Understanding why children under 5 years die at home in rural South Africa

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Abstract

Background

Half of under-5 deaths in South Africa occur at home. However, the reasons remain poorly described and data is limited on the circumstances of death and access to healthcare during the final illness of children who die outside of health facilities. My thesis aimed to understand why children under five years die at home in rural South Africa, and to recommend interventions to reduce home deaths.

Methods

Four studies were conducted for this thesis. First, I reviewed the available evidence on place of death and care-seeking across sub-Saharan Africa, presented as a systematic review and meta-analysis. Second, I used population-based longitudinal data from two health and demographic surveillance system (HDSS) sites in rural South Africa to determine the trends in place of death and care-seeking during fatal child illness from 2000-2015. I assessed whether there was an association between place of death and specific causes of death, using cause of death data from verbal autopsies. I performed bivariate and multivariate logistic regression to identify sociodemographic factors associated with increased odds of a child under-5 dying at home despite having sought healthcare compared to children who died in health facilities. Third, I used primary data collected from a social autopsy study at each HDSS site to characterise the processes of seeking and receiving healthcare during fatal childhood illness. Finally, I conducted qualitative research to explore caregivers' experiences of care-seeking, barriers encountered in accessing healthcare and how this influenced their decision-making when their child was ill. By integrating findings from across all studies in this thesis, I proposed interventions to reduce under-5 mortality particularly outside of formal health services.

Results

The proportion of under-5 deaths that occur at home has remained constant at approximately 50% from 2000-2015, despite a decline in the under-5 mortality rate. Over 80% of the children who died at home were taken for formal healthcare during their final illness. Modifiable factors contributing to home deaths in children under-5 were identified within and outside the home. Within the home, a lack of caregiver knowledge contributed to failure to appreciate the severity of the illness. Outside the home, modifiable factors included delays in accessing transport,

caregivers' negative experiences of seeking healthcare, a lack of safety-netting and follow-up advice from healthcare providers and low referral rates from primary care providers to secondary level facilities. HIV-related deaths were less likely to occur at home than in health facilities after 2012, partly reflecting the social capital earned by HIV-positive caregivers through repeated contact with facilities and a familiarity with the health system. Finally, consulting traditional healers and use of traditional medicines was relatively uncommon. When this did occur, caregivers' decisions seemed driven by a desperate need to help the child rather than a strongly held traditional belief about the underlying cause of the disease.

Conclusions and recommendations

Child deaths at home continue to account for almost half of all under-5 deaths in rural South Africa. My doctoral work has helped to better understand this phenomenon, highlighting that home deaths are not purely a function of a failure of caregivers to seek healthcare. Modifiable factors within and outside the home must be addressed to reduce under-5 deaths at home. Therefore, I recommend 1) all pregnant and recently delivered women should receive routine home visits by community health workers during the antenatal and postnatal period to improve caregivers' knowledge and recognition of severe childhood illness; 2) establish community-based participatory action groups to increase caregivers' knowledge of childhood illness and their confidence to engage healthcare services more assertively; 3) improve data sharing on identified child deaths between HDSS sites and health facilities so that home deaths can also be included in facility-based mortality reviews especially if the child was taken to a healthcare provider during the final illness; 4) implement clear guidelines for safety-netting and follow-up so that caregivers know to monitor their children for signs of deterioration and when to re-seek care; and 5) conduct participatory learning workshops with healthcare workers to identify reasons for negative staff attitudes and attempt to address them.

Further research should be conducted to evaluate the quality of care provided to children who died at home after seeking healthcare, identify barriers health workers face in referring patients to higher facilities and assess which aspects of the current HIV care package confer protection on HIV positive children reducing their odds of dying at home, and whether similar services should be made available to all children under-5. Engaging traditional healers, community members and health practitioners to further understand the role of traditional medicines and healers in fatal child illness offers opportunities to maximise the benefits of medical pluralism and reduce the harms.

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Above all, in both the Agincourt and AHRI sites, I would like to thank the participants: those caregivers whose children died before reaching their fifth birthday, who gave of their time and shared their stories even when it caused them distress, all in the hope that this work will help prevent the deaths of other children in their communities.

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Table of Contents

Abstract 2

Acknowledgements 4

List of Figures 12

List of Tables 14

List of Abbreviations 15

Chapter 1: Introduction 16

1.1 Trends in under-5 mortality in South Africa: 1990-2015 17

1.2 Causes of child deaths 20

1.3 Interventions that have reduced under-5 mortality 21

1.3.1 Prevention of mother-to-child transmission and antiretroviral therapy 21

1.3.2 Removal of user-fees 22

1.3.3 Rotavirus and pneumococcal conjugate vaccines 22

1.3.4 Integrated Management of Childhood Illness 23

1.3.5 Child support grants 25

1.3.6 Nutrition and food fortification policies 25

1.4 Data sources on under-5 deaths 26

1.4.1 Vital registry 27

1.4.2 The District Health Information System 28

1.4.3 The Rapid Mortality Surveillance System 28

1.4.4 The South Africa Demographic and Health Survey 29

1.4.5 The population census 29

1.4.6 The United National Interagency Group on Child Mortality Estimation 30

1.4.7 Facility-based audits 30

1.4.8 Health and demographic surveillance systems 31

1.5 The concept of 'access' in healthcare 32

1.6 The knowledge gap 34

1.7 References 34

Chapter 2: Aims, objectives and thesis structure 41

2.1 Overall thesis aims and objectives 42

2.2 Thesis structure 43

Chapter 3: Place of death, care seeking and care pathway progression in the final illnesses of children under-5 in sub-Saharan Africa - a systematic review 46

3.1 Introduction 46

3.2 Aims and objectives 48
3.3 Methods 49
3.3.1 Search strategy and selection criteria 49
3.3.2 Quality appraisal 50
3.3.3 Statistical Analysis 51
3.4 Results 52
3.4.1 Search 52
3.4.2 Included studies' characteristics 53
3.4.3 Quality appraisal: 54
3.4.4 Synthesis of results 60
3.4.5 Exploration of heterogeneity 65
3.5 Discussion 68
3.5.1 Summary of results 68
3.5.2 Comparison with previous studies 72
3.5.3 Comparison with South Africa 74
3.5.6 Strengths and limitations 74
3.6 Conclusion 75
3.7 References 76
Chapter 4: Description of the study areas 82
4.1 The Agincourt HDSS 83
4.1.1 History 83
4.1.2 Geography and community context 84
4.1.3 Data collection 87
4.2 Africa Health Research Institute (AHRI) 88
4.2.1 History 88
4.2.2 Geography and community context 89
4.2.3 Data collection 90
4.3 Relevant findings on under-5 mortality 92
4.4 Relation to the rest of the thesis 95
4.5 References 96
Chapter 5: Trends and determinants of place of death in under-5 deaths in rural South Africa between 2000-2015 – a population-based longitudinal study 99
5.1 Introduction 99
5.2 Aims and objectives 100
5.3 Methods 100

5.3.1 Study design 100
5.3.2 Study sites and data collection 101
5.3.3 Conceptual framework 104
5.3.4 Study variables 105
5.3.5 Statistical analysis 107
5.3.6 Ethics 109
5.4 Results 109
5.4.1 Descriptors of under-5 deaths 2000-2015 109
5.4.2 Mortality rates by place of death and care-seeking 112
5.4.3 Risk factors for deaths at home amongst those who sought healthcare 113
5.4.4 HIV and place of death 119
5.5 Discussion 120
5.5.1 Summary of results 120
5.5.2 Low maternal education associated with home deaths despite seeking healthcare 122
5.5.3 Child factors associated with home deaths despite seeking healthcare 122
5.5.4 Strengths and limitations 124
5.6 Conclusion 126
5.7 References 127
Chapter 6: The processes of seeking and receiving care during a child's final illness in rural South Africa – a descriptive analysis 130
6.1 Introduction 130
6.2 Aims and objectives 131
6.3 Methods 132
6.3.1 Study design 132
6.3.2 Study sites and population 132
6.3.3 Study tool 133
6.3.4 Training of fieldworkers 137
6.3.5 Data analysis 139
6.3.6 Ethics 142
6.3.7 Funding 142
6.4 Results 143
6.4.1 Sociodemographic characteristics of deceased children and their households 143
6.4.2 Preventive care-seeking 145
6.4.3 Pathways to Survival analysis (curative care-seeking) 145

6.4.4 Care-seeking delays and barriers to accessing healthcare 150
6.5 Discussion 153
6.5.1 Sociodemographic Characteristics 153
6.5.2 Failures along the care pathway 154
6.5.3 Applying the Three Delays Model 159
6.5.4 Utility of the adapted Social Autopsy tool 160
6.5.5 Limitations 162
6.6 Conclusion 164
6.7 References 165
Chapter 7: Caregivers' behaviours and decision-making during a child's final illness - a qualitative study 168
7.1 Introduction 168
7.2 Aims and objectives 170
7.3 Methods 171
7.3.1 Study design 171
7.3.2 Participants and sampling 172
7.3.3 Data collection and processing 173
7.3.4 Data analysis 179
7.3.5 Ethics 180
7.3.6 Funding 181
7.4 Results 181
7.4.1 Caregiver knowledge and advice-seeking 185
7.4.2 Traditional medicine and practices 186
7.4.3 Transport barriers 189
7.4.4 Experiences of care-seeking during the final illness 190
7.4.5 Adapting the Pathways to Survival Framework 197
7.5 Discussion 201
7.5.1 Summary of findings 201
7.5.2 Adapted model of care-seeking during fatal child illness in rural South Africa 202
7.5.3 Social exclusion 202
7.5.4 Social Capital 205
7.5.5 Traditional medicine 206
7.5.6 Strengths and limitations 207
7.6 Conclusion 210
7.7 References 211
Chapter 8: Discussion 215

8.1 Introduction 215
8.2 Half of under-5 deaths occur at home 216
8.3 Care-seeking rates are high for all under-5 deaths, including for those that die outside of facilities 217
8.4 Modifiable factors 219
8.4.1 Within the home 220
8.4.2 Outside the home 222
8.5 Traditional medicine and consulting traditional healers 227
8.6 HIV-related deaths 231
8.7 Policy recommendations 233
8.7.1 Community-level recommendations 233
8.7.2 Facility level recommendations 239
8.7.3 Data collection instruments 242
8.8 Recommendations for future research 244
8.9 Conclusion 246
8.10 References 248
Appendices …… 257
Appendix 3.1: Data extraction template 257
Appendix 3.2: Quality assessment of included studies 258
Appendix 3.3: Suggested definitions for each stage of the care pathway 260
Appendix 3.4: Summary of results, stratified by national income status 261
Appendix 3.5: Summary of results, stratified by whether or not user-fees are charged for health services 263
Appendix 5.1: Model building process for neonatal deaths 265
Appendix 5.2: Place of death and care-seeking, disaggregated by study site. 269
Appendix 6.1: INDEPTH Network Social Autopsy Tool for Newborn Deaths 270
Appendix 6.2: INDEPTH Network Social Autopsy Tool for Child Deaths 274
Appendix 6.3: Findings from full INDEPTH Social Autopsy questionnaire for neonatal and child deaths in Agincourt in 2017 278
Appendix 6.4: Training Scenarios for Verbal and Social Autopsy 281
Appendix 6.5: Individual care pathways for child deaths in AHRI and Agincourt 284
Appendix 7.1: Participant information sheet and consent forms 288
Appendix 7.2: Interview Guide 300

List of Figures

Figure 1.1: Neonatal, infant and under-5 mortality rates, South Africa, 1990-2015. Based on data from UN Inter-agency Group for Child Mortality Estimation (2)……18

Figure 1.2: Proportion of children that died within health facilities. Source StatsSA - VR 2012-2015; Committee on Morbidity and Mortality in Children Under 5 Years (CoMMiC) (6)……..20

Figure 2.1: Thesis structure indicating levels of data and transfer of learnings and policy implications……43

Figure 3.1: PRISMA Flow diagram. From Moher et al (54)……..*53*

Figure 3.2: Map showing number and location of included studies……54

Figure 3.3: Proportion of children who died at home, by age group……60

Figure 3.4: Proportion of children with signs/symptoms of illness, by age group……..63

Figure 3.5: Proportion of children who died immediately or without receiving any care, by age group……63

Figure 3.6: Proportion of caregivers who sought or attempted to seek healthcare outside the home for their child during the final illness, by age group……64

Figure 3.7: Proportion of children who left the first health facility alive of those who arrived alive, by age group……65

Figure 4.1: HDSS monitoring of changing populations in a geographically defined area, adapted from https://www.agincourt.co.za/?page_id=263.....83

Figure 4.2: Map of South Africa, including HDSS site locations, adapted from http://saprin.mrc.ac.za/nodes.html.....86

Figure 4.3: Agincourt HDSS Field Site and surrounding area 2014, From: https://www.agincourt.co.za/?page_id=1896.....86

Figure 4.4: Map of the AHRI HDSS site, adapted from Study Protocol: A longitudinal population-based programme for epidemiology and intervention research (13)……90

Figure 4.5: Under-five mortality rates at the Agincourt site from 1992 to 2013, by age group and by cause of death category. From https://doi.org/10.1371/journal.pmed.1001926.g002 (22)……94

Figure 4.6: Under-5 Age Standardized Mortality at AHRI (Deaths 1, 531, Person Years Observed (PYO) 100 274) from https://doi.org/10.1186/1478-7954-9-47 (24)……94

Figure 5.1: Conceptual hierarchical framework of risk factors for place of death in rural South Africa, adapted from the WHO social determinants of health inequalities (9)……105

Figure 5.2: Place of death and care-seeking in rural South Africa, 2000-2015……112

Figure 5.3: Proportion of deaths at home for HIV-associated or other-cause mortality……..120

Figure 6.1: Pathways to Survival. Source: BASICS 1996 (8) ……..*140*

Figure 6.2: Pathways to Survival analysis of 48 child deaths in rural South Africa……..147

Figure 7.1: Simplified, linear representation of stages of seeking and providing care based on the CDC/BASICS Pathways to Survival framework (4), and the barriers to care identified at each stage of the care-seeking process……..198

Figure 7.2: Modified model of the process of seeking and providing healthcare during childhood illness in rural South Africa……..199

Figure 8.1: Adaptation of the Pathways to Survival Framework showing those modifiable factors identified in this thesis within and outside the home, and the stage of the pathway at which each factor acts……..226

List of Tables

Table 3.1: Characteristics of included studies……55

Table 3.2: Summary of pooled results, stratified by age group……62

Table 3.3: Exploration of heterogeneity using meta-regression……67

Table 4.1: Comparison of study sites……92

Table 5.1: Population descriptors of child deaths and care-seeking behaviour 2000-2015……111

Table 5.2: Predictors of neonatal death at home despite seeking healthcare compared to death in a facility……114

Table 5.3: Predictors of death at home despite seeking healthcare compared to death in a facility for infants and young children……116

*Table 5.4: Implications of HIV*time interaction on death at home despite seeking healthcare compared to death in a facility for infants and young children……119*

Table 6.1: Adapted Social Autopsy Tool……135

Table 6.2: Sociodemographic characteristics of deceased children in both study sites, 2017……144

Table 6.3: Sociodemographic characteristics of the households of deceased children in both study sites, 2017……146

Table 6.4: Three Delays Model……151

Table 7.1: Summary of characteristics of respondents and their deceased children……182

Table 7.2: Individual participant characteristics……183

Table 7.3: Care-seeking experiences……196

List of Abbreviations

AHRI	Africa Health Research Institute
AIDS	Acquired Immune Deficiency Syndrome
ART	Antiretroviral therapy
ARV	Antiretrovirals
BASICS	Basic Support for Institutionalising Child Survival
Child PIP	Child Health Problem Identification Programme
CHW	Community Health Worker
CHERG	Child Health Epidemiology Reference Group
CI	Confidence Interval
DHIS	District Health Information System
END	Early Neonatal Death (0-7 days of life)
GP	General Practitioner
HDSS	Health and Demographic Surveillance System
HIV	Human Immunodeficiency Virus
IMCI	Integrated Management of Childhood Illness
INDEPTH	International Network for the Demographic Evaluation of Populations and Their Health
IQR	Interquartile Range
LMIC	Low and Middle-Income Countries
LND	Late Neonatal Death (8-27 days of life)
MDG	Millennium Development Goal
OR	Odds Ratio
PMTCT	Prevention of Mother-to-Child Transmission
PPIP	Perinatal Problem Identification Programme
RMS	Rapid Mortality Surveillance
SA	Social Autopsy
SADHS	South African Demographic and Health Survey
SAPRIN	South African Population Research Infrastructure Network
SD	Standard Deviation
SDG	Sustainable Development Goal
UN	United Nations
UNICEF	United Nations Children's Fund
UN-IGME	United Nations Interagency Group on Child Mortality Estimation
USAID	United States Agency for International Development
VA	Verbal Autopsy
VASA	Verbal and Social Autopsy
VR	Vital Registry
WHO	World Health Organization

Chapter 1: Introduction

In 2015 I began working at Chris Hani Baragwanath Academic Hospital in Soweto, the largest hospital in the southern hemisphere and the third largest in the world. I was a medical intern, rotating through each of the specialities over the course of two years as part of my clinical training. My final rotation was paediatrics, and it was then that I felt most passionate about clinical work. I loved working with children; they were resilient and generally recovered quickly with the right treatment. When a child cried or felt pain it was easy to empathise. And when they died it felt unnatural and prompted us to ask, almost instinctively, what more we could have done.

However, even my short exposure to clinical work has made it clear that preventing deaths of children under five years is an issue which also requires action beyond individual clinicians. The deaths I saw should have been avoided, but factors at the household, community, facility and health-systems levels often collided to result in the worst possible outcome. My frustration and distress only grew when I learnt that only half of all under-5 deaths in South Africa occurred in health facilities, visible to health professionals. The other half happened outside of health facilities, mostly at home. It was this realisation that underpinned my motivation to pursue a DPhil in Primary Health Care, to better understand why such a high proportion of under-5 deaths occur at home in South Africa, and what can be done to change this.

I will begin by providing some background information on under-5 mortality in South Africa, including the trends in mortality rates over the past two decades, the top causes of death in this age group and key interventions that have contributed to a reduction in under-5 mortality in the country. I will also describe the current methods used to collect data on child deaths in South

Africa, highlighting where knowledge gaps exist. Finally, I will touch on the concept of access to healthcare, which is core to the issue of avoidable mortality, and which underpin many of the hypotheses tested in my doctoral thesis.

1.1 Trends in under-5 mortality in South Africa: 1990-2015

Under-5 mortality remains an important marker of health and development. Millennium Development Goal 4 (MDG 4) challenged each country to reduce their under-5 deaths by two thirds of the 1990 rate by 2015 (1). However, South Africa saw an increase in the under-5 mortality rate in the 1990s and early 2000s despite the global focus on child mortality during this period. This increase was largely attributed to the HIV/AIDS epidemic, which drove the under-5 mortality rate up from 61 deaths per 1000 live births in 1990, to 84/1000 live births in 2003. This trend was reversed, with the under-5 mortality rate returning to 59/1000 live births in 2010 and 40/1000 live births in 2015 based on United Nations (UN) estimates (figure 1.1) (2).

Figure 1.1 also shows the infant and neonatal mortality rates between 1990-2015. The trend of infant mortality mimics that of under-5 mortality, similarly reflecting the impact of the HIV/AIDS epidemic. However neonatal mortality has declined slowly but steadily since 1990. As the under-5 mortality rate has declined, neonatal mortality accounts for a growing proportion of under-5 deaths, in keeping with international development trends (3).

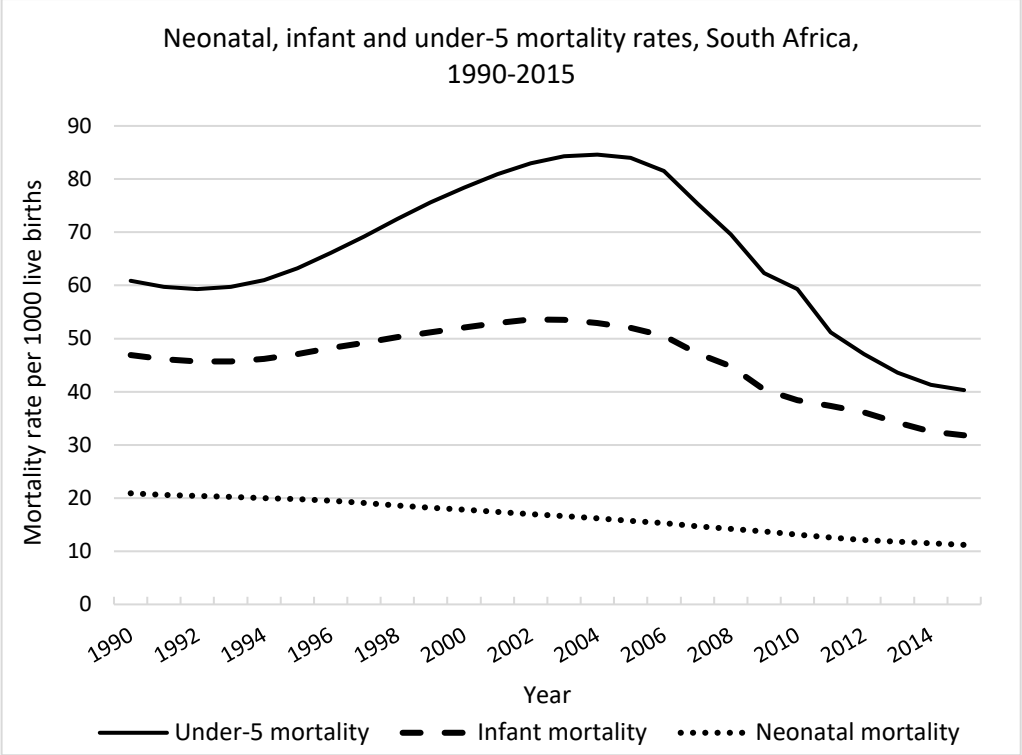


Figure 1.1: Neonatal, infant and under-5 mortality rates, South Africa, 1990-2015. Based on data from UN Inter-agency Group for Child Mortality Estimation (2)

While South Africa failed to meet the MDG targets for neonatal and under-5 mortality, the reversal of the rising trend of under-5 deaths has been described as a "successful failure" (4). South Africa appears to be on track to reach the Sustainable Development Goal 3 (SDG 3) target of reducing neonatal mortality to 12/1000 live births by 2030. However, despite the interventions rolled out to achieve the decline in under-5 mortality in the late 2000s, work is required to further accelerate the reduction of under-5 deaths if South Africa is to meet the SDG 3 target for under-5 mortality of 25/1000 live births by 2030, and to end preventable deaths of newborns and children under five years of age.

Mortality rates vary significantly across the nine provinces reflecting differences in the availability, accessibility and quality of healthcare services. A child living in the Free State is twice as likely to die before their fifth birthday than one living in the Western Cape, where the under-

5 mortality rate is 24/1000 live births, already below the SDG 3 target (5). The Western Cape has consistently lower child mortality rates, while the worst-performing provinces are Free State and North West. (6).

Trends in place of death between 2012-2015 are shown in figure 1.2. In 2015, only 50.9% of under-5 deaths occurred in health facilities, although this has slowly increased nationally. The proportion of children dying within healthcare facilities also varied by province. Surprisingly, despite the Western Cape's lower overall mortality rates, the proportion of child deaths that occurred in health facilities was below the national average. And in Gauteng province, the most urbanised of the provinces with a high density of healthcare facilities, over 45% of children died outside a healthcare facility in 2015 (6). This challenges the assumption that limited access to facilities, measured by number of facilities or distance to the nearest facility, is the primary cause of home deaths.

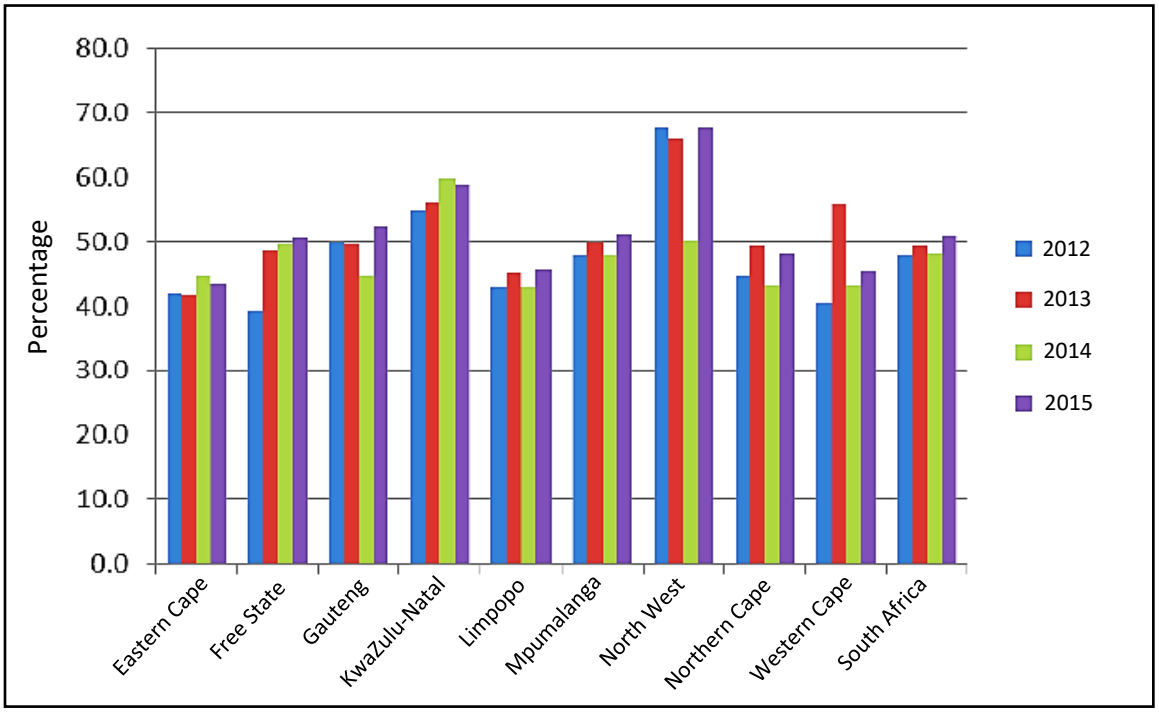


Figure 1.2: Proportion of children that died within health facilities. Source StatsSA - VR 2012-2015; Committee on Morbidity and Mortality in Children Under 5 Years (CoMMiC) (6).

1.2 Causes of child deaths

The main causes of under-5 death in South Africa are neonatal conditions (prematurity, intrapartum asphyxia and neonatal sepsis), pneumonia, diarrhoea, HIV and injuries. This is based on a combined assessment of data from the vital registry, the Child Health Problem Identification Programme and United Nations estimates (3,6). Malnutrition is an important underlying cause, contributing to almost a third of in-facility deaths of children aged 1-59 months (6). The data on nutritional status of children who died outside of facilities is not well documented.

The burden of disease has changed over the years, mostly reflecting a reduction in HIV-related under-5 deaths. At its peak, HIV accounted for 37-39% of under-5 deaths in 2005-2006 (7), whereas in 2015 UN estimates suggested that HIV was the cause of only 8.7% of under-5 deaths (3). Non-HIV related causes have become increasingly important, particularly neonatal causes which accounted for 19.3% of deaths in 2015 (3).

National data on cause of death has not been broken down according to place of death. However, data from two health and demographic surveillance system (HDSS) sites In Mpumalanga and KwaZulu-Natal provinces suggests that aside from neonatal causes – which are more common in deaths that occur in health facilities - there is little difference in the cause of death patterns for deaths of children 1-59 months based on whether they die in health facilities, at home, or elsewhere (8).

1.3 Interventions that have reduced under-5 mortality

1.3.1 Prevention of mother-to-child transmission and antiretroviral therapy

The substantial decline in HIV/AIDS-related mortality is largely attributable to prevention of mother-to-child transmission (PMTCT) and increased availability of antiretroviral therapy (ART) (7). PMTCT monotherapy was piloted in South Africa in 2000 and introduced nationally in 2003. However, implementation of this policy was slow and by 2007 less than half of HIV positive mothers received PMTCT. In 2008 PMTCT dual therapy was introduced, and coverage of the PMTCT programme grew more rapidly: by 2010 over 90% of HIV positive pregnant women received PMTCT. In 2010, guidelines were changed and all pregnant women with a CD4 count below 350 cells/mm^3 were initiated on life-long ART (7). In 2013 South Africa adopted option B+, offering life-long ART to all pregnant women regardless of CD4 counts (9), and as of 2015 South Africa has adopted the WHO test-and-treat guidelines advising initiation of life-long ART for all HIV positive patients regardless of CD4 count (10).

South Africa has largely decentralised HIV treatment programmes, including nurse initiated management of antiretroviral therapy (NIMART) (11,12). As of 2017, 84% of women presenting to antenatal clinics were tested for HIV, and 86% of pregnant women living with HIV were

receiving life-long ART. Vertical transmission of HIV is estimated at 1.3% nationally (13), and 87% of children born to HIV positive mothers received a virological HIV test within two months of birth (14).

1.3.2 Removal of user-fees

South Africa has offered free healthcare for pregnant women and children under six years at all levels of care in the public sector since 1994. As of 1996, this policy was extended to cover free primary healthcare services for everyone at all public health centres and clinics. The removal of user-fees in South Africa was shown to increase access to healthcare by removing financial barriers, particularly for people in rural areas and informal settlements. The policy is credited with leading to increased healthcare service use, particularly of preventative healthcare including family planning and antenatal services, known to reduce neonatal mortality (15).

1.3.3 Rotavirus and pneumococcal conjugate vaccines

The rotavirus and pneumococcal conjugate vaccines were added to the routine vaccination schedule for all children under five years in South Africa in 2009. These vaccines have been shown to be effective in reducing mortality and hospitalisation due to diarrhoeal disease and pneumonia in other middle income countries and across socioeconomic brackets (16–18). It is difficult to fully disentangle the impact of the vaccines on under-5 mortality in South Africa, as their introduction overlapped the expansion of PMTCT and ART programmes. However, case control and ecological studies in South Africa suggest that hospital admissions due to diarrhoea with dehydration and invasive pneumococcal disease declined between 2009-2012 following introduction of the vaccines. Facility-based mortality audits showed that case fatality rates for both diarrhoea and pneumonia also declined significantly (19).

The decline in hospitalisation and mortality from pneumonia was greater for HIV-uninfected children than children with HIV on ART (19). This was despite having adapted the World Health Organization (WHO) pneumococcal vaccine dosing schedule to give the vaccine at 6 and 14 weeks and a booster at 9 months (instead of 6,10 and 14 weeks) to account for the waning immunity in HIV positive children that was demonstrated in the vaccine efficacy trial in South Africa (20). The WHO has subsequently recommended an additional dose of the pneumococcal vaccine for HIV positive children, i.e. at 6, 10, 14 weeks and 9 months.

1.3.4 Integrated Management of Childhood Illness

Integrated Management of Childhood Illness (IMCI) is a strategy for the holistic management of child health, using preventative and curative interventions in the home, community and in health facilities. It was developed by the WHO and United Nations Children's Fund (UNICEF) in 1995 for use in settings with a child mortality rate of over 40/1000 live births (21). IMCI includes three main components:

- Improving case management skills of health-care staff
- Strengthening health systems
- Improving family and community health practices (21).

IMCI was first introduced in South Africa in 1996 and has remained a key component of the Department of Health's strategy to reduce under-5 mortality (22). In health facilities, IMCI focuses on correct identification of symptoms and signs of illness, appropriate assessment of severity of disease, early syndromic management and referral (21). The approach is based on a clinical assessment of common, often co-occurring symptoms and does not require multiple

diagnostic tests before starting treatment. This makes it practical for use in resource-constrained primary care settings. South Africa also led the way in adapting the initial guidelines to high HIV-burden settings – a module that was subsequently formally adopted by the WHO in updated IMCI guidelines (23).

Despite high coverage of IMCI, implementation of this strategy in South Africa has faced many challenges. A lack of adequate training means 25-50% of healthcare workers in primary care facilities are unfamiliar with the guidelines and key components of the IMCI (24). Furthermore, research has shown that some healthcare workers perceive the guidelines to offer lower quality care or inappropriate management, particularly when not aligned with other clinical guidelines that are used in vertical health programmes, including HIV, which are also operational in primary care facilities. Finally, IMCI implementation has to date focused on the first two components – those related to health facilities and the healthcare system – and largely ignored the community and household component (22).

These challenges contributed to IMCI having mixed results. A study in the Western Cape found that IMCI improved recognition of danger signs, rational prescribing and higher rates of initiation of treatment at the clinic (25). However, in Limpopo nurses reported being unable to implement IMCI due to a lack of resources (26), and in Limpopo and KwaZulu-Natal IMCI assessments were often incomplete and failure to refer was common (27). A Cochrane Review suggested that while IMCI may contribute to a reduction in infant and under-5 mortality, the evidence base was weak and confidence intervals of risk reduction ratios crossed zero (23).

1.3.5 Child support grants

Child support grants are available for the primary caregiver of children up to the age of 18 years in South Africa. First introduced in 1998, these are means-tested, non-contributory social grants financed through general taxes. Child support grants have been shown to be associated with improvements in child health by reducing malnutrition as measured by greater height-for-age, improved rates of routine growth monitoring, and reduced likelihood of child illness (28–30). They have also been associated with increased school attendance and academic performance (28–30). This is in addition to old-age pensions, which were the first non-contributory social grant introduced in 1993, available to women over 60 and men over 65, and which similarly were shown to be associated with improved child nutrition, care-seeking behaviours and school attendance, particularly of girls (31).

1.3.6 Nutrition and food fortification policies

South Africa has a variety of nutrition-related policies specifically targeting improved neonatal and child health, though some have been more successful than others. One of the most successful interventions to address congenital abnormalities has been the fortification of all maize and wheat flour with folic acid which was introduced into law in 2003. This intervention is credited with a reduction of over 30% in neural tube defects from 1.41/1000 live births in 2003-2004 (pre-fortification), to 0.98/1000 live births in 2004-2005 (post-fortification), and a decline in neural tube defect-related mortality of 65.9% (32). Maize and wheat flours are also fortified with vitamin A, thiamine, riboflavin, niacin, pyridoxine, iron and zinc.

Children under five years also receive Vitamin A supplementation every six months from 6-59 months as part of routine primary healthcare services, which is known to reduce mortality from

diarrhoea and reduce the number of new cases of diarrhoea and measles (33). The 2016 Demographic and Health Survey found that 72% of children 6-59 months had received vitamin A supplementation in the last six months (34).

