

# Home deaths in children under 5 years in rural South Africa: a population-based longitudinal study

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## Abstract

**Objectives:** Little is known about factors associated with home deaths for children in sub-Saharan Africa. This study aimed to determine the proportion of under-5 deaths that occurred at home in rural South Africa, whether care was sought prior to death, and determinants of home deaths amongst those who sought care.

**Methods:** Verbal autopsy data were used for all under-5 deaths, 2000-2015, in two health and demographic surveillance system sites. Trends in place of death and care-seeking were assessed. Multivariate logistic regressions were used to assess associations between sociodemographic factors and home death despite seeking care.

**Results:** There were 3760 under-5 deaths; 1954 (53%) at home and 1510 (41%) in health facilities. 84% of children who died at home accessed healthcare during their final illness. Amongst neonates who sought care, those aged 8-27 days were more likely to die at home than those 0-7 days (OR=5.56, 95%CI 2.69-11.55,  $p<0.001$ ). In infants and young children, factors associated with home death despite seeking care included low maternal education (OR=1.71, 95%CI 1.31-2.24,  $p<0.001$ ), larger household size (OR=1.56, 95%CI 1.17-2.06,  $p=0.002$ ), traditional medicine use (OR=2.33, 95%CI 1.75-3.12,  $p<0.001$ ) and Mozambican descent (OR=1.47, 95%CI 1.06-2.03,  $p=0.020$ ). The proportion of HIV-related deaths that occurred at home fell from 60% in 2008-2011 to 39% in 2012-2015 ( $\text{Chi}^2=13.86$ ,  $p<0.001$ ).

**Conclusion:** Over half of under-5 deaths in rural South Africa occurred at home despite most having sought healthcare, highlighting that home deaths are not simply a function of poor care-seeking. Interventions should target the high risk sociodemographic groups identified.

## Key Words

Child mortality, verbal autopsy, social autopsy, rural South Africa, home deaths, care seeking, sociodemographic risk factors

## Background:

Over 2.7 million children died in Sub-Saharan Africa in 2016 before reaching their fifth birthday, accounting for almost half of all under-5 deaths globally (1). Furthermore, over 50% of under-5 deaths across sub-Saharan Africa occur at home, though this is as high as 77% in Mali, 76% in Niger, and 67% in Uganda (2–4). In South Africa specifically, the Committee on Morbidity and Mortality in Children under 5 years (CoMMiC) estimated that 55% of child deaths occurred outside of health facilities - at home or in the community (5). Yet little research has been done that focuses specifically on home deaths. A recent systematic review of social autopsies in low resource settings showed high rates of symptom recognition in fatal neonatal and childhood illness, and found that formal care was sought in 78-88% of deaths in children 1-59 months (4). Unfortunately, the analysis was not disaggregated by place of death. Indeed, to the best of our knowledge, no work has been published on differences between home deaths and health facility deaths or care seeking behaviour of children who die at home despite their significant contribution to overall child mortality.

This is perhaps unsurprising as home deaths represent a “hard to reach” though vulnerable group. Home deaths are missed by facility-based audits, such as the existing Perinatal Problem Identification Programme (PPIP) and Child Health Problem Identification Programme (CHIP) in South Africa. Population-based data collection is required to identify, enumerate and investigate cases of home deaths. Health and demographic surveillance systems (HDSS) provide the necessary infrastructure for such population-based research, and verbal and social autopsies used in such settings have provided information not only on the biological causes of death but also on care seeking behaviour during the final illness (6–8).

A recent review of discrepancies in estimates of national under-5 and neonatal mortality rates also pointed towards a failure to count home deaths as an explanation for variations in the reported mortality rates (9,10). This has resulted in a call for further research focused on home deaths to better understand the avoidable factors in these deaths and barriers faced in accessing healthcare (11). Using verbal autopsy (VA) data from two rural South African HDSS sites, this paper aimed to establish the proportion of under-5 deaths that occurred at home, to determine whether care was sought during the final illness for children who died at home, and if this pattern has changed over time. Finally, in

those cases where care was sought, it aimed to understand differences between children who died at home and those who died in a health facility.

## Methods:

This population-based longitudinal study used VA and household data for all deaths of children under five years from 2000-2015 from two South African HDSS sites: Agincourt and the Africa Health Research Institute (AHRI) (figure 1). Both are members of the International Network for the Demographic Evaluation of Populations and Their Health (INDEPTH) ([www.indepth-network.org](http://www.indepth-network.org)). Stillbirths were excluded from the analysis.

