RESEARCH ARTICLE

Trends in the prevalence and incidence of orphanhood in children and adolescents <20 years in rural KwaZulu-Natal South Africa, 2000-2014

Gabriela Mejia-Pailles1, Ann Berrington2, Nuala McGrath2,3,4, Victoria Hosegood2*

1 Independent Consultant, Mexico City, Mexico, 2 Department of Social Statistics & Demography, University of Southampton, Southampton, United Kingdom, 3 Department of Population Sciences & Primary Care, University of Southampton, Southampton, United Kingdom, 4 Africa Health Research Institute, KwaZulu-Natal, South Africa

* v.hosegood@soton.ac.uk

Abstract

Background

In South Africa, large increases in early adult mortality during the 1990s and early 2000s have reversed since public HIV treatment rollout in 2004. In a rural population in KwaZulu-Natal, we investigate trends in parental mortality and orphanhood from 2000–2014.

Methods

Using longitudinal demographic surveillance data for a population of approximately 90,000, we calculated annual incidence and prevalence of maternal, paternal and double orphanhood in children and adolescents (<20 years) and, overall and cause-specific mortality of parents by age.

Results

The proportion of children and adolescents (<20 years) for whom one or both parents had died rose from 26% in 2000 to peak at 36% in 2010, followed by a decline to 32% in 2014. The burden of orphanhood remains high especially in the oldest age group: in 2014, 53% of adolescents 15–19 years had experienced the death of one or both parents. In all age groups and years, paternal orphan prevalence was three-five times higher than maternal orphan prevalence. Maternal and paternal orphan incidence peaked in 2005 at 17 and 27 per 1,000 person years respectively (<20 years) before declining by half through 2014. The leading cause of parental death throughout the period, HIV/AIDS and TB cause-specific mortality rates declined substantially in mothers and fathers from 2007 and 2009 respectively.

Conclusions

The survival of parents with children and adolescents <20 years has improved in tandem with earlier initiation and higher coverage of HIV treatment. However, comparatively high
levels of parental deaths persist in this rural population in KwaZulu-Natal, particularly among fathers. Community-level surveillance to estimate levels of orphanhood remains important for monitoring and evaluation of targeted state welfare support for orphans and their guardians.

Introduction

In all societies, the death of a parent during childhood and adolescence, especially the death of a mother, is widely acknowledged as having potentially profound consequences on child health and wellbeing [1–8]. Studies in South Africa conducted since the start of the HIV epidemic have shown orphaned children to be at increased risk of poorer health and educational outcomes compared to other children (See for example, [9–11]). The severity and duration of negative consequences are influenced by the type, cause and timing of orphaning. For example, there is consistent evidence that double or maternal orphans are at greater risk than paternal orphans [2,12,13]. Compared to other causes of parental death, children experiencing the death of a parent due to AIDS or injuries have higher risks of poorer child mental health [14] and, significant changes in their living arrangements due to household dissolution and migration [14–16].

In rural KwaZulu-Natal, South Africa, men and women become parents in a context of very high HIV population prevalence [17,18]. In the early 2000s, forecasts based on population data suggested that even if HIV incidence remained stable, in the absence of public HIV treatment, between 24% and 33% of children would go on to become maternal and paternal orphans by their 18th birthday [19,20]. When antiretroviral treatment (ART) was rolled out from 2004 onwards, overall adult mortality rates declined reflecting reduced adult mortality due to HIV/AIDS [21–23]. Consequently, the previously forecasted level of orphan incidence are no longer expected even in communities that experienced severe HIV epidemics and where the prevalence of HIV is still increasing due to the improved survival of people living with HIV. However, there are very few recent and detailed published population orphanhood estimates for South Africa, especially of orphan incidence rates. Given that orphans and vulnerable children (OVC) are a key population group targeted by statutory and private support services [24–27]; uncertainty about recent changes in the numbers and types of orphans in HIV affected communities is a challenge for planning relevant and effective health and welfare-related policy responses.

This paper contributes to filling this gap with robust estimates of the levels and trends in age-specific orphan prevalence and incidence in rural KwaZulu-Natal over the period 2000–2014. We are able to situate these new estimates of orphanhood in the context of changes in the level and pattern of adult mortality documented by previously published studies from the same area [9,15,19,21,28–31]. We describe changes over the 15 year period (2000–2014) in the ages at which children are orphaned, different types of orphans, children’s exposure to different causes of parental mortality. We discuss the implications of these recent trends in orphaning for programme and research activities focusing on orphans and other children affected by HIV in South Africa.

Methods and data

Study site and setting

We analysed longitudinal, population-based demographic and health surveillance data available in the Africa Centre Demographic Information System (ACDIS) for the period 2000–
2014. The population data were collected prospectively in approximately 11,000 households resident in part of the Umkanyakude district in northern KwaZulu-Natal, South Africa. The Zulu-speaking communities in this predominantly rural area are broadly similar to many other rural parts of the province where governance is a mixture of tribal and municipal authorities. Waged employment and government grants are the main source of household income rather than agriculture. The level of local unemployment in the study area is high and consequently many men and women migrate to other places within South Africa in order to work or seek work [28,32]. Substantive proportions of adults and children belonging to households in rural KwaZulu-Natal are circular migrants [33]. Circular migration is a long-established form of oscillatory mobility involving households in multiple rural or urban locations and work sites. In South Africa, the apartheid migrant labour system deeply entrenched the importance of circular migration for household livelihoods and family functioning [34]. Typically circular migrants remain socially and physically connected through visits, involvement and shared financial and material support [35]. It is also common for children living in rural areas to experience periods of parental absence and caregiving by non-biological parents, due both to parental migration and low rates of marriage and cohabitation of parents [36,37].

The severe HIV epidemic experienced in KwaZulu-Natal since the end of the 1990s has been well-described elsewhere (See for example, [21,38]). Calculated using data from routine, HIV testing surveys conducted within the surveillance system study population, estimates of HIV prevalence between 2003 and 2014 in resident men and women (15–49 years) increased from 21% (20.9–22.7) in 2003/4, to 33% in 2014 [38,39]. In the study area, public access to HIV treatment has been delivered through the Hlabisa HIV Treatment and Care Programme of the South African Department of Health (Hlabisa HTCP) [40]. Between 2000 and 2014, public ART in the study area can be broadly characterised into two periods: 2000–2005 in which public ART was unavailable or beginning to be rolled out across primary health care (PHC) clinics in the local health district; and, 2006 onwards when public ART was widely available and where treatment could be initiated at several local PHC clinics [40,41]. In the same health district, estimated population ART coverage in HIV-positive adults was 31.7% in 2012 and 45% in 2017 [38,42].