Less successful has been the exclusive breastfeeding campaign. South Africa officially promotes exclusive breastfeeding of all children until six months of age in all health documents and nutrition guidelines. However, mixed messages previously questioning the safety of breastfeeding in HIV positive women still cause doubt and often discourage women from breastfeeding. Aggressive marketing and promotion of formula feeding, and previous distribution of formula to HIV positive mothers by clinics as part of PMTCT efforts also contributed to low breastfeeding rates (35). South Africa's breastfeeding rate was the lowest in the world at only 8.7% in 2012 (36), and remains low at 31.6% in 2016 (37). Ongoing high rates of infant and child deaths from pneumonia, diarrhoea and malnutrition have been partly attributed to the low breastfeeding rates (35).

1.4 Data sources on under-5 deaths

Routinely collected data on the number and causes of child deaths are available from eight sources in South Africa: the vital registration (VR) system, the District Health Information System (DHIS), the Rapid Mortality Surveillance (RMS) system, the South African Demographic and Health Survey (SADHS), the population census, the United Nations Inter-agency Group for Child Mortality Estimation (UN-IGME), facility based audits - the Perinatal Problem Identification Programme (PPIP) and Child Health Problem Identification Programme (Child PIP), and from health and demographic surveillance system (HDSS) sites.

1.4.1 Vital registry

South Africa's vital registration (VR) system has improved significantly over the past 20 years. Approximately 95% of births and 90% of adult deaths are registered (38,39). The registration of child deaths under five years is also thought to have improved, though estimates suggest it is still lower than for adult deaths, likely closer to 78% (39). VR data is reported annually by Statistics South Africa, though with a 2-year lag time.

While the data on the total number of births and deaths has improved over time, the cause of death data from the vital registry is much less reliable. First, cause of death data is only included in death notification forms, completed by doctors (or nurses in the case of stillbirths). Where a death occurred in the community and was not attended by a medical professional, a death reporting form is completed by a local traditional leader. This form ensures that the death is counted but does not include an assessment of cause of death (3). Therefore, cause of death data is missing for most deaths that occur at home, including child deaths.

Second, the cause of death recorded by doctors or nurses on the death notification form is often inaccurate. HIV-related deaths are frequently misclassified as deaths due to tuberculosis or pneumonia, or given euphemisms such as immunosuppression or retroviral disease which are not captured as ICD-10 codes by statisticians and so are excluded from cause of death statistics (40,41). Doctors were previously discouraged from recording AIDS as the cause of death due to the stigma of the illness (as this document is given to the family and therefore is not confidential) (42).

In addition, lack of adequate training on the correct completion of death certificates has led to many doctors using 'garbage codes', which do not signify an underlying cause of death (43). The most commonly used garbage codes include septicaemia, volume depletion and other disorder of fluid, hepatic failure, renal failure and heart failure (40). A national cause of death validation study is currently underway in South Africa following recognition of the challenges of using the existing VR cause of death data to model burden of disease in the country (44).

1.4.2 The District Health Information System

The District Health Information System (DHIS) is a routine reporting system that collects data on all under-5 deaths that occur in a public health facility. While this data is available within 6 weeks from the last month period, it is limited in that it only reports deaths that occur in public health facilities, and only reports cause of death if related to diarrhoea, pneumonia or malnutrition (3).

1.4.3 The Rapid Mortality Surveillance System

The Rapid Mortality Surveillance system (RMS) was developed to provide more timely data on mortality trends. This system relies on VR data for infant and under-5 deaths, identifying all children who have been removed from the National Population Register by the Department of Home Affairs. Neonatal deaths are identified from the DHIS. Both data sets are adjusted for estimated under-reporting, and mortality rates are calculated based on mid-year population estimate and an age-distribution consistent with the 2011 census. The RMS mortality rate estimates are published annually with a 1-year lag time, however this does not include data on cause of death, nor disaggregated data of the mortality rate by province or district (3,45).

1.4.4 The South Africa Demographic and Health Survey

The South African Demographic and Health Survey (SADHS) was last conducted in 2016. A nationally representative sample of over 8000 participants were interviewed to collect data on key health issues including child and maternal mortality, child and maternal health, fertility levels and preferences, contraception, HIV/AIDs and other STIs. Although it should ideally be conducted every 5 years, the previous DHS was in 2003.

The SADHS data is broken down by province, and for urban and non-urban settings. It provides valuable household and individual level data on health status and social determinants of health. However, the SADHS does not include cause of death data. Furthermore, while estimates of under-5 mortality rates from the 2016 SADHS were in line with estimates from other data sources (42/1000 live births for 2011-2015), the estimate of neonatal mortality was 21/1000 live births - almost double the neonatal mortality rate estimated by the VR, DHIS and United Nations Interagency Group on Child Mortality Estimation (UN-IGME) which are all closer to 12/1000 live births. It was suggested that this might have been the result of misclassification of stillbirths as neonatal deaths, and that given the consistency of other data sources policy makers should use those sources for neonatal mortality trends (34).

1.4.5 The population census

The population census is conducted every 10 years, most recently from 9-31 October 2011. As part of the census all households are asked about child deaths in the preceding year. This should mean that all under-5 deaths in the previous year are identified, regardless of where they occurred – whether in a health facility or at home, across all provinces, whether urban or rural. However, the census may over-estimate deaths if a death is reported by more than one

household and so is double-counted, if the household misreports a stillbirth as a neonatal death, or if deaths are reported that occurred more than 12 months ago. As with the SADHS and RMS, the census does not collect data on cause of death.

1.4.6 The United National Interagency Group on Child Mortality Estimation

The UN-IGME uses statistical models applied to estimates produced from averaging available nationally representative population-based primary data, to produce smoothed trend curves of mortality. These models also allow for the mortality trends to be extrapolated prospectively to a target year. While often thought to be more accurate than any of the single primary data sources individually, the UN-IGME estimates will still be skewed by inaccurate or poor-quality primary data sources, or inaccurate assessments of missing data leading to over or under-adjustment. The UN-IGME does not collect data on cause of death, nor does it break down data into sub-national estimates (3,46).

1.4.7 Facility-based audits

The Perinatal Problem Identification Programme (PPIP) and Child Health Problem Identification Programme (Child PIP) are facility-based audits designed not only to count perinatal and child deaths in facilities and record the biological cause of death, but also to improve the quality of care provided by identifying modifiable factors that contributed to perinatal and child deaths and prompt action to address those factors.

PPIP was first introduced in the 1990s and collected data on all perinatal deaths (stillbirths and early neonatal deaths) in participating facilities. As of 2012, it is mandatory for all facilities with a maternity service to participate in PPIP. By 2013, 588 sites (92% of hospitals) participated in

PPIP representing 75.6% of births that occur in facilities and covering all 52 health districts in the country. In Mpumalanga province, 100% of facilities with maternity services participate in PPIP, while the Western Cape and Free State also have near complete participation. In contrast, KwaZulu-Natal is the worst performing province with 46.3% of deaths identified through DHIS not captured in PPIP (47).

Child PIP was first piloted in 2004 and records information on child deaths from 0-18 years that occur in paediatric wards in hospitals. Child PIP is not mandatory and coverage is lower than for PPIP with data collected by 205 hospitals (61% of hospitals in South Africa), though this ranges from 100% coverage of hospitals in Mpumalanga to only 20% of hospitals in the Eastern Cape (48).

Both PPIP and Child PIP are important sources of information on the social circumstances of child deaths, and have led to the development of policies and interventions to target modifiable factors identified as contributing to avoidable perinatal and child deaths (6,49). However, these audits fail to capture deaths which occur outside facilities. Furthermore, these audits are conducted by healthcare workers and do not include caregivers' perspectives on the critical modifiable factors that contributed to the child's death.

1.4.8 Health and demographic surveillance systems

There are three health and demographic surveillance system (HDSS) sites in South Africa: the Agincourt HDSS, Dikgale HDSS, and the Africa Health Research Institute (AHRI) – previously called the Africa Centre (50). HDSS sites are "geographically-defined populations under continuous demographic monitoring, with timely production of data on all births, deaths and

migrations" (51) . These sites were established between 1992-2000 and cover a total population of 315 000 as of 2017 (50). Household surveys are conducted every 4-12 months depending on the HDSS, during which time all pregnancies, births, deaths and in- and out-migrations are identified, ensuring that the communities are accurately enumerated.

All deaths are investigated using a verbal autopsy – a structured interview with the caregiver of the deceased – to determine probable biological cause of death (52–54). In addition, since 2012, verbal autopsies have included a series of questions on social circumstances of death and so increasingly allow for an assessment of the caregiver- and community-level modifiable factors that contributed to deaths (55). These HDSS sites are considered to be representative of rural resource-poor South African communities (56), and trends in mortality rates in each site are broadly in keeping with national mortality trends.

HDSS data is the only routinely collected, population-based longitudinal data to comprehensively collect cause of death information for deaths that occur within *and* outside health facilities. Additionally, this is the only data source that offers insights into the social circumstances of deaths that occurred outside of health facilities and considers the perspectives of the caregivers.

1.5 The concept of 'access' in healthcare

The concept of 'access' to healthcare has long been included in health policy interventions to reduce child mortality in low and middle-income countries (LMIC) (57,58). Yet the term 'access' remains ill-defined. Some use it to refer to factors affecting the supply of health services such as the number and location of clinics or hospitals, medications stocked, availability of trained

health practitioners and the cost of services (59). Others use 'access' more broadly to refer to all factors influencing the degree of use of health services by those with a health need. In this case, 'access' incorporates the determinants of treatment-seeking behaviour including symptom recognition, cultural beliefs, wealth status and transport availability (in addition to supply-side factors) (60,61).

Pentachsky and Thomas (1981) argue that access to healthcare is a function of the "fit" of the health service and user needs. Their model identified five dimensions of access: availability, accessibility, accommodation, affordability and acceptability. A deficiency in any of these dimensions can result in lower rates of health service utilisation, poor patient satisfaction and undesirable provider practices (61).

In this thesis I build on the model identified by Pentachsky and Thomas and use 'access to healthcare' to refer to the interplay of supply side factors, demand side factors and process factors (62–64). Access is realised when one is able to identify a healthcare need, decide to seek healthcare, reach the healthcare resource, obtain or use healthcare services and actually receive appropriate services for the given health need (62). Multiple factors interact at each stage of this process to promote or limit access including cost of healthcare, geography (distance to clinic, and rural versus urban residence), wealth and maternal education (58,62,65–71). Increasingly, socio-cultural factors such as cultural beliefs, household power dynamics and female autonomy are recognised as significant influences on care-seeking behaviour and in shaping care pathways (58,71).

1.6 The knowledge gap

Under-5 mortality is clearly on a downward trend, however more work remains if South Africa is to meet the SDG 3.2 target of reducing under-5 deaths to below 25/1000 live births by 2030 and ending all preventable deaths of newborns and children under-5. Policy makers have relied heavily on data on cause of death and modifiable factors collected mostly from under-5 deaths that occur in healthcare facilities to guide development of interventions. This despite evidence to show that almost half of all under-5 deaths occur outside of health facilities. There is a growing call for work to help identify and understand factors that contribute to child deaths outside of health facilities. Are these deaths due to a lack of access to healthcare? And if so, what are the critical barriers that limit access? What interventions would be most effective in reducing these deaths? In my thesis I aim to better understand why children under five years die at home in rural South Africa, and so to suggest appropriate interventions to reduce under-5 mortality.

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Chapter 2: Aims, objectives and thesis structure

Chapter 1 has provided a summary of trends in under-5 mortality in South Africa over the past two decades, key interventions that have resulted in a reduction of the mortality rates to pre-HIV/AIDS levels, and the recognition that in addition to understanding biological cause of death, it is also important to collect data on social circumstances of death. I also highlighted findings which showed that approximately 50% of under-5 deaths in South African populations occur at home – a statistic that I found both striking and surprising as a clinician working in paediatrics in South Africa. It was this finding which served as the departure point for my thesis.

It is unclear whether this finding is unique to South Africa, or whether place of death distributions are similar across sub-Saharan Africa, in which case there might be transferable learnings from elsewhere in the region. Furthermore, little is known about the social circumstances of home deaths and care-seeking behaviours of caregivers whose children died at home. Are home deaths a result of caregivers' failure to recognise signs of serious illness? Are caregivers reluctant to seek care due to past negative experiences of the healthcare system? Are there cultural beliefs and practices that serve as barriers to care-seeking? Are there problems retaining children within the formal healthcare system resulting in subsequent death at home?

In this thesis I begin by reviewing the available evidence on place of death and care-seeking across sub-Saharan Africa, presented as a systematic review and meta-analysis. I then conduct secondary data analysis using population-based longitudinal data from two health and demographic surveillance system sites to identify trends in place of death and care-seeking in children under-5 over the past 15 years in rural South Africa. Using primary data collected during social autopsy and qualitative studies nested within the longitudinal data platforms, I

characterise the processes of providing care inside the home, and seeking and receiving healthcare outside the home for children during their final illness. I explore caregivers' experiences of care-seeking, barriers encountered in accessing healthcare and how this influenced their decision-making when their child was ill. By integrating findings from across all methods in this thesis, I propose evidence-based, targeted interventions to reduce under-5 mortality particularly outside of formal health services.

2.1 Overall thesis aims and objectives

Aims

1. To understand why children under-5 die at home in rural South Africa.
2. To identify targets for interventions and produce recommendations to reduce under-5 mortality, particularly outside of health facilities.

Key Objectives

1. To determine the proportion of under-5 deaths occurring within and outside health facilities in sub-Saharan Africa, and to characterise the processes of seeking and receiving healthcare during the fatal illness, as defined by the Pathways to Survival Framework.
2. To describe trends and determinants of place of death and care-seeking in under-5 deaths in rural South Africa between 2000-2015.
3. To investigate the processes of, and barriers to, seeking and receiving healthcare during a child's final illness in rural South Africa, using an adapted social autopsy tool.
4. To understand caregivers' behaviours and decision-making in providing care within the home and seeking and receiving healthcare outside the home during a child's final illness.

5. To produce recommendations for interventions to reduce under-5 mortality in rural South Africa, particularly child deaths outside of health facilities.

2.2 Thesis structure

My thesis is structured around three levels of data (figure 2.1): I begin by looking at evidence from across sub-Saharan Africa, before focussing specifically on rural South Africa. I analyse data on under-5 mortality from 2000-2015, and then concentrate on a single cohort of caregivers whose children died below the age of 5 years in 2017 to provide more detailed descriptive quantitative and qualitative analysis. Findings from each level of analysis inform the research questions and methods chosen for the subsequent level. Policy implications based on learnings from more detailed data are applied to larger settings.

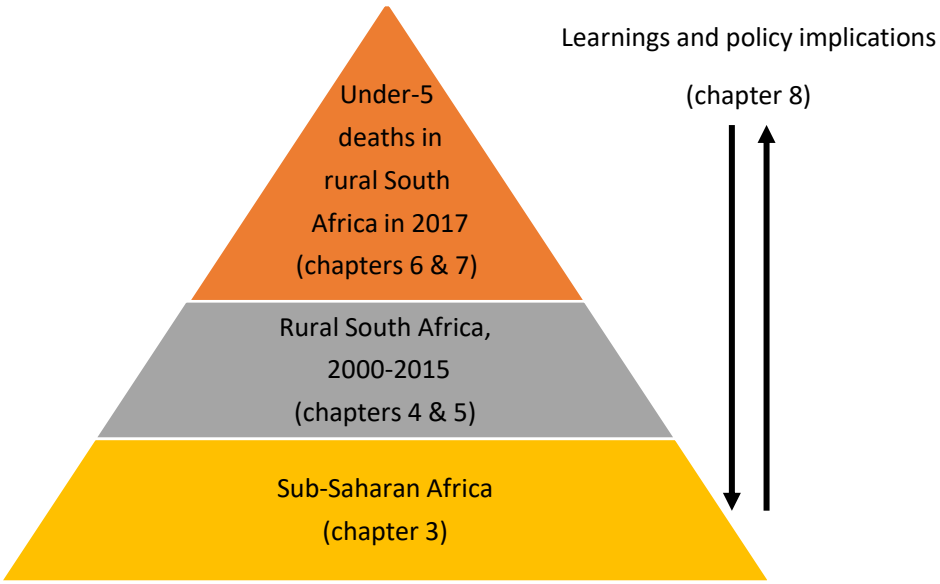


Figure 2.1: Thesis structure indicating levels of data and transfer of learnings and policy implications.

Chapter 3 presents findings from a systematic review to determine whether the proportion of home deaths noted in South Africa was similar to findings from elsewhere in sub-Saharan Africa,

and to summarise the available data on care-seeking processes during a child's final illness from studies across the region. This review also highlights significant gaps in the existing body of evidence, particularly a lack of disaggregated care-seeking data by place of death, and a lack of detailed data from South Africa on place of death and care-seeking processes in fatal childhood illness.

Chapter 4 provides a detailed description of the health and demographic surveillance systems (HDSS) at the two study sites where my doctoral work was conducted. This is necessary to contextualise and interpret results presented in the subsequent chapters. I detail the methods used to define and enumerate the populations in each HDSS site, including the identification of all births and deaths. The longitudinal datasets already available at each site formed the basis of initial exploratory analyses to understand the landscape of under-5 mortality in the region and were analysed in detail to answer the specific objectives laid out in chapter 5. Chapter 4 also highlights the existing research infrastructure at each study site within which the additional social autopsy and qualitative studies were conducted, providing the data used in chapters 6 and 7. Details of the methods specific to each chapter are described in depth in the given chapter i.e. verbal autopsy is included in chapter 5, social autopsy in chapter 6 and the qualitative methods in chapter 7.

Chapter 5 presents longitudinal data from the two HDSS sites, analysing trends in place of death in children under five years between 2000-2015. In this chapter, I also categorise deaths based on whether healthcare was sought outside the home (as a binary yes/no question). Finally, I report on the analysis of a series of individual and household factors that are associated with home deaths independently of care-seeking behaviour.

Chapter 6 builds on these findings to describe in more detail the process caregivers follow in providing care within the home seeking and receiving healthcare outside the home during the child's final illness using an adapted social autopsy tool. I determine the proportion of children whose caregivers recognised signs of illness, provided care inside the home, sought healthcare outside the home, and were referred from the first healthcare provider for further care. I also quantify the contribution of different types of delays to child deaths, namely home delays, transport delays and health facility delays. This is an important step in understanding the relative importance of different factors linked to children dying at home.

Chapter 7 uses qualitative methods including semi-structured in-depth interviews and focus group discussions to understand caregivers' behaviours during their child's final illness. I explore caregivers' experiences of seeking healthcare for their child, and how these experiences impacted decision-making around the child's death. This, in turn, likely contributed to whether a child died at home or in a health facility. Chapter 7 also highlights barriers that caregivers faced which limited access to healthcare and strategies employed to overcome these barriers.

In chapter 8 I discuss my findings, bringing together the quantitative and qualitative data to produce a comprehensive picture of place of death and care-seeking processes in fatal childhood illness, providing a better understanding of why children under-5 die at home in rural South Africa. I suggest a way forward highlighting the policy implications of my findings and additional research questions that emanate from my thesis.

Chapter 3: Place of death, care seeking and care pathway progression in the final illnesses of children under-5 in sub-Saharan Africa - a systematic review

This work has been accepted for publication:

Price J, Lee J, Willcox M, Harnden A. Place of death, care-seeking and care pathway progression in the final illnesses of children under five years of age in sub-Saharan Africa - a systematic review. J Glob Health. 2019. Accepted for publication

3.1 Introduction

As noted in Chapter 1, evidence from South Africa suggests that approximately half of under-5 deaths occur outside of healthcare facilities, which is problematic for multiple reasons: first, deaths in the community are more difficult to count and less likely to have an accurate cause of death recorded (1,2). Second, infective causes continue to account for a large proportion of under-5 deaths in South Africa (including acute respiratory infections, diarrhoeal disease and HIV/AIDS) (3). This is true too for out of hospital deaths where cause of death data is available (4) suggesting that deaths outside of health facilities represent, at least in part, avoidable mortality had in-patient care been available. Third, these deaths are missed by the Perinatal Problem Identification Programme (PPIP) and Child Health Problem Identification Programme (Child PIP), the facility-based audits described in chapter 1 that investigate perinatal and child deaths that occur in health facilities, to assess the quality of care received and identify modifiable factors that contributed to the death.

It is unclear whether the rates of out-of-facility deaths in South Africa are in keeping with other countries in sub-Saharan Africa. Some population-based studies from countries across the region have shown that high proportions of under-5 deaths occur outside health facilities (5–7).

Furthermore, some studies have used social autopsies not only to count deaths in communities, but also to investigate social circumstances of deaths and identify modifiable factors at different stages of the care pathway that might have contributed to death. A social autopsy is a structured interview with the caregiver of the deceased which attempts to make a "social diagnosis" of cause of death by identifying its cultural, social and health-systems antecedents (6,8,9). It is a population-based data collection strategy, and as such provides information on deaths in facilities *and* those at home.

Studies which focus on care pathways in fatal childhood illness often use the Pathways to Survival Framework as the basis for thinking through the processes of providing care within the home and seeking and receiving healthcare outside the home during a child's illness (10). Despite the growing number of studies using this framework, individual studies do not give a sense of whether patterns identified apply across sub-Saharan Africa, nor whether there are characteristics which influence care-seeking processes universally. This also makes it difficult to assess South Africa's performance compared to the rest of the region.

This review aimed to systematically gather and appraise all available evidence to 1) determine the proportion of under-5 deaths occurring within and outside health facilities in sub-Saharan Africa, 2) characterize the processes of seeking and providing healthcare during the fatal illness, as defined by the Pathways to Survival Framework and 3) to determine whether place of death or care-seeking behavior varied based on the age of the child, income status of the country or presence of user-fees.

3.2 Aims and objectives

Aim

To determine the proportion of under-5 deaths occurring within and outside health facilities in sub-Saharan Africa, and to characterize the processes of seeking and receiving healthcare during the fatal illness, as defined by the Pathways to Survival framework.

Objectives

1. To determine the proportions of under-5 deaths which occurred at home and in health facilities in sub-Saharan Africa.
2. To determine the proportion of children taken outside the home for care during the final illness in sub-Saharan Africa.
3. To determine the proportion of deceased children in sub-Saharan Africa that moved through each stage of the care pathway, as defined by the Pathways to Survival Framework.
4. To determine whether there are significant differences in the proportion of children dying at home or in health facilities based on age, national income status or presence of user-fees at health facilities.
5. To determine whether there are significant differences in the proportion of children that move through each stage of the care pathway, as defined by the Pathways to Survival Framework, based on age, national income status or presence of user-fees at health facilities.

3.3 Methods

3.3.1 Search strategy and selection criteria

I published the systematic review protocol prospectively. It is available from PROSPERO (PROSPERO 2018 CRD42018111484, http://www.crd.york.ac.uk/PROSPERO/display_record.php?ID=CRD42018111484).

I conducted a systematic search of the literature to identify studies relating to deaths of children under-5 from sub-Saharan Africa, that included information on place of death and/or care seeking behaviour during a child's final illness. I searched PubMed, Embase, Global Health and the Cochrane Library using the following search terms in various combinations: care pathway*, pathways to care, care seeking, healthcare seeking, treatment seeking, "pathway to survival", "three delay", social autopsy, verbal autopsy with terms to identify children under years (child, under-5 under 5, infant, neonat*, newborn) and countries in sub-Saharan Africa as defined by the World Bank (11). Mesh terms were included where appropriate. An initial search was conducted in September 2017, and updated on 15 August 2018. I also conducted a manual review of the reference lists of relevant articles to identify any additional resources that should be included and contacted leading authors in the field to identify relevant unpublished data.

I included studies if they were conducted in a country in sub-Saharan Africa, reporting on deaths in children under-5 years, and included data on at least one of the following:

1. The number or proportion of children who died at home.
2. The number or proportion of children who died in a health facility.
3. Treatment seeking behavior during the final illness, including one or more of the stages of care as identified by the Pathways to Survival Framework (i.e. recognition of illness,

provision of care in the home, care seeking outside the home from formal and informal providers, referral and acceptance of referral).

I excluded studies that focused only on stillbirths or did not separate stillbirths from neonatal or under-5 deaths, or if results were reported purely qualitatively. Review articles were not included as this systematic review focused on primary research, however they were used to confirm that relevant references were identified and included in the analysis. I did not exclude articles based on publication date or language.

Two reviewers (JL and I) independently screened all titles and abstracts for relevance, then independently selected full texts for inclusion in the final review. Discrepancies were resolved by consensus. Data from each included study were independently extracted by the same reviewers and cross checked using a standardized template to record details including country; age group (neonatal/1-59 months/under-5); total number of deaths; number of deaths at home, in health facilities, on route to facilities or elsewhere; and care-seeking data (broken down into the stages identified by the Pathways to Survival Framework). The data extraction template is provided as appendix 3.1. Where the published manuscript did not disaggregate the data in a way that could be aligned to the criteria we used in this review, I contacted the authors to ask for a more detailed breakdown of the original data.

3.3.2 Quality appraisal

I adapted the AXIS tool for cross sectional studies to assess study quality (12) (appendix 3.2). This was necessary as I included studies with different objectives to those of the review, as long as they reported data I could use. I adapted the scoring system retaining points relevant to data collection but removing points not relevant to the review objectives (and thus to assessing those

aspects of the study relevant to the inclusion of the data in the meta-analysis) e.g. I removed the question “were the author’s discussions and conclusions justified by the results?”.

Quality indicators were also re-worded from the negative to the affirmative such that the presence of each indicator (which demonstrated improved quality) was associated with a higher score. For studies that had different aims and objectives to ours, we evaluated each quality indicator in relation to the aims and objectives of this review rather than the aim of the original study. Two reviewers (JL and I) independently assessed each study, awarding 1 point where the criterion was met, and resulting in a final score calculation as a proportion between 0 (poor quality) and 1 (high quality). Conflicts were agreed with discussion.

3.3.3 Statistical Analysis

I pooled proportions using random effects meta-analysis, after the Freeman-Tukey Double Arcsine Transformation of variances, using Stata command *metaprop* (13). I used score (Wilson) estimation to calculate 95% confidence intervals. I used the I^2 statistic as the measure of statistical heterogeneity. I estimated proportions for place of death and each stage of the care pathway in pre-specified sub-groups according to age group (neonatal or infants and young children), national income status (low income, lower middle income and upper middle income), and the presence of user-fees in each country (yes/no). (See appendix 3.3 for definitions of each stage of the care pathway.) Where studies only reported results for under-5 deaths overall, and I was unable to get an appropriate age breakdown after contacting the authors of the original publication, I grouped this data with results for infants and young children.

I used random-effects meta-regression to explore heterogeneity for each stage of the care pathway. The proportion of children reported at each stage of the care pathways (i.e. each outcome) was log-transformed and then assessed in relation to age group (neonatal or infants and young children as a binary categorical variable), national income status (low income, lower middle income or upper middle income as an ordinal categorical variable) and user-fee policy (yes/no binary categorical variable), using the Stata command *metareg* (14).

3.4 Results

3.4.1 Search

The literature search found 5102 citations. After deduplication, 2794 citations remained for title and abstract screening. In addition, through review of reference lists I identified one further research report that was included giving a total 2795 abstracts. Two reviewers independently screened all titles and abstracts; 60 studies were included for full text review, and 34 were included in the final analysis. (figure 3.1).

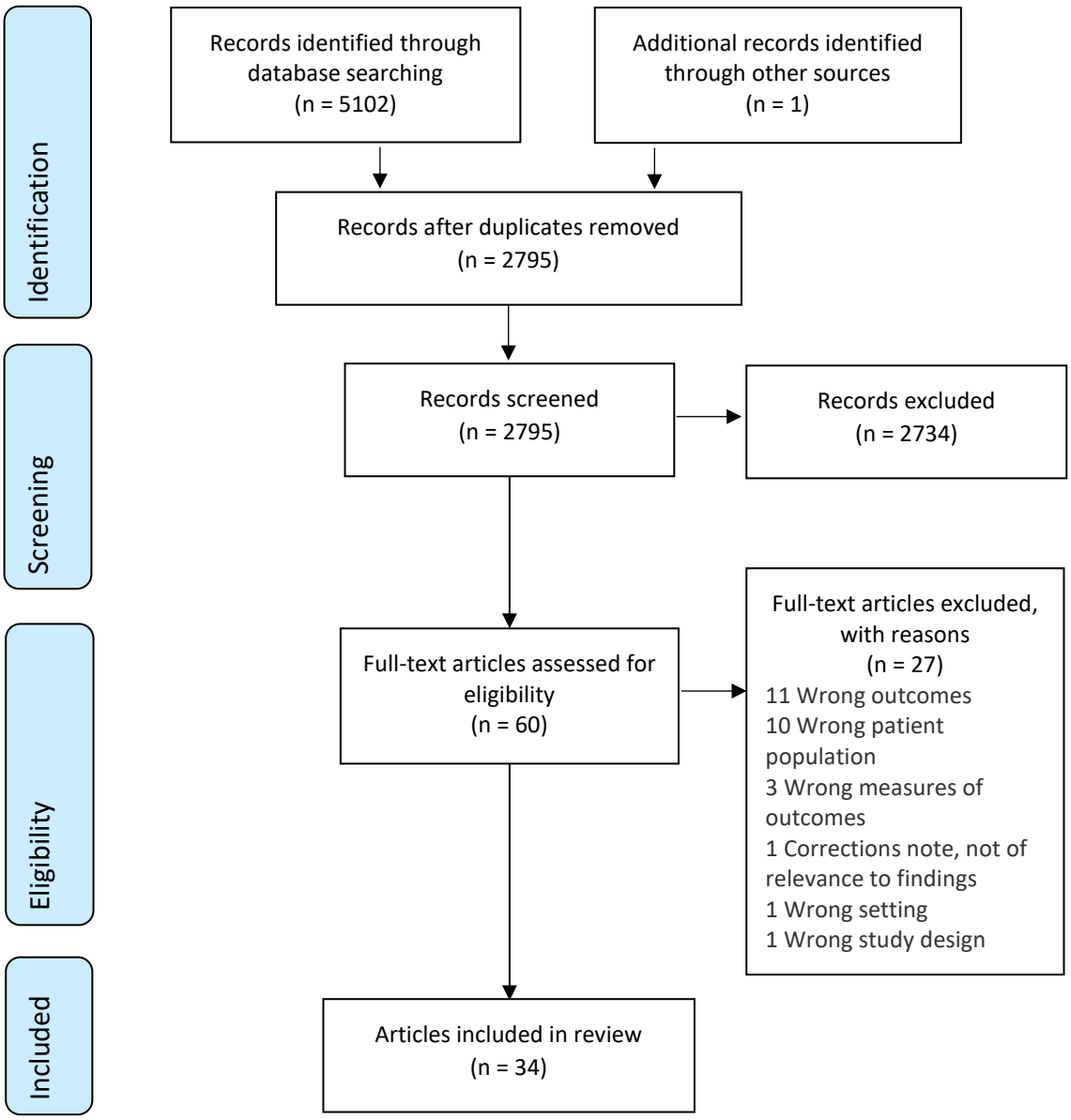


Figure 3.1: PRISMA Flow diagram. From Moher et al (54).

3.4.2 Included studies' characteristics

Characteristics of the included studies are summarised in table 3.1. Sixteen studies reported on neonatal deaths, 22 on deaths of infants and young children and seven on overall under-5 deaths. Data was drawn from 17 countries (figure 3.2); 13 low income countries, 3 lower middle income countries and 1 upper middle income country. Sixteen studies were conducted in settings where user-fees are charged at government facilities at the point of care, while 21 were from settings where governments had abolished user-fees. In one study in Ghana (15) the user-

fee policy was changed during the observation period, and in Nigeria (5) user-fee policy varies across states (16), and so both studies were excluded from the relevant sub-analysis.

3.4.3 Quality appraisal:

Study quality ranged from 0.21-1.00 (table 3.1, appendix 3.2). The most common problems identified in the included studies were failing to report on all stages of the care pathway, failing to report the response rate and failing to categorise non-responders where the response rate was less than 90%. Appropriate categorisation of non-responders included descriptions of age and other demographic details, and reasons for non-participation to allow an assessment of risk of bias.

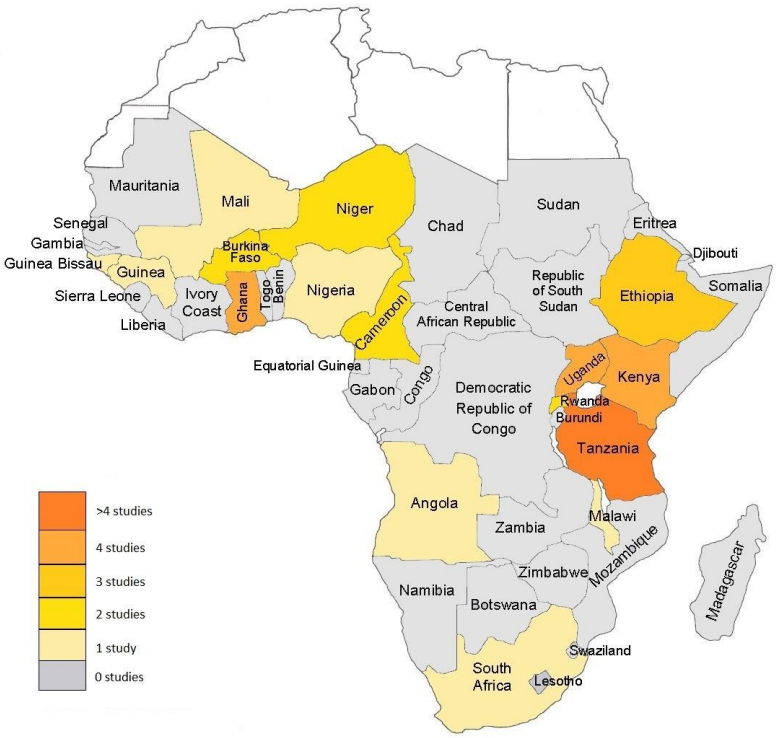


Figure 3.2: Map showing number and location of included studies.

