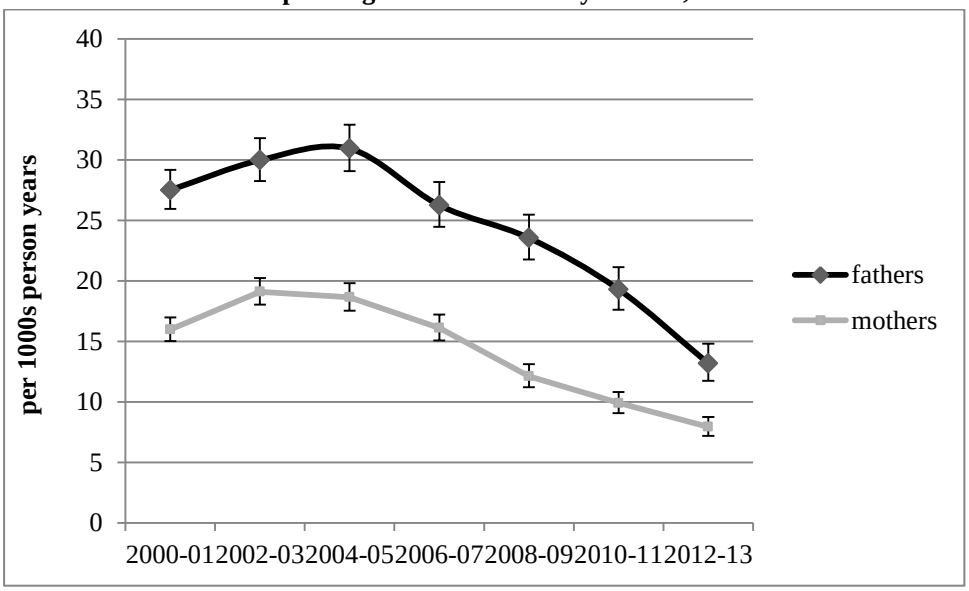
Zaidi J, Grapsa E, Tanser F, Newell M, Bärnighausen T: HIV prevalence trends after scale-up of antiretroviral treatment: a population-based study in a poor rural community in KwaZulu-Natal. J Int AIDS Soc 2012, 15(Suppl 3).

Figure 1. Reported Orphanhood Prevalence for children 0-17 years old, ACDIS, 2000-2013.



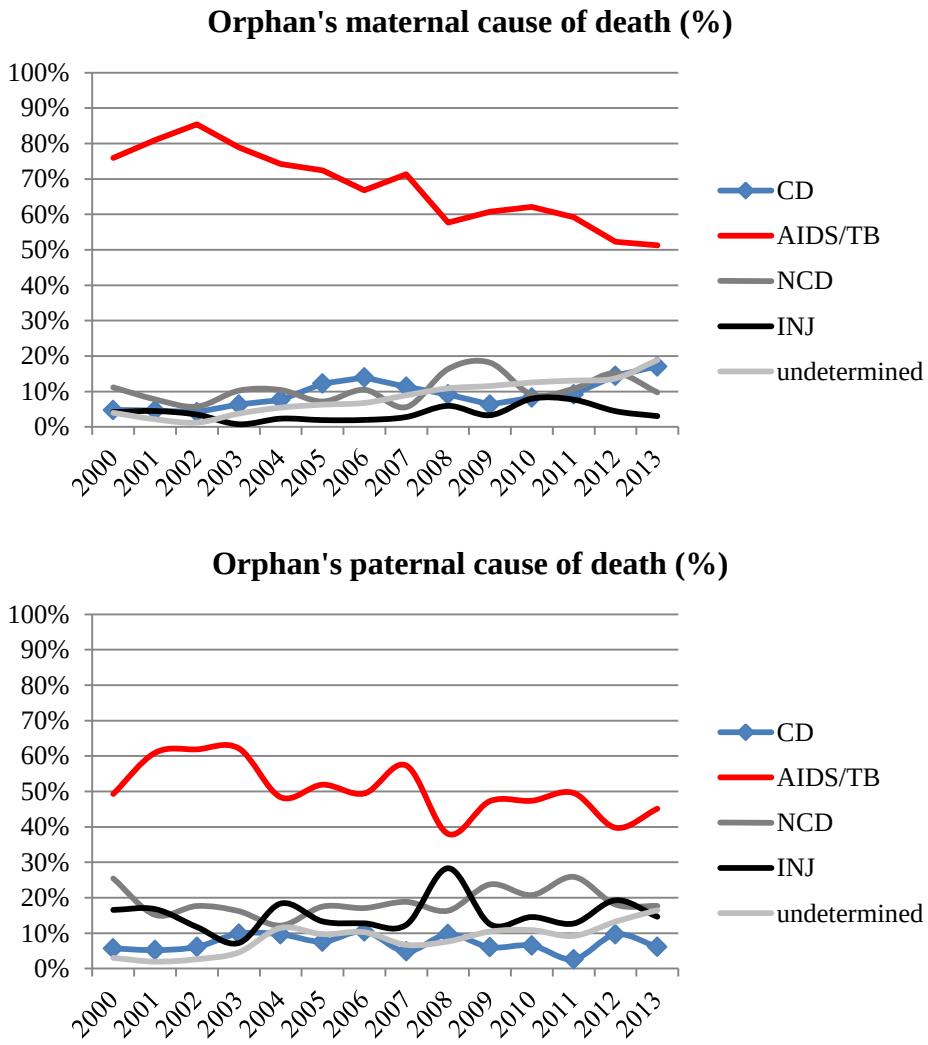
Source: Authors' calculations based on ACDIS.

Figure 2. Incidence rate of orphaning for children 0-17 years old, ACDIS 2000-2013.



Source: Authors' calculations based on ACDIS.

Figure 3. Percentage distribution of parental causes of death for orphaned children 0-17 years of age, ACDIS 2000-2013.



NOTE: HIV=AIDS/TB, INJ=Injuries; NCD=non-communicable diseases; CD=communicable diseases; UNDET.=undetermined cause of death.