**Study population data**

The study population comprises approximately 90,000 members of households in the study area. ACDIS procedures and data collection systems are described in detail elsewhere [33,43,44]. In brief, from January 2000 data on all resident and non-resident household members were collected every 3–4 months, including all new births, deaths and migrations. When an adult or child death is recorded, a verbal autopsy (VA) interview is conducted within 3 to 10 months with the deceased family or carers. During the interview additional information about the death is recorded in order that a cause of death can be assigned using InterVA-4 software [29]. In 2016, the ACDIS study area and data collection activities were incorporated into a new Population Intervention Platform Study Area (PIPSA) conducted by the Africa Centre Health Institute (AHRI).

**Parental data**

During routine household visits, household respondents are asked to confirm or update the survival status of biological mothers and fathers for every resident and non-resident household member. In cases where the biological parent has also been registered in ACDIS, typically when the parent is or has been a member of the same household as his or her child, the parent’s and child’s data are linked in the surveillance system. Linked biological parent-child records
provide researchers with another, indirect source of longitudinal data from which to ascertain if, and when the parent died. An exception was the period between the end of 2000 and January 2004 during which questions about the survival status of unlinked, biological parents were not asked at every household visit. However, using other information we were able to reconstruct survival histories of most parents with gaps in prospective data collection.

In this study, we developed a set of pre-analysis validation criteria to guide the detection and adjustment of inconsistencies across repeated observations of the survival status of biological mothers and fathers. Increasing with age due to longer periods of follow up, most children and adolescents have repeated observations of parental survival status. For example, an average of 20 maternal orphan status observations are available for resident children aged 17 years. Of children with multiple reports of parental survival status, less than 3% had inconsistencies between two or more observations. We examined inconsistent observations to reconcile information where possible using detailed individual data on parents or subsequent reports by household respondents. In the estimates, unlinked parents for whom no survival information was available were included with dead parents. This approach is similar to that used by international agencies and some researchers to calculate estimates of orphan prevalence from cross-sectional survey data [45]. In non-conflict settings in Africa, it unusual for household respondents not to know or want to say whether a child’s mother or father is alive or dead. Thus, it has been argued that when information on a parent is not known, the parent is effectively unavailable to his or her child [24]. After pre-analyses validation for inconsistencies in data, less than one percent of all children and adolescents had no valid observation of maternal or paternal status. These children were not included our analyses (see S1 Table footnote for details of the number of missing children and adolescents in each year).

Measures

Categorising orphans. The term ‘orphan’ is variously conceptualised in the global literature with a wide range of different definitions used in descriptions and measurement of orphanhood [27]. In this study, we define four non-overlapping types of orphan: Non-orphan —both biological parents are alive. Maternal orphan—mother is dead or her survival is not known, father is alive. Paternal orphan—father is dead or his survival is not known, mother is alive. Double orphan: mother and father are dead or survival status unknown. We also include a summary measure of whether ‘one or both parents are dead’ as this measure is often included in survey and national reports. All measures of orphaning presented in this paper are for both sexes combined as we found no significant differences in the levels or patterns of orphanhood in girls and boys. In this paper, we use an upper age limit of 19 years. Older South African youth have a high degree of dependency of on financial and material support from family given that the majority attend school until 18 or 19 years and, over half of all school leavers in this community are unemployed [9,32,46]. Furthermore, commentators have highlighted knowledge gaps caused by the omission of older adolescents in orphanhood statistics and programmes in sub-Saharan Africa [47].

Prevalence and incidence of orphanhood. Annual orphan prevalence estimates were calculated for all children and adolescents (<20 years) resident in the study area on the 31st July (mid-year population). Prevalence estimates were calculated for the four types of orphan separately (maternal, paternal, double and non-orphan) and for a combined measure (one or more parents are dead). Maternal and paternal orphaning incidence were estimated as the number of maternal or paternal deaths per 1,000 person (i.e. child) years observed (PYO) among resident children (<20 years) whose mothers and father were alive at the start of the follow-up period. Observed years were censored for children that died, migrated outside the
demographic surveillance area or ended their household membership before the end of 2014. For children whose parents died during the observation period, exposure was estimated as the time between the start of follow-up and the date of death of the parent. The time of exposure for these children was censored at the time when they were last observed. We present the orphan incidence data for four years within the follow-up period: 2000, 2005, 2010 and 2014.

Causes of parental death. Parental deaths were assigned to one of five groups of causes: HIV/AIDS and TB, communicable, non-communicable, injury and undetermined [29]. In this paper, we consider deaths due to HIV/AIDS and TB together to reflect the high levels of comorbidity of HIV and TB in the study community, as well as the similarity of associated symptoms. For mothers and fathers of children in the study population, we estimated the annual all-cause mortality rates for the years 2000–2014 and the relative contribution of the five groups of causes of death to overall mortality. When calculating cause-specific mortality each deceased parent was included only once. Given the different age distribution of deceased mothers and fathers and, the marked differences in cause-specific mortality at older ages, we disaggregated the cause-specific mortality data further and present the results separately for mothers in two age groups: <35 years and 35+ years, and fathers aged: <40 years and 40+ years.

In order to examine whether the rate at which children and adolescents experience different cause-specific maternal or paternal deaths changes with age or over the period before and after ART, we calculated the maternal and paternal incidence for the years 2000, 2005, 2010 and 2014, by age group and cause of death category. We also calculated annual cause-specific incidence estimates for maternal and paternal orphaning in years 2000, 2005, 2010 & 2014. Stata software was used for all statistical analyses (Version 13, StataCorp).

Ethics approval
Ethics approval for the demographic surveillance study and analyses of these data was given by the College of Health Sciences Biomedical Research Ethics Committee, University of Kwa-Zulu-Natal, South Africa. The study project received approval from the research ethics committee of the University of Southampton: ID:9841.

Results
The levels and trends in age-specific maternal, paternal and double orphan prevalence are presented in Fig 1 for the years 2000, 2005, 2010 and 2014 (S1 Table presents additional detailed data related to Fig 1 including absolute numbers, estimates and 95% confidence intervals). The proportion of children and adolescents (<20 years) for whom one or both parents had died rose from 26% in 2000 to peak at 36% in 2010, followed by a decline to 32% in 2014. In all age groups and years, the level of paternal orphan prevalence was three-five times higher than maternal orphan prevalence. The pattern of maternal orphan prevalence rose from 2000 to plateau between 2005 and 2010, declining slightly by 2014. In contrast, paternal orphan prevalence continued to rise through 2010—declining later and more slowly than maternal orphan prevalence. The largest difference between paternal and maternal orphan prevalence was in the youngest age group (0–4 years). In this age group, the seven-fold difference in 2000, 15% and 2% respectively, remained very similar across the period. Orphaning is a cumulative experience with age, with the oldest age group of children (15–19 years) experiencing the highest prevalence of every orphan type. By 2010, 53% of children aged 15–19 years had experienced the death of one or both parents; with 10% in this age group being maternal orphans and 27% paternal orphans. Increases in double orphaning among older age groups of children were very pronounced through 2010; more than doubling from 7.5% (2000) to 16% (2010) in 15–19 year olds. By the end of the study period in 2014, the prevalence of all orphan types had
declined close to, but had not yet reached, the lower levels observed at the start of data collection in 2000.