Table 3.1: Characteristics of included studies

First author and year of publication	Period of data collection	Country	Age	National income status	User-fees (Yes/ No/ Mixed)	Setting (Rural/ Urban/ Mixed)	Total deaths	Methods used to identify deaths	Instrument used	Recall period	Data collected on the care-seeking process[₮]	Conceptual model used to drive analysis	Quality score
Snow 1994 (17)	1992-1993	Kenya	1-59 months	Low income	Y	Rural	137	Field staff visited all households every 6 weeks; population re-enumerated in December 1992 and May 1993.	Site-specific pro-forma	Unspecified	7	None	0.71
Sodemann 1997 (18)	1992-1993	Guinea-Bissau	1-30 months	Low income	Y	Urban	125	Routine surveillance system within DSS[ϕ]; full census in 1994	Unspecified	Median 7 months (IQR 6-9 months)	4a, 4b, 7	None	0.50
Garg 2001 (19)	1998	Kenya	0-59 months	Low income	Y	Rural	97	Review of community health workers' monthly household registers; health workers identified any children who had died in their village each month but were not recorded in the registers.	Unspecified	Median 29 days (range 7-152 days)	4b, 7	None	0.57
Armstrong Schellenberg 2002 (20)	1997-2000	Tanzania	1-59 months	Low income	N	Rural	427	Trained interviewers/ supervisors visited households in the DSS[ϕ] every 4 months	Unspecified	6 weeks-3 months	4a, 4b, 7	None	0.71
Schumacher 2002 (21)	1998-1999	Guinea	0-59 months	Low income	Y	Rural	133	Deaths were reported to study staff by local CVS members, health posts and centers, village and religious leaders, traditional birth attendants, other traditional healthcare providers, clan leaders and "elder" women	BASICS/JHU standardised VASA questionnaire	Unspecified	1, 2, 3, 4a, 4b, 7	Pathways to Survival	0.93
Hinderaker 2003 (22)	1995-1996	Tanzania	0-27 days	Low income	N	Rural	76	Prospective follow up of pregnancy outcome in a cohort of 3618 antenatal clinic attendees; Retrospective household survey in selected subvillages in the study area.	Medical interviews plus study-specific VA questionnaire	Unspecified	4a, 7	None	0.57
Muller 2003 (23) *	1999	Burkina Faso	11-32 months	Low income	Y	Rural	17	Daily visits by village-based field staff to households in the study over 6 months	Physician interview, non-standardised	6 months	3, 4a, 4b	None	0.64

First author and year of publication	Period of data collection	Country	Age	National income status	User-fees (Yes/ No/ Mixed)	Setting (Rural/ Urban/ Mixed)	Total deaths	Methods used to identify deaths	Instrument used	Recall period	Data collected on the care-seeking process[Ŧ]	Conceptual model used to drive analysis	Quality score
de Savigny 2004 (24) *	1999-2001	Tanzania	0-59 months	Low income	N	Rural	320	Village key informants conduct routine household surveys across the DSS[Φ] every 4 months	National Sentinel System VA tool	2 weeks	3, 4a	None	0.93
Beiersmann 2007 (25) *	1999-2002	Burkina Faso	0-59 months	Low income	Y	Rural	100	Study nested within a DSS[Φ], however DSS vital events identification process and frequency not specified.	Unspecified	1-3 months	4b	None	0.29
Kamugisa 2007 (26)	Unspecified	Tanzania	0-59 months	Low income	N	Rural	53	Population census in study villages to identify all deaths in preceding 2 years	WHO VA 1999	2 years	7	None	0.79
Edmond 2008 (27)	2003-2004	Ghana	0-28 days	Low income	Y	Rural	590	Women enrolled in parent study were visited at home by village-based field workers every 4 weeks	WHO VA 1999	6 months	4a, 4b, 7	None	0.71
Hildenwall 2008 (28) *	2006	Uganda	1-59 months	Low income	N	Rural	26	Routine household visits every 6 months across the DSS[Φ]; village scouts continuously relay information on deaths to DSS staff	INDEPTH Network VA merged with the social autopsy from the Bolivian Mortality Survey	4-6 weeks	4a, 4b, 7	Pathways to Survival	0.79
Kallander 2008 (29) *	2005-2007	Uganda	1-59 months	Low income	N	Rural	44	Routine household visits every 3 months across the DSS[Φ]; village scouts continuously relay information on deaths to DSS staff	INDEPTH Network VA merged with the social autopsy from the Bolivian Mortality Survey	4-6 weeks	2, 3, 4a, 4b, 5, 6, 7	None	0.86
Kaatano 2009 (30) *	2006	Tanzania	1-59 months	Low income	N	Rural	141	Population census in study villages to identify all deaths in preceding 10 years	WHO VA 2007	10 years	1, 3, 4a, 4b, 7	None	0.50
Waiswa 2010 (31)	2005-2008	Uganda	0-27 days	Low income	N	Rural	64	Routine household visits every 6 months across the DSS[Φ]; village scouts continuously relay information on deaths to DSS staff	VASA questionnaire blends INDEPTH Network VA merged with CHERG SA questionnaire	4-6 weeks	4a, 4b, 7	Three Delays Model	0.86

Kallander 2011 (6)	2008-2010	Ghana Uganda	1-59 months	Ghana: low income Uganda: low income	Ghana: N Uganda: N	Ghana: rural Uganda: rural	Ghana: 40 Uganda: 434	Ghana: Routine household visits across the DSS$^{\Phi}$ every 6 months; health facility death reports; continuous death reporting by community informants to DSS staff Uganda: Routine household visits every 6 months across the DSS$^{\Phi}$; village scouts continuously relay information on deaths to DSS staff	INDEPTH Network Social Autopsy for child deaths	6 months	1, 2, 3, 4a, 4b, 5, 6, 7	Pathways to Survival & Three Delays Model	0.71
Manortey 2011 (15)	2005-2010	Ghana	0-27 days, 1-59 months	Low income	Mixed	Rural	118	Door-to-door visits in study community to identify deaths; referrals from local community members and leaders	WHO VA 2007	5 years	7	None	0.86
Mrisho 2012 (32)	2007	Tanzania	0-27 days	Low income	N	Rural	219	Household survey of all households in the study area of the parent study identified deaths of children born in the preceding 5 years	INDEPTH Network VA	3 years	4a, 7	None	0.71
Olack 2014 (33) *	2007-2010	Kenya	0-59 months	Low income	Y	Urban	309	Home visits by trained community interviewers to all households in the study area every 2 weeks	Site specific - interview conducted with household proxy after death	Unspecified	4a	None	0.57
Rahman 2014 (34) *	2000-2012	Ghana Ethiopia Tanzania Uganda	1-59 months	Ghana: low income Ethiopia: low income Tanzania: low income Uganda: low income	Ghana: N Ethiopia: Y Tanzania: N Uganda: N	Ghana: rural Ethiopia: mixed Tanzania: rural Uganda: rural	Ghana: 145 Ethiopia: 61 Tanzania: 38 Uganda: 103	Ghana: home visits to women in parent trial by village-based field workers every 4 weeks Ethiopia: routine quarterly household visits across the DSS$^{\Phi}$ Tanzania: routine quarterly household visits across the DSS$^{\Phi}$ Uganda: routine biannual household visits across the DSS$^{\Phi}$	WHO verbal autopsy tool - versions varied by site	Unspecified	4a	None	0.21
Koffi 2015 (35)	2012	Cameroon	0-27 days	Lower middle income	Y	Mixed	164	Census of households in parent study in 2010	PHMRC/ CHERG VASA questionnaire$^{¥}$	4 years	1, 2, 3, 4a, 4b, 5, 6, 7	Pathways to Survival	0.86
Koffi 2015 (36)	2013	Malawi	0-27 days	Low income	N	Mixed	380	Household survey for parent study from 2011-2012	PHMRC/ CHERG VASA questionnaire$^{¥}$	4 years	1, 2, 3, 4a, 4b, 5, 6, 7	Pathways to Survival	0.79
Assefa 2016 (37)	2008-2013	Ethiopia	0-27 days	Low income	Y	Mixed	301	Routine home visits every 6 months by DSS$^{\Phi}$ fieldworkers	WHO VA 2007	1-3 months	7	None	0.79

First author and year of publication	Period of data collection	Country	Age	National income status	User-fees (Yes/ No/ Mixed)	Setting (Rural/ Urban/ Mixed)	Total deaths	Methods used to identify deaths	Instrument used	Recall period	Data collected on the care-seeking process[ŦŦ]	Conceptual model used to drive analysis	Quality score
D'Ambruoso 2016 (38)	2012-2013	South Africa	0-27 days, 1-59 months	Upper middle income	N	Rural	110	Routine annual household visits by DSS[Φ] field workers	WHO VA 2012	Unspecified	1, 4b	Thematic coding framework home-to-hospital pathway	0.79
Kalter 2016 (39)	2007-2010	Niger	0-27 days	Low income	N	Mixed	453	Home visits to all households included in the 2010 Niger National Mortality Survey identified neonatal deaths in past 4 years	PHMRC/ CHERG VASA questionnaire[¥]	4 years	1, 2, 3, 4a, 4b, 5, 6	Pathways to Survival	0.86
Koffi 2016 (40)	2012	Niger	1-59 months	Low income	N	Mixed	620	Home visits to all households included in the 2010 Niger National Mortality Survey identified under-5 deaths in past 4 years	PHMRC/ CHERG VASA questionnaire[¥]	Mean 2.7 years (range 2-5 years)	1, 2, 3, 4a, 4b, 5, 6, 7	Pathways to Survival	1.00
Obor 2016 (41)	2003-2012	Kenya	0-28 days	Low income	Y	Rural	533	Routine household visits across the DSS[Φ] every 4 months; continuous community reporting of vital events to DSS staff	Unspecified	Unspecified	4a, 4b	None	0.43
Rosario 2016 (42)	2009-2010	Angola	0-27 days, 1-59 months	Lower middle income	N	Mixed	340	Routine household visits across the DSS[Φ] every 4 months until 2011, and every 6 months in 2012.	INDEPTH/ WHO VA 1999	6 weeks	7	None	0.79
Bogale 2017 (43)	2016	Ethiopia	0-28 days	Low income	Y	Mixed	37	Routine household visits across the DSS[Φ] every 6 months.	INDEPTH Network VA and SA	18 months	4a	Three Delays Model	0.86
Koffi 2017 (5)	2009-2013	Nigeria	1-59 months	Lower middle income	Mixed	Mixed	2057	Households sampled from the 2013 Nigeria Demographic and Health Survey where an under-5 death was recorded.	PHMRC/ CHERG VASA questionnaire[¥]	5 years	1, 2, 3, 4a, 4b, 5, 6, 7	Pathways to Survival	1.00
Koffi 2017 (44)	2012	Cameroon	1-59 months	Lower middle income	Y	Mixed	635	Census of households in parent study in 2010	PHMRC/ CHERG VASA questionnaire[¥]	5 years	1, 2, 3, 4a, 4b, 5, 6, 7	Pathways to Survival	0.93

Navale 2017 (45)	2013-2014	Rwanda	0-11 months	Low income	Y	Rural	133	Triangulation of Ministry of Health reporting systems, community level data collection through the Monitoring of Vital Events Using Information Technology program, and CHW household registry books	VASA tool merging WHO VA 2012, Rwanda MOH's Death Audit Tool and the 2010 Rwanda Demographic and Health Survey	Unspecified	1, 2, 4a, 4b, 7	Unique to this study - created a driver framework for infant mortality from review of the literature.	0.57
Kagabo 2018 (46)	2013-2014	Rwanda	0-27 days, 1-59 months	Low income	Y	Rural	618	Triangulation of Ministry of Health reporting systems, community level data collection through the Monitoring of Vital Events Using Information Technology program, and CHW household registry books	VASA tool merging WHO VA 2012, Rwanda MOH's Death Audit Tool and the 2010 Rwanda Demographic and Health Survey	Unspecified	1, 4a, 4b, 7	Behavioural model of predictors of care-seeking: predisposing factors, enabling resources, need, care-seeking behaviour	0.93
Willcox 2018 (47)	2011-2015	Mali Uganda	0-27 days, 1-59 months	Mali: low income Uganda: low income	Mali: Y Uganda: N	Mali: rural Uganda: mixed	Mali: 762 Uganda: 313	Volunteer community informants notified study staff of all deaths; notification incentivised by a small payment. Validation of death reports by re-investigation of a random sample, cross-checking with other sources of information where available, and snowball sampling by asking families of children who died about other recent child deaths in the village.	Semi-structured qualitative interview plus modified QUARITE questionnaire	Unspecified	1, 2, 3, 4a, 4b, 5, 6, 7	None	0.64

* These studies report on mortality related to diarrhoeal disease, pneumonia, acute febrile illnesses, or malaria only. All other studies report all-cause mortality.

Ŧ Data collected on the care-seeking process 1) illness recognition; 2) recognition of severe illness; 3) home care; 4a) sought care outside the home; 4b) type of health care sought; 5) referral; 6) compliance referral advice; 7) place of death

ϕ DSS: Demographic Surveillance System

¥ PHMRC/CHERG VASA questionnaire: questionnaire blends the Population Health Metrics Research Consortium (PHMRC) VA questionnaire with the CHERG SA questionnaire

3.4.4 Synthesis of results

Proportions varied between studies, and statistical heterogeneity in pooled estimates as estimated by I^2 was high (table 3.2, appendices 3.4 and 3.5).

Place of death

As shown in table 3.2 and figure 3.3 place of death was similar across age groups. Approximately half of all children died at home (53.2% of neonates, 95% CI 40.0-66.2, I^2=97.5% and 53.1% of infants and young children, 95% CI 44.2-62.0, I^2=98.0%) and over a third died in health facilities (37.8% of neonates, 95% CI 26.4-49.8%, I^2=97.0% and 33.4% of infants and young children, 95% CI 25.5%-41.9%, I^2=97.6%). Small fractions of deaths happened on route to a healthcare facility or elsewhere.

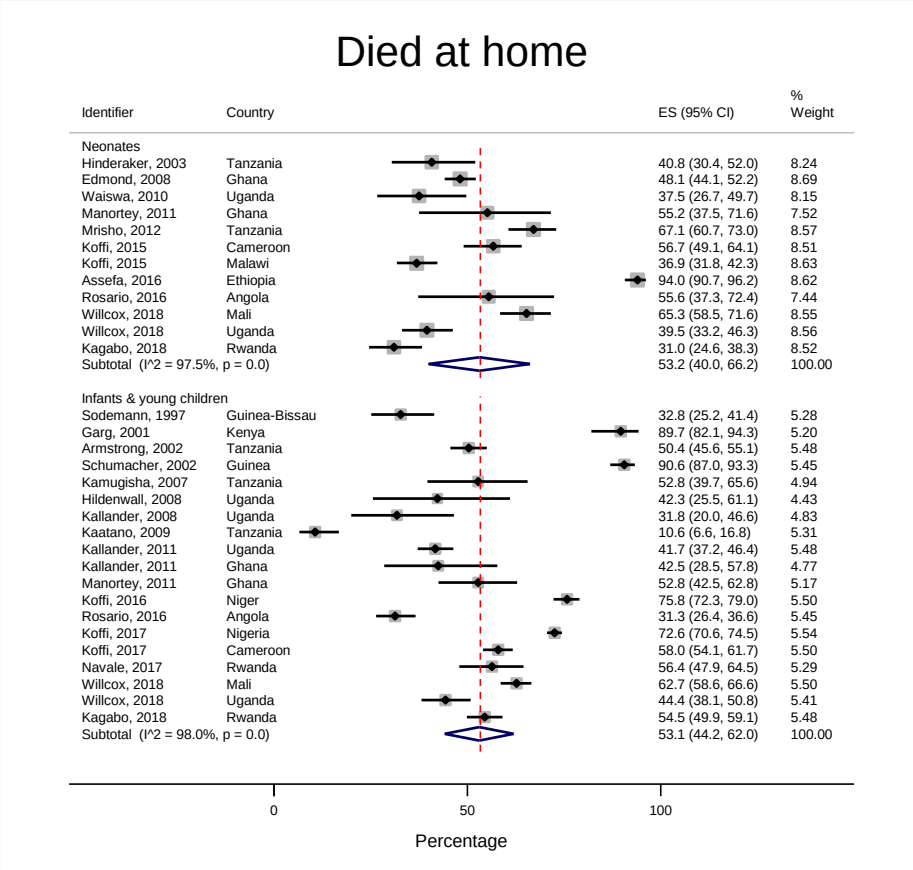


Figure 3.3: Proportion of children who died at home, by age group.

The place of death also did not vary significantly by national income status (appendix 3.4). Countries where user-fees were charged appeared to have a bimodal distribution of home deaths (appendix 3.5). Therefore, while a comparison of pooled proportions across settings with and without user-fees would suggest that user-fees are associated with a higher proportion of home deaths (appendix 3.5), this should be interpreted with caution.

Care pathways analysis - curative care seeking

Patterns of care-seeking were different for neonates and older children, as shown in table 3.2 and figures 3.4-3.7.

Home and travel to care

Over 95% of caregivers of all children recognized their child was unwell (figure 3.4) and over 80% reported potentially serious signs. However, 40.1% of neonates (95% CI 20.7-61.3, I^2=98.0%) died without care of any sort being provided, whereas very few infants and young children died with no care at all (6.4%, 95% CI 4.2-9.0%, I^2=90.6%, figure 3.5). Fourteen percent of neonates (95% CI 8.8-21.0% I^2=87.9%) received care in the home compared to over half of infants and young children (52.6%, 95% CI 37.8-67.1%, I^2=99.0%). Care-seeking outside the home was less common in neonatal deaths (50.5%, 95% CI 35.6-65.3, I^2=98.3%) compared to infants and young children (82.4%, 95% CI 79.4-85.2%, I^2=87.5%, figure 3.6). In both age groups, more children were taken for formal care (41.2% of neonates, 95% CI 29.3-53.5%, I^2=97.2% and 73.1% of infants and young children, 95%CI 66.5%-79.2% I^2=96.5%) than informal care (12.7% of neonates, 95% CI 6.5-20.3%, I^2=94.7%, and 23.5% of infants and young children, 95% CI 14.2-34.3%, I^2=98.6%). A small minority of children died before setting out or arriving at a healthcare facility (5.8% of neonates, 95% CI 3.5-8.6%, I^2=66.4% and 10.4% of infants and young children, 95%CI 6.1-15.7%, I^2=94.3%).

Table 3.2: Summary of pooled results, stratified by age group.

Outcome	Neonates					Infants and young children				
	Number of studies*	Number of deaths	Proportion	95% CI	I^2	Number of studies*	Number of deaths	Proportion	95% CI	I^2
Died at home	12	2373	53.2	40.0-66.2	97.5	17	6803	53.1	44.2-62.0	98.0
Died in a health facility	12	2373	37.8	26.4-49.8	97.0	14	6153	33.4	25.5-41.9	97.6
Died on route to a health facility	4	577	5.1	3.3-7.1	0.0	7	3997	5.6	3.2-8.6	89.0
Died elsewhere	8	1444	3.4	0.6-7.7	89.5	11	5314	6.2	3.0-10.4	96.3
Signs/Symptoms of illness	7	1294	95.0	84.9-99.9	97.2	11	5345	98.2	95.2-99.9	97.0
Signs/Symptoms of severe illness	5	1097	84.3	60.0-98.5	98.8	9	5003	88.1	78.4-95.3	98.7
Died immediately/no care given	6	1134	40.1	20.7-61.3	98.0	14	5692	6.4	4.2-9.0	90.6
Home care given	5	1097	14.4	8.8-21.0	87.9	12	5392	52.6	37.8-67.1	99.0
Sought/attempted to seek care outside the home	11	2695	50.5	35.6-65.3	98.3	22	7044	82.4	79.4-85.2	87.5
Sought/attempted to seek formal care	12	2539	41.2	29.3-53.5	97.2	19	6500	73.1	66.5-79.2	96.5
Sought/attempted to seek informal care	9	1948	12.7	6.5-20.3	94.7	12	5565	23.5	14.2-34.3	98.6
Died before setting out/on route to provider	5	1097	5.8	3.5-8.6	66.4	8	4223	10.4	6.1-15.7	94.3
Arrived alive at formal health facility (out of all deaths)	5	1097	36.5	25.2-48.5	93.8	9	4553	58.7	48.0-68.9	97.5
Arrived alive at formal health facility (of those who sought formal care)	5	455	85.8	76.5-93.1	84.0	9	2956	88.4	79.4-95.3	97.0
Left formal health facility alive (out of all deaths)	5	1097	21.4	14.4-29.4	89.0	6	4180	42.7	30.4-55.4	98.3
Left formal health facility alive (of those who arrived alive)	5	385	62.9	40.9-82.4	94.6	6	2266	69.6	59.6-78.7	95.5
Referred for further care (out of all deaths)	5	1097	8.7	2.4-18.4	95.4	9	4681	17.9	9.5-28.2	98.3
Referred for further care (of those who left the facility alive)	4	29	30.7	7.1-61.3	94.7	5	136	34.9	15.1-57.9	98.7
Accepted referral (of all deaths)	5	1097	5.7	0.9-13.9	95.3	8	4584	11.9	6.7-18.3	96.6
Accepted referral (of those referred)	5	101	65.9	49.3-81.0	50.3	8	560	69.3	57.7-79.9	85.6

**Note: In cases where data was collected from more than one country as part of the same study, each country was counted as a separate study for the purpose of the meta-analysis*

† Figures in red: significant at P<0.05; figures in orange: significant at P<0.1

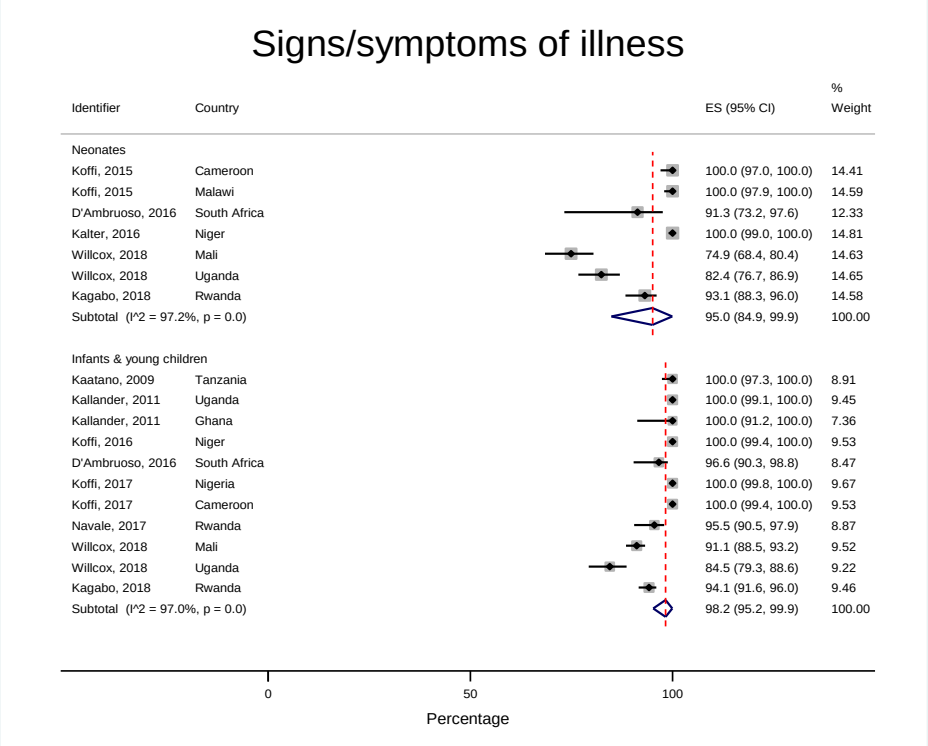


Figure 3.4: Proportion of children with signs/symptoms of illness, by age group.

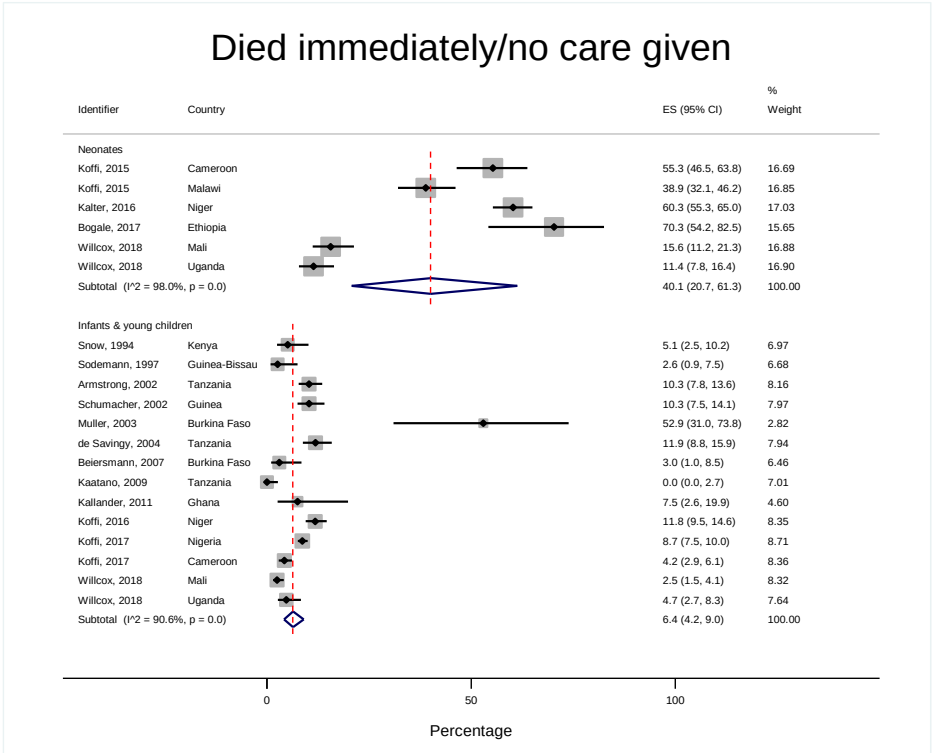


Figure 3.5: Proportion of children who died immediately or without receiving any care, by age group.

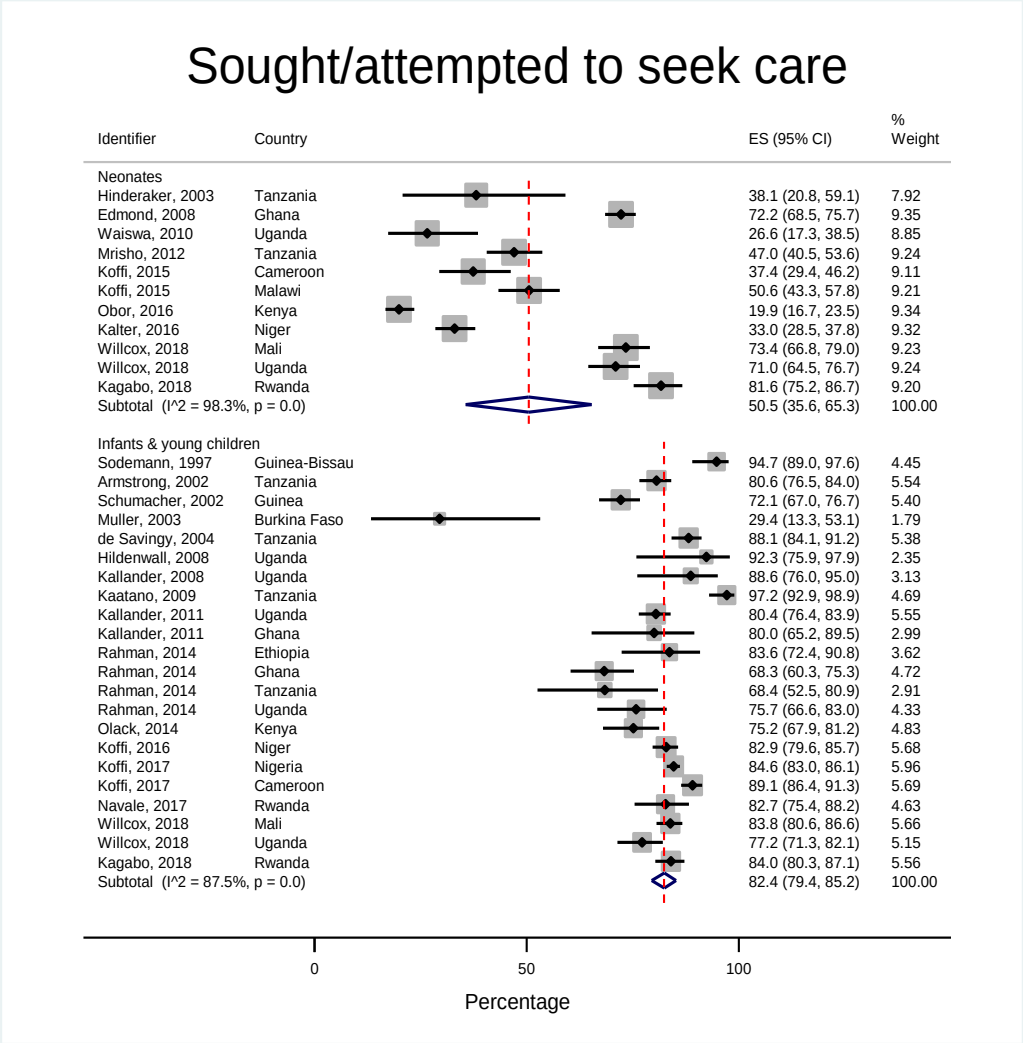


Figure 3.6: Proportion of caregivers who sought or attempted to seek healthcare outside the home for their child during the final illness, by age group.

At healthcare facilities

A minority of neonates in their final illnesses were alive when they arrived at a healthcare facility (36.5%, 95% CI 25.2-48.5%, I^2=93.8%) whereas the majority of infants and young children made it to a formal healthcare facility alive (58.7%, 48.0-68.9%, I^2=97.5%). However, in both age groups this represented a large majority of those who sought formal healthcare (85.8% of neonates, 95% CI 76.5-93.1%, I^2=84.0% and 88.4% of infants and young children, 95% CI 79.4-95.3, I^2=97.0%). Also, in both age groups most of those children who arrived alive left the healthcare facility alive (62.9% of neonates, 95% CI 40.9%-82.4%, I^2=94.6% and 69.6% of infants and young

children, 95%CI 59.6-78.7, I^2=95.5%, figure 3.7), though only a minority of those discharged were referred for further care (30.7% of neonates, 95%CI 7.1-61.3%, I^2=94.7% and 34.9% of infants and young children, 95% CI 15.1-57.9, I^2=98.7%). Most caregivers who were offered referral for their baby accepted it (65.9%, 95%CI 49.3-81.0%, I^2=50.3%). The same was true for caregivers of infants and young children (69.3%, 95%CI 57.7-79.9, I^2=85.6%).

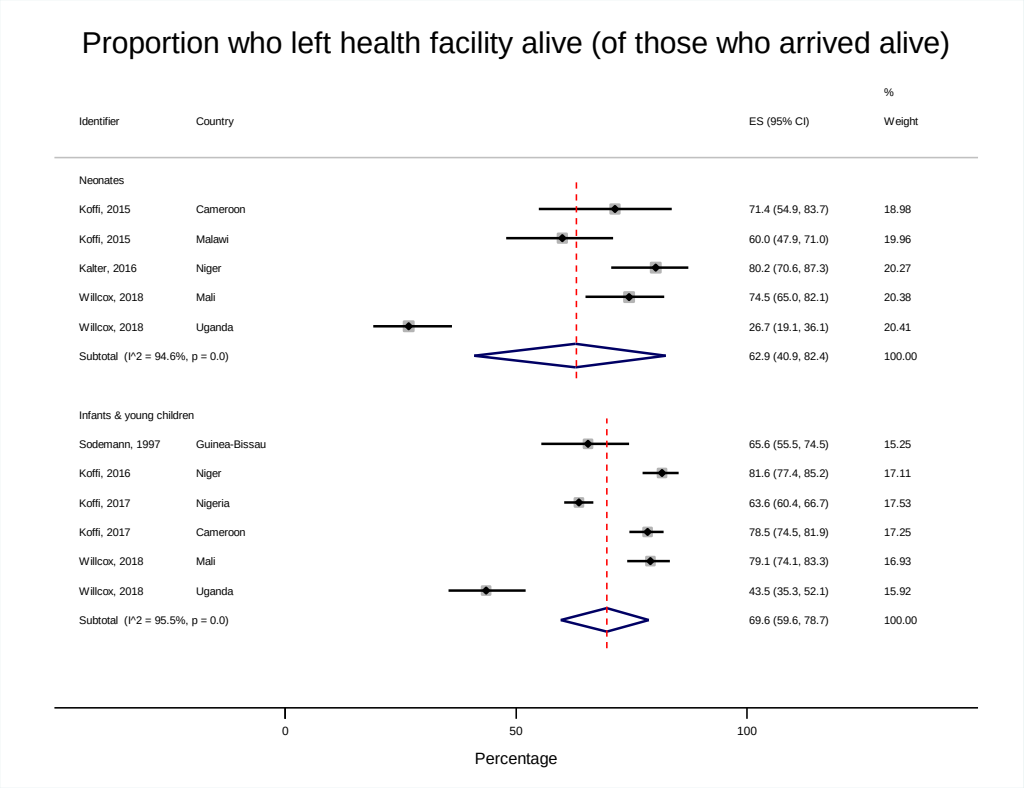


Figure 3.7: Proportion of children who left the first health facility alive of those who arrived alive, by age group.

3.4.5 Exploration of heterogeneity

Heterogeneity was high even within subgroups. This is common in meta-analyses of proportions. Meta-regression results are presented in table 3.3. Exponentiating the co-efficient for each moderator demonstrates the change in proportion of children that experienced each outcome, adjusting for the other two moderators included in each model. The effect size of

each moderator is small, even where statistically significant. This is to be expected when fitting a random effects model with large random effects, which tends to shrink the fixed effects.

Heterogeneity in place of death was partly explained by user-fee policy such that the proportion of under-5 deaths at home increased by 1.45% in settings with user fees compared to settings without user fees, adjusted for age and national income status (adjusted co-efficient for death at home 0.37, 95%CI 0.05-0.70, p=0.027, R^2=10.68%). In contrast variation in care-seeking patterns was partly accounted for by age (for example, the average difference in the proportion of neonates and infant and young children taken for care outside the home was 3.39%; adjusted co-efficient for whether care was sought outside the home 0.53, 95%CI 0.27-0.79, p<0.001) (see table 3.3 for each stage of the care pathway). Neither national income status nor user-fee policy was consistently associated with differences in care seeking patterns (appendices 3.4 and 3.5).