Insert Figure 1 here

## Study sites:

Both AHRI and Agincourt HDSS sites are in poor, rural areas of South Africa with limited infrastructure. The AHRI population health surveillance started in 2000 and now involves three-monthly monitoring of over 150 000 people in the Hlabisa region in northern KwaZulu-Natal Province. The Agincourt HDSS, in Mpumalanga province, has conducted annual censuses of key demographic and health data since 1992. It now covers a population of 116 000 people, including about 30% who are of Mozambican descent following an influx of refugees during the Mozambican civil war. Both sites have high levels of temporary labour migration (33-36%) with household members oscillating between their place of work and their rural home (12-14). VA – a structured interview with the caregiver of the deceased - is used to determine biological cause of death at both sites. VAs have been validated as a means of establishing cause of death in a rural South African population (7).

## Conceptual framework:

We used the World Health Organization (WHO) Commission on Social Determinants of Health conceptual framework (15) as the basis for grouping social determinants of health into distal and intermediate factors. We then applied this framework to the question of place of death in children under five to identify differences in the determinants of home and health facility deaths amongst children who sought care. Variables were grouped into four levels: distal determinants relating to the sociopolitical context of the community, intermediate factors relating to the socioeconomic position of

the deceased's household within its community, intermediate factors relating to household composition, and maternal and child conditions (Figure 2).

Insert Figure 2 here.

### **Study variables:**

Our primary outcome of interest was place of death (home or health facility) for neonates and infants and young children (children aged 1-59 months). We further broke down home deaths into those who consulted a formal medical provider (clinic, private GP, pharmacy or hospital) during the final illness, and those who did not. By comparing home deaths where care was sought with deaths in health facilities, we were able to control for care seeking behavior, and so consider additional factors that contribute to place of death.

We classified exposure variables according to our modified conceptual framework (figure 2). We included year of death as a proxy for changes in political context, government policy and infrastructure development (building of new roads, clinics etc.) that took place over the course of the study period but were not measured individually. We assessed period of death in four-year intervals which broadly overlap with the HIV epidemic and changes to the prevention of mother-to-child-transmission (PMTCT) programme: 2000-2003 (pre-PMTCT; HIV-related mortality rising), 2004-2007 (PMTCT introduced: nevirapine prophylaxis for pregnant women and their newborn children; HIV-related mortality peaks), 2008-2011 (dual prophylaxis for pregnant women initially from 28 weeks' gestation, then from 14 weeks' gestation; HIV-related mortality steady), and 2012-2015 (lifelong highly active anti-retroviral therapy for all pregnant women; HIV-related mortality declining) (16,17). Given changes in policy relating to HIV and availability of PMTCT over time, we assessed HIV as an interaction term with year of death.

We assessed socioeconomic position of the household using asset ownership data collected during the household surveys. We grouped households into low socioeconomic status (SES) (poorest two quintiles) and medium/high SES (upper 3 quintiles). We also used maternal education to assess the socioeconomic position of the household, which we grouped into low maternal education (no education, or started or completed primary school) and intermediate/high maternal education (started or completed secondary school, or started or completed tertiary education).

We determined cause of death for all deaths from VA data, using [InterVA](#) 4.3. An HIV-associated death was defined as a death where the first, second or third cause identified by InterVA was “HIV/AIDS related death”.

### **Statistical analysis:**

We used bivariate and multivariate logistic regression models to assess relationships between socio-demographic exposures and place of death despite seeking care (home or health facility) for both neonatal deaths and deaths of children 1-59 months. Analysis was split by age group based on the hypothesis that the mechanisms through which social determinants of health might impact on place of death differ for very young children, particularly neonates, compared to older children. Signs of illness are less precise and recognizable in neonates compared to older children, neonates decompensate more quickly than older children and so opportunities to seek care may differ. Furthermore, for early neonates who are born and die in hospital without discharge, care seeking is often in response to maternal labour-related symptoms rather than those of the child. Finally, neonates who are born and die in hospital bypass the primary care level and related referral processes.

We used the hierarchical approach described by Victora and colleagues (18) to develop multivariate logistic regression models in both age groups. We used a four-stage model starting with the most distal determinants and then adding intermediate determinants (according to the groupings in figure 2). We included year of death and study site in model 1. We then used a forward-building model approach to determine the significant intermediate factors for socioeconomic position of the household (model 2), the addition of variables reflecting household composition (model 3) and finally the addition of maternal and child factors (model 4). Model 4 therefore reflects the causal effects of the most proximal maternal and child factors, after adjusting for confounding of those factors included from model 3 (and therefore are reported as adjusted odds ratios). The odds ratios for the distal and intermediate factors included in the final model represent the residual causal effect not mediated by any of the other explanatory variables in the model. To avoid underreporting the association between the distal and intermediate explanatory variable and the outcome of interest, we refer to the crude odds ratios. The full model building process is presented in appendix 1 which would provide adjusted odds ratios for the distal and intermediate explanatory variables. Statistical significance was set at  $p < 0.05$ .