Fig 2 presents age-specific incidence of maternal and paternal orphaning (S2 Table presents additional detailed data related to Fig 2 including numbers and 95% confidence intervals). Estimates of maternal and paternal orphaning incidence (age < 20 years) peaked in 2005, 17 and 27 per 1,000 person years respectively. As with orphan prevalence, the difference between maternal orphaning incidence and the higher rates of paternal orphaning incidence is greatest in the youngest children (0–4 years). Across the period, the two oldest age groups (10–14 and 15–19 years) experience the highest incidence of maternal and paternal orphaning. The highest level of paternal orphaning incidence estimated in these age groups was in 2005, 30 and 33 per 1,000 person years respectively. Compared with orphan prevalence, orphaning incidence declined earlier and more rapidly; by 2014, the incidence of all types of orphan was less than half those in 2000.

Causes of parental death

Fig 3A–3D show the trends in annual cause-specific mortality in mothers and fathers by age. HIV/AIDS and TB was the dominant cause of parental mortality throughout the period. Substantial reductions in the rates of mothers and fathers dying due to HIV/AIDS and TB occurred
Fig 2. Maternal and paternal orphaning incidence (per 1,000 PYO) by orphan status and age group in children and adolescents <20 years, 2000, 2005, 2010, 2014.

https://doi.org/10.1371/journal.pone.0238563.g002
after 2007 and 2009 respectively. The cause-specific mortality of older mothers (35+ years at death) closely resembles younger mothers (<35 years at death) with HIV/AIDS and TB remaining the largest category of mortality across the period 2000–2014. In contrast, at the beginning of the period and most years from 2008, a larger proportion of deaths in older fathers (40+ years at death) were attributable to non-communicable diseases and injuries than HIV/AIDS and TB. For younger fathers (<40 years at death), the rate of deaths due to HIV/AIDS and TB only fell below those due to non-communicable diseases and injuries several years later, from 2012.

Table 1 shows the estimated incidence of maternal and paternal orphaning overall and by separate age groups for each cause of death in 2000, 2005, 2010 and 2014. The incidence of maternal and paternal orphaning due to HIV/AIDS and TB reduced by more than half over the period in all age groups of children. The exception was the slightly smaller decline in the incidence rate of paternal orphaning due to HIV/AIDS and TB in the oldest age group (15–19 years). In 2000, at the beginning of the period the age-specific rate of orphaning was much higher in this age group, 14.5 per 1,000 person years, than in younger age groups. Rates of paternal orphan incidence due to injury-related deaths were more than four-fold higher than maternal orphan incidence. The overall incidence of each cause of parental death declined across the period. In contrast, the incidence of orphaning due to communicable diseases and undetermined causes increased slightly; more so with respect to deaths of mothers than fathers.

**Discussion**

Our analyses of long-term trends over the pre- and post-ART periods (2000–2014) show recent declines in maternal and paternal orphan prevalence and incidence. Having already
reached high levels by the start of the period (2000), the proportions of children orphaned continued to rise further, only starting to decline after 2010. Despite huge progress in scaling up the HIV treatment programme since the mid-2000s, these longitudinal population-based data provide evidence that the experience of a parent(s) during childhood or adolescence remained very common in this rural South African community. In 2014, a third (32%) of all children and adolescents (0–19 years) and half (51%) of the older adolescents (15–19 years) had experienced the death of one or both parents respectively. As expected given the broad similarity of social and economic characteristics and public services in the study area to rural communities elsewhere in rural KwaZulu-Natal; these estimates of orphanhood mirror provincial those

| Age group (years) | Maternal orphaning incidence | Paternal orphaning incidence |
|------------------|-------------------------------|-----------------------------|
|                  | 2000  | 2005  | 2010  | 2014  | 2000  | 2005  | 2010  | 2014  |
| HIV/AIDS and TB  |       |       |       |       |       |       |       |       |
| 0–4              | 6.6   | 6.5   | 3.9   | 1.7   | 8.6   | 8.9   | 5.8   | 2.9   |
| 5–9              | 11.8  | 12.7  | 7.2   | 3.7   | 12.8  | 12.9  | 8.3   | 4.0   |
| 10–14            | 11.9  | 13.8  | 7.1   | 4.6   | 12.4  | 12.6  | 11.6  | 4.7   |
| 15–19            | 9.5   | 15.2  | 8.2   | 3.7   | 14.5  | 15.5  | 10.5  | 9.0   |
| 0–19             | 9.9   | 11.8  | 6.3   | 3.3   | 12.1  | 12.6  | 9.1   | 5.4   |
|                  |       |       |       |       |       |       |       |       |
| Injuries         |       |       |       |       |       |       |       |       |
| 0–4              | 0.3   | 0.3   | 0.3   | 0.4   | 5.2   | 3.7   | 4.0   | 2.4   |
| 5–9              | 0.6   | 0.5   | 1.0   | 0.7   | 3.2   | 3.7   | 3.5   | 4.0   |
| 10–14            | 1.1   | 1.2   | 0.7   | 0.7   | 5.1   | 4.8   | 2.5   | 2.9   |
| 15–19            | 0.6   | 0.1   | 0.4   | 0.4   | 4.3   | 4.8   | 1.9   | 1.9   |
| 0–19             | 0.7   | 0.3   | 0.6   | 0.6   | 4.5   | 3.8   | 2.9   | 2.9   |
|                  |       |       |       |       |       |       |       |       |
| Non-communicable |       |       |       |       |       |       |       |       |
| 0–4              | 0.6   | 0.3   | 1.0   | 0.1   | 3.3   | 2.2   | 2.0   | 1.9   |
| 5–9              | 1.2   | 1.0   | 0.6   | 0.9   | 5.3   | 3.7   | 3.7   | 0.3   |
| 10–14            | 1.6   | 2.4   | 0.9   | 1.9   | 7.5   | 6.3   | 7.2   | 1.8   |
| 15–19            | 3.6   | 2.4   | 1.1   | 2.0   | 13.2  | 7.2   | 8.6   | 3.6   |
| 0–19             | 1.7   | 1.5   | 0.9   | 1.0   | 7.2   | 4.9   | 5.5   | 1.9   |
|                  |       |       |       |       |       |       |       |       |
| Communicable     |       |       |       |       |       |       |       |       |
| 0–4              | 0.4   | 1.2   | 0.2   | 0.4   | 0.7   | 1.2   | 1.2   | 1.5   |
| 5–9              | 0.8   | 0.8   | 0.8   | 0.8   | 0.8   | 1.7   | 1.2   | 0.9   |
| 10–14            | 0.8   | 2.4   | 0.9   | 1.2   | 1.7   | 0.8   | 0.8   | 1.5   |
| 15–19            | 0.9   | 1.1   | 0.5   | 1.5   | 1.7   | 1.7   | 1.9   | 0.6   |
| 0–19             | 0.7   | 1.7   | 0.9   | 0.7   | 1.6   | 1.3   | 1.1   | 1.1   |
|                  |       |       |       |       |       |       |       |       |
| Undetermined     |       |       |       |       |       |       |       |       |
| 0–4              | 0.1   | 0.7   | 1.0   | 1.5   | 0.3   | 1.5   | 1.7   | 0.5   |
| 5–9              | 0.4   | 1.6   | 2.0   | 1.1   | 0.5   | 2.2   | 1.7   | 1.2   |
| 10–14            | 0.2   | 0.7   | 0.5   | 0.7   | 0.7   | 1.9   | 0.2   | 0.0   |
| 15–19            | 1.4   | 0.6   | 0.7   | 0.9   | 2.4   | 3.8   | 2.2   | 1.3   |
| 0–19             | 0.5   | 1.0   | 1.3   | 1.0   | 0.6   | 2.3   | 2.4   | 0.8   |