Table 3.3: Exploration of heterogeneity using meta-regression.

Outcome	Age group			Income status			User fees			Number of studies	Adjusted R^2 (%)
	Co-eff	95%CI	p value	Co-eff	95% CI	p value	Co-eff	95% CI	p value		
Died at home	-0.02	-0.33, 0.30	0.918	0.06	-0.51, 0.39	0.780	0.38	0.06, 0.70	0.020	29	11.00
Died in a health facility	-0.13	-0.64, 0.38	0.601	0.25	-0.45, 0.94	0.466	-0.57	-1.09, -0.05	0.033	24	11.33
Died on route	Incalculable										
Died elsewhere	Incalculable										
Illness recognition	0.05	-0.04, 0.14	0.272	0.04	-0.05, 0.13	0.372	-0.04	-0.13, 0.05	0.342	17	11.51
Signs of severe illness	0.13	-0.20, 0.45	0.399	0.34	-0.15, 0.83	0.149	-0.16	-0.52, 0.19	0.322	13	1.13
Died immediately/no care given	-1.52	-2.48, -0.55	0.005	0.00	-1.52, 1.52	0.998	-0.10	-1.08, 0.88	0.833	17	37.29
Home care	1.18	0.43, 1.92	0.005	-0.20	-1.40, 1.00	0.726	0.18	-0.63, 1.00	0.632	16	39.87
Sought/attempted to seek care	0.53	0.27, 0.79	<0.001	-0.04	-0.57, 0.48	0.862	0.01	-0.25, 0.28	0.928	31	36.90
Sought/attempted to seek formal care	0.59	0.28, 0.90	0.001	0.03	-0.26, 0.31	0.851	-0.08	-0.39, 0.23	0.604	29	33.29
Sought/attempted to seek informal care	0.50	-0.30, 1.30	0.201	0.09	-0.54, 0.71	0.770	0.73	-0.08, 1.54	0.073	20	10.22
Died before setting out/on route to 1st provider	Incalculable										
Arrived at facility alive	0.47	-0.07, 1.01	0.082	0.24	-0.55, 1.03	0.499	-0.24	-0.84, 0.37	0.391	12	12.60
Left facility alive	0.67	0.05, 1.29	0.039	-0.10	-1.03, 0.82	0.785	0.46	-0.31, 1.24	0.184	9	53.15
Referred for further care	0.96	-0.09, 2.00	0.068	-0.89	-2.56, 0.78	0.257	0.33	-0.91, 1.56	0.565	13	22.01
Accepted referral	1.39	-0.13, 2.91	0.068	-1.33	-3.91, 1.24	0.266	1.05	-0.99, 3.10	0.269	12	21.28

* Figures in red: significant at $P<0.05$; figures in orange: significant at $P<0.1$

3.5 Discussion

3.5.1 Summary of results

This review and meta-analysis demonstrated that approximately half of deaths of neonates and infants and young children occur at home in those countries across sub-Saharan Africa where data is available. In both age groups signs and symptoms of illness were reported in the large majority of children (over 95%). However, whereas care-seeking for dying neonates is poor, many older children die at home despite their caregivers engaging formal healthcare services before they die.

Forty percent of neonates received no care of any sort during their final illness. Only half of caregivers attempted to seek healthcare outside the home, and fewer still sought formal healthcare. Only a third of all neonates arrived at formal healthcare facilities alive, though most studies which reported on this stage of the care pathway excluded neonates who were born and died in a healthcare facility without being discharged. It is probable that this would be a much higher proportion if one were to include those who were alive *in utero* when the mother presented for delivery at the health facility. Health facilities discharged almost two thirds of the ill neonates, with less than a third referred on for further care.

These findings suggest that modifiable factors contributing to neonatal deaths include a failure of caregivers to recognise early signs of illness, or to appreciate the severity of neonatal illness (even if they report signs and symptoms of disease), which contribute to delays in seeking healthcare. Barriers to care-seeking resulting in even minor delays can be fatal as neonatal illness tends to progress rapidly which reduces the likelihood of reaching a facility alive compared to older children.

However, high rates of discharge and low referral rates might suggest that when caregivers sought and received healthcare it was inadequate.

In contrast, only a small minority of children older than one month died without receiving care of any sort. Some caregivers sought informal care, but almost three quarters of the children were taken to a formal healthcare provider and a majority arrived at that provider alive. Healthcare facilities discharged over two thirds of these children, and of those only a third were referred for further care. This would suggest that for older children, modifiable factors might be more concentrated at the health facility level.

Statistical heterogeneity was high, even across sub-groups. This is common in studies that pool proportions and continuous measures. Proportions are less stable between settings than ratio effect measures. Thresholds of I^2 used for pooling trials are not appropriate for meta-analysis of continuous variables (48). Furthermore, four factors may have contributed to the statistical heterogeneity across sub-groups: first, heterogeneity at certain stages of the care pathway may have arisen due to narrow confidence intervals for individual studies (48) e.g. illness recognition by caregivers of infants and young children was high despite the total range of findings across all studies for deaths of infants and young children being 79.3%-100%. Similarly, the range reported for neonates being given home care was 5.1%-27.8%. The differences in these proportions are clinically small and would not change the practical interpretation of the results.

Second, outlier studies contributed to heterogeneity at some stages of the care pathway e.g. the full range of the proportion of infants and young children who died immediately or did not receive any care across 13 studies was 0.9-19.9%, but there was one "outlier" study from Burkina Faso with a 95% confidence interval of 31.0% and 73.8% (figure 3.5). Similarly, regarding the proportion of infants and young children whose parents sought or attempted to seek healthcare, most studies ranged from 52.5%-98.9%, however the same study from Burkina Faso reported much lower rates of attempted care-seeking in the same age group (95% CI 13.3%-53.1%). This was the smallest of all the studies I included (investigating only 17 deaths) and was also one of the earliest (conducted in 1999) in a very remote part of Burkina Faso, which probably explains the low levels of care-seeking and the very wide confidence interval.

Third, differences in study design and methods of identifying deaths may have resulted in heterogeneity across studies. Most studies used household surveys and home visits to identify deaths in all households in the health and demographic surveillance system (HDSS) sites, or in the parent studies, and so were more likely to identify both home deaths and health facility deaths. In contrast in Kenya deaths were identified through review of community health worker monthly household registers and health workers' reviews to identify deaths not already on registers. The lack of additional validation of community health worker records may mean that deaths were missed – particularly those at home. Furthermore, even amongst studies set in HDSS sites, some authors noted undercounting of deaths (as reported by Kallander et al in Ghana (6)). In Tanzania, a population census attempted to identify all deaths dating back 10 years: the long recall period may have increased the risk of inaccurate information relating to the care-seeking pathway and specific place of death (30). Finally, the use of community health workers and ministry of health registers to identify deaths rather than village informants or lay field workers as was the case in Rwanda (46),

may contribute to a social desirability bias prompting more households to report care seeking during a child's final illness (even in the case of neonates) – though this was not noted as a concern by the authors.

Fourth, while I tried to account for certain "macro" differences, such as national income and user-fee policy, these were nonetheless crude markers of known social determinants of health. I was unable to adjust for rural or urban setting as there was limited data from urban settings to use as a comparator (only 2 studies), and data on other known predictors of care-seeking behaviour - such as distance to clinics and levels of education - was simply unavailable consistently across the included studies.

The question of context might explain the seemingly bimodal pattern of home deaths in settings with user-fees (appendix 3.5): almost all deaths in the studies from Ethiopia (37), Kenya (19) and Guinea (21) appeared to happen at home. In Ethiopia, the authors suggested that the high proportions of home deaths might reflect high levels of unattended home births in this community, and limited access to health facilities due to terrain and location of villages far from main roads (37). In Kenya, home deaths occurred despite a majority having sought healthcare outside the home. Important contextual factors here were low follow-up and referral rates from formal health providers, underuse of community health workers and a preference for traditional healers (19). In Guinea, home deaths were attributed to a combination of a lack of trained traditional birth attendants for home births, poor recognition of danger signs and poor care-seeking outside the home (21). Both the studies in Kenya and Guinea were conducted in the late 1990's in rural areas, prior to the expansion of primary care initiatives such as the Integrated Management of Childhood

Illness (IMCI); it is possible that care-seeking behaviour and place of death has changed in more recent years.

3.5.2 Comparison with previous studies

Findings from this review are consistent with previous studies that highlighted failures to recognise signs of illness, particularly in neonates (49–51). As this review included only children who died, care-seeking would have been appropriate for most if not all of them. Failure to provide or seek healthcare for a child despite the presence of symptoms and signs of illness has been linked to low health literacy in the communities where these studies were conducted (35). As noted by Koffi et al (2016), a lack of care-seeking could suggest that caregivers do not appreciate the significance of clinical features as markers of severe illness requiring urgent medical care (7). Different conceptions of the aetiology of disease, and cultural beliefs regarding appropriate treatment providers also contribute to delays in care-seeking (44,52,53). Low levels of maternal education may contribute to the overall mortality risk of children, and also to the specific care-seeking patterns demonstrated (5,7,46).

I also found relatively high rates of care-seeking during a child's final illness – particularly for infants and young children. Multiple studies have commented on similar findings, emphasising that attention needs to be directed to modifiable factors at the healthcare facility level (6,18,24). The low referral rates I found across both age groups have also been noted before, though without adequate explanation (5,7). Some studies have suggested that barriers to referral include lack of transport, cost and distance to the referral facility (7), however my findings suggest these may not be insurmountable obstacles for caregivers as demonstrated by the high rates of referral acceptance

when referral is made. My findings are consistent with other studies which have suggested that staff who are the first point of contact, including community health workers and primary healthcare facility staff, might benefit from further training on the recognition of danger signs, and on familiarisation with indications for referral and the establishment of clear referral guidelines and pathways (5,19).

Because I have brought together all the available evidence, I was able to analyse factors across settings. No differences were noted in place of death or care-seeking behaviour between countries of different income status. User-fees were associated with a higher proportion of home deaths (69% in settings with user-fees as opposed to 44% in settings without user-fees), however this association is difficult to interpret given the bimodal distribution pattern for home deaths in countries with user-fees (as shown in appendix 3.5).

Furthermore, no statistically significant differences were seen across the care pathway based on user-fees, suggesting that despite charges caregivers sought healthcare - although there was a trend towards higher rates of seeking formal healthcare in settings without user-fees (65%, compared to 53% in countries with user-fees), and higher rates of informal care in settings with user-fees (25%) compared to those without user-fees (11%). Many studies highlight cost as a barrier to care-seeking (7,35). It is possible that user-fees also affect the decision to accept hospital admission, or caregivers' abilities to follow home recommendations including the purchase of medications – neither of which I captured in this review, but which would warrant further investigation to understand how different health system financing models affect specific care-seeking decisions in childhood illness.

3.5.3 Comparison with South Africa

This review suggests that the rates of out-of-facility deaths found in South Africa are consistent with other countries in sub-Saharan Africa, though higher than the average in other countries where user-fees have been removed (43% in countries without user-fees as opposed to ~50% in South Africa). Furthermore, this review makes it clear that while place of death might be similar across age groups, care seeking behaviour differs, suggesting that the modifiable factors contributing to death at home differs in the different age groups. No work has yet attempted to track the care-seeking processes of children who died at home in South Africa. It would therefore be valuable to conduct a formal social autopsy study to better articulate care pathways in child deaths, across different age groups and places of death - in or outside health facilities - in South Africa.

3.5.6 Strengths and limitations

This study had three important strengths and corresponding limitations. First, I sought to pool studies from different settings in sub-Saharan Africa. This has contributed to the findings of high heterogeneity. Whilst this means it is unlikely that there would be a single numerical answer for every setting, it also allows me to draw conclusions with a broad evidence base.

Second, the studies included only children who had died. This meant that there was no comparison made with live children, and so I cannot determine whether there are differences at specific stages of the care pathway that might increase mortality risk. The strength of including only children who died is that it allows me to say that most if not all of the included children should have had medical

care sought and provided. It is likely that the children were seriously unwell so this should have been recognised, though it is possible that a small minority of children died from sudden infant death syndrome and so would have appeared well prior to death.

Finally, by pooling evidence across multiple study designs I was able to present data across each of the stages of the care pathways as defined by the Pathways to Survival Framework. However, I was unable to disaggregate the data based on place of death, and so drawing direct conclusions about why high proportions of children die at home across sub-Saharan Africa remains difficult. In some studies, I was also unable to identify whether they included or excluded neonates who had arrived alive at a health facility *in utero*, and were delivered, but died prior to discharge.

3.6 Conclusion

This review is the first to present a common picture for care-seeking behaviour in fatal childhood illness across sub-Saharan Africa, across each of the stages of the Pathways to Survival Framework. Despite high heterogeneity, findings nevertheless suggest a majority of under-5 deaths occur outside of health facilities, and that 95% of caregivers identify signs or symptoms of illness in their child. But there are differences in care-seeking behaviour between neonatal deaths and deaths of infants and young children. Half of caregivers attempted to seek healthcare outside the home for neonates who fell ill, whereas almost three quarters of infants and young children were taken outside the home for healthcare, most arriving alive at a formal healthcare provider. For both neonates and infants and young children, a minority of children discharged from the health facility were referred for further care. This suggests that a lack of treatment-seeking is not the only problem

contributing to under-5 deaths in the region, and that improvements are needed in quality of care, safety-netting and referral rates.

Despite South Africa's relative wealth and progressive health policies, the proportion of children who die at home is in keeping with findings from the rest of sub-Saharan Africa. However, limited data is available to compare care-seeking patterns with those found elsewhere in the region. Further work is required to understand the sociodemographic factors that are associated with place of death, and to analyse the processes of seeking and providing healthcare during a child's final illness in South Africa. The remaining chapters of my thesis will focus on work in two health and demographic surveillance sites in rural South Africa to better understand why high proportions of under-5 death continue to occur at home, which modifiable factors contribute to these deaths and what policies might help to reduce under-5 mortality at home.

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Chapter 4: Description of the study areas

The remaining chapters of this thesis present findings from work conducted at two health and demographic surveillance system (HDSS) sites in rural South Africa, the Agincourt HDSS and the Africa Health Research Institute (AHRI) HDSS. Health and demographic surveillance systems monitor how populations change over time in a clearly defined geographical area (1). This requires tracking all vital events (births and deaths) as well as in- and out-migrations (see figure 4.1) after an initial baseline census in a defined geographic population.

Both the Agincourt and AHRI HDSS sites are members of the International Network for the Demographic Evaluation of Populations and Their Health (INDEPTH) (www.indepth-network.org), and serve as two nodes in the South African Population Research Infrastructure Network (SAPRIN), a national research infrastructure aimed at strengthening the platform for population research on the health, social and economic challenges facing the country (http://saprin.mrc.ac.za/). Both sites are considered broadly representative of rural South African settings, and cover populations in the lowest socioeconomic brackets nationally (2,3). This chapter provides context to the results presented in chapters 5, 6 and 7 by describing the history, geography, population and methods of surveillance at each study site.

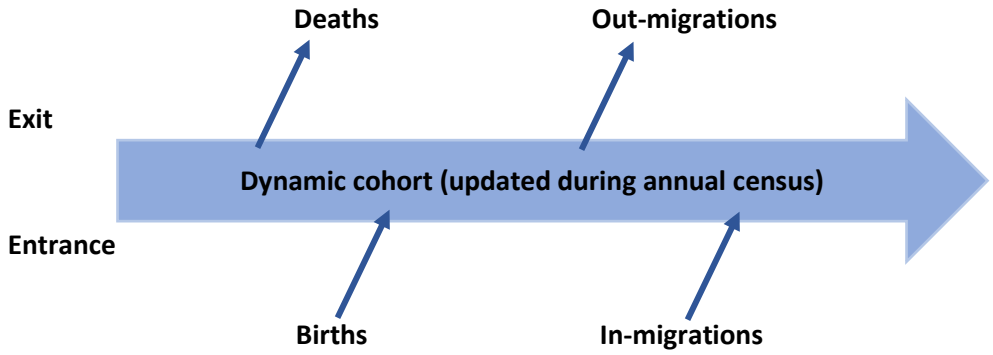


Figure 4.1: HDSS monitoring of changing populations in a geographically defined area, adapted from https://www.agincourt.co.za/?page_id=263

4.1 The Agincourt HDSS

4.1.1 History

The Agincourt HDSS was established in 1992 in northeast South Africa, near the Mozambique border. It was initially established to support district health systems development in post-Apartheid South Africa, and now supports a broad range of research on health, population and social transitions in South Africa, under the umbrella of the SAMRC/Wits University Rural Public Health and Health Transitions Research Unit. The HDSS site provides a research infrastructure for observational work, with established longitudinal cohorts at multiple stages of the life course; policy evaluation at individual, household and community levels; and randomised controlled trials. By nesting studies within the existing research infrastructure, researchers can draw on data already collected as part of routine population surveillance including household characteristics such as assets, food security, education of the household head, gender of the household head, fertility, mortality and migrancy rates as well as cause of death data which is determined using a verbal autopsy (4).

The Agincourt HDSS area initially included 56 700 people in 8900 households in 20 villages (5). This grew to reach 70 000 people in 11 700 households by 2006 (6). The study area was expanded to 26 villages in 2007 to include the catchment area of a new privately supported health centre, built in an HDSS village, that delivered antiretroviral treatment before it was readily available in the public sector (4). Between 2010-2012, the site was expanded again to enlarge cohorts for a number of trials and evaluation studies (3). As of June 2018, the study site covered 31 research villages, 116 549 people in 22 721 households with a median household size of five members (7).

4.1.2 Geography and community context

The Agincourt HDSS area is located in Mpumalanga province, in the northeast of South Africa, close to the Kruger National Park and the border with Mozambique (figures 4.2 and 4.3). The site covers 450km^2 (figure 4.3). Most homes are electrified, though the cost of electricity means that people use it selectively and still tend to cook on open fires or paraffin stoves. Few households have piped water to their home – most people rely on communal taps in the villages to collect clean drinking water, however these taps often run dry. Sanitation remains rudimentary with almost three quarters of households still using traditional pit latrines in outhouses.

Every village has a primary school, and most have a high school, though the quality of education is generally poor (3,4). Access to healthcare is via seven primary healthcare clinics (open from 7am to 4pm Monday-Sunday, staffed by nurses), two community health centres (open 24 hours Monday-Sunday, staffed by nurses) and three district hospitals 25-60km away (open 24 hours Monday-Sunday, staffed by doctors and nurses). There are also approximately 300 traditional healers registered in the wider Bushbuckridge area (8).

The population is black African, most of whom speak Xitsonga as their first language. Almost a third of the population is of Mozambican descent, with the first generation of Mozambican refugees having crossed the border in the 1980s to escape the Mozambican civil war (9). There is little employment in the area, so people need to migrate for work. Between 50-70% of adult males, and 25-35% of adult females are temporary labour migrants. Male labour migration rates have remained fairly stable post-Apartheid, however female migration has increased 1.5 fold between 2000-2011 (10). Although female migration rates remain lower than male migration, the increase in female migrancy is predominantly in the reproductive age group and so raises issues around child care.

Income to rural households are remittances from labour migrants. Other major sources of income are social grants including old age pensions and child support grants. As described in chapter 1, these non-contributory social support grants are part of a government poverty-alleviation programme and are fairly unique to South Africa. Both have been shown to improve child outcomes including greater food security, reduced stunting and higher rates of school enrolment and attendance (11–14). Eighty percent of households receive at least one child support grant (15).

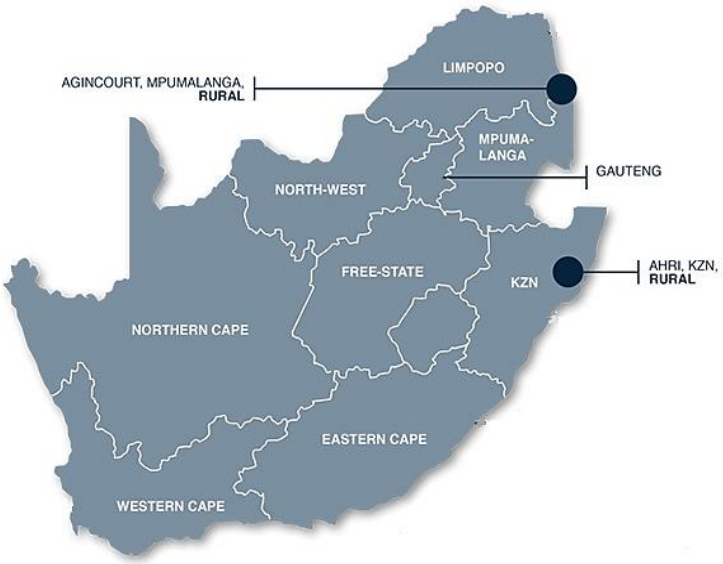


Figure 4.2: Map of South Africa, including HDSS site locations, adapted from http://saprin.mrc.ac.za/nodes.html

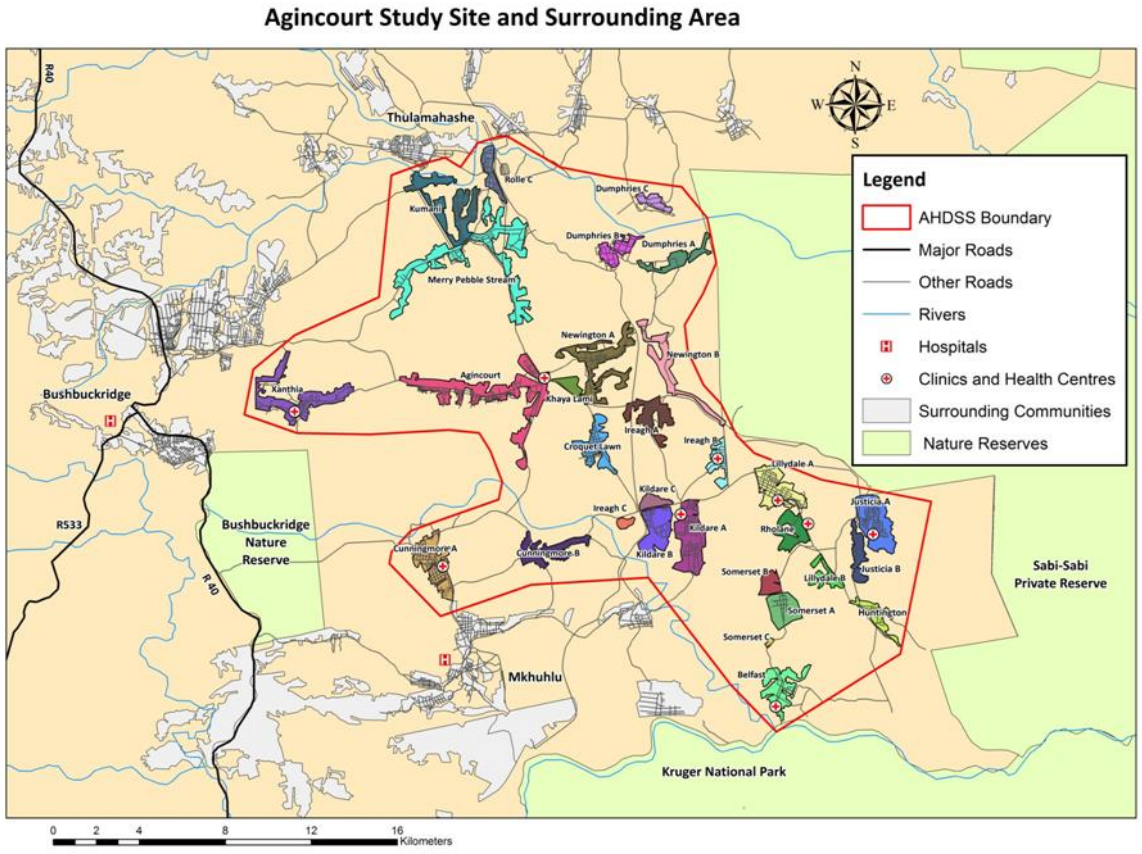


Figure 4.3: Agincourt HDSS Field Site and surrounding area 2014, From: https://www.agincourt.co.za/?page_id=1896

4.1.3 Data collection

Data is collected for individuals and updated annually. Each individual is also linked to a household, with household membership adjusted as individuals move – either joining another household or establishing their own new household. Household membership is self-defined, using the broad definition of "people who eat from the same pot of food" and includes individuals who spend less than 6 months of the year residing at their rural home, but who retain close ties to the household (identified as temporary migrants) (4). Vital statistics and demographic characteristics are still captured for migrant household members.

Annual censuses are conducted to update data on vital events (pregnancies, births, marriages, deaths), residency and migration. The pregnancy outcome is recorded for all pregnancies, and full childbirth histories are collected for all women. The annual update will also include household information on asset ownership used to determined socio-economic status, level of education of each household member, employment status of household members and reception of social grants (old age pensions, child support grants, disability grants). Additional modules have been included in specific years e.g. a healthcare utilisation module was included in 2003, 2006 and 2010, and a food security module has been completed every 3 years from 2004 onwards (4,7).

Where a death is identified, a dedicated verbal autopsy team made up of trained lay fieldworkers who have completed high school, conduct a follow-up visit to the household to complete a verbal autopsy interview with the closest caregiver of the deceased. Verbal autopsy has been validated in this setting to determine probable cause of death (16). Importantly verbal autopsies are conducted for all deaths, regardless of the age or migrancy status of the deceased, whether the death occurred

within or outside the study site, and whether it was in a health facility or elsewhere. Further details on verbal autopsy methods are provided in chapter 5.

4.2 Africa Health Research Institute (AHRI)

4.2.1 History

The Africa Health Research Institute (AHRI) was formed in 2000 in northern KwaZulu-Natal, close to the market town of Mtubatuba. Originally called the Africa Centre for Population Health, it was established in response to the HIV epidemic, to monitor the social, demographic and health changes in a high-prevalence HIV population and to evaluate interventions. As in Agincourt, vital statistics including births, deaths, in and out migrations are tracked, establishing the population profile and providing an infrastructure onto which more specific research questions can be added.

However, unique to AHRI is a nested population-based HIV cohort: this cohort is identified through HIV testing offered as part of the routine individual health surveillance (first offered in 2003 to women 15-49 years of age and men 15-54 years resident in the study site, and from 2006 extended to all residents 15 years and older). There is also a non-resident HIV cohort, with 12.5% of the migrant population sampled in each data collection round (2).

The Africa Centre HDSS initially covered 428km^2, with 85 000 people in 11 000 households. In 2016, the Africa Centre merged with KwaZulu-Natal Research Institute for TB-HIV (K-RITH) in Durban to form AHRI. In this way AHRI was envisioned as a multidisciplinary research unit bringing together basic sciences, experimental medicine and population-based epidemiological research. The AHRI HDSS also increased in size by incorporating the area used in a population-based HIV treatment as

prevention trial (ANRS 12249 TasP trial) in 2017 to cover 845km^2 and a population of 130 000 people in 18 600 households, with a median household size of seven people.

4.2.2 Geography and community context

The AHRI HDSS is located in the Umkanyakude district of KwaZulu-Natal (figure 4.2 and figure 4.4). It is a predominantly rural area but also contains informal peri-urban settlements and an urban township which are much more densely populated than surrounding rural settlements. The population is almost uniformly Zulu-speaking and as in Agincourt, is highly mobile. Most households rely on government grants (old age pensions and child support grants) and paid employment to cover their basic needs – few people earn a living from agriculture despite it being predominantly rural. Most households have access to electricity for lighting, though many still cook with paraffin or wood. Only 77% of the population have access to toilet facilities (mostly ventilated improved pit latrines) and piped water (some at home but most from communal taps) (2). There are 85 primary schools and 32 secondary schools in the area.

Access to healthcare is via 11 clinics including one health centre open 24 hours. The nearest district hospital is 45 km away, on the other side of a nature reserve which is poorly lit and where wild animals roam free making it unsafe to walk through, and dangerous to drive through at night (2). There are also approximately 300 traditional healers operating in and around the study site.

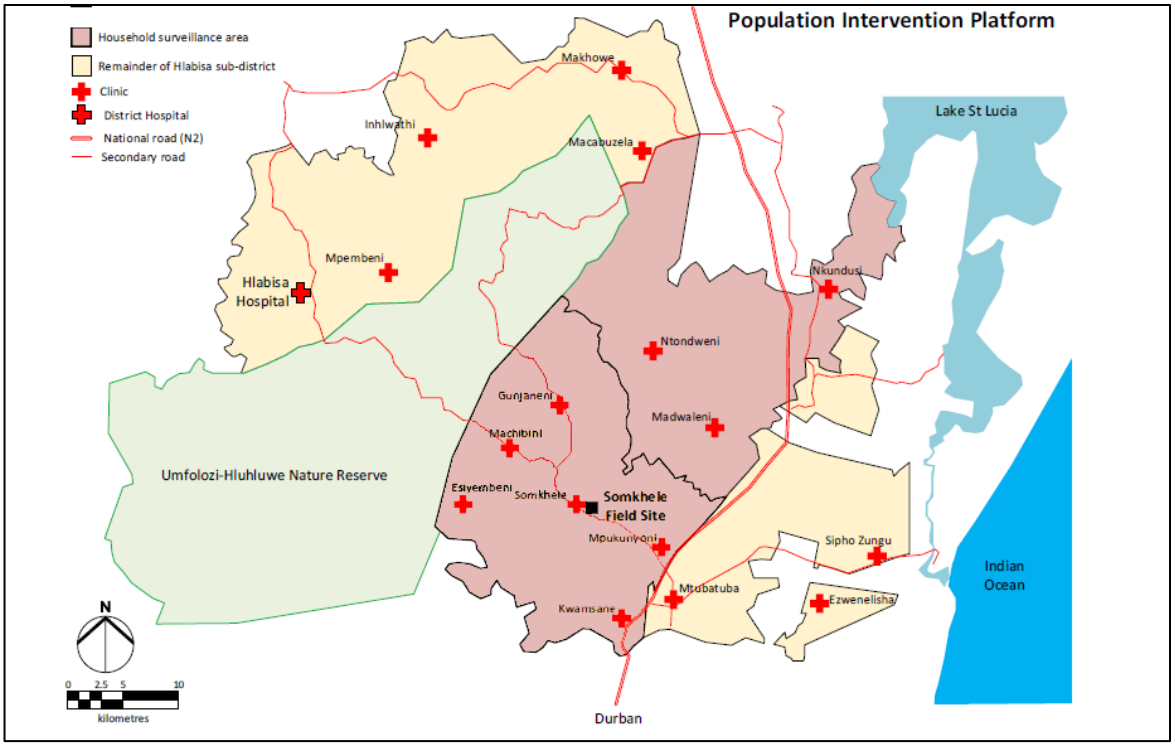


Figure 4.4: Map of the AHRI HDSS site, adapted from Study Protocol: A longitudinal population-based programme for epidemiology and intervention research (13)

4.2.3 Data collection

The AHRI population is broken down into homesteads (the physical bounded structure where one or more households live), households and individuals. As in Agincourt, household membership is self-defined, but AHRI differs in that individuals may be members of multiple households at once (such as in the case of polygamous marriages). Therefore, one differentiates between resident household members (who intend to sleep in the same bounded structure as other household members for most days of the week) and non-resident household members (who spend most of the time elsewhere – be that at another household within the study site, or further afield as in the case of temporary labour migrants) (17).

Data collection in AHRI is structured into three components: the household component, the individual component and verbal autopsies. Household data is collected four-monthly: once a year during a face-to-face household census interview and twice a year via telephonic interviews. This serves to update the household registers including all pregnancies, births and deaths, migrancy status, household assets and expenditure, energy, water source, sanitation and the number and state of each home/building on the bounded structure (17). Over 99% of households participate in the household component (2).

The individual component is completed once a year, in face-to-face interviews. Data is only collected for individuals 15 years and older, and includes individual demographics (such as partnership, education and employment status), health (particularly use of healthcare services, symptoms of TB and HIV care), sexual relationships, weight and height measurements, blood pressure, and a finger prick blood test for HIV (17).

Verbal Autopsies are conducted on a rolling basis over the full year, at least one month after the death of a household member occurs. As in Agincourt, a verbal autopsy is completed for deaths of all resident and non-resident household members, regardless of where the death occurred. In AHRI, trained nurses are employed to complete the verbal autopsies (17).

Table 4.1: Comparison of study sites

Site characteristics	Agincourt	AHRI
Province	Mpumalanga	KwaZulu-Natal
Year of baseline census	1992	2000
HDSS site size as of 2017	450km^2	845km^2
Total population as of 2017	116 549	130 000
Number of households	22 721	18 600
Median household size	5	7
Percentage of population under five years in 2017	8.4%	9.4%
HDSS setting	Rural	Mostly rural, 1 urban township
Language	Xitsonga	isiZulu
Frequency of household survey	Annually (1 per year)	Every 4 months (3 per year)
Method of death enquiry	Verbal autopsy using standardised WHO VA tools	Verbal autopsy using standardised WHO VA tools
Verbal autopsy interviewer	Trained lay fieldworkers who have completed high school	Nurses

4.3 Relevant findings on under-5 mortality

Work at both study sites has been critical in advancing our understanding of child mortality in South Africa. Methodologically, the development of the World Health Organization (WHO) standardised verbal autopsy tools (https://www.who.int/healthinfo/statistics/verbalautopsystandards/en/) and demonstration of the value of the InterVA software (http://www.byass.uk/interva/), which assigns probable cause of death, was based in part on work in Agincourt and other INDEPTH Network HDSS sites (18–20). Verbal autopsy is at the core of population-based cause of death data collection and enabled analysis of burden of disease patterns in these communities.

The HIV epidemic had an enormous impact on under-5 mortality at both study sites, resulting in a rise in child deaths over the 1990s and early 2000s (21,22). This increase in mortality, driven by HIV, occurred through two main mechanisms. The first was an increase in the number of child deaths directly as a result of HIV/AIDS, and increased susceptibility of HIV-positive children to pneumonias, tuberculosis and diarrhoeal disease (21,22). The second was as a result of mothers dying (largely but

not only from HIV/AIDS), which in turn has been shown to increase the child's risk of dying seven-fold in the two months both before and after her death, and by up to 12-fold in the month of her death (23).