We used Stata12 for all analysis (19).

## Ethics:

The University of Witwatersrand Human Research Ethics Committee (HREC) approved protocols for the regular household census and VA data collection at the Agincourt HDSS (M960720; M110138). Similar protocols for three-monthly census and VA data collection were approved by the University of Kwa-Zulu Natal Biomedical Research Ethics Committee (BREC) in the case of the AHRI HDSS (BE290/16).

## Results:

There were 3760 under-5 deaths recorded from 2000-2015: 2033 in AHRI and 1727 in Agincourt. Overall 1954 deaths (53%) occurred at home, 1510 (41%) in a health facility and 229 (6%) elsewhere. No significant differences were noted in frequency of place of death between the two study sites. There were 500 neonatal deaths (13%), and 2259 infant deaths (60%). Of the children who died, 1775 (47%) were female. In Agincourt, 39.7% (684/1721) were of Mozambican descent. The top five causes of death overall were acute respiratory infections (30%), HIV/AIDS (26%), diarrhoeal diseases (7%), neonatal pneumonia (4%) and birth asphyxia (3%). However, this differed across the two sites. In Agincourt, HIV/AIDS accounted for 28% of under-5 deaths (cause-specific mortality rate 13/1000 live births), followed by acute respiratory infections (25%, 12/1000 live births), diarrhoeal disease (12%, 5/1000 live births), neonatal pneumonia (6%, 3/1000 live births) and malaria (4%, 2/1000 live births). In AHRI, acute respiratory infections accounted for 41% of deaths with a cause-specific mortality rate of 20/1000 live births, followed by HIV/AIDS (31%, 15/1000 live births), diarrhoeal disease (4% 2/1000 live births), neonatal pneumonia (4%, 2/1000 live births) and severe malnutrition (3%, 2/1000 live births). Care seeking from a formal medical provider was reported in 92% of all deaths and 26% reported having used traditional medicine and/or having consulted a traditional healer; only 6% did not report any care seeking at all. Fifty three percent of deaths occurred in low SES households; 31% of mothers had no secondary school education, including 225 (9%) who had no formal education at all. Maternal death had occurred in 9% of cases, and 20% reported that the mother was a temporary migrant at the time of the child's death (table 1).

Insert Table 1 here.

### **Mortality rates by place of death and care seeking:**

The under-5 mortality rate peaked in 2003, at 90 deaths per 1000 live births, before declining to 30 deaths per 1000 live births in 2015 ( $p < 0.001$ , figure 3). The rate of under-5 deaths *at home* also declined from 49 deaths per 1000 live births in 2003, to 11 deaths per 1000 live births in 2015 ( $p < 0.001$ , figure 3, green bars represent home deaths). However, the proportion of deaths at home (as a percentage of total deaths) declined more slowly between 2000-2011, from 54% to 51% over the 12 years, before falling to 46% of deaths in 2012-2015 (total decline 8%, 95%CI 3.2-12.6%,  $p = 0.001$ ).

Insert Figure 3 here.

Ninety two percent of deceased children had sought care from a formal medical provider during the final illness, including 84% of children who died at home. As shown in figure 3, there has been a decline in the absolute rate of in-facility deaths and deaths at home having sought care. This has resulted in a relative increase in the proportion of home deaths that failed to seek care (lowest in 2004, accounting for only 8% of home deaths and rising to 49% in 2015, excluding those deaths where care seeking was unknown; total increase 41%, 95% CI 23.5%-58.0%,  $p < 0.001$ ). The absolute rate of deaths at home without seeking care has remained consistent over time at 3-4 deaths per 1000 live births.

### **Risk factors for deaths at home amongst those who sought care:**

Amongst neonates who sought care during their final illness, late neonatal deaths (8-27 days) were significantly more likely to occur at home compared to early neonatal deaths (0-7 days) (adjusted OR=5.56, 95% CI 2.69-11.55,  $p < 0.001$ ). Female neonates were significantly less likely to die at home having sought care (adjusted OR=0.47, 95%CI 0.22-0.99,  $p = 0.047$ ), as were neonates of Mozambican descent (in Agincourt only, crude OR=2.83, 95%CI 1.14-7.07,  $p = 0.026$ ) (table 2). No socioeconomic, household or maternal predictors were found to be significantly associated with place of death in neonates (the full model building process is shown in appendix 1).