1 Maternal (or paternal) orphaning incidence is estimated for the year period for resident children <20 years whose mothers (or fathers) were alive at the start of the year; and is expressed 1000 person (i.e.child) years of observation.

2 (95% confidence intervals).

3 Deaths due attributed to a communicable disease other than HIV/AIDS and TB.

https://doi.org/10.1371/journal.pone.0238563.t001
from national Census and survey data [9,28,48]. However, compared with other South African provinces, KwaZulu-Natal has higher levels of orphanhood. In 2011, the province had more than double the number of single and double orphans (<18 years) then the next highest province—Eastern Cape based on the 2011 Census data [49].

The peak levels of paternal and double orphan prevalence (<20 years) in the study population 2010 (S1 Table) are much higher than the national estimates in the 2011 Census: 21% vs 15% and 7% vs 4% respectively [49]. Whereas estimates of maternal orphan prevalence (<20 years) was the same in the study and nationally (7%). In KwaZulu-Natal, exceptionally high levels of excess male mortality in young adults have been documented at different stages of the HIV epidemic. The causes of excess male mortality particularly in young men, is not only due to HIV/AIDS and TB deaths but also higher rates of road traffic accidents, intentional injuries and non-communicable diseases [20,50,51].

A strength of the directly observed data available from longitudinal population surveillance is that it enables us to estimate and monitor trends in orphan incidence, a much rarer indicator. The levels of both orphan incidence and prevalence that we report for the early period before public ART rollout are very similar to the estimates and forecasts of orphanhood reported on the basis of studies conducted in the early 2000s in the same population [19] and, in KwaZulu-Natal [52,53]. However, after ART rollout, our study shows that there was an immediate decline in orphan incidence but not orphan prevalence. The trend in orphan incidence closely mirrors the timing of reversals in adult mortality reported in the study population [21,23]. In contrast, orphan prevalence is a cumulative indicator and therefore, is less responsive than orphan incidence to immediate impacts of HIV treatment or other factors that improve parental survival. As discussed by Reniers et al (2017), recent declines in adult mortality due to HIV/AIDS is not only a consequence of ART roll-out but of long-term declines in HIV incidence and improvements in coverage and effectiveness of HIV treatment and care programmes [23]. In the study population, estimated HIV incidence in women and men declined year on year from 2014 and 2012 respectively [38].

Understanding the trends in survival of HIV-infected parents in the period post-ART rollout is complicated by changes in treatment access and, testing and treatment guidelines for ART eligibility over the same period. After national roll-out in 2004, local ART services were initially available from the hospital clinic [40]. Later ART services rolled out to all sixteen clinics in the health district offering ART initiation and follow-up by late 2007. Until March 2010, treatment guidelines were for ART initiation of adults with poor levels of immunity and health (CD4 cell count < 200 cells/μl or WHO stage 4) [54]. Eligibility criteria were first increased to CD4 <350 cells/μl for pregnant women and people with active tuberculosis (TB) disease, then later for all HIV-infected adults. After the end of study follow-up for this paper, eligibility criteria for ART initiation rose to CD4<500 cells/μl in January 2015 and irrespective of CD4 count from September 2016 [42]. Despite increased availability of ART, the estimated population ART coverage in HIV-positive adults in this area only increased from 31.7% in 2012 to 45% in 2017 [38,42].

Several factors may contribute to the consistently higher proportion and incidence of death among fathers compared with mothers. Mortality rates increase with age and irrespective of the effects of the HIV epidemic, fathers are on average older than mothers. Among married and regular couples belonging to the same household in the study area, men are more than 6 years older than their female partner on average [55]. There are also reasons to expect an earlier and larger impact of ART treatment on the survival of HIV-infected mothers than fathers in this population and others in South Africa. The Prevention of Mother-to-Child Transmission (PMTCT) national programme started in 2002 i.e. before the national rollout of ARV started [56]. Similar to other areas of South Africa, pregnant and recently delivered mothers have very high rates of contact with antenatal and delivery and child vaccination services [57,58]. During
the study period therefore, not only were HIV-infected mothers more likely than HIV-infected fathers to have been tested for HIV, there would have been earlier improvements in the average time from HIV infection to ART eligibility and survival for women on ART treatment. A prospective study of a large cohort of HIV-infected pregnant women in the study area (2010–2014) showed that the majority of women (96%) were either on lifelong ART or ART prophylaxis within 6 months of the first antenatal visit [57]. Men’s poorer levels of engagement with healthcare generally, and specifically with HIV care, has been well documented in the study area and KwaZulu-Natal [22,42,59]. Compared with women, HIV-infected men are more likely to have a late HIV diagnosis, delay in seeking healthcare, and not remain engaged [60].

In the period before ART rollout, increasing trends in adult mortality in HIV-infected and HIV-uninfected adults and, as a result in maternal, paternal and double orphan prevalence and incidence, were reported in rural study populations in Malawi and Tanzania (1998–2004) [19] and Zimbabwe (1998–2003) [61] where comparable demographic and HIV surveillance was undertaken. The levels of all orphanhood indicators reported in the South African study population were however, much higher than those in the other rural study populations. In the years after the implementation of national HIV treatment programmes across the region, we expect more variation to have emerged in the pattern and timing of reversals in orphanhood due to differences in the underlying HIV prevalence between populations, the timing of ART rollout and variations in the extent of ART coverage [62,63]. Few comparable data in other African communities are available on changes in orphan incidence and prevalence trends before and after ART rollout. A similar pattern of decline in orphanhood in the Rakai study population in Uganda following HIV treatment was reported [64]. The prevalence and incidence of children (0–14 years) with one or both parents deceased declined significantly pre-HIV care period (2001–2003) levels of 17.2% and 2.10 /100 person years respectively to 12.6% and 1.07 /100 person years after HIV care was expanded (2006–2009).