The under-5 mortality rate began to fall earlier and more rapidly in AHRI than Agincourt (under-5 mortality dropped by 40% in 2004 in AHRI (24) whereas a similar sustained decline only occurred from 2007 onwards in Agincourt (3)). This reflects the uneven implementation and roll out of national policy regarding prevention of mother-to-child transmission (PMTCT) and antiretrovirals (ARVs) and Mpumalanga seemed to lag behind KwaZulu-Natal. Following the roll-out of ARVs in AHRI, Ndirangu et al (2012) demonstrated that the mortality risk of children born to HIV positive mothers on ARVs was equivalent to those born to HIV negative mothers (25). Figures 4.5 and 4.6 demonstrate the under-5 mortality trends in Agincourt and AHRI respectively, covering much of the time of the millennium development goals (MDGs) (22,24). They reflect what has been termed "a successful failure" as a means of contextualising the failure to meet the MDG target of reduced under-5 mortality by two thirds, which nonetheless represented a turnaround in the management and control of the HIV/AIDS epidemic (22).

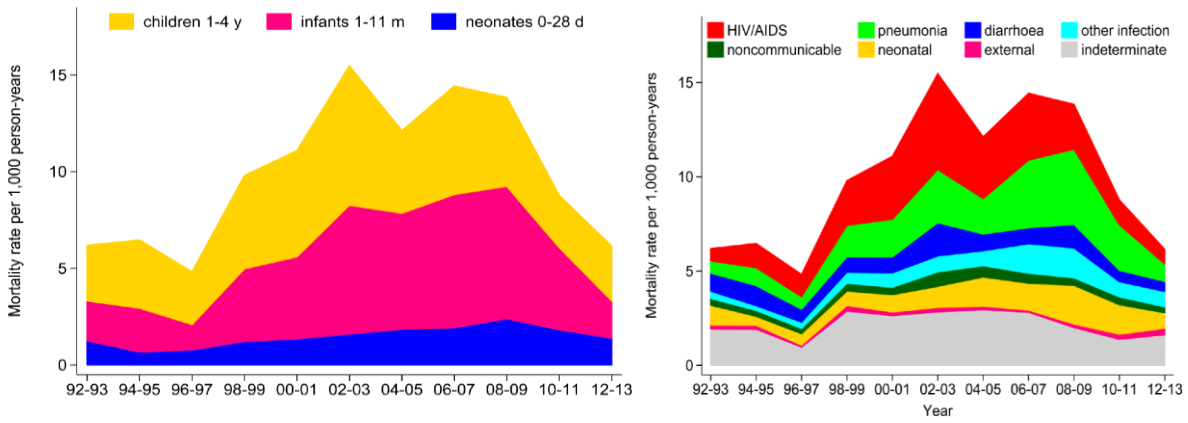


Figure 4.5: Under-five mortality rates at the Agincourt site from 1992 to 2013, by age group and by cause of death category. From https://doi.org/10.1371/journal.pmed.1001926.g002 (22)

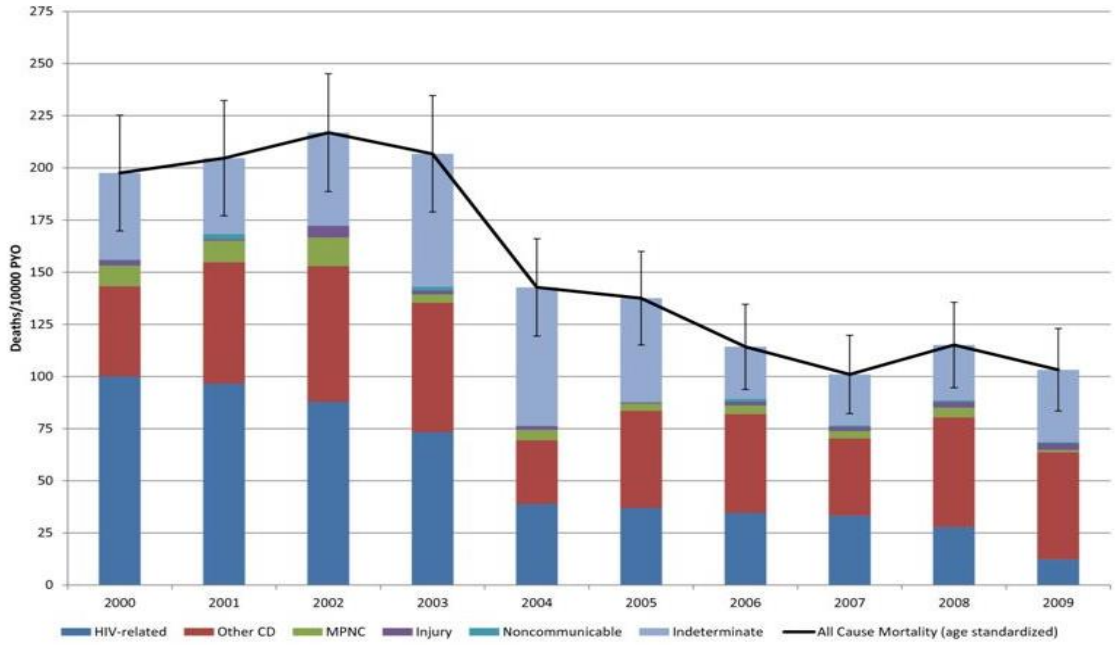


Figure 4.6: Under-5 Age Standardized Mortality at AHRI (Deaths 1, 531, Person Years Observed (PYO) 100 274) from https://doi.org/10.1186/1478-7954-9-47 (24)

Analyses of the social determinants of health has focused on the changing socioeconomic status, family structure and orphanhood over time. The socioeconomic status of households increased steadily in Agincourt since 2001 and the population became better educated (9% of adults had completed high school in 2001 and this increased to over 25% in 2013). Increased socioeconomic status was associated with an increase in life expectancy at birth and a reduction in child mortality risk (3,26). Work on the Mozambican population in Agincourt has further emphasised the role of socioeconomic status on health outcomes, with this population generally being in the lower socioeconomic quintiles and experiencing poorer health outcomes (9). In terms of family structure, both study sites have been affected by substantial increases in orphanhood (either single- or double-orphaned children) as a result of AIDS-related mortality. This affects the mobility of children and households and has been shown to negatively impact children's educational achievement and reduce their access to social grants (12,27,28).

4.4 Relation to the rest of the thesis

In this chapter I have described the context, routine data collection methods and existing research infrastructure at the HDSS sites which serve as the basis for the remainder of the work presented in this thesis. In addition, a detailed description of verbal autopsy methods is included in chapter 5. The following chapters build on this base, first analysing the longitudinal data on child deaths available from each HDSS to identify factors associated with home deaths of children under five years (chapter 5), then adding a new data collection tool (a social autopsy) to the existing verbal autopsies at each site to articulate the care pathways during fatal childhood illness (chapter 6), and finally conducting a qualitative study with caregivers of deceased children at each site to understand the experiences of seeking and receiving healthcare during a child's final illness (chapter 7). The final

chapter (chapter 8) brings findings together and recommends interventions that are targeted to rural contexts similar to the study areas in which this doctoral work was conducted.

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Chapter 5: Trends and determinants of place of death in under-5 deaths in rural South Africa between 2000-2015 – a population-based longitudinal study

This work has been published:

Price J, Willcox M, Kabudula CW, Herbst K, Kahn K, Harnden A. Home deaths of children under 5 years in rural South Africa: a population-based longitudinal study. Trop Med Int Heal. 2019 Jul;24(7):862–878.

5.1 Introduction

Chapters 1 and 3 have demonstrated that approximately 50% of under-5 deaths occur at home, both in South Africa and across sub-Saharan Africa. However, little is known about why this is the case. It is often assumed that children die at home due to a failure to seek healthcare, implicitly placing responsibility on the caregiver either for failing to recognise signs of illness, or being unable to overcome barriers to accessing health services (1). Yet the systematic review (chapter 3) found high rates of care-seeking during a child's final illness, particularly for infants and young children. Although data could not be disaggregated by place of death, it would be unwise to assume that home deaths are purely a result of failing to access healthcare services.

This chapter serves as the first step in investigating why children die at home in rural South Africa. Analyses examine whether the distribution of place of death has changed over time, whether children who died at home had indeed sought healthcare, and if this is the case, whether there were any distinguishing features at an individual or household level that might identify increased risk of home death despite seeking healthcare.

5.2 Aims and objectives

Aim

To describe trends and determinants of place of death and care-seeking in under-5 deaths in rural South Africa between 2000-2015.

Objectives

1. To describe the trends in place of death and care-seeking between 2000-2015 in the Agincourt and AHRI health and demographic surveillance system sites in rural South Africa.
2. To determine the proportion of children under-5 who died at home that were taken to a formal healthcare provider during the final illness.
3. To identify determinants of under-5 death at home despite seeking formal healthcare in rural South Africa.

5.3 Methods

5.3.1 Study design

This was a population-based longitudinal study using verbal autopsy and household survey data for all under-5 deaths between 2000-2015 in the Agincourt and AHRI health and demographic surveillance system (HDSS) sites, regardless of whether they occurred within or outside health facilities. Stillbirths were excluded from the analysis.

5.3.2 Study sites and data collection

This study used verbal autopsy and household data from the Agincourt and AHRI HDSS sites, for all under-5 deaths between 2000-2015. Full details of the study sites and household surveys are provided in chapter 4. Briefly, both sites conduct regular household surveys during which all deaths in the household since the previous update round are identified and recorded. Employment, migrancy and education status are also updated, as is a record of household assets used to determine relative socioeconomic status (2,3). Both sites are considered to be broadly representative of rural South Africa (3,4).

Any death of a household member, regardless of where it occurred, that is identified during the household survey is investigated using a verbal autopsy.

Verbal autopsy

A verbal autopsy (VA) is a structured interview with the primary caregiver of the deceased to determine probable biological cause of death (5,6). Both sites use the World Health Organization (WHO) standardised Verbal Autopsy tools, https://www.who.int/healthinfo/statistics/verbalautopsystandards/en/) as the basis of the VA interview. These tools consist of a series of close-ended questions to determine the presence of specific signs and symptoms during the final illness and, where present, include follow up questions that gather greater detail and determine their duration and severity. An open narrative is also collected from the respondent, where s/he recounts the final illness of the deceased, giving the sequence of signs and symptoms as well as response to treatment if any. VA has been validated as a means of determining cause of death in rural South African settings (7), and research has found

that a recall of up to 1 year does not alter the cause of death patterns derived compared to shorter recall periods (8).

There are three WHO Verbal Autopsy Tools depending on the age of the deceased: one for neonatal deaths, one for deaths of children 1 month to 12 years, and one for adults (age 12 years and older). A specific module on maternal deaths is included in the adult WHO Verbal Autopsy Tool where a death of a woman of child-bearing age is being investigated. The WHO 2012 Verbal Autopsy Tool was introduced in 2012 and was still in use in 2015.

Cause of death was determined using the InterVA 4.3 algorithm (http://www.byass.uk/interva/). InterVA uses probabilistic modelling to assign cause of death based on the presence and combination of "yes" answers to the close-ended questions from the VA interview. The algorithm is set to reflect whether the death occurred in a high, low or very low HIV-burden setting, in a setting where malaria is prevalent or not, and whether the death occurred in the wet or dry season (9). Previously cause of death was assigned by physicians who reviewed the interview material and developed a conclusion based on an assessment of the history and clinical presentation reported by the caregiver. However, algorithmically-assigned cause of death has become increasingly common as VA use has grown as it is cheaper, faster and more internally consistent than case-by-case physician review (9–11). The InterVA algorithm has been shown to perform comparability to physician coded interviews at a population level – i.e. the overall mortality patterns are similar and would prompt similar public-health policy conclusions (10). However at an individual level, InterVA performance is sub-optimal compared to physician review (11). The InterVA software is designed to be compatible with WHO Verbal Autopsy Tools.

Both HDSS sites have dedicated VA teams: as noted in chapter 4, in Agincourt this team is composed of lay fieldworkers who have completed secondary school, and who are specifically trained as VA interviewers. In AHRI, the VA team is made up of nurses. The VA teams must complete in-house training on conducting VA interviews to ensure high quality data is collected. This includes identifying the most appropriate respondent, who is the person best able to recount the final illness episode of the deceased, and ensuring that data collection is complete. This is especially important as the InterVA algorithm can only assign probable cause of death based on the information fed into the software.

The timing of the VA in relation to the death is slightly different across the two HDSS sites. In Agincourt, the VA teams follow an annual cycle, visiting those households where a death during the previous year was identified during the annual household survey. This means that the VA will occur between 1-11 months after the death. In AHRI, the household survey is conducted every four months and so deaths are identified more regularly throughout the year. In this case the VA team will visit the household at least one month after the death to allow for the traditional mourning period to have passed.

The overall completion rate of VAs for under-5 deaths between 2000-2015 was 91% in AHRI and 92% in Agincourt.

5.3.3 Conceptual framework

I used the WHO Commission on Social Determinants of Health conceptual framework (12) as the basis for grouping social determinants of health into distal and intermediate factors. I then applied this framework to the question of place of death in children under-5 to identify differences in the determinants of home and health facility deaths amongst children who were taken outside the home for healthcare. Variables were grouped into four levels (figure 5.1): 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.

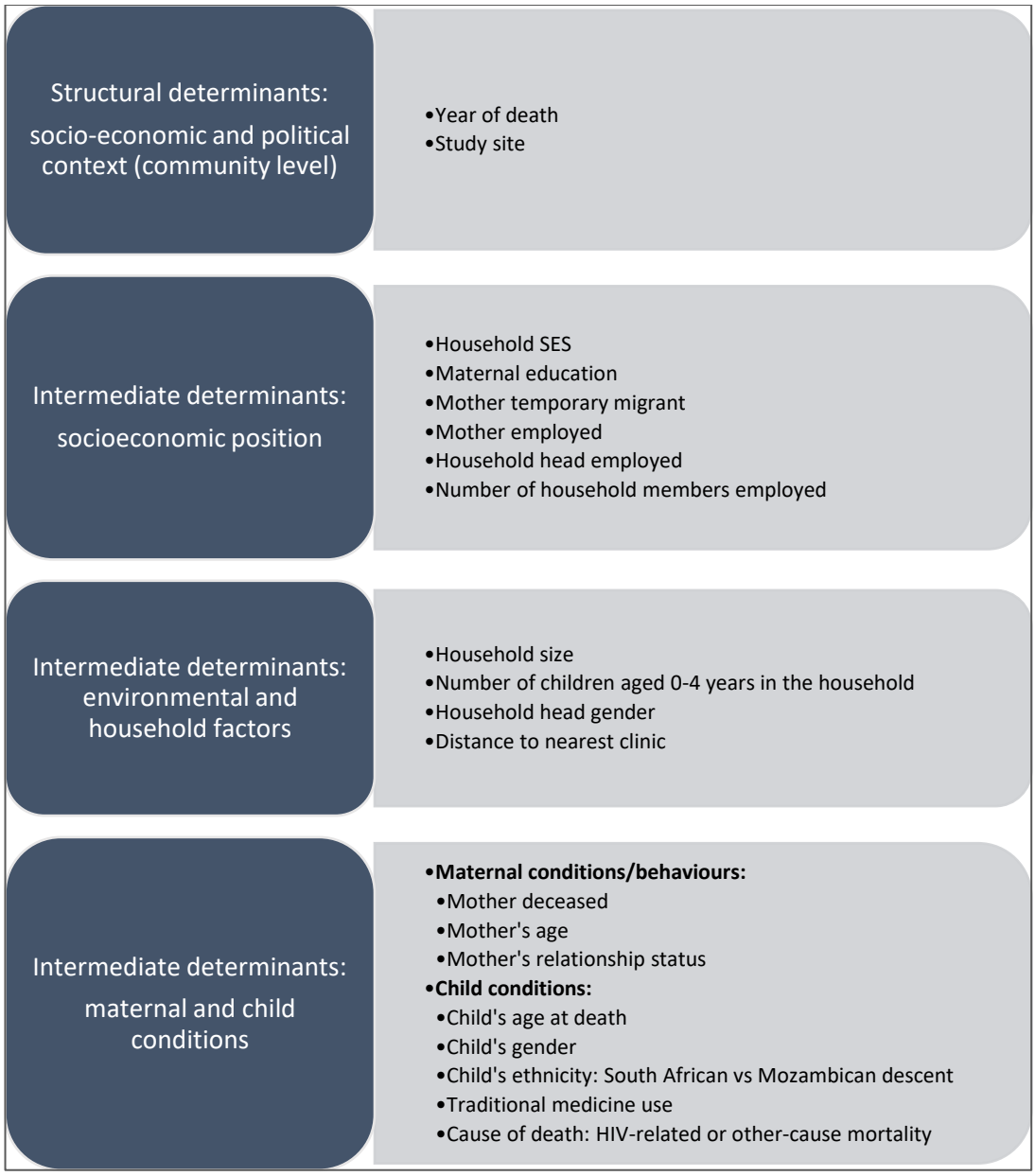


Figure 5.1: Conceptual hierarchical framework of risk factors for place of death in rural South Africa, adapted from the WHO social determinants of health inequalities (9)

5.3.4 Study variables

The outcomes of interest were place of death (home or health facility) and care-seeking outside the home. I broke down home deaths into those where a formal health provider (clinic, private GP, pharmacy or hospital) was consulted during the final illness, and those where not. By comparing

home deaths where care was sought with deaths in health facilities, I was able to control for care-seeking behavior, and so consider additional factors that contributed to place of death. Both place of death, and whether healthcare was sought outside the home are recorded as part of the standardised VA.

I classified exposure variables according to the modified conceptual framework (figure 5.1). I 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. I 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 (HAART) for all pregnant women; HIV-related mortality declining) (13,14). Given changes in policy relating to HIV and availability of PMTCT over time, I assessed HIV as an interaction term with year of death.

As noted in Chapter 4, changes in PMTCT and HAART policy were enacted earlier in AHRI than in Agincourt, which resulted in an earlier decline in HIV/AIDS-related child deaths in AHRI, and so study site was also included as a potential confounder in the model.

I assessed socioeconomic position of the household using asset ownership data collected during the household surveys. Households were grouped into five quintiles, from poorest [1] to least poor [5]. I also used maternal education to assess the socioeconomic position of the household, which I split into four categories: no education [1], started or completed primary school [2], started or completed secondary school [3], and started or completed tertiary education [4].

As noted above, cause of death for all deaths was determined 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".

5.3.5 Statistical analysis

I used bivariate and multivariate logistic regression models to assess relationships between socio-demographic exposures and place of death despite seeking healthcare (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 recognisable in neonates compared to older children; neonates decompensate more quickly than older children and so opportunities to seek healthcare may differ. Furthermore, for neonates who are born and die early in hospital without discharge, care-seeking is 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.

I used the hierarchical approach described by Victora and colleagues (15) to develop multivariate logistic regression models in both age groups. This approach recognises that the causal pathway is unlikely to be unidirectional (i.e. explanatory variables likely impact on each other, partly as confounders, but also as mediators along a shared causal pathway). I used a four-stage model starting with the most distal determinants and then adding intermediate determinants (according to the groupings in figure 5.1). I included year of death and study site in model 1. I 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 socioeconomic and household intermediate explanatory variable and the outcome of interest, I refer to the crude odds ratios. The full model building process is presented in appendix 5.1 which provides adjusted odds ratios for the distal and intermediate explanatory variables. Statistical significance was set at $p<0.05$.

I used Stata12 for all analyses (16).

5.3.6 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; M180585). Similar protocols for three-monthly census and verbal autopsy 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).

5.4 Results

5.4.1 Descriptors of under-5 deaths 2000-2015

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 (including at the roadside and on route to facilities). No significant differences were noted in frequency of place of death between the two study sites. There were 500 neonatal deaths (0-27 days) (13%), and 2259 infant deaths (<12 months) (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. Twenty-six percent of caregivers reported having given their child traditional medicine and/or having consulted a traditional healer of which just under a quarter (23%) did so before using formal health services. In Agincourt, reported use of traditional medicines and services were significantly more likely in children of Mozambican descent (OR 1.88, 95%CI 1.51-2.36, $p<0.001$). Only 6% did not report any care-seeking at all. Fifty-three percent of deaths occurred in households in the lowest two socioeconomic quintiles; 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 5.1).

Table 5.1: Population descriptors of child deaths and care-seeking behaviour 2000-2015

Variable	Total (N=3760)		AHRI (N=2033)		Agincourt (N=1727)		P value
	n/N*	%	n	%	n	%	
Child descriptors							
Female	1775	47	961	47	814	47	0.992
Child age:							<0.001
0-7 days	369	10	138	7	231	13	
8-27 days	131	3	49	2	82	5	
28 days-1 year	1759	47	1009	50	750	43	
1-4 years	1501	40	837	41	664	38	
Mozambican descent	684/1721	40	-	-	684/1721	40	-
Maternal descriptors							
Mother deceased	349/3694	9	71/1967	4	278/1727	16	<0.001
Mother's age (mean ± SD)	27±7	-	26±7	-	27±7	-	0.012
Relationship Status							<0.001
Single	2145	57	1596	79	549	32	
Married/Cohabiting	712	19	300	15	412	24	
Divorced/Separated	51	1	3	0.2	48	3	
Widowed	68	2	31	2	37	2	
Unspecified	784	21	103	5	681	39	
Household descriptors							
Household size (median, IQR)	10 (7-13)	-	11 (8-15)	-	8 (6-11)	-	<0.001
Number of children in the household aged 0-4 years (median, IQR)	2 (1-3)	-	2 (1-3)	-	2 (1-2)	-	0.244
Household head female	1485/3689	40	764/2008	38	721/1681	43	0.003
Socioeconomic descriptors							
Socioeconomic quintile							<0.001
Quintile 1 (poorest)	960/3340	29	617/1783	35	343/1557	22	
Quintile 2 (poor)	807/3340	24	460/1783	26	347/1557	22	
Quintile 3 (medium)	655/3340	20	342/1783	19	313/1557	20	
Quintile 4 (less poor)	508/3340	15	207/1783	12	301/1557	19	
Quintile 5 (least poor)	410/3340	12	157/1783	9	253/1557	16	
Mother's education							<0.001
None	225/2557	9	44/925	5	181/1632	11	
Primary School	572/2557	22	185/925	20	387/1632	24	
High School	1657/2557	65	645/925	70	1012/1632	62	
Tertiary Education	103/2557	4	51/925	6	52/1632	3	
Mother temporary migrant	718/3532	20	564/1967	29	154/1565	10	<0.001
Mother working	480/2258	21	216/967	22	254/1291	20	0.278
Household head working	1292/3298	40	466/1763	26	826/1535	54	<0.001
Number of household members working (median, IQR)	2 (1-2)		2 (1-3)		1 (1-2)		<0.001
Descriptors of death and care-seeking behaviour							
Deaths at home	1954/3693	53	1068/1966	54	886/1727	51	0.067
Sought care from a formal healthcare provider during the final illness	2796/3050	92	1539/1607	96	1257/1443	87	<0.001

Traditional medicine used/traditional healer consulted during the final illness	747/2880	26	294/1381	21	453/1499	30	<0.001
Proportion of home deaths who sought care from a formal healthcare provider	1139/1361	84 ϕ	652/712	92	487/649	75	<0.001

*Where N is not specified, data is available for all deaths.
ϕ % of deaths at home who sought care, where data were available on care-seeking behaviour.

5.4.2 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 5.2). 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 5.2, 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).



Figure 5.2: Place of death and care-seeking in rural South Africa, 2000-2015

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 5.2, 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 healthcare (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). This pattern predominantly reflects trends in Agincourt, where 60% of home deaths in 2015 failed to seek care, whereas in AHRI the proportion of home deaths that failed to seek healthcare has remained low, between 0-16% (see appendix 5.2). The absolute rate of deaths at home without seeking healthcare has remained consistent over time at 2-5 deaths per 1000 live births.

5.4.3 Risk factors for deaths at home amongst those who sought healthcare

Table 5.2 shows the risk factors for neonatal deaths at home despite seeking healthcare, while table 5.3 shows risk factors for deaths at home despite seeking healthcare for infants and young children (compared to those who died in a health facility).

Amongst neonates who sought healthcare 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) as were neonates of Mozambican descent (in Agincourt only, crude OR=2.83, 95%CI 1.14-7.07, p=0.026). Female neonates were significantly less likely to die at home having sought healthcare (adjusted OR=0.47, 95%CI 0.22-0.99, p=0.047) (table 5.2). 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 5.1).

Table 5.2: Predictors of neonatal death at home despite seeking healthcare compared to death in a facility

Variable	Total deaths despite seeking care in each category		Total deaths at home despite seeking care in each category		Unadjusted Model			Model 4: Model 3 + individual level variables		
	n	%	n	%	Crude OR	95% CI	P value	Adjusted OR*	95% CI	P value
Distal determinants:										
Year of death (reference: 2012-2015)	62	18	4	6	1	-	0.024	1	-	0.091
2000-2003	108	31	20	20	1.16	0.33-4.02	-	0.62	0.16-2.45	-
2004-2007	77	22	9	12	1.92	0.56-6.56	-	0.95	0.25-3.58	-
2008-2011	100	29	8	7	3.63	1.18-11.17	-	2.13	0.65-6.97	-
Study site (reference: AHRI)	138	40	20	14	0.66	0.34-1.27	0.212	0.46	0.21-1.01	0.053
Socioeconomic position:										
Socioeconomic status (reference: quintile 1 – poorest)	69	22	5	7	1	-	0.207	-	-	-
Quintile 2 – poor	68	21	14	21	3.32	1.12-9.81	-	-	-	-
Quintile 3 – medium	60	19	8	13	1.97	0.61-6.38	-	-	-	-
Quintile 4 – rich	67	21	9	13	1.99	0.63-6.27	-	-	-	-
Quintile 5 - richest	54	17	5	9	1.31	0.36-4.76	-	-	-	-
Maternal education (reference: none)	14	6	1	7	1	-	-	-	-	-
Started/completed primary school	52	21	3	6	0.80	0.08-8.30	0.849	-	-	-
Started/completed secondary school	166	67	22	13	1.99	0.25-15.94	0.518	-	-	-
Started/completed tertiary education	14	6	0	0	(empty)			-	-	-
Mother temporary migrant	60	18	7	12	0.97	0.41-2.31	0.942	-	-	-
Mother working	53	25	5	9	0.68	0.24-1.90	0.462	-	-	-
Household head working	134	44	18	13	1.00	0.51-1.94	0.996	-	-	-
Number of household members working	248	-	-	-	1.25	1.00-1.56	0.053	-	-	-
Environmental and household factors:										
Household size (reference 1-5 members)	61	18	3	5	1	-	0.357	-	-	-
6-10 members	166	48	22	13	2.95	0.85-10.25	-	-	-	-
10-15 members	87	25	11	13	2.80	0.75-10.49	-	-	-	-
>15 members	33	10	5	15	3.45	0.77-15.48	-	-	-	-

Number of children aged 0-4 in the household	347	-	-	-	1.17	0.89-1.55	0.255	-	-	-
Household head female	145	43	18	12	1.05	0.55-2.03	0.876	-	-	-
Distance to clinic	347	-	-	-	1.16	0.99-1.37	0.072	-	-	-
Maternal conditions:										
Mother deceased	19	5	5	26	2.98	1.01-8.77	0.047	-	-	-
Young mother (<20 years)	93	27	8	9	0.63	0.28-1.42	0.265	-	-	-
Mother relationship status (reference: single)	193	65	25	13	1	-	-	-	-	-
Married/cohabiting	92	31	10	11	0.82	0.38-1.79	0.617	-	-	-
Divorced/separated	8	3	2	25	2.24	0.43-11.72	0.339	-	-	-
Widowed	2	1	0	0	(empty)			-	-	-
Child conditions:										
8-27 days (reference 0-7 days)	80	23	24	30	6.30	3.18-12.51	<0.001	5.56	2.68-11.55	<0.001
Female child	164	47	14	9	0.54	0.27-1.06	0.074	0.47	0.22-0.99	0.047
Mozambican descent[Ŧ]	63	30	11	17	2.83	1.14-7.07	0.026	-	-	-
Traditional medicine	11	4	4	36	3.94	1.10-14.11	0.035	-	-	-

*Adjusted OR is adjusted for all other variables in the table.

Ŧ in Agincourt only

Table 5.3: Predictors of death at home despite seeking healthcare compared to death in a facility for infants and young children

Variable	Total deaths despite seeking care in each category		Total deaths at home despite seeking care in each category		Unadjusted Model			Model 4: Model 3 + individual level variables		
	n	%	n	%	Crude OR	95% CI	P value	Adjusted OR*	95% CI	P value
Distal Determinants:										
Year of death (reference: 2012-2015)	317	14	136	43	1	-	<0.001	1	-	<0.001
2000-2003	667	29	283	42	0.98	0.75-1.29	-	0.85	0.52-1.41	-
2004-2007	699	31	378	54	1.57	1.20-2.05	-	1.01	0.66-1.55	-
2008-2011	588	26	302	51	1.40	1.06-1.84	-	1.05	0.73-1.51	-
Study site (reference: AHRI)	1306	58	632	48	1.00	0.84-1.18	0.962	0.65	0.50-0.84	0.001
Socioeconomic Position:										
Socioeconomic status (reference: quintile 1 - poorest)	556	27	269	48	1	-	0.031	-	-	-
Quintile 2 - poor	515	25	271	53	1.18	0.93-1.51	-	-	-	-
Quintile 3 – medium	422	20	202	48	0.98	0.76-1.26	-	-	-	-
Quintile 4 – rich	316	15	150	47	0.96	0.73-1.27	-	-	-	-
Quintile 5 - richest	263	13	106	40	0.72	0.54-0.97	-	-	-	-
Maternal education (reference none)	123	8	69	56	1	-	0.005	1	-	<0.001
Started/completed primary school	294	20	152	52	0.84	0.55-1.28	-	0.82	0.50-1.34	-
Started/completed secondary school	1002	68	440	44	0.61	0.42-0.89	-	0.51	0.33-0.80	-
Started/completed tertiary education	61	4	22	36	0.44	0.23-0.83	-	0.36	0.18-0.74	-
Mother temporary migrant	419	20	184	44	0.78	0.63-0.97	0.024	-	-	-
Mother working	263	20	110	42	0.82	0.63-1.08	0.164	-	-	-
Household head working	710	36	318	45	0.78	0.65-0.94	0.009	-	-	-
Number of household members working	1417	-	-	-	0.97	0.91-1.05	0.481	-	-	-
Environmental and household factors:										
Household size (reference 1-5 members)	353	16	159	45	1	-	0.066	-	-	-
6-10 members	948	42	460	49	1.15	0.90-1.47	-	-	-	-
10-15 members	606	27	282	47	1.06	0.82-1.38	-	-	-	-

>15 members	364	16	197	54	1.44	1.07-1.93	-	-	-	-
Number of children aged 0-4 in the household	2271	-	-	-	1.09	1.02-1.17	0.015	-	-	-
Household head female	931	42	457	49	1.04	0.86-1.23	0.676	-	-	-
Distance to clinic	2269	-	-	-	0.99	0.95-1.04	0.770	-	-	-
Maternal conditions:										
Mother deceased	213	10	112	53	1.20	0.91-1.60	0.200	-	-	-
Young mother (<20 years)	284	13	130	46	0.89	0.69-1.14	0.354	-	-	-
Mother relationship status (reference: single)	1389	73	685	49	1	-	0.014	-	-	-
Married/cohabiting	410	22	180	44	0.80	0.64-1.00	-	-	-	-
Divorced/separated	28	1	19	68	2.17	0.97-4.83	-	-	-	-
Widowed	46	2	28	61	1.60	0.88-2.92	-	-	-	-
Child conditions:										
29 days-1 year (reference 1-4 years)	1231	54	594	48	0.99	0.84-1.17	0.921	-	-	-
Female child	1090	48	509	47	0.88	0.75-1.04	0.130	-	-	-
Mozambican descent ₸	372	39	221	59	2.07	1.59-2.69	<0.001	-	-	-
Traditional medicine	552	26	363	66	2.10	1.72-2.58	<0.001	2.43	1.83-3.22	<0.001
HIV/AIDS*time (ref category 2012-2015)	90	30	34	38	1	-	0.009	1	-	0.009
HIV*time (2000-2003)	294	47	128	44	1.61	0.88-2.92	-	1.59	0.73-3.48	-
HIV*time (2004-2007)	242	39	150	62	2.29	1.25-4.20	-	2.66	1.29-5.48	-
HIV*time (2008-2011)	169	31	106	63	2.63	1.41-4.94	-	2.96	1.49-5.87	-
HIV/AIDS	90	30	34	38	0.66	0.40-1.09	0.103	0.53	0.31-0.91	0.023

*Adjusted OR is adjusted for all other variables in the table, excluding Mozambican descent which is only measured in Agincourt.

₸ in Agincourt only

For infants and young children, 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 and mother's education (table 5.3). 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 after adjusting for maternal education. Similarly, none of the household factors significantly improved the model (see appendix 5.1 for full model building process).

Children aged 1-59 months were significantly less likely to die at home despite seeking healthcare if their mother was more educated ($p<0.001$). Traditional medicine use was associated with significantly increased risk of home deaths despite seeking healthcare (adjusted OR=2.43, 95%CI 1.83-3.22, $p<0.001$), as was 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 healthcare in 2008-2011 when compared to HIV-unrelated deaths in the same period (adjusted OR=1.41, 95%CI 1.03-2.36, $p=0.034$). However, this association was reversed in 2012-2015 when HIV-related deaths were significantly less likely to occur at home compared to HIV-unrelated deaths (adjusted OR=0.53, 95%CI 0.31-0.91, $p=0.023$) (table 5.4). No other causes of death were found to be associated with place of death (analysis not shown).