Insert Table 2 here.



Table 3 shows risk factors for deaths at home despite seeking care for infants and young children (compared to those who died in a health facility). The final model reflects only those factors related to the maternal and child conditions that were significant after adjusting for year of death, study site, mother's education, and household size. When determining which socioeconomic-level variables to include in the model, the addition of socioeconomic quintile, mother's migrancy status, number of household members working, and whether the household head was working, did not significantly improve the model. Similarly, when assessing household factors, overall household size had the greatest impact on place of death; further addition of the number of children aged 0-4 years, gender of the household head, and distance of the household to the clinic did not improve the model (see appendix 1 for full model building process).

Insert Table 3 here.

Children aged 1-59 months were significantly less likely to die at home despite seeking care if their mother was more educated ( $p=0.005$ ). Traditional medicine use significantly increased the risk of home deaths despite seeking care (adjusted OR=2.44, 95%CI 1.84-3.24,  $p<0.001$ ), as did being of Mozambican descent in the Agincourt study site (crude OR=2.07, 95%CI 1.59-2.69,  $p<0.001$ ). HIV-associated deaths were more likely to occur at home despite seeking care in 2004-2007 and 2008-2011 when compared to deaths in 2012-2015 (adjusted OR=2.62, 95%CI 1.27-5.41, and adjusted OR=2.89, 95% CI 1.46-5.74 respectively,  $p=0.011$ ).

### **HIV and place of death:**

Changes in place of death over time differed between deaths which were HIV-associated and those which were not (figure 4). Around 60% of HIV-associated deaths occurred at home between 2000-2011; this declined sharply to 39% in 2012-2015 (within-group change:  $\chi^2=13.86$ ,  $p<0.001$ ). In contrast, about 50% of deaths from other-cause mortality occurred at home, a trend which remained stable from 2000-2015. This finding reinforced the need to analyse HIV as an interaction term with year of death in the logistic regressions (table 3, OR=2.89, 95%CI 1.46-5.74,  $p=0.002$  for HIV\*time in 2008-2011, compared to OR=0.54, 95%CI 0.31-0.94,  $p=0.028$  for HIV\*time 2012-2015). No other causes of death were found to be associated with place of death (analysis not shown).

Insert Figure 4 here.

## Discussion:

This study showed that home deaths accounted for over 50% of under-5 deaths at two rural South African HDSS sites between 2000-2015. Despite a significant decline in the under-5 mortality rate at both study sites, the proportion of under-5 deaths occurring at home has declined more slowly, especially in HIV-unrelated deaths where no real change has been observed. Furthermore, the large majority of child deaths at home occurred despite the family having sought care from a formal medical provider during the child's final illness.

Following our modified conceptual framework (figure 2), socioeconomic and household factors that were significantly associated with dying at home despite seeking care included low maternal education and large household size (>15 people). Significant child factors included age (early neonatal deaths less likely to occur at home despite seeking care), traditional medicine use, cause of death (HIV-associated or other) and being of Mozambican descent, all of which were associated with greater odds of having died at home despite seeking care.

Improved female education is known to reduce child mortality risk and improve care seeking behaviour overall (15,20). This study adds to the existing body of research demonstrating that lower maternal education was significantly associated with home death despite seeking care. This might arise through two mechanisms. Firstly, maternal education reflects the socioeconomic position of the household. Secondly, educated mothers might hold greater social capital and medical staff might take their concerns more seriously. Such social capital might also give them confidence to re-seek care should a child's condition fail to improve (15).

Household size was significantly associated with dying at home despite seeking care in post-neonatal deaths, though only when comparing households of 15 people or more, to those with up to five members. This partially reflects lower socioeconomic position of larger households (less income per capita), but also might reflect the physical and emotional burden of caring for dependents in large families: caregivers might be less likely to identify that a child's condition has deteriorated when stretched to care for more people at once (21).

With regard to the child-related determinants, early neonatal deaths were significantly more likely to occur in a health facility, reflecting those neonates who were born and died in a facility without discharge. Over 90% of deliveries in South Africa occur in health facilities attended by nurses, midwives or doctors (22) and so babies in a serious condition (e.g. birth asphyxia, and prematurity) can be admitted to hospital immediately after birth.