The demographic surveillance data analysed in this study are of high quality and provide very detailed information on all children and adults belonging to households in this rural community over a 15-year period. There are two particularly useful features of ACDIS data for orphanhood studies: i) the deliberate distinction of biological mothers and fathers from non-biological parents and from non-parental primary carers; and, ii) the follow-up of biological parents who are not resident with their child in the study area, for example, as labour migrants [65,66]. Thus, our estimates of orphanhood are reliable and robust, as well as generalizable to other communities in KwaZulu-Natal with similar demographic and health characteristics. Some limitations remain. Although efforts were made to maximize the completeness and ensure the quality of repeated rounds of parental survival data [65,66], ‘missing’ or erroneous information about parental survival may result in under- or overestimations of orphanhood in this population. An ‘adoption effect’ in which interviewers or respondents report information about non-biological rather than biological parents has been described elsewhere [65]. In South Africa, Udjo (2011) has also suggested that African households are more likely to over-report paternal deaths than other population groups [67]. In this study however, the effects of response bias on orphanhood estimates are likely to be small given the numerous visits to households to update ACDIS information and, specific attention in questionnaire design and interviewer training. Orphanhood estimates could also be biased by parents, particularly fathers, whose survival status was not known for the whole period of follow-up [68]. However, although we expect rates of mortality to be higher in parents of unknown survival than in parents with complete data, parental survival status was unknown for only 0–2% of children at each mid-year time point. We therefore, grouped children with unknown parental survival status together with children known to be orphaned. This approach is similar to that used by UNICEF and other agencies in defining children with one deceased parent as an orphan.
irrespective of the survival status of the other parent [69]. This study has implications for future research on children and parents in communities with high HIV prevalence. Our results, together with the findings of other recent longitudinal studies of HIV and adult mortality [22,23] suggest that we can anticipate further gains in life-expectancy of HIV-infected adults and a continued decline in HIV/AIDS as a cause of premature adult death. Given the scale of the HIV epidemic in rural KwaZulu-Natal, there is also likely to be an increase in the number of children living with HIV-infected parents and carers for some years to come. However, the multiple determinants of overall and age-specific fertility and mortality means less certainty in the future levels of different orphanhood types [7].

The value of continuing to collect and measure orphanhood in longitudinal African population cohorts is also given emphasis by recent studies highlighting important discrepancies between the international modelled orphanhood prevalence estimates reported by the United National Programme on HIV/AIDS (UNAIDS) and similar estimates derived from survey and census data [70]. There is no current consensus about how changes in the HIV epidemic such as age and sex patterns of HIV incidence and changes in HIV treatment coverage are affecting differences in orphanhood estimates or which statistical methods are appropriate for adjusting the modelled estimates [71].

The findings of this population-based study have implications for South Africa’s formal statutory policies and social assistance programmes targeted towards orphans such as the Foster Care Grant (FCG). FCGs are a non-means tested cash payment to foster carers with legal custody of a child <18 years. Widely perceived as a de facto orphan grant [72], in reality only a small proportion of orphans are subject to foster care court orders [73]. In 2014, 500,000 FCGs were paid to foster carers (80% of whom were caring for orphaned children). The FCG was provided to 7.1% and 1.2% of carers for maternal and paternal orphans compared with one in three carers of double orphans (33.8%) [74]. The most commonly accessed form of assistance is the child support grant (CSG), a means-tested, unconditional grant aimed at reducing poverty and promoting investment in poor children [48]. However, parental and non-parental carers of children who are single orphans do not currently have preferential access to the CSG [75]. Government efforts to improve the capacity and delivery of South Africa’s social welfare system including the foster care arrangements and financial assistance for orphans, are ongoing [76]. Analyses of detailed, longitudinal population-based data can make a valuable contribution in ensuring statutory definitions and eligibility criteria align more closely with the diversity of residential, parenting and care arrangements in which children live [65,75,77].

In the last decade, policy and research focusing specifically on orphans and childhood adversity in South Africa have increasingly concentrated on children affected by HIV and AIDS (See for example, [78]). Related intervention programmes typically include targeted interventions to prevent sexual violence and HIV acquisition in orphans affected by HIV and AIDS, especially during adolescence [3,78]. Although the incidence of HIV/AIDS and TB maternal and paternal deaths was still higher than any other causes among older children and adolescents by 2014, it is problematic to overlook children experiencing parental deaths from other causes, particularly with respect to the impacts on early development in younger children. For example, the challenging situations faced by children and households who experience a sudden and/or violent adult death of a family member, may require specialist support. Studies conducted before HIV treatment was available in this study population described significant differences in the impact of parental death on health and wellbeing outcomes of orphans depending on the cause of parental death and the child and family circumstances before and after the death [9,15]. Consequently there is a need to continuously re-evaluate the value and effectiveness of support, particularly in relation to education, training and entry into employment, for children, adolescents and possibly young adults, who are affected by parental illness and death [3,12,79].
In conclusion, these empirical findings demonstrate that widespread availability of HIV treatment has made a profound contribution to checking and reversing mortality in mothers and fathers of young children and adolescents. Therefore, the bleakest forecasts of orphanhood levels based on orphan incidence in the 1990s and early 2000s have not been realised. However, given the dynamic and complex epidemiological and demographic changes in South Africa and other countries with HIV epidemics, we should continue to monitor the nature and level of impacts of all causes of parental ill-health and mortality in order to ensure that programme and policy responses best meet the needs of all children and adolescents.

Supporting information

S1 Table. Orphanhood prevalence by orphan status and age group in children and adolescents <20 years, ACDIS, 2000, 2005, 2010, 2014.

S2 Table. Maternal and paternal orphaning incidence (per 1,000 PYO) by orphan status and age group in children and adolescents <20 years, 2000, 2005, 2010, 2014.

Acknowledgments

We thank the communities that contributed their data to the demographic surveillance system and to other linked studies. We acknowledge the Africa Health Research Institute (formerly Africa Centre for Health and Population Studies) in making data available and to the many operational and scientific colleagues involved in the collection, validation and management of data. We also thank PloS One anonymous reviewers for their helpful comments and suggestions.

Author Contributions

Conceptualization: Ann Berrington, Nuala McGrath, Victoria Hosegood.

Data curation: Gabriela Mejia-Pailles.

Formal analysis: Gabriela Mejia-Pailles, Nuala McGrath.

Funding acquisition: Ann Berrington, Victoria Hosegood.

Investigation: Gabriela Mejia-Pailles, Nuala McGrath, Victoria Hosegood.

Methodology: Gabriela Mejia-Pailles, Ann Berrington, Nuala McGrath, Victoria Hosegood.

Project administration: Gabriela Mejia-Pailles, Victoria Hosegood.

Supervision: Ann Berrington, Nuala McGrath, Victoria Hosegood.

Validation: Gabriela Mejia-Pailles, Nuala McGrath, Victoria Hosegood.