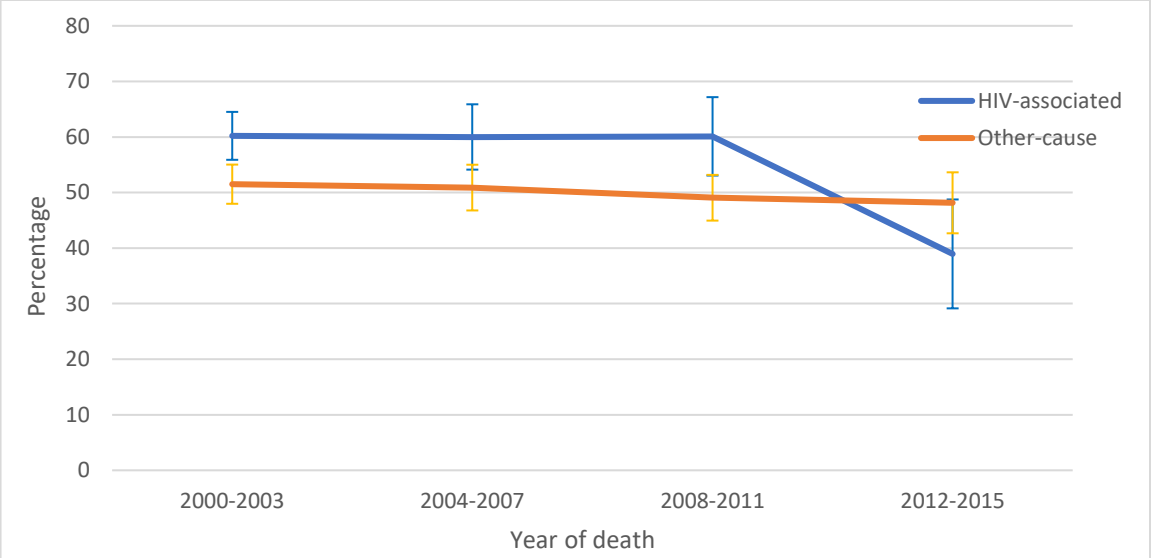
*Table 5.4: Implications of HIV*time interaction on death at home despite seeking healthcare compared to death in a facility for infants and young children*

	OR*	95% CI	p-value
Impact of year of death on place of death for HIV-related deaths			
Year of death: 2012-2015 (reference year)	1	-	-
2000-2003	1.36	0 .73 -2.53	0.337
2004-2007	2.70	1.49-4.88	0.001
2008-2011	3.11	1.74-5.55	<0.001
Impact of year of death on place of death for HIV-unrelated deaths			
2012-2015 (reference)	1	-	-
2000-2003	0.85	0.52-1.41	0.533
2004-2007	1.01	0.66-1.55	0.947
2008-2011	1.05	0.73-1.51	0.787
Impact of HIV on place of death in each time period (year of death):			
2000-2003	0.84	0.48- 1.48	0.584
2004-2007	1.41	0.87-2.26	0.159
2008-2011	1.56	1.03-2.36	0.034
2012-2015	0.53	0.31-0.91	0.023

* Adjusted for all explanatory variables listed in model 4 in Table 5.3.

5.4.4 HIV and place of death

Changes in place of death over time differed between deaths which were HIV-associated and those which were not (table 5.4 and figure 5.3). 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 5.4, HIV-related deaths were 3.11 times as likely to occur at home despite seeking care in 2008-2011 compared to 2012-2015 (95%CI 1.74-5.55, p<0001), whereas there was no difference in place of death amongst HIV-unrelated deaths over the same period (OR=1.05, 95%CI 0.73-1.51, p=0.787).



Cause of death	Proportion who died at home 2008-2011 (%)	Proportion who died at home 2012-2015 (%)	Chi2 (within group change over time)	p-value
HIV-associated	60	39	13.86	<0.001
Other-cause mortality	49	48	0.18	0.669

Figure 5.3: Proportion of deaths at home for HIV-associated or other-cause mortality.

5.5 Discussion

5.5.1 Summary of results

This study showed that home deaths accounted for over 50% of under-5 deaths in two rural South African settings 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 healthcare from a formal medical provider during the child's final illness.

The under-5 mortality rate declined from a peak of 90 per 1000 live births in 2003 to 30 per 1000 live births in 2015. Both settings have benefited from PMTCT, albeit at different times (as noted in chapter 4), resulting in the significant decline in under-5 mortality seen in the 2000's. This is in keeping with the national picture described in chapter 1. The impact of HIV/AIDS on under-5 mortality was largely seen as an increase in deaths of infants and young children, resulting in a relatively low proportion of neonatal deaths (13%, table 5.1). Under-5 mortality data from 2017, used in the next chapter, demonstrates that neonatal deaths account for an increasing proportion of under-5 deaths in the region following the decline HIV-related mortality.

The high rates of care-seeking during a child's final illness are in keeping with findings from the systematic review (chapter 3) which looked more broadly at care-seeking in under-5 deaths across sub-Saharan Africa. However, by disaggregating care-seeking data by place of death, this study shows definitively that even amongst children who died at home, there were high rates of engagement with formal healthcare services. This adds to the growing body of work on post-discharge mortality which has shown similar rates of in-hospital and post-discharge mortality amongst under-5s, and further that approximately two thirds of post-discharge deaths occur outside of health facilities (17–19). This study suggests that these findings on post-hospital discharge might be applicable to children who are seen at all levels of care, including children who are seen by health professionals but not admitted as inpatients.

Following the modified conceptual framework (figure 5.1), the socioeconomic factor that was significantly associated with dying at home despite seeking healthcare was low maternal education. 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 healthcare.

5.5.2 Low maternal education associated with home deaths despite seeking healthcare

Improved female education is known to reduce child mortality risk and improve care-seeking behaviour overall (12,20). This study demonstrates that lower maternal education was significantly associated with home death despite seeking care, a new finding that builds on the existing literature. This might arise through several mechanisms. Firstly, maternal education reflects the socioeconomic position of the household. Secondly, educated mothers may be better able to identify signs of deterioration which might prompt them to return to a health facility (19). Thirdly, educated mothers might hold greater social capital and medical staff might take their concerns more seriously. Such social capital might also give them greater confidence to re-seek formal care should a child's condition fail to improve (12).

5.5.3 Child factors associated with home deaths despite seeking healthcare

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 (21) 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 is most often used in combination with western medicine, termed medical pluralism (22). Traditional beliefs about disease aetiology, loss of confidence in formal medical treatment, previous experiences of negative attitudes from health workers, stigma, ease of access and shorter waiting times all contribute to traditional medicine use (23–25). Medical pluralism was found in this study too, with about a quarter of participants using traditional medicines or consulting traditional healers in addition to accessing formal healthcare services. It is unclear whether formal healthcare and traditional medicines continued to be used in parallel after consulting both services, and why the reported use of traditional medicines and services 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. However, it is also possible that children who died in health facilities also received traditional medicines, but that their caregivers were less willing to report this; respondents are aware of the negative attitudes of formal healthcare providers towards traditional medicine and may even have been "told off" at the health facility, as is reported in chapter 7. Challenges in accurately recording the use of traditional medicines and healers are discussed in more detail in Chapter 8.

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 (13). 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 healthcare, 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. This might also explain the contrasting findings from this study with work elsewhere in sub-Saharan Africa, which showed that HIV infection was a risk factor for home deaths following hospital discharge in children under-5 (17,18).

Finally, in Agincourt, being of Mozambican descent was significantly associated with dying at home despite seeking healthcare in the infants and young children. As noted in chapter 4, 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). The association seen between having used traditional medicine or consulted a traditional healer and being of Mozambican descent could arise from either explanation. Further work on this question is required to understand the specific barriers in this community.

5.5.4 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 me 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. First, neonatal deaths may be missed by the HDSS update rounds, as the death might occur before the birth was captured. However, multiple strategies are used to minimise this risk including capturing data on all pregnancies, and training fieldworkers to specifically ask about pregnancy outcomes, births and neonatal deaths during each census. Second, VA methodology has some inherent limitations: data is collected from caregivers and so one is limited by what the caregiver knows. The deceased (or in the case of child deaths, the child's mother) may not have disclosed their medical history to the VA respondent, especially where certain conditions are highly stigmatised as with HIV. Furthermore, caregivers may not recall all details of the final illness – though evidence suggests that recall periods of up to one year do not reduce the accuracy of the cause of death assignment (8).

Third, as with the data on signs and symptoms, 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.

Fourth, as the data is cross-sectional, it is impossible to draw causal inferences from the associations we have reported. Further qualitative research is needed to more fully understand the reasons for these associations.

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

5.6 Conclusion

This study confirms that home deaths account for over half of all under-5 deaths in rural South Africa, despite high rates of care-seeking during the final illness. As the first study to disaggregate care-seeking data by place of death, it should prompt a shift in dialogue to focus on as yet unanswered questions about where and why children fall out of formal care pathways in rural South Africa only to subsequently die at home. The following chapters use a social autopsy tool and in-depth qualitative research to further this discussion and provide greater understanding of the processes of providing care within the home, and seeking and receiving healthcare outside the home during a child's final illness. Finally, by controlling for care-seeking, this study has identified several socio-demographic and disease-specific factors that are associated with dying at home despite

seeking healthcare and serves as a starting point for developing targeted interventions to reduce under-5 deaths, which are discussed in chapter 8.

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Chapter 6: The processes of seeking and receiving care during a child's final illness in rural South Africa – a descriptive analysis

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6.1 Introduction

In the last chapter, I showed that home deaths continue to be a cause for concern, accounting for almost half of under-5 deaths in recent years, despite the decline in the overall under-5 mortality rate in each study site. Furthermore, it is clear that child deaths at home are not simply a function of failure to seek healthcare. This is in keeping with evidence from elsewhere in sub-Saharan Africa, presented in chapter 3, which found high rates of care-seeking overall in child death. The last chapter also provided a clearer picture of which households are more likely to experience a child death at home despite seeking healthcare (namely households where the child's mother is less educated, and where caregivers used traditional medicine to manage their child's final illness).This chapter will build on the findings from chapter 5 to describe, in more detail, the processes of providing care within the home, and seeking and receiving healthcare outside the home during a child's illness – referred to as care pathways.

Investigation of such social circumstances of death is increasingly prioritised and valued as a means of identifying modifiable factors that contributed to death (1). Modifiable factors are described as circumstances, actions, delays or omissions which contributed to death and, had they been changed,

may have averted the death (2). Social autopsies are one tool available to investigate care pathways and modifiable factors. As noted in chapter 3, a social autopsy is a structured interview with the caregiver of the deceased that aims to identify "social causes of death" by detailing the preventive and curative care-seeking actions taken during the final illness, and identifying barriers to and delays in accessing care which contributed to death (3,4). Social autopsies have been used in multiple low- and middle-income countries to investigate neonatal and child deaths (5). As a population-based data collection tool, a social autopsy offers advantages over facility-based audits as it captures both deaths at home and those that occurred in health facilities. This is of particular interest in the South African setting where despite supportive policies (including the removal of user-fees at primary healthcare facilities), and relatively high health expenditure by government, health outcomes remain well below those seen in other upper middle income countries (6).

6.2 Aims and objectives

Aim

To investigate the processes of, and barriers to, providing care within the home and seeking and receiving healthcare outside the home during a child's final illness in rural South Africa, using an adapted social autopsy tool.

Objectives

1. To investigate care-seeking behaviour for fatal child illness, as encompassed by the Pathways to Survival Framework.
2. To determine the contributions of home, transport and health facility delays to under-5 deaths in the Agincourt and AHRI HDSS sites, using the Three Delays Model.

3. To identify barriers to access to healthcare during a child's final illness in rural South Africa using an adapted social autopsy tool.

6.3 Methods

6.3.1 Study design

This was a population-based, cross-sectional verbal and social autopsy (VASA) study.

6.3.2 Study sites and population

This study was located in the same two rural health and demographic surveillance system (HDSS) sites in rural South Africa, the Agincourt HDSS and the Africa Health Research Institute (AHRI) (see chapter 4 for full details of the study sites). Importantly, during the study period, both sites had readily available prevention of mother-to-child transmission (PMTCT) and antiretroviral (ARV) programmes and HIV was no longer the leading cause of death in under-5's. As noted in chapter 4, household characteristics including household size, household member migrancy rates and income reliance on social grants are similar across the two sites, as are median distance to the nearest health facility.

VASA interviews were conducted with the caregivers of children who died below the age of five, where the death was identified during household surveys between January 2017 and January 2018. The primary caregiver of the child was defined as the main person who was looking after the child during their final illness, and so who would be able to explain what was wrong with the child and what actions were taken during the final illness. While in many cases this would be the mother,

grandmothers, aunts, cousins and older siblings often fill this role when the mother is a migrant labourer or deceased. The VASA was conducted between July 2017 and February 2018, at least one month after the death to allow for the customary mourning period to pass, and up to 18 months after the death if there were delays in arranging a convenient VASA interview time with the most appropriate respondent.

6.3.3 Study tool

I added a social autopsy module to the World Health Organization (WHO) 2016 Verbal Autopsy tools for neonatal and child deaths used at each study site to further investigate the processes of providing home care and seeking and receiving care outside the home during a child's final illness. I adapted the International Network for Demographic Evaluation of Populations and Their Health (INDEPTH) Social Autopsy tools for neonatal and child deaths (accessible at http://www.indepth-network.org/resources/tools, and included as appendices 6.1 and 6.2) which were developed in 2008 by a team from INDEPTH Network HDSS sites in Kenya, Uganda, Ghana and Guinea-Bissau. A full description of the development of the tools is provided by Kallander et al (3). The INDEPTH Network tools combined questions from the nine social autopsy questionnaires that already existed at that time, and were structured to enable analysis based on the BASICS/CDC Pathways to Survival Framework (3,7). This framework is explained in full in the methods of analysis section below.

However, the full INDEPTH Network Social Autopsy tool for child deaths has 28 questions, and for neonatal deaths has 55 questions. A pragmatic approach to the implementation of social autopsy studies in routine vital statistics recognises the constraints on human resources, time and money, hence interviews need to be as short as possible whilst still providing the necessary information to

answer a given research question. Such considerations are even more pronounced when adding a module to an existing verbal autopsy where the interview already takes between 30-45 minutes to complete.

Therefore, I selected a subset of questions from the INDEPTH Network Social Autopsy questionnaires, considering their relevance to the South African healthcare context, and the potential impact of the information gathered by each question in understanding modifiable factors contributing to child deaths. All decisions were discussed with a local expert familiar with the South African healthcare landscape. I ensured that there was at least one question for each stage of the care pathway, as identified in the Pathways to Survival Framework. Questions on preventive care-seeking behaviours such as antenatal and perinatal care-seeking, and childhood vaccinations are already included in the WHO 2016 Verbal Autopsy and so were not repeated. The final social autopsy tool is presented in Table 6.1.

Table 6.1: Adapted Social Autopsy Tool

Pathway to Survival stage	**Question**	**Answers**
Care inside the home	1. a. Was care initiated in the home?	Yes…… □ No…… □ Don't Know…… □
	b. How much time after first symptom was recognised was care initiated in the home?	Days…… □□ Don't know…… □
Care outside the home	2. a. Was the child taken for outside care?	Yes…… □ No…… □ Don't Know…… □
	b. If no, why not?	…… …… ……
	3. How much time after the first symptom was recognised was the child taken outside of the home for care?	Days…… □□ Don't know…… □
(cross stage)	4. a. Did the child receive any treatment before he/she died?	Yes…… □ No…… □ Don't Know…… □
	b. If no, why did the child not receive any treatment? (Select all that apply)	Did not seem sick enough…… □ Thought illness would get better on its own… □ Sudden death, no time for treatment…… □ Did not know what to do…… □ No time, too busy…… □ Not enough money for consultation…… □ Transport too expensive…… □ Too far to travel…… □ Needed permission of another person e.g. husband/father/mother etc, and they were not available/refused…… □ Nobody to go with the child…… □ Nobody to care for other children at home…. □ No drugs at health care facility…… □ Staff attitudes poor…… □ Not enough privacy…… □ Too little time with health worker…… □ Queue too long/wait too long…… □ Western care could do nothing for illness…… □ Other (specify)…… □ Don't know…… □

Care outside the home	5. Specify care sought in chronological order				
	Type of Provider	When?	Facility name:	Village	District:
	1._____	Day_____	_____	_____	_____
	2._____	Day_____	_____	_____	_____
	3._____	Day_____	_____	_____	_____
	4._____	Day_____	_____	_____	_____
Receives (quality) care from the healthcare provider	6. How long after you arrived at the care provider was treatment given?		Immediately…… □ Hours…… □□ Don't know…… □		
Referral	7. a. Was the child referred to another place for care?		Yes…… □ No…… □ Don't Know…… □		
	b. Where were they referred to?		Hospital…… □ Health Centre…… □ Clinic…… □ Chemist/Pharmacy…… □ Traditional Healer…… □ Other (specify)…… □ Don't know…… □		
	c. What was the reason for referral?		Lack of equipment…… □ For better care…… □ Lack of blood…… □ Lack of drugs…… □ Lack of oxygen…… □ Other (specify)…… □ Don't know…… □		
	d. Did they reach the place they were referred to?		Yes…… □ No…… □ Don't Know…… □		
	e. If not why?		Died before arrival…… □ Thought it wasn't necessary…… □ Hoped/waited for an improvement…… □ Lack of money…… □ Lack of transport…… □ Other (specify)…… □ Don't know…… □		

In Agincourt, I had the opportunity to use the full INDEPTH Network Social Autopsy questionnaires for neonatal and child deaths (appendices 6.1 and 6.2). I was therefore able to retrospectively consider whether the additional information gained from those questions not included in Table 6.1

would have changed my conclusions and recommendations. These findings are discussed in appendix 6.3.

6.3.4 Training of fieldworkers

I trained the VASA teams at each study site on the use of the WHO 2016 Verbal Autopsy tool (as both sites introduced this updated tool for the first time in 2017), and the additional social autopsy questions.

In AHRI, the VASA team was composed of four qualified nurses, whereas in Agincourt the VASA team had three lay fieldworkers with at least 12 years of schooling from the study communities. In both sites there were interviewers who had not conducted verbal autopsy interviews before. In addition, some were unfamiliar with the use of tablets for data collection. Therefore, I ran the same training for both teams. I used the WHO Verbal Autopsy training guide (accessible at https://www.who.int/healthinfo/statistics/verbalautopsystandards/en/) as an aid in developing the training schedule and materials. The training covered 5 broad areas:

1) Introducing the concept of the verbal autopsy and the importance of identifying the correct respondent i.e. the person who cared most directly for the deceased during the final illness.

2) Familiarising the interviewers with the WHO 2016 Verbal Autopsy tool, including being able to describe or explain the sign or symptom that was being asked about, and where relevant being able to act out the symptom. To this end, I used pictures and videos to demonstrate the relevant clinical signs e.g. stridor, wheeze, chest indrawing and whooping cough. The

videos were freely available for streaming off YouTube, but could not be downloaded for storage on the tablets due to copyright restrictions. This meant that they could only be used for training purposes when we were at the office with adequate Wi-Fi, and not during data collection which happens in the community at the respondents' homes.

We ensured that each question had been correctly translated into isiZulu in AHRI and Xitsonga in Agincourt from the English verbal autopsy questionnaire and corrected any translation errors that had occurred. Often this involved simplifying the translation from a formal/technical word that had been used to directly translate the medical terminology to a more colloquial and easily understandable term.

I made sure the nurses/fieldworkers felt comfortable asking certain "sensitive" questions which are included in the WHO 2016 Verbal Autopsy tool. We role-played scenarios to help develop strategies to ask questions which might be difficult e.g. asking about the process of labour and delivery where a male interviewer is asking a woman who lost her young child.

3) The addition of the social autopsy questions, ensuring they had been correctly translated and were correctly understood by the interviewers.

4) The use of tablets for digital data collection.

5) We discussed some of the important cultural sensitivities related to conducting interviews about death. I reminded the teams of the existing protocols which were developed in conjunction with community leaders e.g. verbal autopsies must be at least 30 days after the

death to respect the cultural mourning period, interviewers must have identification with them to show that they are Agincourt or AHRI staff, interviewers should reassure respondents that the cause of death attributed to the deceased is confidential and will not be disclosed which is important given ongoing stigma around HIV. This includes explaining that any research that is published or presented to communities and public sector stakeholders using this data includes causes of death only at an aggregate level.

Before commencing fieldwork, all interviewers worked through paper cases that I had created (appendix 6.4), which were used to role play the full VASA interview and ensure that all interviewers were comfortable with the interview and competent in administering the VASA questionnaire.

6.3.5 Data analysis

Descriptive data analysis was conducted using the BASICS/CDC Pathways to Survival Framework and the Three Delays Model. Data was pooled across the two sites to give a more representative picture of rural South Africa. However, where any differences were found I have highlighted results for each site.

The BASICS/CDC Pathways to Survival Framework (figure 6.1) was developed in 1996 as part of the Basic Support for Institutionalising Child Survival (BASICS) programme funded by the United States Agency for International Development (USAID) (8). This framework acknowledged that much of the care for an ill child occurs outside of health facilities and so provided a way to think about the interface between caregiver recognition of illness, care provided in the home and that which was

accessed outside the home. The framework has been modified slightly over the years, but all versions include the following key steps: 1) caregiver recognition of illness, 2) care provided in the home, 3) the decision to seek care outside the home, 4) the healthcare provider gives quality care, 5) the child is referred for further care, or given recommendations for care at home and 6) the caregiver follows the referral advice and home recommendations. In the vast majority of cases where the child has a treatable illness, the logic of the framework suggests that if all actions are timely and appropriate the child should survive and return to a state of wellness. In contrast, failure at any stage of the care pathway may result in death of the child.

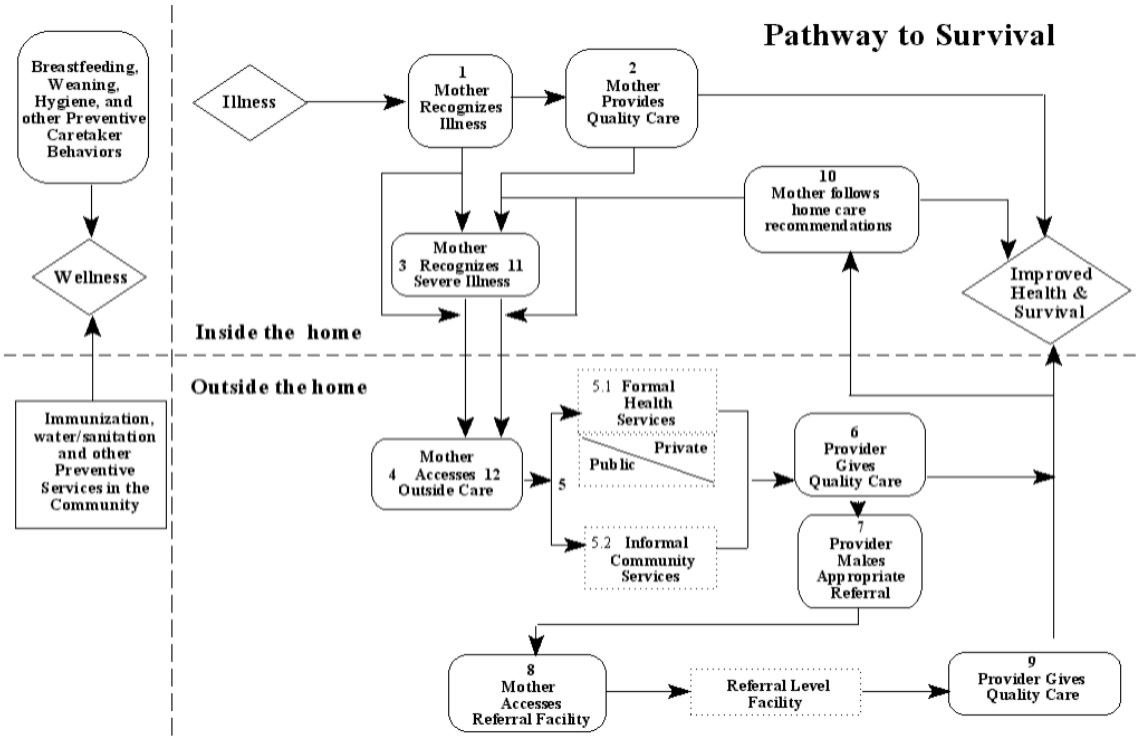


Figure 6.1: Pathways to Survival. Source: BASICS 1996 (8)

The Three Delays Model has also been used as a framework to identify avoidable factors contributing to child deaths. This model was originally developed by Thaddeus and Maine in 1994 to describe delays in care-seeking in relation to maternal deaths (9). Three types of delays were described: Delay 1 - delay in recognising illness or deciding to seek care outside the home; Delay 2 – a delay in reaching the health facility (also referred to as transport delay); and Delay 3 - a delay in receiving quality care at the health facility. In a Ugandan study, Waiswa et al (10) demonstrated the value of applying the Three Delays Model to neonatal deaths, a logical extension given that delays in maternal care-seeking also result in neonatal complications.

The model has subsequently been applied to older children too. As described by Kallander et al (3), determining the contributing proportion of each delay cluster (home, transport and health facility) to overall under-5 mortality is undertaken in four steps. First, divide the number of children exposed to each delay indicator by the relevant denominator (specified for each indicator in table 6.4) to calculate the conditional proportion of the children exposed to that delay indicator. Second, multiply the conditional proportion of each delay indicator by the pre-specified fraction of each delay cluster to determine the relative contribution of the full delay cluster. This process adjusts the weights of the delay indicators to take account of the fact that some delay clusters have more indicators than others (i.e. for delay one, the conditional proportion of each delay indicator is multiplied by $^1/_6$ to account for the fact that there are 6 delay indicators in this cluster; similarly for delay 2, each conditional proportion is multiplied by ½ given that there are two delay indicators in this cluster). Third, add the relative weights of each delay indicator calculated in step 2, to obtain the total contribution for the delay cluster. Finally, the proportion of the total delay attributable to each cluster is calculated by dividing the delay cluster total by the overall total delay (3).

Both the Pathways to Survival Framework and the Three Delays Model refer to the recognition of illness and differentiating signs of severe and possibly severe illness. In defining these terms, I followed the Integrated Management of Childhood Illness (IMCI) guidelines, as has been done by others who have applied these models to child mortality studies (3,10). Severe illness was defined by the presence of any of the danger signs included in the IMCI guidelines, i.e. convulsions, signs of severe respiratory distress (chest indrawing, nasal flaring, grunting), bulging fontanelle, umbilical redness extending to the skin, lethargy or unconsciousness, not able to drink or breastfeed, vomiting everything, loose stools or diarrhoea > 2 days, and heavy bleeding. Possibly severe illness included wheezing, fast breathing, difficulty breathing or fever.

6.3.6 Ethics

This study was approved by the University of Oxford Medical Sciences Inter-divisional Research Ethics Committee (R52414/RE001), the University of Witwatersrand Human Research Ethics Committee (M1705102) and the University of KwaZulu Natal Biomedical Research Ethics Committee (BE 290/16).

6.3.7 Funding

My travel, accommodation and living costs while at each HDSS site were covered by the Africa Oxford Travel Grant (grant number AfiOx-19) and the Murray Speight Research Grant (no award reference provided). The costs of fieldworker salaries and transport to participant households were covered by each study site as part of their standard operating costs to conduct verbal autopsies.

6.4 Results

6.4.1 Sociodemographic characteristics of deceased children and their households

Overall there were 53 under-5 deaths in 2017 in both Agincourt and AHRI, of which 12 (23%) were neonatal deaths (9 early neonatal deaths between 0-7 days of life, 3 late neonatal deaths 8-27 days of life), and a further 17 (32%) were infant deaths between 1-11 months. Twenty-one children (40%) died outside health facilities; 15 (28%) at home, 4 (8%) on route to a health facility and 2 (4%) elsewhere. A higher proportion of deaths occurred at home in AHRI (38%), compared to Agincourt (21%), though this was not statistically significant (p=0.176). Over half of VASA respondents (31/53, 58%) were parents, 16 (30%) were family members in the same household as the child, 1 (2%) was another relative not in the same household, 1 (2%) was a friend of the family, 3 (6%) had other relationships to the deceased and in 1 case (2%) the respondent's relationship to the child was unspecified. Table 6.2 provides a full description of the sociodemographic characteristics of the deceased children, overall and by study site.

Table 6.2: Sociodemographic characteristics of deceased children in both study sites, 2017

	Total n=53		AHRI n=24		Agincourt n=29		P value
	n	%	n	%	n	%	
Age group							0.469
0-27 days	12	23	7	29	5	17	
1-11 months	17	32	6	25	11	38	
12-59 months	24	45	11	46	13	45	
Median age at death, in months (IQR):	10 (1-26)	-	8 (0-25)	-	11 (2-29)	-	0.362
Sex							
Female	27	51	12	50	15	52	
Male	26	49	12	50	14	48	
Masculinity ratio (Boy/Girl x100)	96	-	100	-	93	-	0.350
Place of birth							
Hospital	43	81	19	79	18	62	
Other health facility	3	6	1	4	2	7	
Home	2	4	1	4	0	0	
On route to provider	0	0	0	0	0	0	
Other	0	0	0	0	0	0	
Unknown	5	9	3	13	9	31	
Place of death							0.490
Hospital	26	49	9	38	17	59	
Other health facility	4	8	2	8	2	7	
Home	15	28	9	38	6	21	
On route to provider	4	8	1	4	3	10	
Other	2	4	1	4	1	3	
Unknown	2	4	2	8	0	0	
Child's immunisation status							
Child immunised (self-reported)	42	79	17	71	25	83	0.225
Child vaccination card seen by interviewer	9	17	4	17	5	17	0.154

Table 6.3 details the sociodemographic characteristics of the mothers and households of the deceased children. All 53 mothers were still alive at the time of their child's death. Over 80% of mothers (43/53) were resident in the household, while 17% (9/53) were temporary migrants; in 1 case the mother's residency status was unknown. Migrancy rates in AHRI (25%) appeared to be double that of Agincourt (11%), though this was not statistically significant (p=0.174). Almost one third of mothers (7/24) were known to be HIV positive and one child was reported as HIV positive. The median household size was 10 people, with a median of two children under the age of five years per household. Overall, deaths were fairly evenly distributed across socioeconomic quintiles,

however this distribution differed between the sites. In Agincourt, 83% of deaths were from households in the lowest three socioeconomic quintiles - only 17% of deaths occurred in households that fell into the less poor and least poor quintiles. In contrast, in AHRI 66% of deaths occurred in households that were in the top two socioeconomic quintiles (less poor/least poor), and no deaths occurred in households in the poorest quintile.

6.4.2 Preventive care-seeking

Antenatal and perinatal care-seeking was consistent across the two sites. Over 70% (38/53) of mothers had been tested for HIV at least once, 13% (7/53) reported the mother was never tested, and 9% of respondents (5/53) were unsure. Eighty-nine percent (47/53) of mothers received professional assistance during delivery; 6% (3/53) did not and 9% (5/53) were missing data.

In total, 79% of children (42/53) were reportedly immunised appropriately for their age, though only 40% (21 respondents) reported that they still had a vaccination card for the child, and of those only 17% (9 vaccination cards) were available to be seen by the VA interviewer (table 6.2).

6.4.3 Pathways to Survival analysis (curative care-seeking)

Of the 53 deaths, five were excluded from further analysis, including one child who was born and died in a health facility without being discharged, and four deaths where no care-seeking data were available. Figure 6.2 shows the care pathway for the remaining 48 deaths.

Table 6.3: Sociodemographic characteristics of the households of deceased children in both study sites, 2017

	Total (n=53)		AHRI (n=24)		Agincourt (n=29)		P value
	n	%	n	%	n	%	
Maternal characteristics							
Mother Alive	53	100	24	100	29	100	-
Mother residency status at time of death							0.175
Resident household member	43	81	18	75	25	86	
Temporary migrant	9	17	6	25	3	11	
Unknown/unreported	1	2	0	0	1	3	
Mother's highest level of education							0.071
None	5	9	3	13	2	7	
Started/completed primary school	3	6	0	0	3	10	
Started/completed high school	36	68	14	58	22	76	
Tertiary education	6	11	5	21	1	3	
Unknown/unreported	3	6	2	8	1	3	
Mother employed	8	15	5	21	3	10	0.264
Mother's HIV status*							0.148
Positive	11	21	7	29	4	14	
Negative	34	64	12	50	22	76	
Unknown/unreported	8	15	5	21	3	10	
Mother's nationality**	(Not totalled)						-
South African			-	-	17	59	
Mozambican descent			-	-	8	28	
Unknown			-	-	4	14	
Household characteristics							
Median Household size (IQR) (including resident and non-resident members)	10 (6-13)	-	11 (8-18)	-	9 (5-11)	-	0.010
1-5 members	8	15	1	4	7	24	
6-10 members	20	38	9	38	11	38	
11-15 members	14	26	6	25	8	28	
>15 members	11	21	8	33	3	10	
Median number of children under-5 in the household (IQR)	2 (1-3)	-	2 (1-2)		2 (1-3)	-	0.089
Median number of household members employed (IQR)	1 (1-3)	-	2 (1-3)		1 (0-3)	-	0.057
Household head female	21	40	9	38	12	43	0.712
Household SES							<0.001
Poorest	9	17	0	0	9	32	
Poor	11	21	4	17	7	25	
Medium	12	23	4	17	8	29	
Less poor	14	27	13	54	1	4	
Least poor	6	12	3	13	3	11	
Mean distance to nearest clinic in km (SD)	2.56 (1.77)	-	2.70 (1.61)	-	2.44 (1.92)	-	0.599

*HIV status: the gold standard at AHRI was the recorded HIV status based on home testing. If this was unavailable, I used the HIV status as reported in the verbal autopsy. In Agincourt, all HIV data is as reported in the verbal autopsy.

**Immigration status only recorded in Agincourt. Assessment of immigration status was based first on the household classification in the Agincourt Household Data, and if unknown, then on reported nationality or former refugee status in answer to the verbal autopsy questionnaire.