Traditional medicine use is a common feature of the South African healthcare landscape and was most often used in combination with western medicine, as in other studies (23). Traditional beliefs about disease aetiology, loss of confidence in formal medical treatment, stigma, ease of access and shorter waiting times all contribute to traditional medicine use (24,25). Medical pluralism was found in this study too. However, it remains unclear whether traditional medicine is used before, after or in parallel with formal care during the child's final illness, and why it is associated with death at home. It is possible that traditional care is a marker for serious and chronic illness, and for discharge from a health facility with inadequate follow-up, as parents try all options to treat their child.

The place of HIV-related deaths changed over time, reflecting changes in South African HIV policy on testing and treatment. In the early 2000s the country was still struggling with AIDS denialism, and only introduced a PMTCT programme in 2002 following a court order (16). However, by 2011 South Africa had the largest antiretroviral rollout programme globally (26), and current policy supports the WHO's test and treat guidelines (27). Significant gains have been made in improving access to HIV care, both in the form of available, acceptable and effective treatment and in terms of overcoming barriers created by stigma. The changing pattern in place of death could partly reflect these improvements in access to care, successful integration of HIV patients into formal healthcare systems, and a greater sensitivity to clinical signs and symptoms by parents and health professionals in HIV positive children. The current package of HIV-related care (including health promotion materials and education of mothers about breastfeeding, growth and danger signs of illness) could be applied more broadly in the provision of primary care child health services to motivate for greater emphasis on health promotion, education of caregivers about common danger signs, developmental milestones and nutrition.

Finally, in Agincourt, being of Mozambican descent was significantly associated with dying at home despite seeking care in the infants and young children. Mozambican descent is partially a proxy for socioeconomic position in Agincourt, but likely also reflects differences in cultural beliefs around illness

and treatment seeking (28). Of concern is the possibility of xenophobia experienced at healthcare facilities which has been noted elsewhere in the country (29,30). Further work on this question is required to understand the specific barriers in this community.

### **Strengths and limitations:**

This study uses population-based data, which is essential to provide information on deaths at home or in the community that are unavailable in facility-based studies. Furthermore, the duration of the dataset (going back to 2000) allows us to track changes in under-5 mortality over much of the HIV/AIDS epidemic in South Africa, and how this relates to place of death and care seeking behaviour over that time.

However, there are a number of important limitations. Firstly, neonatal deaths may be missed by the HDSS update rounds, as the death might occur before the birth was captured. To minimise this risk, data is captured on all pregnancies in the household. Secondly, care seeking data is self-reported. The rate of care seeking from traditional healers is likely underestimated as participants may be hesitant to report such activity to researchers who are seen to be “western”. For similar reasons, it is possible that care-seeking from formal healthcare facilities could be over-reported. Furthermore, care seeking data is only available as a binary response (yes care was sought, or no it wasn’t), and so it is not possible to explore issues related to the timing of care seeking which might help explain the high proportion of home deaths that had sought care. Thirdly, as the data is observational it is impossible to draw causal inferences from the associations we have reported. Further qualitative research is needed to understand the reasons for these associations, and whether causality can be attributed to any of them. Finally, data on some of the explanatory variables of interest, particularly maternal education and maternal employment, was incomplete, which may bias the associations noted in this analysis. Analysis of the patterns of missing data suggest that for both maternal education and maternal employment, records with missing data were overrepresented in the lower socioeconomic quintiles (1-3), and in children who died at home despite seeking care, which may have weakened the associations (towards the null) between maternal education, maternal employment and place of death despite seeking care. No patterns were identified between the missing maternal education data and other explanatory variables, however records with missing data on maternal employment tended to have a younger maternal age at the child’s death, have smaller households and fewer children under 5 years in the

household, and so the current estimate may exaggerate the association between maternal employment and home death despite seeking care.

## Conclusions and recommendations:

This study confirms that home deaths account for the over half of all under-5 deaths in rural South Africa, despite high rates of care seeking during the final illness. Therefore, a shift in dialogue is required, to include not only questions of symptom recognition, caregiver response and barriers to accessing care, but also questions about where and why children fall out of formal care pathways only to subsequently die at home. By controlling for care seeking, this study has identified several socio-demographic and disease-specific factors that are associated dying at home despite seeking care, and should serve as a starting point to target interventions to reduce under-5 deaths.

## Author Contributions:

JP, MW, KK and AH designed the study. KH, KK and CK were responsible for the longitudinal population-based data collection and data management at the HDSS sites. JP and CK analysed the data with input from KH, KK, MW and AH. All authors contributed to the writing of the article and have seen and approved the final draft.

## Declaration of interests:

The authors declare that they have no competing interests.

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