Writing – original draft: Gabriela Mejia-Pailles, Ann Berrington, Nuala McGrath, Victoria Hosegood.

Writing – review & editing: Gabriela Mejia-Pailles, Ann Berrington, Nuala McGrath, Victoria Hosegood.

References

1. Case A, Paxson C, Abeleidinger J. Orphans in Africa: parental death, poverty, and school enrollment. Demography. 2004; 41(3):483–508. https://doi.org/10.1353/dem.2004.0019 PMID: 15461011.
11. Cluver LD, Orkin M, Gardner F, Boyes ME. Persisting mental health problems among AIDS-orphaned children in South Africa. AIDS. 2014; 28 Suppl 3:S251–9. Epub 2014/07/06. https://doi.org/10.1097/QAD.0000000000000327 PMID: 24991900.

12. De Weerdt J, Beegle K, Dercon S. Orphanhood and Self-esteem: an 18-year longitudinal study from an HIV-affected area in Tanzania. J Acquir Immune Defic Syndr. 2017. https://doi.org/10.1097/QAI.0000000000001504 PMID: 28777261.

13. Kidman R, Anglewicz P. Are adolescent orphans more likely to be HIV-positive? A pooled data analyses across 19 countries in sub-Saharan Africa. J Epidemiol Community Health. 2016; 70(8):791–7. https://doi.org/10.1136/jech-2015-206744 PMID: 26865695.

14. Hosegood V, Vansteenkiste A-M, Timaeus IM. Levels and causes of adult mortality in rural South Africa: the impact of AIDS. AIDS. 2014; 28(4):663–71. https://doi.org/10.1097/QAD.000000000000001504 PMID: 15090772.
21. Herbst AJ, Cooke GS, Bärmighausen T, KanyKany A, Tanser F, Newell M-L. Adult mortality and antiretroviral treatment roll-out in rural KwaZulu-Natal, South Africa. Bulletin of the World Health Organization. 2009; 87(10):754–62. https://doi.org/10.2471/blt.08.058982 PMID: 19876542

22. Bor J, Rosen S, Chimbindi N, Haber N, Herbst K, Mutevedzi T, et al. Mass HIV Treatment and Sex Disparities in Life Expectancy: Demographic Surveillance in Rural South Africa. PLoS Med. 2015; 12(11):e1001905; discussion e. Epub 2015/11/26. https://doi.org/10.1371/journal.pmed.1001905 PMID: 26599699; PubMed Central PMCID: PMC4658174.

23. Reniers G, Blom S, Calvert C, Martin-Onnaet A, Herbst AJ, Eaton JW, et al. Trends in the burden of HIV mortality after roll-out of antiretroviral therapy in KwaZulu-Natal, South Africa: an observational community cohort study. Lancet HIV. 2017; 4(3):e113–e21. https://doi.org/10.1016/S2352-3016(16)30225-9 PMID: 27956157; PubMed Central PMCID: PMC5405557.

24. Madhavan S, Moultrie T, Adjiwanou V, 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 Africa2014.

25. Meintjes H, Hall K, Marera DH, Boule A. Orphans of the AIDS epidemic? The extent, nature and circumstances of child-headed households in South Africa. AIDS Care. 2010; 22(1):40–9. https://doi.org/10.1080/0954012090330329 PMID: 20390479; PubMed Central PMCID: PMC2840873.

26. Richter LM, Sherr L, Adato M, Belsey M, Chandan U, Desmond C, et al. Strengthening families to support children affected by HIV and AIDS. AIDS Care. 2009; 21 Suppl 1:3–12. https://doi.org/10.1080/0954012090293211 PMID: 22390973; PubMed Central PMCID: PMC2903779.

27. Sherr L, Varrall R, Mueller J, Members JW, Richter L, Wakhweya A, et al. A systematic review on the meaning of the concept ‘AIDS Orphan’: confusion over definitions and implications for care. AIDS Care. 2008; 20(5):527–36. Epub 2008/05/20. https://doi.org/10.1080/09540120701867248 PMID: 18484320.

28. Case A, Hosegood V, Lund F. The Reach of The South African Child Support Grant:Evidence from KwaZulu-Natal. Development Southern Africa. 2005; 22(4):467–82.

29. Herbst AJ, Mafojane T, Newell M-L. Verbal autopsy-based cause-specific mortality trends in rural KwaZulu-Natal, South Africa, 2000–2009. Population Health Metrics. 2011; 9(47):0–4. https://doi.org/10.1186/1478-7954-9-47 PMID: 21819602.

30. Hill C, Hosegood V, Newell M-L. Children’s care and living arrangements in a high HIV prevalence area in rural South Africa. Vulnerable Children and Youth Studies. 2008; 3(1):65–77.

31. Tlou B, Sartorius B, Tanser F. Space-time patterns in maternal and mother mortality in a rural South African population with high HIV prevalence (2000–2014): results from a population-based cohort. BMC Public Health. 2017; 17(1):543. Epub 2017/06/06. https://doi.org/10.1186/s12889-017-4463-9 PMID: 28576674; PubMed Central PMCID: PMC5475651.

32. Ardington C, Case A, Hosegood V. Labor supply responses to large social transfers: Longitudinal evidence from South Africa. Am Econ J Appl Econ. 2009; 1(1):22–48. Epub 2009/09/15. https://doi.org/10.1257/app.1.1.22 PMID: 19750139; PubMed Central PMCID: PMC2742429.

33. Hosegood V, Benzler J, Solarsh G. Population mobility and household dynamics in rural South Africa: implications for demographic and health research. Southern African Journal of Demography. 2005; 10(1):43–67.

34. Smit W. The rural linkages of urban households in Durban, South Africa. Environment and Urbanization. 1998; 10(1):77–88. https://doi.org/10.1177/095624789801001119.

35. Posel D. Households and labour migration in post-apartheid South Africa. Studies in Economics and Econometrics. 2010; 34(3):129–41.

36. Bennett R, Hosegood V, Newell ML, McGrath N. An Approach to Measuring Dispersed Families with a Particular Focus on Children ‘Left Behind’ by Migrant Parents: Findings from Rural South Africa. Popul Space. 2015; 21(4):322–34. Epub 2015/05/20. https://doi.org/10.1002/psp.1843 PMID: 25983668; PubMed Central PMCID: PMC4430828.

37. Hosegood V, McGrath N, Moultrie TA, Dispensing with marriage: marital trends in rural KwaZulu-Natal, South Africa 2000–2006. Demographic Research. 2009; 20(13):279–312. https://doi.org/10.4054/DemRes.2009.20.13 PMID: 25793222.

38. Vandomsmael A, Cuadros D, Kim HY, Barnighausen T, Tanser F. The state of the HIV epidemic in rural KwaZulu-Natal, South Africa: a novel application of disease metrics to assess trajectories and highlight areas for intervention. Int J Epidem. 2020. Epub 2020/01/14. https://doi.org/10.1093/ije/dyza269 PMID: 31930292.