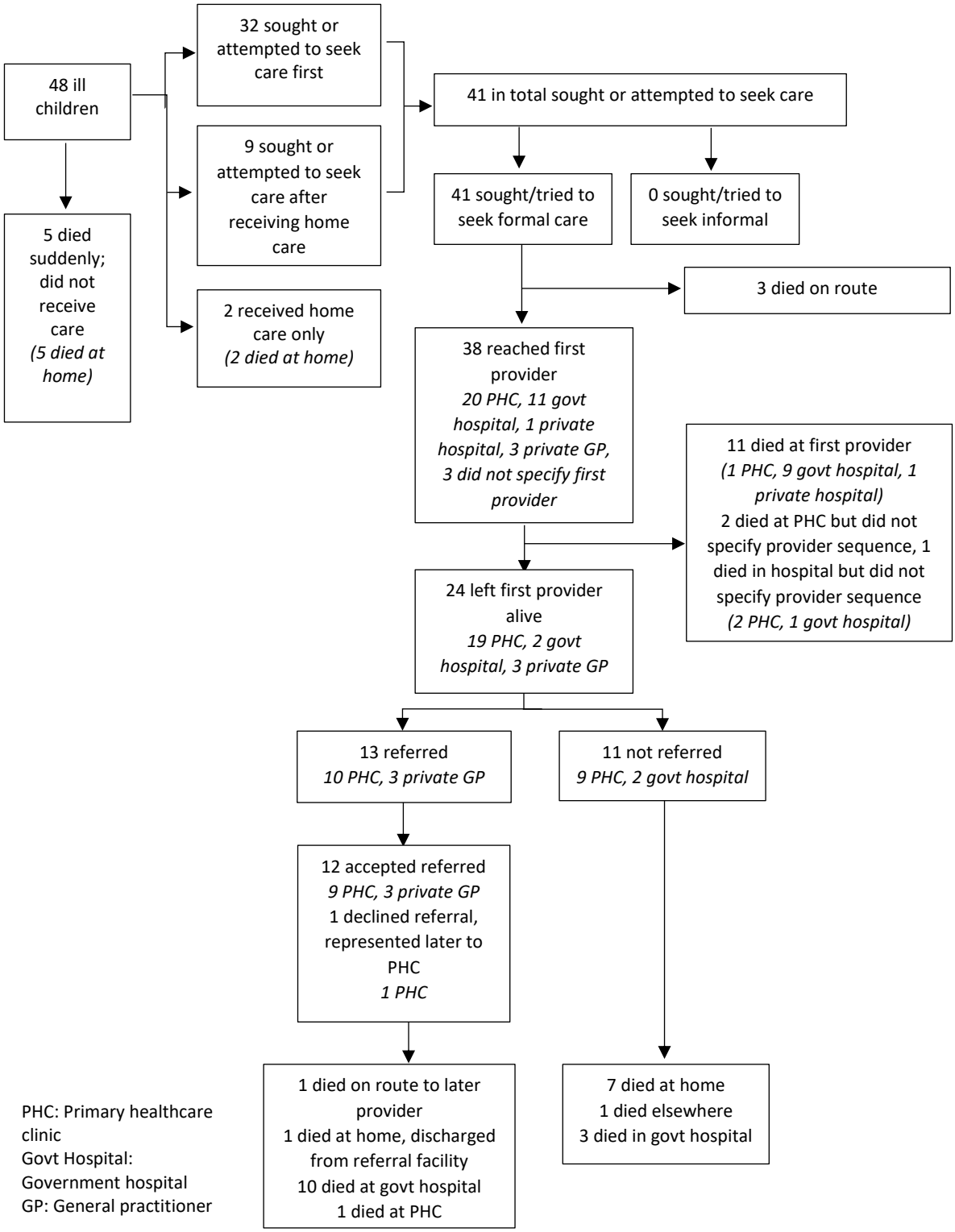


Figure 6.2: Pathways to Survival analysis of 48 child deaths in rural South Africa

Within the home

Of the 48 deaths, five children (10%) died suddenly without receiving any care including two children who reportedly did not display any signs of illness. Of the remaining 43 deaths, 39 children had symptoms or signs of illness including 34 with signs of severe or possibly severe illness; 4 caregivers did not recall any symptoms or signs of illness. Home care was given to 11 children (23%), including nine children with at least one severe or possibly severe symptom. All those given home care reportedly received western medicine; one also received traditional medicine.

Seeking healthcare outside the home

Forty-one caregivers (85%) sought or attempted to seek healthcare for their child outside the home. The median delay to seeking healthcare from the first provider was 0 days (IQR 0-1 day), however four caregivers of children with a severe or possibly severe illness delayed more than 24 hours to seek healthcare outside the home. Thirty-eight children (93% of those taken outside the home for care) arrived at a formal healthcare provider alive; three children died on route to the first provider.

Twenty-four children left the first provider alive (50% of all deaths, and 63% of those arriving at the provider alive). Only 13 of these children were referred to another facility (27% of all deaths, 54% of those leaving the facility alive) (figure 6.2). However, referral rates varied significantly between the study sites; in AHRI only two children were referred out of 10 who left the first provider alive (20%), whereas 11 of the 14 children leaving the first provider alive in Agincourt were referred (79%) (p=0.004). Reasons for referral included for better care (7 children), due to a lack of equipment (3 children), and the child was deteriorating (2 children). Almost all caregivers (12/13) accepted the referral for further healthcare. Of those children not referred, three sought healthcare again of their

own accord and died in a health facility, one died elsewhere and seven subsequently died at home (15% of all deaths, 47% of home deaths, 64% of those not referred). The median total duration of illness was two days (IQR 0-4 days).

All children taken outside the home for healthcare sought care from a formal public or private healthcare provider (General Practitioner (GP)/public clinic/hospital). Over half of children who attended a formal healthcare provider sought care from a primary care clinic first (figure 6.2). No child was reportedly taken to a traditional healer. Minimal difference was found in the proportion of children who sought or attempted to seek healthcare based on age group (90% of neonates taken for healthcare and 84% of infants and young children, p=0.644), or HIV-status of the mother (80% of children of HIV-positive mothers were taken for healthcare compared to 87% of children of HIV-negative mothers, p=0.581).

Seeking healthcare from multiple providers

Whether by referral or self-presentation, 16 children (33%) went to a second provider: four went to primary care clinics, 11 to government hospitals and one to a private GP. Overall, 21 children were taken to a single provider (including the three who died on route to the first provider), 12 to two providers, three to three providers and one to four providers. This excludes the two children who died in health facilities without specifying additional information about the number of providers accessed.

Place of death and care-seeking behaviour

Of the 48 deaths, 42% of children (20/48) died outside the health facility; 31% (15/48) at home, 8% (4/48) on route to a healthcare provider, and 2% (1/48) elsewhere. Twenty-one percent of children (10/48) died without receiving formal healthcare, including seven children who died at home and three children who died on route to the first health provider. Seventeen percent (8/48) of children died at home after receiving healthcare from a formal health provider.

Of deaths occurring in facilities, 10 of the 11 deaths that occurred at the first provider were in a hospital (i.e. the highest level of care). A further 13 deaths occurred in hospital following referral (resulting in 49% of all deaths occurring in hospitals). Only 4 deaths (8%) occurred in primary care facilities.

6.4.4 Care-seeking delays and barriers to accessing healthcare

As shown in table 6.4, Delay 1 (home delays) accounted for 44% of care-seeking delays. Approximately 29% of caregivers failed to recognise any severe or possibly severe symptoms, though this differed across the two sites, being a problem in 21% of cases in Agincourt but 40% of cases in AHRI (p=0.163). The median time to seeking care from the first provider was zero days from the onset of the illness (IQR=0-1 day; range 0-14 days). Four children with a severe or possibly severe symptom were not taken for care on the first day, again this affected a greater proportion of children in AHRI than in Agincourt (25% and 5% respectively, p=0.077).

Table 6.4: Three Delays Model

	Number of children	Denominator	Conditional proportion[1]	Relative weight[2]	Cluster total weight[3]	Proportional contribution[4]
Denominators						
# who went to at least one outside provider (a)	**39**					
# who went to more than one outside provider (b)	**16**					
# children reported with at least one severe/possibly severe symptom (c)	**34**					
# children referred (d)	**13**					
Total # child deaths (e)	**48**					
Delay 1 – home delay				**1/6**	**0.12**	**44%**
# children whose caregivers did not mention at least one severe or possibly severe symptom	14	e	29%	0.05		
# children with severe/possibly severe symptoms who received treatment at home	9	c	26%	0.04		
# children only receiving home treatment without going outside for care	2	e	4%	0.01		
# children delaying seeking care>1 day with severe/possibly severe symptom	4	c	12%	0.02		
# children who received informal care as both first and last source of care	0	b	0%	0.00		
# not going for referral because of caretaker decision-making	0	d	0%	0.00		
Delay 2 – transport delay				**1/2**	**0.00**	**0%**
# delaying >2 hrs to reach first and last provider	0	a	0%	0.00		

# children not going for referral because of lack of money for transport	0	d	0%	0.00		
Delay 3 – health facility delay				**1/3**	**0.15**	**56%**
# children obtaining treatment from provider after >1 hour from first or last provider	3	a	8%	0.03		
#children referred because of lack of equipment or lack of drugs	3	d	23%	0.08		
# deceased children who did not receive any treatment after visiting first or last provider	5	a	13%	0.04		

1 Conditional proportion calculated as Number of children/Denominator
2 Relative weight calculated as Conditional proportion*cluster weight
3 Cluster total weight calculated as the sum of the relative weights of each delay indicators in each delay cluster
4 Proportional contribution calculated as cluster weight/total possible weight

Delay 2 (transport delay) did not contribute to care-seeking delays when using the indicators included in this model. The majority of caregivers (27/39) used motorised transport to access care with their children. All caregivers reported that their nearest health facility was less than 2 hours away. Nine caregivers (19%), all from AHRI, reported that the total cost related to the final illness prohibited other household payments, however lack of money for transport did not result in failure to accept referral in any case at either study site.

Delay 3 (health facility delays) was the largest contributor to care-seeking delays, accounting for 56% of all delays. Most children were treated shortly after arrival at a health facility – only 3 children (8%) had to wait an hour or more to be attended to. However, 13% of children who accessed at least

one provider did not receive any treatment at the first provider or last provider, and 23% of referrals were due to lack of equipment or drugs (all in Agincourt).

6.5 Discussion

This study aimed to characterise the processes for providing care within the home and seeking and receiving care outside the home for children dying below the age of five, as a means of identifying modifiable factors that contribute to child deaths and which might serve as targets for intervention. This research reaffirmed findings from the previous chapter, namely that almost half of all under-5 deaths occurred outside of health facilities, including 28% of deaths that occurred at home, and that the large majority of children were taken for care during their final illness. However, this study goes further, highlighting that multiple failures existed at various points of the care pathway that contributed to mortality, particularly outside of facilities. These included failings both within the home and when accessing healthcare outside the home.

6.5.1 Sociodemographic Characteristics

Household characteristics were similar to those described in chapter 5, where the sample was much larger, and where data is consistent with national trends. As found in chapter 5, the median household size was large (10 members), with a median of 2 children under the age of five in each household. There were however differences between the study sites in terms of different distributions of deaths across socio-economic quintiles. In AHRI, over two thirds of deaths (67%) occurred in households in the less poor and least poor quintiles, whereas in Agincourt the majority of deaths (57%) occurred in households in the lowest two socioeconomic quintiles (poorest and poor households). This is a small sample and would not necessarily be representative of long-term

trends in the population. However, it is possible that the pattern of under-5 deaths across socioeconomic quintiles in AHRI is representative of patients who initially access private providers (general practitioners or paediatricians), paying for services with out-of-pocket payments. However, caregivers run out of money if the child needs to be hospitalised or required follow-up as they don't have medical aid or hospital plan cover. This group may also be increasingly sceptical of the quality of care in government facilities and so delay going to the public sector services even when they can no longer afford private care. These children fall into the gap between private and public health services. Finally, this study reaffirmed the high in-facility delivery rates, which is consistent with national data (11). However, numbers were too small to repeat the analysis of social determinants and place of death in this sample.

6.5.2 Failures along the care pathway

Care within the home

Overall 81% of caregivers recognised illness, including 69% with signs of severe or possibly severe disease. This is in keeping with rates of symptom recognition found elsewhere in sub-Saharan Africa, as described in chapter 2. However, nine children (26%) with severe or possibly severe symptoms received home treatment before being taken for formal care, and caregivers of four children (12%) with severe or possibly severe symptoms delayed more than one day to seek care. This might suggest that caregivers did not fully appreciate the severity of the symptoms and required urgency in seeking care. Similar concerns have been noted in other studies, which have suggested that contributing factors include underlying low levels of maternal education, low health literacy and differences in cultural interpretations of symptoms and causes of illness (12–15).

However, the social autopsy is not able to exclude other explanations for an apparent failure to seek care in the presence of severe illness. While the tool attempts to differentiate between the intention to seek care and the actual act of care-seeking and arriving at a health facility alive, such nuance may be missed by a respondent. The respondent might deny seeking care if delays prevented them from acting on an intention to seek care. Similarly, in cases where the cost of care-seeking is prohibitive (be that related to transport costs, doctors' fees, medications or even child care for those left at home), caregivers may have been unable to seek healthcare despite recognising the severity of the child's illness. These issues are explored in further detail in the next chapter, using qualitative data to explore these nuances and better understand caregivers' responses to signs of illness.

Care outside the home

Both preventive and curative care-seeking patterns suggest broadly high rates of access to formal healthcare services: 80% of caregivers reported that the child was vaccinated, with no difference noted based on place of death. Eighty-five percent of caregivers sought or attempted to seek care outside the home for their child during the final illness, including over 50% of children who died at home. All children reportedly used only formal healthcare providers, and about a third of children were taken to more than one provider (order of care-seeking presented in appendix 6.5). However, referral rates from primary care facilities to higher levels of care were low (54% overall and only 20% in AHRI).

Referral for further care

Referral might be an appropriate metric for quality of care at primary care clinics, the ability of healthcare workers to recognise signs of severe illness and also the degree of safety-netting or

follow up care that is in place. This is especially given the short duration of the final illness episode (median reported illness duration 2 days, IQR 0-4 days), suggesting that while it is possible that children were seen when they were still relatively well, it is unlikely to account for the failure to refer in all cases. Low referral rates have been reported in other social autopsy studies, particularly for neonates, where poor training in care for the sick newborn has been suggested as an important contributing factor (14). However, the social autopsy tool is an account of the final illness from the caregivers' perspective. It is possible that healthcare workers recognised the need for referral but were unable to overcome barriers to referral such as delays in, or a lack of ambulance transport, or a lack of available beds at the referral hospital. In such cases, healthcare workers may not have told caregivers of their desire to refer the child onwards and would have had to discharge children from the primary care clinics that did not offer 24-hour services.

Differences in the barriers to referral may best explain the significant difference in referral rates between the two study sites. On the one hand, if referral is a marker of care quality, this difference might reflect differences in the quality of care in the two provinces, which have been noted in the most recent District Health Barometer report (16).There is no evidence to suggest a difference in the severity of symptoms recognised by caregivers in the two study sites, or that the patients in Agincourt delay seeking care until the illness is more severe compared to caregivers in AHRI. However, on the other hand, an additional anecdotal explanation for this difference from members of the community and healthcare workers involved in the AHRI HDSS draws attention to the geography of the AHRI study site. The clinics serving this community are separated from the main referral hospital by a wildlife conservation area. This area is poorly lit and generally considered unsafe to cross at night, even in a car, as wild animals roam free. Ambulance services are also very slow to arrive at the clinics to transfer patients to the hospital, which adds to the difficulty of

referring children. Further data would need to be collected from the health facilities and relevant stakeholders to verify this hypothesis.

Care-seeking by age group

I did not find a difference in care-seeking patterns for neonates and infants and young children. In contrast, findings from the systematic review (chapter 3) showed much lower care-seeking rates for neonates – both as an absolute rate (approximately 50% of neonates taken for care in sub-Saharan Africa compared to 70% in this study) and when compared to infants and young children (elsewhere in sub-Saharan Africa care-seeking for neonates was lower than for children 1-59 months in the same region). The higher rates of care-seeking overall are likely to reflect the greater ease of access to healthcare facilities in South Africa – even in rural areas – compared to other sub-Saharan African countries. The average distance to the clinic from the households in this study was only 3km, and healthcare is free of charge for mothers and children under six years at government facilities. Furthermore, transport seemed more readily accessible with the majority of caregivers reporting that they used motorised transport to get to facilities, though we do not know how long they were delayed trying to find such transport.

The high in-facility delivery rates might also explain the higher rates of neonatal care-seeking in South Africa compared to elsewhere in sub-Saharan Africa. All neonates tracked through the care pathway had been discharged from the health facility where they were born. It is likely that children who are premature, low birthweight or ill after birth are identified in the facilities during routine post-natal checks and admitted for further care. This means that those children discharged after delivery are mostly healthy newborns with better survival chances, and in whom it is slightly easier

for caregivers to identify signs of illness. In this study, recognition of signs of illness amongst neonates was high with only one 27-day-old neonate having died without the caregivers identifying any signs of illness. Term, mostly well neonates also have more reserve to survive slightly longer after developing signs of illness, giving caregivers time to seek care. In contrast, in settings with high home delivery rates, there might be a greater delay in recognising signs of distress soon after birth, deciding to seek care and in being able to reach a healthcare facility resulting in lower care-seeking rates and more home deaths (17).

Choice of healthcare provider

Public healthcare providers were used much more frequently than private providers: 90% of caregivers sought healthcare for their child from a government provider (either primary care clinic or hospital) as their first provider, and all referrals were to a government healthcare facility. Only 6 caregivers (13%) utilised the private sector, and four (67%) went to a GP. While the high rates of care-seeking from government facilities may suggest relatively easy access to healthcare services, this finding might also reflect financial barriers which limit access to private GPs (whereas government healthcare is free). This is of concern as government clinics are notorious for having long waiting times, medication stockouts, variable quality of care and poor staff attitudes (18–20), Therefore, while rates of use are high, further research is required before I can determine whether this figure is a marker of good access to healthcare, or a function of lack of access to better quality health services. The challenge in understanding and evaluating access to healthcare was noted in the introduction to this thesis, and will be explored in further detail in the following chapter.

6.5.3 Applying the Three Delays Model

Delay 3 (health facility delay) was the largest contributor to deaths accounting for over 56% of delays, whereas Delay 1 (home delays) contributed the remaining 44% of delays. Using the Three Delays analytic framework which has been applied to neonatal and child deaths in Uganda and Ghana (3,10), Delay 2 (transport delay) is not an important contributing factor to childhood mortality in rural South Africa. However, previous studies, both qualitative and quantitative have highlighted the challenges of accessing transport when needing to get to a healthcare facility in South Africa, often noting that these difficulties are exacerbated in rural settings (19,21–23).

The conflicting results might reflect that the particular measures used as delay indicators are inappropriate for the South African setting e.g. the cut-off value of two hours travel time to a healthcare facility is too large for most communities (as in our study where the average distance to a clinic was 3km – much less than two hours to reach even by foot). Failure to accept referral due to lack of availability of transport is a necessary inclusion but does not account for the availability of hospital transfers or ambulances which, although often very delayed, are theoretically available across South Africa. It might be valuable to attempt to measure the time delay in securing transport (be that privately arranged or ambulance) as a more appropriate metric for transport delay in the South African setting.

One might also consider additional ways of collecting data about the relative importance of the cost of transport as a barrier to care-seeking. Surprisingly, the cost of transport was not highlighted as a problem by participants in this study. This could mean that such costs are genuinely lower than we expect, or that access to private transport through friends and family is more readily available.

However, this could also reflect respondent's reluctance to admit that cost was a barrier to seeking healthcare for their child. I explore this issue further in the next chapter.

Concerns of the appropriateness of the specific delay indicator metrics also arise in the estimation of Delay 3: health facility delays. Although poor referral processes are referenced as a potential source of health facility delays in the original model proposed by Thaddeus and Maine (9), the model applied to neonatal and child deaths in sub-Saharan Africa thus far fails to account for children lost from the formal care pathways due to lack of referral (3,10). Rather, it assumes that referral is always made when appropriate and so instead attempts to determine the reasons for referral as metrics for the quality of care available. Again, while the current measures are important, I would argue that the addition of "number not referred" would be valuable given that all children subsequently died. This information is readily available from the social autopsy which differentiates between 1) the number of children referred for further care, 2) the number of children who accept the referral and 3) the number of children who actually reach the referral facility.

6.5.4 Utility of the adapted Social Autopsy tool

The social autopsy provided insights into barriers to access and modifiable factors in under-5 deaths in these rural South African communities by detailing the processes of providing home care and seeking and receiving care outside the home during children's final illness. When added to the WHO 2016 verbal autopsy, it enabled a more comprehensive assessment of "cause of death", determining both biological and social causes. As a population-based data collection tool, the social autopsy identified modifiable factors for deaths outside of health facilities and provided greater clarity on pre-hospital factors as it collected data directly from the caregivers.

The VASA data supplements data collected by the existing facility-based audits in South Africa - the Perinatal Problem Identification Programme (PPIP) and the Child Health Problem Identification Programme (Child PIP) - which only collect data on deaths that occur in health facilities. These audits also offer limited insight into pre-hospital factors as they are completed by healthcare workers, without any input from caregivers or community members. Furthermore, while PPIP is performed in 92% of hospitals across South Africa (24), Child PIP coverage is much lower – estimated at 61% of hospitals (25).

Finally, by embedding the social autopsy tool into an existing longitudinal dataset, repeated use will allow for an assessment of changes in modifiable factors over time. This is important when evaluating the impact of interventions to increase access to quality healthcare and reduce mortality.

As with the verbal autopsy, it is critical that one identifies the appropriate respondent for the social autopsy interview, in other words the individual who was providing care for the deceased during the final illness and is able most accurately to recount the events around the time of death. However, even with the appropriate respondent, the social autopsy has limitations. First, it only collects data from the perspective of the caregiver as opposed to confidential enquiries, where stakeholders from multiple sectors are involved or facility-based audits. Possible implications of this have already been noted above with regards to collecting data on barriers to referral. Similar challenges arise when trying to accurately assess quality of care. Without medical records or input from healthcare workers who managed the child, one is unable to assess care quality, or indeed many of the avoidable factors that contributed to death at an administrative or health facility level.

Second, VASAs rely on the caregiver to remember and accurately recall the period around the child's death. Although evidence suggests that recall of symptoms is accurate up to a year after the death (26), recall bias remains a concern particularly in recounting the timing and sequence of care-seeking actions (3).

Third, social autopsies assume that caregivers will tell the truth about what happened. However, this might be especially difficult in the case of a child's death where caregivers might feel shame, guilt or fear that they will be blamed for the child's death if they did not recognise signs of illness, were unable to access healthcare or used traditional medicines and services (27,28). Indeed, even when children are taken to a healthcare provider, caregivers report that healthcare workers still blame them for their child's death often criticising them for failing to seek care sooner or using traditional medicines (19). It is therefore critical that interviewers conducting social autopsies create rapport with the respondent and remain non-judgmental.

6.5.5 Limitations

There are a number of important limitations to this study in addition to those inherent to the social autopsy methodology as described above. The first, as discussed in detail in the methods chapter (chapter 4), relates to the possibility of missing neonatal deaths. This is particularly the case in Agincourt where data collection happens annually and might partially account for a lower percentage of neonatal deaths (17% of the under-5 deaths in this sample compared to 29% in AHRI). Whilst at each household census, the household head is asked about all pregnancies, births and

deaths, it is possible that one might miss a full episode (pregnancy, birth and neonatal death) if it fell between census update rounds and was not reported by a household member. However, as discussed previously, there are many safeguards put in place to reduce the risk of missing neonatal deaths, including capturing pregnancies independently and training census workers to ask specifically for information about births and neonates.

Second, as mentioned above, although this study included all under-5 deaths identified at each study site for 2017, there were too few deaths to perform tests for associations between sociodemographic factors and particular care-seeking patterns. I was also limited in the trends I could identify in terms of the care pathways and would need to update this analysis following the subsequent VASA surveys to identify more subtle differences in care-seeking behaviors across age groups and study sites.

Third, I relied on self-reporting to collect vaccination status as very few vaccination cards were available to be reviewed. This is partly due to cultural practices of burying the vaccination card with the deceased child (as part of their possessions). It is likely that self-reporting overestimates the vaccination rates, and fails to account for children who were only partially vaccinated (and so their immunisations were not up to date given their age). For accurate vaccination data one would need to audit live children whose vaccination cards are still accessible.

Finally, it is likely that the rate of traditional medicine use, and consultation of informal healthcare providers was underreported, as noted in the previous chapter. HDSS teams are still seen as conducting “western research” and communities may fail to report practices which would be undesirable or criticised in those circles – such as the use of traditional medicine. This is even more

likely when nurses, clearly practitioners of “western medicine”, conduct the interviews as is the case in AHRI. By this same logic, it is possible that care-seeking from formal providers is overreported by caregivers.

6.6 Conclusion

Children who die at home represent a vulnerable group whose access to quality healthcare has been inadequate. The previous chapter identified those social determinants which were associated with home deaths, notably low maternal education. But importantly, it also demonstrated clearly that home deaths were not purely a function of failure to seek healthcare, suggesting that there might be problems with accessing and receiving healthcare further along the care pathway. By using an adapted social autopsy tool, I characterised the processes of seeking and receiving healthcare during a child’s final illness, including where and when care was accessed, and barriers which delayed the provision of healthcare and contributed to death.

Overall rates of care-seeking were high across all age groups at both study sites. Nevertheless, improved caregiver recognition of signs of illness is still needed, particularly to reduce home deaths. However, this alone is insufficient – parallel efforts are required to adequately retain children in formal care pathways with particular attention paid to referral and follow-up care services. Furthermore, if such interventions are to be effective, in-depth qualitative research is required to understand not just where, but why children are lost from formal care pathways looking at both supply- and demand-side factors. Insights into the impact of caregivers’ experiences of seeking healthcare, the impact of these experiences on subsequent decision-making during their child’s illness, whether they were able to overcome barriers to access quality healthcare and how they

achieved this, are crucial to designing effective interventions targeting different stages of seeking and receiving healthcare. Recommendations arising from these findings are discussed in chapter 8.

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Chapter 7: Caregivers' behaviours and decision-making during a child's final illness - a qualitative study

7.1 Introduction

The previous chapters have shown that home deaths in rural South Africa persist despite high rates of care-seeking during a child's final illness. By one measure of access to care – namely that of health service utilisation – this finding may be interpreted as demonstrating that access to healthcare was high during the child's final illness. However, defining access to healthcare in terms of utilisation of services has long been criticised as an inappropriate metric, particularly if used in isolation (1). Low utilisation rates may reflect inability to utilise healthcare services when desired, which would indeed suggest limited access. But they may also reflect patients' choices, either to use an alternative service, or just not to use a given healthcare service if, for example, it is perceived to be of low quality and patients can afford to pay to go elsewhere. Similarly, high utilisation rates may mask lack of access to higher quality services. Utilisation of public services by vulnerable populations may appear good on the surface, but in fact reflect inability to use private healthcare or better quality paid services (1).

As has been argued throughout this thesis, a broader way of interpreting access is the "freedom to utilise services" (2). This approach takes into account not just the final utilisation rates (which may both over or under-estimate access), but the "degree of fit" between patient and provider (3) and the extent to which patients can truly choose where and when they engage with different healthcare service providers. Access is therefore a *relational* concept involving both supply and demand-side factors, reflecting that patients *interact* with the healthcare system, and that this interaction can

adapt to create a better "fit" (1,2). In this broader understanding of access, the acceptability and adequacy of healthcare services are as important as their availability (1).

To this end, the identification of modifiable factors is an important first step in trying to unpack whether access to healthcare is adequate and which factors act as barriers to access. In chapter 6, I identified modifiable factors both within and outside the home, highlighting the different stages where children were lost from formal care pathways. I used the Pathways to Survival Framework (4) as the conceptual model for analysing care-seeking processes and demonstrating the fluid interaction between healthcare provided within and outside the home. This model was also used in the systematic review in chapter 3 for the very reason that it provides a standard shared conceptual model that can be applied across contexts to discuss processes of seeking healthcare and the associated modifiable factors active at each stage of those processes. However, the Pathways to Survival Framework is an outline of how we envision care-seeking *should* work. It is an over-simplification of the care-seeking process and relies on the assumption that if each stage of the process "works" then the child will survive. This model may not reflect what *actually* happens in a given context.

Understanding these actual care-seeking processes is important if we are to go beyond identifying modifiable factors, to designing interventions. A richer understanding of caregivers' lived experiences of seeking healthcare and the reasons underlying caregivers' decisions helps support the development of more effective, targeted and tailored interventions.

This chapter therefore aims to describe and explain caregivers' accounts of care-seeking processes in fatal child illness in rural South African communities by better understanding caregivers' experiences. This approach recognises the "socialized nature of healthcare" (5), and therefore the importance of caregivers' wider household and community context. I will explore the shaping of caregivers' experiences of seeking healthcare through the lens of social exclusion and capability deprivation (6), arguing that their experiences tend to reinforce the lived experience of poverty, although in some cases, caregivers draw on their social capital to claim decent healthcare (7). These experiences drive deviations away from the Pathways to Survival conceptual model which will be discussed is Section 7.4.5.

7.2 Aims and objectives

Aim

To better understand caregivers' behaviours and decision-making in seeking and receiving healthcare during a child's final illness.

Objectives

1. To better understand caregivers' experiences of seeking healthcare during their child's final illness.
2. To better understand factors that contributed to delays in accessing healthcare.
3. To explore what strategies caregivers found useful in overcoming the barriers they faced in accessing formal healthcare services in South Africa.
4. To adapt the Pathways to Survival Framework to reflect the caregivers' accounts of the processes of seeking and receiving healthcare during a child's final illness in rural South Africa.

7.3 Methods

7.3.1 Study design

This was a qualitative study using semi-structured in-depth interviews and focus group discussions with caregivers of deceased children. This study was conducted in the Agincourt and AHRI health and demographic surveillance system (HDSS) sites: the history, geography and community-context of these study sites have been described in chapter 4.

In-depth Interviews were used to gather personal narratives of the time around the child's death, from the point at which the caregiver noted that something was wrong, through the processes of providing care within the home and seeking and receiving healthcare outside the home, to the child's deterioration and death and what happened afterwards. I chose to use semi-structured interviews as they offered the opportunity for respondents to describe events "in their own words"(8), while also allowing interviewers to explore pre-specified topics (8,9).

Focus group discussions are fairly formal discussions with a suggested topic guide, but not rigid in their structure (10). This format was felt to have particular advantages for this study, notably that it provides a supportive environment to discuss sensitive topics, often encouraging participants to disclose information they might not have been comfortable to discuss with a researcher in an in-depth interview (a much more contrived environment); and that it encourages participation in research where people might be intimidated to participate one-on-one (11,12). Participants may also jointly undertake a sense-making exercise from shared experiences thereby producing a communal narrative (12). Focus groups had the potential to offer insights into how issues such as

traditional medicine use, the quality of healthcare and child death are or are not discussed within the community. Focus groups were also used to validate findings from individual interviews.

7.3.2 Participants and sampling

Primary caregivers self-identified as the main person who cared for the child during the illness leading to death. In most cases this was the child's mother, however given high levels of temporary migration in the community (as described in chapter 4), grandmothers and aunts were sometimes the more appropriate respondent. This is the same technique used to identify the respondent for verbal autopsies conducted routinely for all deaths across the study sites.

Caregivers were eligible to participate if their child died below the age of five years and a verbal and social autopsy had been completed between June 2017-January 2018 by the Agincourt and AHRI HDSS verbal autopsy teams. Maximum variation purposive sampling was used to select caregivers for interviews and focus group discussions, who were then re-approached to participate in this qualitative study. This sampling strategy ensured we had the widest variety of perspectives, capturing both those which are more typical and those which are unusual or more extreme (13). Consideration was given to place of death (at home or in a health facility), the age of the child at death, the socioeconomic status of the household, whether the child or mother was known to be HIV positive and whether the mother was a temporary migrant at the time of the child's death. These factors were selected based on data from chapter 5 and previous work which has shown associations between these socio-demographic characteristics and child mortality, place of death, and care-seeking during the final illness (14–17). Selection of participants for the final focus group discussion in AHRI largely sampled participants based on place of death (first approaching caregivers

whose children had died at home), as we did not yet have a clear understanding of why children died at home despite seeking healthcare during the final illness.

7.3.3 Data collection and processing

Data collection took place from July 2018 to January 2019.

Semi-structured in-depth interviews

Interviews were conducted by three local researchers fluent in isiZulu or Xitsonga (the local languages in AHRI and Agincourt respectively). All interviewers were non-medical (i.e. they were not doctors, nurses or community health workers) so as to minimise the effect of the social desirability bias (8) which often leads to under-reporting of traditional medicine use, and may discourage participants from speaking freely about their experiences of the healthcare system (particularly negative experiences).

I reviewed interview techniques with all interviewers and trained them on the use of the interview guide. One interviewer was new to qualitative research and I worked with her on how to approach a participant, explain the study and obtain consent, build rapport, ask probing questions, take field notes while conducting the interview and what to include in the field notes. The participant information sheet and consent form are included as appendix 7.1.

I developed the initial interview guide on the basis of findings from chapters 5 and 6, and background literature (18–22). I worked closely with my supervisor Dr Lisa Hinton to develop a suggested topic structure which would build rapport and allow participants time to settle in to the interview before focussing in on the details of the child's death given the sensitivity of the topic and

possibility for participant distress. The topic guide therefore included “safer” questions about household and community context early on in the interview which were possible entry points that the interviewers could use in situations where participants did not readily jump into talking about their deceased child. The full interview guide, attached as appendix 7.2, broadly covered the following issues:

- Household and community context
- The child’s final illness - how it started, when caregivers first noticed symptoms and what action they took
- Caregivers’ experiences of seeking healthcare during the child’s final illness
- Traditional medicine
- Reasons for choosing the health providers that they did (both formal and informal providers)
- Barriers in accessing healthcare and strategies used to overcome those barriers.

Interviews were conducted at the participant’s home, at a time that was convenient for them. Interviews lasted between 30-60 minutes on average and were digitally audio-recorded. The interviewers were responsible for transcribing and translating each interview into English. I reviewed each transcript with the interviewer and made adjustments to the interview guide as appropriate. This was an iterative process, using a combination of inductive and deductive approaches (23,24), starting from the initial interview guide described above and adapting this to include new issues which arose from each interview.

Focus group discussions

The same three interviewers acted as moderators for the focus group discussions – two in AHRI and one in Agincourt. In addition, a fourth research assistant from the qualitative research team in Agincourt was brought in to assist with the management and logistics of the focus group in Agincourt. Additional training was provided to all four moderators to review core skills around managing group dynamics, moderating discussions, note taking and to go through the topic guide. The focus groups were held at the main offices in AHRI and Agincourt respectively. Moderators arranged to fetch each participant from their home to bring them to the office, and to drop them off at home afterwards as access to transport is limited in these areas.

Each focus group discussion was small – there were four participants in Agincourt and five in AHRI. I specifically chose to have smaller groups as this tends to produce richer discussion with greater opportunities for each member of the group to participate in the discussion. They are also easier to manage particularly given the sensitive nature of the discussion where there was a greater risk of distress (12,25). The smaller size was also favourable logistically as we could more readily arrange transport to and from the venue for a given date and time for smaller groups. However, I was aware of some of the disadvantages of smaller groups, such as a more homogenous expression of experiences, and a possible "stuttering" of the discussion whereby participants either disengage or the discussion slows (12,26).