39. Welz T, Hosegood V, Jaffar S, Bätzinger-Feigenbaum J, Herbst K, Newell M-L. Continued very high prevalence of HIV infection in rural KwaZulu-Natal, South Africa: a population-based longitudinal study. AIDS. 2007; 21(11):1467–72. https://doi.org/10.1097/QAD.0b013e3280e6af2 PMID: 17589193.
40. Houlihan C, Bland R, Mutvedzi P, Lessells R, Ndirangu J, Thuliare H, et al. Cohort profile: Hlabisa HIV Treatment and care programme. International Journal of Epidemiology. 2010; 40(2):318–26. https://doi.org/10.1093/ije/dyp402 PMID: 20154009

41. Zaidi J, Grapsa E, Tanser F, Newell ML, Barnighausen T. Dramatic increase in HIV prevalence after scale-up of antiretroviral treatment. AIDS. 2013; 27(14):2301–5. Epub 2013/05/15. https://doi.org/10.1097/QAD.0b013e32836e832 PMID: 23689155; PubMed Central PMCID: PMC4264533.

42. Iwuji CC, Orne-Gliemann J, Larmarange J, Balestre E, Thiebaut R, Tanser F, et al. Universal test and treat and the HIV epidemic in rural South Africa: a phase 4, open-label, community cluster randomised trial. Lancet HIV. 2018; 5(3):e116–e25. Epub 2017/12/05. https://doi.org/10.1016/S2352-3018(17)30205-9 PMID: 29199100.

43. Bärnighausen T, Tanser F, Newell M-L. Lack of a decline in HIV incidence in a rural community with high HIV prevalence in South Africa, 2003–2007. AIDS Research and Human Retroviruses. 2009; 25 (4):405–9. https://doi.org/10.1089/aid.2008.0211 PMID: 19320571

44. Robertson L, Gregson S, Madanhire C, Walker N, Mushati P, Garnett G, et al. Discrepancies between UN models and DHS survey estimates of maternal orphan prevalence: insights from analyses of survey data from Zimbabwe. Sex Transm Infect. 2008; 84 Suppl 1:i57–i62. Epub 2008/07/25. https://doi.org/10.1136/sti.2008.029926 PMID: 18647868; PubMed Central PMCID: PMC2556835.

45. Timaeus I, Simelane S, Letsoalo T. Poverty, Race, and Children’s Progress at School in South Africa. The journal of development studies. 2013; 49(2):270–84.

46. Robertson L, Gregson S, Madanhire C, Walker N, Mushati P, Garnett G, et al. Discrepancies between UN models and DHS survey estimates of maternal orphan prevalence: insights from analyses of survey data from Zimbabwe. Sex Transm Infect. 2008; 84 Suppl 1:i57–i62. Epub 2008/07/25. https://doi.org/10.1136/sti.2008.029926 PMID: 18647868; PubMed Central PMCID: PMC2556835.

47. Timeus I, Simelane S, Letsoalo T. Poverty, Race, and Children’s Progress at School in South Africa. The journal of development studies. 2013; 49(2):270–84.

48. Government of South Africa. Child support grant 2019. Available from: https://www.gov.za/services/child-care-social-benefits/child-support-grant.

49. Statistics South Africa. Census 2011 Statistical release –P0301.4/. 2012.

50. Garrub A, Herbst AJ, Hosegood V, Newell ML. Injury mortality in rural South Africa 2000–2007: rates and associated factors. Trop Med Int Health. 2011; 16(4):439–46. Epub 2011/02/03. https://doi.org/10.1111/j.1365-3156.2011.02730.x PMID: 21284789; PubMed Central PMCID: PMC3085120.

51. Reniers G, Blom S, Lieber J, Herbst AJ, Calvert C, Bor J, et al. Tuberculosis mortality and the male survival deficit in rural South Africa: An observational community cohort study. PLoS One. 2017; 12(10): e0185692. Epub 2017/10/11. https://doi.org/10.1371/journal.pone.0185692 PMID: 29016619; PubMed Central PMCID: PMC5634548.

52. Bradshaw D, Johnson L, Schneider H, Bourne D, Dorrington R. Orphans of the HIV/AIDS epidemic: The time to Act Is Now. Medical Research Council, South Africa, 2002.

53. Johnson L, Dorrington R. The impact of AIDS on orphanhood in South Africa: a quantitative analysis. Cape Town: Centre for Actuarial Research, 2001 October 2001. Report No.: CARE Monograph No.4.

54. McGrath N, Lessells RJ, Newell ML. Time to eligibility for antiretroviral therapy in adults with CD4 cell count > 500 cells/muL in rural KwaZulu-Natal, South Africa. HIV Med. 2015; 16(8):512–8. Epub 2015/05/12. https://doi.org/10.1111/hiv.12255 PMID: 25959724; PubMed Central PMCID: PMC4682449.

55. Channon M, Hosegood V, McGrath N. A longitudinal population-based analysis of relationship status and associated factors. Trop Med Int Health. 2011; 16(4):439–46. Epub 2011/02/03. https://doi.org/10.1111/j.1365-3156.2011.02730.x PMID: 21284789; PubMed Central PMCID: PMC3085120.

56. Chetty T, Thorne C, Tanser F, Bärnighausen T, Coutousois A. Cohort profile: the Hlabisa pregnancy cohort, KwaZulu-Natal, South Africa BMJ Open. 2016; 6. https://doi.org/10.1136/bmjopen-2016-012088 PMID: 27798004

57. Burton R, Giddy J, Stinson K. Prevention of mother-to-child transmission in South Africa: an ever-changing landscape. Obstetric medicine. 2015; 8(1):5–12. Epub 2015/03/01. https://doi.org/10.1177/1753495X15570994 PMID: 27512452; PubMed Central PMCID: PMC4934997.

58. Chetty T, Thorne C, Tanser F, Bärnighausen T, Coutousois A. Cohort profile: the Hlabisa pregnancy cohort, KwaZulu-Natal, South Africa BMJ Open. 2016; 6. https://doi.org/10.1136/bmjopen-2016-012088 PMID: 27798004

59. Horwood C, Butler L, Haskins L, Phakathi S, Rollins N. HIV-Infected Adolescent Mothers and Their Infants: Low Coverage of HIV Services and High Risk of HIV Transmission in KwaZulu-Natal, South Africa. PLoS ONE. 2013; 8(9). https://doi.org/10.1371/journal.pone.0074568 PMID: 24073215

60. Sahn E, Basinger J, Read S, Todes J, DiMaggio A. The impact of AIDS on orphanhood in South Africa: a quantitative analysis. Cape Town: Centre for Actuarial Research, 2001 October 2001. Report No.: CARE Monograph No.4.

61. Burton R, Giddy J, Stinson K. Prevention of mother-to-child transmission in South Africa: an ever-changing landscape. Obstetric medicine. 2015; 8(1):5–12. Epub 2015/03/01. https://doi.org/10.1177/1753495X15570994 PMID: 27512452; PubMed Central PMCID: PMC4934997.

62. Chetty T, Thorne C, Tanser F, Bärnighausen T, Coutousois A. Cohort profile: the Hlabisa pregnancy cohort, KwaZulu-Natal, South Africa BMJ Open. 2016; 6. https://doi.org/10.1136/bmjopen-2016-012088 PMID: 27798004

63. Horwood C, Butler L, Haskins L, Phakathi S, Rollins N. HIV-Infected Adolescent Mothers and Their Infants: Low Coverage of HIV Services and High Risk of HIV Transmission in KwaZulu-Natal, South Africa. PLoS ONE. 2013; 8(9). https://doi.org/10.1371/journal.pone.0074568 PMID: 24073215

64. Cornell M, Schomaker M, Garone DB, Giddy J, Hoffmann CJ, Lessells R, et al. Gender differences in survival among adult patients starting antiretroviral therapy in South Africa: a multicentre cohort study. PLoS Med. 2012; 9(9):e1001304. Epub 2012/09/14. https://doi.org/10.1371/journal.pmed.1001304 PMID: 22973181; PubMed Central PMCID: PMC3433409.
60. Chikovore J, Gillespie N, McGrath N, Orne-Gliemann J, Zuma T. Men, masculinity, and engagement with treatment as prevention in KwaZulu-Natal, South Africa. AIDS Care. 2016; 28 Suppl 3:74–82. Epub 2016/07/16. https://doi.org/10.1080/09540121.2016.1178953 PMID: 27421054; PubMed Central PMCID: PMC5096677.

61. Watts H, Lopman B, Nyamukapa C, Gregson S. Rising incidence and prevalence of orphanhood in Manicaland, Zimbabwe, 1998 to 2003. AIDS. 2005; 19(7):717–25. Epub 2005/04/12. doi: 00002030-20050429-00009 [pii]. https://doi.org/10.1097/01.aids.0000166095.62187.df PMID: 15821396.

62. Jahn A, Harries AD, Schouten EJ, Libamba E, Ford N, Maher D, et al. Scaling-up antiretroviral therapy in Malawi. Bull World Health Organ. 2016; 94(10):772–6. Epub 2016/11/16. https://doi.org/10.2471/BLT.15.166074 PMID: 27843168; PubMed Central PMCID: PMC5043204.

63. Mee P, Rice B, Lemsalu L, Hargreaves J, Sambu V, Harkerode R, et al. Changes in patterns of retention in HIV care and antiretroviral treatment in Tanzania between 2008 and 2016: an analysis of routinely collected national programme data. J Glob Health. 2019; 9(1):010424. Epub 2019/04/18. https://doi.org/10.7189/jogh.09.010424 PMID: 30992984; PubMed Central PMCID: PMC6445500.

64. Makumbi FE, Nakigozi G, Sekasanvu J, Lukabwe I, Kagaayi J, Lutalo T, et al. Incidence of orphanhood before and after implementation of a HIV care programme in Rakai, Uganda: Alpha Network HIV Supplement. Trop Med Int Health. 2012; 17(8):e94–102. https://doi.org/10.1111/j.1365-3156.2012.03031.x PMID: 22716203; PubMed Central PMCID: PMC4169214.

65. Hosegood V, Madhavan S. Data availability on men’s involvement in families in sub-Saharan Africa to inform family-centred programmes for children affected by HIV and AIDS. J Int AIDS Soc. 2010; 13 Suppl 2:S5. Epub 2010/06/25. https://doi.org/10.1186/1758-2652-13-S2-S5 PMID: 20573287; PubMed Central PMCID: PMC2890974.

66. Hosegood V, Madhavan S. Understanding fatherhood and father involvement in South Africa: Insights from surveys and population cohorts. Fathering: A Journal of Theory, Research and Practice about Men as Fathers 2012; 10(3):257–73.

67. Udjo EO. Magnitudes and trends in orphanhood among younger persons in the era of HIV/AIDS in South Africa, 2001–2015. African Population Studies. 2011; 25(2):267–85.

68. Anderson BA, Phillips HE. Trends in the percentage of children who are orphaned in South Africa: 1995–2005. Report No. 03-09-06. Pretoria: Statistics South Africa 2006.

69. UNICEF. Orphans 2020. Available from: https://www.unicef.org/media/orphans.

70. Case KK, Gregson S, Mahy M, Ghys PD, Hallett TB. Editorial: methodological developments in the Joint United Nations Programme on HIV/AIDS estimates. AIDS. 2017; 31 Suppl 1:S1–S4. Epub 2017/03/16. https://doi.org/10.1097/QAD.0000000000001330 PMID: 28296795.

71. Masquelier B, Eaton JW, Gerland P, Pelletier F, Mutai KK. Age patterns and sex ratios of adult mortality in countries with high HIV prevalence. AIDS. 2017; 31 Suppl 1:S77–S85. https://doi.org/10.1097/QAD.0000000000001332 PMID: 28296803.

72. McEwen H, Woolard I. The Changing Dynamics of Child Grants in the Context of High Adult Mortality in South Africa: a simulation to 2015. University of Cape Town; 2010.

73. Martin P. Government-funded programmes and services for vulnerable children in South Africa Cape Town: HSRC Press, 2010.

74. Hall K, Skelton A, Sibanda S. Social assistance for orphaned children living with family. In: Delany A, Jehoma S, Lake L, editors. South African Child Gauge 2016. Cape Town: Children’s Institute, University of Cape Town; 2016. p. 68–74.

75. Hall K, Skelton A. Introducing a child support grant top-up for orphaned children living with family members. In: Delany A, Jehoma S, Lake L, editors. South African Child Gauge 2016. Cape Town: Children's Institute, University of Cape Town; 2016. p. 91–4.

76. Department of Social Development. Foster Care Progress Report on the Implementation of the North Gauteng High Court Order: Turn Around Plan. Presentation to Portfolio Committee on Social Development Portfolio Committee on Social Development engagements with Department, 04 September 2019; Pretoria: Government of South Africa; 2019.

77. Hosegood V. The demographic impact of HIV and AIDS across the family and household life-cycle: implications for efforts to strengthen families in sub-Saharan Africa. AIDS Care. 2009; 21(S1):13–21. https://doi.org/10.1080/095401209022923063 PMID: 22380974.

78. Department of Social Development. The National Action Plan for Orphans and Other Children Made Vulnerable by HIV and AIDS South Africa, 2009–2012 Pretoria: Department of Social Development, 2009.

79. Cluver LD, Orkin M, Boyes ME, Gardner F, Nikelo J. AIDS-orphanhood and caregiver HIV/AIDS sickness status: effects on psychological symptoms in South African youth. J Pediatr Psychol. 2012; 37 (8):857–67. https://doi.org/10.1093/jeppy/jss004 PMID: 22313551.