Each focus group discussion was divided into two parts, and a meal offered to participants in the middle. Each part lasted about an hour, with a thirty-minute break for lunch. The first part of the discussion focused on personal experiences of childhood illness, and impressions of whether these were consistent across the community at large. Moderators probed around experiences of seeking

and receiving healthcare during the final illness, whether these were convergent or divergent and what factors participants thought led to these differences. They also probed around communal attitudes towards traditional medicine, differences in care for HIV positive patients, and participants' impressions of challenges specifically contributing to home deaths of children. The second part of the focus group discussion was structured around sharing some of our findings from the in-depth interviews with the group as a means of validating this data. Moderators sought recommendations from the group for interventions to address the challenges they had identified in the first part of the discussion, and that we had identified from the interviews.

Data storage

All data storage and sharing was managed as per the local HDSS and Oxford data protection protocols. Audio-recordings were only stored on HDSS local servers, encrypted and password protected, and only accessible to the interviewer. Transcripts were anonymised as part of the transcription process and were stored in a separate folder on each HDSS server, accessible to authorised study staff (including the interviews, local co-investigators and me). All data is to be kept by the HDSS sites for 10 years.

Participant reimbursement

Participant reimbursement varied across the two study sites in accordance with standard practice at each HDSS. In Agincourt, no monetary participant reimbursement is permitted as the population is poor and monetary incentives might drive community members to agree to participate out of financial desperation. One can reimburse travel costs if directly incurred by the participant and provide meals. Interview participants were not reimbursed as they did not incur any costs and

interviews were held at their homes. Participants in the focus group discussions received a meal, and we provided free transport.

In AHRI, standard practice is to reimburse participants with R50.00 (50 South African Rands), which we gave to all participants. However, the amount was not advertised as part of the consent procedure so as to avoid pressuring caregivers to participate out of financial need. Participant reimbursement was not conditional on participants completing the interview or focus group. We also provided lunch for those who attended the focus group discussion and covered the transport costs.

Reflexivity

At all stages of the data collection process the interviewers kept notes on their own biases, and responses to the interviews which would be discussed with me to consider the impact of their own positionality on the data. I was conscious of my own biases and experiences, being a white South African of high socioeconomic status, having trained as a doctor and worked in the pubic healthcare system. After consulting with colleagues who work at each of the HDSS sites, I decided that given my own positionality, and the inherent power imbalances that exist based on race, class and educational training between myself and many of the caregivers, it would be best not to attend the interviews in person as an observer. I attended the first focus group discussion in Agincourt, as I thought that my presence would be less problematic in a larger group, and where I would be able to observe body language and better appreciate the flow of the discussion. However, my inability to understand the language meant that I could not respond appropriately to the conversation and

this seemed to make participants uncomfortable; some felt they needed to translate or explain for my benefit. I therefore decided not to attend the second focus group discussion in AHRI.

My experience as a doctor also impacted on my analysis and interpretation of data: I was tempted to pass judgment on the appropriateness of care-seeking actions and the quality of care received based on my own assessment of the child's condition from the caregiver's description. I was also conscious of the harmful effects of certain traditional medicines on children. Discussing the coding scheme with co-investigators, and reviewing the analysis with my supervisors Dr Lisa Hinton, Dr Merlin Willcox and Dr Kathleen Kahn reduced the impact of this bias and helped contain the conclusions within the limits of what could reasonably be drawn from the data.

The positionality of the interviewers may also have influenced the interviews and focus group discussions. Interviewers were from the same communities as participants and often shared their world view, including beliefs around illness, appropriate treatment practices, and had used the same healthcare services. This may have meant that participants felt more comfortable to discuss traditional medicine use and problems with the health service with them. However, interviewers may also have taken certain behaviours and practices, particularly around the use of traditional medicines in the home, for granted. As a result, interviewers did not always probe participants to fully explain these locally accepted practices. Interviewers may also still have felt uncomfortable to fully probe issues of traditional medicine use, despite having been trained, given my own affiliation with the formal healthcare service, Agincourt's positionality as a research unit affiliated to the University of Witwatersrand school of Public Health and AHRI's affiliation to University College London (UCL) and the London School of Hygiene and Tropical Medicine (LSHTM).

7.3.4 Data analysis

I undertook a thematic analysis (27,28) to identify and analyse the main themes emerging from the interviews and focus group discussions. Thematic analysis refers to a "method for identifying, analysing and reporting patterns (themes) within data" (Braun and Clarke, 2006) (28). Using this definition, thematic analysis is not merely a description of what was said by participants, but a process by which the researcher interprets the data to answer a specific research question (28). I developed a coding scheme based on the topic guide (deductive codes) and interview and focus group content (inductive codes) and grouped related codes into themes. I developed the initial coding scheme from a sample of six interview transcripts, which I discussed with my supervisor, Dr Lisa Hinton. These transcripts were then independently coded by one of my supervisors (Dr Merlin Willcox) to confirm and expand the coding scheme. Thereafter a team meeting was held including all co-investigators (JP, MW, LH, AH, JS, KK) to agree on a coding framework, which I then used to code all 29 interviews and the focus group discussions. Additional analysis meetings were held with my supervisor Dr Lisa Hinton to discuss emerging themes and interpretations. I used the One Sheet of Paper (OSOP) method (27) to summarise each of the codes relating to a given theme, being careful to retain nuances across different accounts to represent both convergent and divergent experiences. Findings from the interviews were validated by presenting them to focus group discussions.

In developing my analysis, I adapted the Pathways to Survival Framework (4), demonstrating the stages of the care-seeking process at which each major theme acted, and how caregivers' accounts of the processes of seeking and receiving healthcare in rural South Africa communities deviated from the those outlined in the original model.

I used NVivo 11 (QSR International, Australia) to assist in data management, coding of transcripts and organisation of codes into themes.

Data saturation

Data saturation is said to be reached at the point where further data collection (in this case additional interviews) do not yield new information, new themes or new coding. It is a reflection of the depth of the data and suggests a replicability of the study (29,30). In consultation with my supervisor Dr Lisa Hinton, I considered that data saturation was reached for the major themes after 10-12 interviews at each study site, and a further 3-4 interviews per site did not alter the understanding of the main themes. In the end 14 semi-structured in-depth interviews were conducted in AHRI and 15 in Agincourt.

7.3.5 Ethics

This study was approved by the Oxford Tropical Research Ethics Committee (OxTREC ref: 509-18), the University of Witwatersrand Human Research Ethics Committee (Medical) (M180102), the Mpumalanga provincial health research committee (MP_201804_006) and the University of KwaZulu-Natal Biomedical Ethics Research Committee (BE259/18). Prior to approval, I sought input from the relevant community engagement fora at each study site, which resulted in additions to the protocol to ensure adequate psychological support was available for participants and researchers given the sensitive nature of the questions being asked.

7.3.6 Funding

This work was funded by the Grand Challenges Research Fund (0005119), the Africa Oxford Travel Grant (AfiOx-19), the Murray Speight fund and Green Templeton College, through a Green Templeton Competitive Conference or Fieldwork Funding grant.

7.4 Results

Respondent demographics and key case details are presented in tables 7.1 and 7.2 respectively. Of a total of 38 respondents, 29 were parents (27 mothers, two fathers), seven grandmothers and two aunts. Interviews and focus group discussions detailed events relating to a total of 38 deaths, comprising four neonatal deaths (0-27 days), 16 deaths of infants 1-11 months and 18 deaths of children 1-4 years. Nineteen children had died in health facilities, 16 at home and three on route to a health facility. Overall 32 caregivers had sought formal healthcare for their child during the child's final illness. Eight caregivers used traditional or faith-based medicines and practices during the final illness, all of whom also sought formal healthcare. A further four indicated that traditional medicines and practices had been used in previous illness episodes for the child or other family members even if not used in the final illness. Three caregivers did not provide home care or seek either formal, traditional or faith-based care outside the home (table 7.1 and 7.2).

Table 7.1: Summary of characteristics of respondents and their deceased children

Characteristic	Total (N=38)		Agincourt (N=19)		AHRI (N=19)	
	n	%	n	%	n	%
Age of the deceased child						
0-27 days (neonate)	4	11	2	11	2	11
1-11 months	16	42	9	47	7	37
12-59 months	18	47	8	42	10	53
Relationship of respondent to the deceased						
Mother	27	71	10	53	17	89
Father	2	5	2	11	0	0
Grandmother	7	18	5	26	2	11
Aunt	2	5	2	11	0	0
Place of death						
Home	16	42	6	32	10	53
Healthcare facility	19	50	12	63	7	37
On route	3	8	1	5	2	11
Household socioeconomic quintile						
1	8	21	7	37	1	5
2	9	24	5	26	4	21
3	7	18	4	21	3	16
4	7	18	1	5	6	32
5	7	18	2	11	5	26
Mother HIV status						
Positive	8	21	3	16	5	26
Negative	23	61	14	74	9	47
Unknown/unreported	7	18	2	11	5	26
Mozambican descent	Not totalled		4	21	-	-
Sought formal healthcare outside the home	32	84	16	84	16	84
Used traditional medicine or consulted a traditional healer for child's final illness	6	16	1	5	5	26
Used traditional medicine or consulted a traditional healer for previous childhood illness	10	26	3	16	7	37

Table 7.2: Individual participant characteristics

Participant ID	Method: IDI or FGD[Ŧ]	Age group of child who died	Respondent's relationship to deceased child	Place of death	Cause of death	Household socio-economic quintile (1=poorest, 5=least poor)	Sought healthcare outside the home	Used traditional medicine or consulted a traditional healer for child's final illness
1	IDI	1-11 months	Mother	Home	Acute respiratory infection	4	Yes	No
2	IDI	1-11 months	Mother	Home	Acute respiratory infection	3	No	No
3	IDI	1-4 years	Grandmother	Home	Unknown	5	Yes	No
4	IDI	1-4 years	Grandmother	Health facility	Other and unspecified external cause of death	5	Yes	No
5	IDI	1-11 months	Grandmother	Health facility	Acute respiratory infection	2	Yes	No
6	IDI	Neonatal	Grandmother	Health facility	Acute respiratory infection	1	Yes	No
7	IDI	1-4 years	Mother	Health facility	Acute abdomen	3	Yes	No
8**	IDI	Neonatal	Father	On route	Neonatal sepsis	1	Yes	Yes
9	IDI	1-11 months	Father	Health facility	Acute respiratory infection	3	Yes	No
10	IDI	1-4 years	Mother	Home	Burns	1	Yes	No
11	IDI	1-11 months	Mother	Home	Unknown	1	No	No
12	IDI	1-4 years	Aunt	Health facility	Unknown	1	Yes	No
13**	IDI	1-11 months	Mother	Home	Unknown	2	No	No
14	IDI	1-11 months	Mother	Health facility	Acute respiratory infection	2	Yes	No
15	IDI	1-11 months	Mother	Health facility	Acute respiratory infection	3	Yes	No
16	FGD	1-4 years	Grandmother	Health facility	Burns	2	Yes	No
17	FGD	1-4 years	Aunt	Health facility	Acute abdomen	1	Yes	No*
18	FGD	1-11 months	Mother	Health facility	Acute respiratory infection	1	Yes	No
19	FGD	Neonatal	Mother	Health facility	Birth Asphyxia	2	Yes	No
20	IDI	Neonatal	Mother	Health facility	Birth asphyxia	2	Yes	No
21	IDI	1-11 months	Mother	Home	Meningitis or Encephalitis	4	No	No
22	IDI	1-4 years	Mother	Health facility	Unknown	3	Yes	No
23	IDI	1-11 months	Mother	Health facility	Meningitis or Encephalitis	4	Yes	No
24	IDI	1-4 years	Mother	Home	Unknown	4	Yes	No
25	IDI	1-4 years	Mother	Home	Diarrhoeal disease	4	Yes	No
26	IDI	1-4 years	Mother	Home	Unknown	2	Yes	No
27	IDI	Neonatal	Mother	Health facility	Acute respiratory infection	4	Yes	No

Participant ID	Method: IDI or FGD[Ŧ]	Age group of child who died	Respondent's relationship to deceased child	Place of death	Cause of death	Household socio-economic quintile (1=poorest, 5=least poor)	Sought healthcare outside the home	Used traditional medicine or consulted a traditional healer for child's final illness
28	IDI	1-4 years	Mother	Home	Unknown	3	No	Yes
29	IDI	1-4 years	Mother	Health facility	Acute respiratory infection	4	Yes	Yes
30	IDI	1-4 years	Mother	Health facility	Acute respiratory infection	3	Yes	Yes
31	IDI	1-11 months	Mother	Home	Unknown	2	Yes	Yes
32	IDI	1-4 years	Mother	Home	HIV/AIDS related death	1	Yes	No
33	IDI	1-11 months	Mother	On route	Diarrhoeal disease	5	No	Yes
34	FGD	1-11 months	Grandmother	Home	Unknown	5	Yes	No
35	FGD	1-11 months	Mother	On route	Diarrhoeal disease	5	Yes	No
36	FGD	1-4 years	Grandmother	Health facility	Severe malnutrition	2	Yes	No
37	FGD	1-11 months	Mother	Home	Diarrhoeal disease	5	Yes	Yes
38	FGD	1-4 years	Mother	Home	Meningitis or encephalitis	5	Yes	No

*This participant did not use traditional medicines or consult a traditional healer, but went to consult "prophets" (considered faith-based healers)

** The respondent was a traditional healer

Ŧ IDI - In-depth Interview; FGD - focus group discussion

The main themes to emerge from the analysis relate to **(i) caregiver knowledge and advice-seeking, (ii) the use of traditional medicines and practices, (iii) transport barriers, and (iv) experiences of care-seeking during the final illness**. Caregivers' knowledge and understanding of childhood illness varied: while in some cases caregivers clearly did not appreciate the severity of the child's symptoms or the cause of the illness, at other times they correctly identified problems but were dismissed by healthcare workers. There were frequently mismatched expectations and assumptions of knowledge both on the part of the caregiver and on the part of the healthcare provider. The role of traditional medicine and practices must also be viewed in this context of mismatched expectations and knowledge. Transport was consistently identified as a barrier to seeking and receiving care – both private and ambulance transport, from home to the health facility, and between facilities. Finally, experiences of care-seeking (both positive and negative) were clearly coloured by caregiver's pre-existing expectations and past experiences of the healthcare system.

7.4.1 Caregiver knowledge and advice-seeking

Some caregivers appear to have lacked insight into their child's condition, failing to recognise or appreciate the severity of symptoms or understand why the child died. Participant 29, a young mother still attending secondary school, described her child having a seizure in the early hours of the morning. *"During 01:00 am she had fits and was foaming at the mouth. We then called my in-laws, they took her here at home. They burnt incense for her and she was getting better. We left her, and I went to school in the morning."* Participant 21, a mother in her mid-20's whose infant died at home, admitted that she *"never thought that he [her child] cried because he was sick, (she) thought it was normal for all the babies."* She expressed regret at not taking the child to the hospital sooner, but she just *"never thought"* the child was ill. Older caregivers also sometimes inappropriately assessed a child's condition as 'normal': participant 6 described that her grandchild, who was a

month old when she died, was *"very thin" but "we were just telling ourselves that it does happen for a child to be born while thin and gains weight while growing up."*

When caregivers were uncertain about a child's illness, they sometimes turned to family members and neighbours for advice in assessing the child's illness and the need to seek care outside the home. Participant 10, a mother whose child was burnt with boiling water, was uncertain about the severity of the injury and consulted with *"the old ladies from nearby, the one from that family and the one who is our neighbour. They are the ones who told me that I have to go to the clinic".* However, in general, mothers felt that such consultations were not about seeking family members' permission to take a given action, but rather consulting them in an exercise of joint decision-making based on a joint assessment of the child's condition. Participant 26, mother of a neonate who died in a health facility, explained their household's usual processes of assessing child illness and whether further care is needed: *"we normally discuss [the child's condition] with whoever is around home. If it's my sister's child who is sick I can decide to take the child to the clinic, but we see to it together. With anyone who is at home by that time".* A similar experience was noted by participant 6, who reflected that she, the child's grandmother, and the child's mother, were both uncertain about the child's illness. *"We were sharing ideas on what to do. Even my daughter's sister in-law was also here and she is the one who said that it is better to take the child to the clinic."*

7.4.2 Traditional medicine and practices

Traditional medicine and practices in this setting exist within a complex set of interactions and belief systems which are important to disentangle. On the one hand, it is clear from the data that almost all households practice cultural traditions or rituals related to African ancestral belief systems which underpin their worldview. These include burning incense and slaughtering animals to communicate

with the ancestors. Such rituals are part of creating a sense of wellbeing, and are used to *"ask for something and speak [to the ancestors]"* (participant 21). Most participants believed such rituals would provide *"protection"* (participant 21), or *"give us good luck"* (participant 27), or more generally provided *"assistance that we need"* (participant 29).

Layered over these cultural rituals and traditions are specific health-related practices and belief systems. These may include the use of traditional healers and medicines (either exclusively or in combination with allopathic medical care). However, participants were clear about differentiating belief in traditional healers from the practicing of cultural rituals and traditions, with the former being much less common than the latter.

> Participant 25, the mother of a young child who died at home, commented:
> *"Yes, [we practice] the burning of incense, also that we do slaughtering. In most times maybe we slaughter goats when we have something we will be doing…It happens that maybe we do our late granny's ceremony, you see that? It is something like that. "*
> *But this participant also noted "In our church we don't go for traditional healers nor faith healers. We don't believe in traditional healers, we don't believe that there are witches while there is God, we don't know that."*

The motivations for using traditional medicines and traditional healers varied. In the case of traditional medicines, some caregivers admitted to administering enemas as part of the care they provided within the home. For some, enemas were used commonly as part of a general routine to promote well-being or treat common symptoms of mild illness. As described by participant 30, whose mother frequently administered enemas to the grandchildren: *"children here at home are*

being given enemas when the sun is too hot to release the gall. She used to enema them, not only my child but all the kids at home. As hot as it is today, she would enema them to cool the heat". Participant 31 noted that her mother had given the child an enema as *"she thought it was just the cold or flu because he was coughing".*

For others this treatment choice seemed driven by a desperate desire to help their child, to do *something* while at home. Many were aware that nurses and doctors advise against giving traditional enemas to children because they can be dangerous, but caregivers did not seem to know what to do instead and didn't want to do nothing. This came through particularly strongly in the AHRI focus group: participant 35 commented *"it's not easy. They say children should no longer be given enemas. [But] you are also trying to help."* Participant 36 noted that *"you start treating [the internal sore] yourself because the clinic is far."*, and when asked to clarify what treatment she would start with she clarified *"Putting the Colgate [toothpaste] in the child's behind."* Caregivers did not express a strongly held belief that the illness had an underlying traditional cause.

Those caregivers who consulted traditional healers during the child's final illness all did so as a last resort, out of desperation as they did not know what else to do to help their child. *"I thought I will go to someone [a traditional healer] to hear what is really happening for I've been to the clinic there were no help, I go to the doctor I get no help"* (participant 24, mother of young child who died at home despite seeking care). Participant 29, whose child died in a health facility, described similar reasoning: *"my father-in-law insisted that we should take her to the doctor. She got worse after we return from the doctor. My father-in-law and my husband said we should take her to the traditional healer."*

This reasoning was also echoed in the AHRI focus group discussion in relation to the use of traditional healers in other illness (be that for adults or children): as participant 37 put it *"you can see that maybe you need pills or rubbing ointment and get them, but if it continues…what must you do? Go to a traditional healer to give you something that will relieve you. And you see that this really needed traditional medicine".* However, some caregivers also indicated that in previous illnesses of their other children or family members, they believed that the cause of the illness was traditional and so sought traditional treatment first, believing it was the most appropriate means of healthcare. This was the case for participant 35 who described that *"(her) older child was easily startled, and at home they kept on saying (she) must do a traditional ritual".*

7.4.3 Transport barriers

Caregivers from both study sites consistently identified a lack of transport as a significant barrier to accessing healthcare, in contrast to the quantitative data presented in the previous chapter. Transport costs could be prohibitive and *"there are people who end up not getting to clinic because they don't have money for transport."* (participant 26, mother of a young child that died at home). Participant 9, a father from Agincourt, and participant 30, a mother from AHRI, noted that ambulances were slow or unavailable. Arranging a private car was difficult and often caused delays with disastrous consequences. As noted by participant 9: *"I was not having a car by that time. Then we found my wife's father's car. While we were on our way to the hospital around [the village] the car just stopped. We waited for another car to come and assist us. The car came and when we arrived at [the hospital], we found that … I am not sure if the child died at the gate of the hospital or he died inside the hospital, I can't remember. We never got any assistance because he was dead already."*

Many were ultimately able to overcome this barrier, borrowing money from family and neighbours to cover the costs of taxis or hire private cars, or by asking others to help with lifts to the health facilities. But a lack of transport frequently caused a delay in accessing healthcare and was an important consideration in deciding when and where to access healthcare. Participants from the focus group discussion added that transport barriers were exacerbated at night as *"there is no other option but to pay for someone's car and go to [the 24-hour clinic] as it is always open"* (Participant 36, grandmother for poor household, child died in health facility).

7.4.4 Experiences of care-seeking during the final illness

Table 7.3 summarises the specific features of care-seeking interactions during the final illness that caregivers associated with a positive or negative experience. Caregivers had more positive experiences if they perceived tangible interventions or treatments were being offered and if staff communicated well. Negative experiences were associated with poor communication, being shouted at or blamed for the death by healthcare workers. Caregivers had very low expectations of the healthcare system but continued to engage formal health services even when they experienced seeking healthcare negatively.

Tangible interventions

For many, a positive experience of receiving treatment was linked to the visible and tangible interventions that followed assessment of the child's condition, such as *"giving oxygen"* (participant 37) when a child had difficulty breathing, or giving medication in the form of syrups or injections. Participant 24, who seemed satisfied with the treatment her child received, noted *"they helped us*

and gave him panado [paracetamol]…she then injected the child and gave him medication". Similarly, the perception of a complete assessment was linked to whether the health professional actually physically examined the child, particularly whether they listened to the child's chest with a stethoscope.

Communication

Communication clearly influenced caregivers' experience of care. Features of good communication included demonstrating respect for the caregiver's knowledge of their child, explaining what procedures or treatments were being administered and not shouting at or blaming caregivers. One mother recounted an example of empowering, positive communication at the first hospital where the child was admitted, which was even more poignant by its direct comparison to the negative experience of communication when the child was referred to another hospital.

> Participant 22, mother of a young child that died in a health facility:
>
> *"The nurses from [the first hospital] communicate with you as the children's parents, ask how the child is and what changes you see or that you don't see change. [At the second hospital] there is no communication, the nurses there enter like you are not there, do what they are doing to your child, and you are there but they don't ask you anything or tell you anything about what they are doing, do what they do and then write down what you don't know then they leave. You can't go read the doctor's file, we are scared we will be shouted at. It is good for someone to tell you if they come to do something on you… that I am here to do this, it will help you with this, please take note after I have done this whether there is any change you see any minutes or hours later; at [the second hospital], there is none of that."*

Safety-netting was another important part of communication, though few caregivers recalled being given any advice about what danger signs to look out for and when to come back for review. Participant 8 had consulted a GP and recalled "*he* (the GP) *told us that he is going to give us some medication that we need to go and give to the child. He also said to us as it is Monday today, if you don't see any changes on Tuesday, please come back*". This experience stood out from the experiences of many other participants. In general healthcare workers' failure to explain what treatment was being prescribed, or to give safety-netting advice meant that caregivers did not know what they should expect of the treatment including how quickly it would work or that the child might deteriorate despite receiving medication and need to return to the healthcare facility. This was especially clear from the focus group discussion in AHRI, where participants expressed the perception that caregivers are *"ignorant"*, and that *"you tell yourself that you have been to the clinic but your child is not getting better. So what is the reason for you to go back to the clinic and queue on those benches meanwhile there is no change"* (participant 37, mother of an infant who died at home).

Poor communication often resulted in caregivers failing to understand why their child died. This left caregivers feeling anxious, often doubting their own assessment of the child's condition, and they lost confidence in their ability to assess and manage future child illness (even mild cases). Many caregivers said that, following their child's death, they now relied fully on clinic staff to assess the severity of their other children's illnesses and provide treatment guidance. As participant 13 put it: *"I don't do anything by myself. I take the child to the clinic. Even if it can be something that I know, I do take the child to the clinic…the problem is that sometimes things can be a coincidence. For me,*

because of what happened to me last time, I think that something like that can happen again" (mother, child died at home).

This finding was strongly supported by feedback from the AHRI focus group: Participant 36, whose grandchild had died in a health facility, admitted that she cannot tell the difference between a mildly ill or severely ill child, saying: *"whether the child is a bit or very ill, when a child is ill it is the same."* Participant 37, a mother whose child had died at home despite seeking healthcare, noted that *"I use the clinic a lot because I learnt a lesson with the one that died."* This attitude existed despite the very real barriers to seeking healthcare from the clinic such as having to look after multiple children – as Participant 37 described *"I put one on my back and pull the other by the hand to the clinic, I no longer make a mistake"* or having to travel long distances: *"the clinic is really far but I jump to the clinic, if coughing or anything else"* (participant 34, grandmother, child died at home despite seeking care).

Caregivers' expectations of the healthcare system

Often examples given of positive experiences of care-seeking reflected very low caregiver expectations of the healthcare system and an *absence* of poor care rather than the *presence* of good care practices. For example, participants were satisfied with a care-seeking interaction when nurses *"didn't blame me or say something that was out of line"* (participant 3), and when *"they didn't shout at me"* (participant 21). Low expectations of the healthcare system also exaggerated the caregivers' positive responses when standard protocols or treatment guidelines were followed e.g. all health facilities are expected to triage patients, yet when this actually happened and resulted in severely ill patients being moved to the front of the queue, respondents were surprised and impressed. Participant 23 recounted *"they treated me good because I never waited in the line. I arrived and they*

said the temperature was too high and that I should not wait in line." Participant 34 was attended to *"immediately"* when she brought her child with burns to the clinic. Similarly, respondents made note when ambulances were available or arrived quickly.

Some focus group participants reflected that positive experiences of care were more likely if you had a personal connection to staff working at the facility. Participant 37 admitted *"I was treated well but I don't know if maybe it was because there was someone from my family who is a sister there".* Participant 38 observed that patients who attend a clinic regularly, such as HIV positive patients, consciously invest in their relationships with nurses as *"if you know you have HIV, you need to be close to them [nurses], at times you don't get pills and are told to come fetch them another time and when you see others have a lot of pills and you received nothing."*

Despite low expectations, many still had very negative experiences of care-seeking. Healthcare workers were often hostile, shouting at parents for bringing children at the wrong time (either too late in the day, or on a weekend). Healthcare workers blamed caregivers for the child's illness – especially if traditional medicine was used - saying they *"killed the child"*, a phrase that was recollected by participant 30, a mother, and participant 36, a grandmother, both of whose children died in health facilities.

Healthcare workers also blamed caregivers for failing to alert nurses to a deterioration of the child's condition once in the health facility (often discounting the fact that parents had indeed tried to attract nurses' attention to a concern that the child was getting worse). This was particularly distressing for participant 27, who recounted what happened when she went to breastfeed her child with other mothers of newborns in the neonatal ICU and noticed that her baby had deteriorated.

The participant eventually found the neonatal ICU nurses in the labour ward but they turned the blame onto her and said *"why I didn't scream rather than left the baby alone and come to them? I told them that I screamed, we were all screaming".*

Some caregivers felt that health professionals did not care about their patients, particularly younger staff who participants felt *"are not behaving in a good way when it comes to treating patients"* and are *"just sitting down busy with social networks [referring to Facebook or WhatsApp]"* (participant 11, a mother whose child died at home).

In some cases, healthcare workers were dismissive of caregivers' concerns, despite caregivers being clear that something was seriously wrong with their child. Participant 25, the mother of a child who died at home, was worried: *"I woke up with him in that morning and he was not fine"*. She took her child to the clinic, but the nurses dismissed her *saying "they don't work on nominals [meaning non-emergency patients] on Sunday, they only work on worse illness and injuries only."* Despite waiting many hours at the clinic, the staff refused to even assess the child and eventually she left the facility *"bare handed"*. She sought care again from a private GP the following day who prescribed oral rehydration solution for the child as he was dehydrated. Participant 8, a father who took his neonate to the clinic, explained that *"we didn't get any help from the clinic"* after he and his wife were dismissed by nurses despite their child not eating or drinking and crying all the time. These caregivers were not able to assert their concerns to force staff to take them seriously, and generally left the health facility with the situation unresolved.

Finally, low expectations of care-seeking and previous experiences of negative treatment also discouraged caregivers from complaining about the quality of care or asking questions related to

the diagnosis or management of their child, but it did not seem to discourage them from seeking care. Caregivers felt they would *"regret"* asking questions (participant 35) and that *"it's better to shut up and when a nurse talks bad to you say no word in return. Because some of the time you will find that when you reply, he/she will not give your child a proper treatment"* (participant 25).

Table 7.3: Care-seeking experiences

Positive care-seeking experiences	**Negative care-seeking experiences**
Tangible sense of "being treated" - Receiving interventions (Drips, injections, tablets, oxygen, bandages) - Physical examination performed by the nurse or doctor Timings - Seen and treated immediately or urgently, skipping the queues - Ambulance arriving quickly Good communication - Respect for caregivers' opinion and knowledge of a change in the child's condition - Offering safety-netting advice - Not being shouted at	Healthcare workers shouting at caregiver - For arriving late in the afternoon or at the weekend (if the child is deemed to be too well) - For alerting the provider too late to the deterioration Blaming caregiver for death - For using traditional medicine, particularly for giving enemas Delays or waiting: - Ambulance transport very delayed in arrival Inattentive staff - Distracted by mobile phones while seeing patients, or while patients are waiting to be seen - Taking lunch when still many patients to see - Not coming to review patient when caregiver alerts them to a change in the child's condition - Sense that nurses are not "passionate" about their jobs (particularly younger nurses). Poor communication - Failing to take caregivers' opinions seriously - Not explaining what procedure is being performed or why it is being performed - Not explaining which treatment was being given or why it was being given - Not providing safety-netting advice - Not explaining the cause of death

7.4.5 Adapting the Pathways to Survival Framework

Each theme described above highlighted barriers to accessing high quality healthcare at different stages of the process of seeking and receiving healthcare. Figure 7.1 shows a simplified version of the Pathways to Survival Framework (4) used in the previous chapter. The key issues identified by participants are overlaid on this model, demonstrating the stage and manner in which these issues act as barriers to accessing high quality healthcare. Given the barriers that caregivers in this study experienced at each stage of the care pathway, I believe that the care-seeking process in rural South Africa more closely resembles the model shown in figure 7.2.

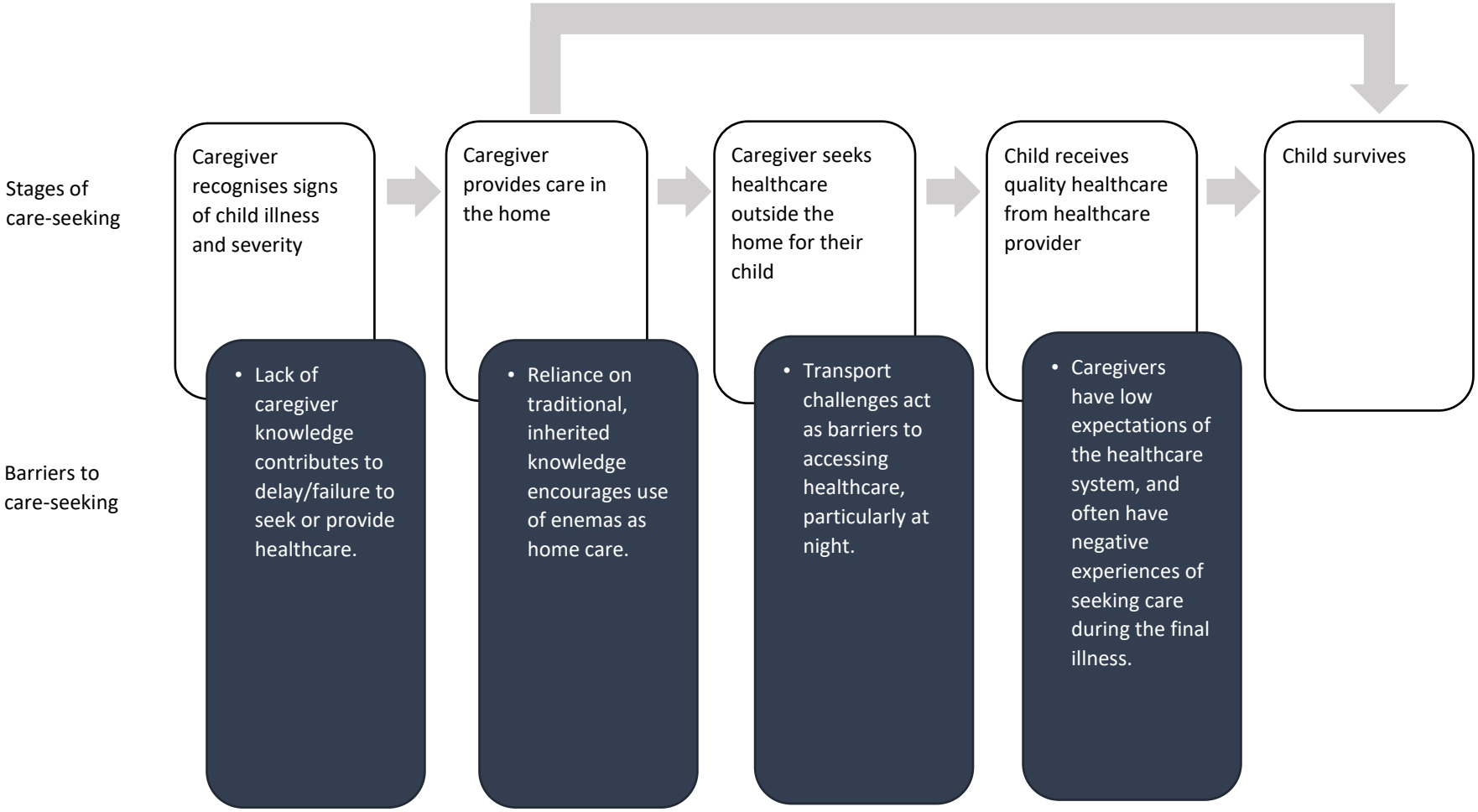


Figure 7.1: Simplified, linear representation of stages of seeking and providing care based on the CDC/BASICS Pathways to Survival framework (4), and the barriers to care identified at each stage of the care-seeking process.

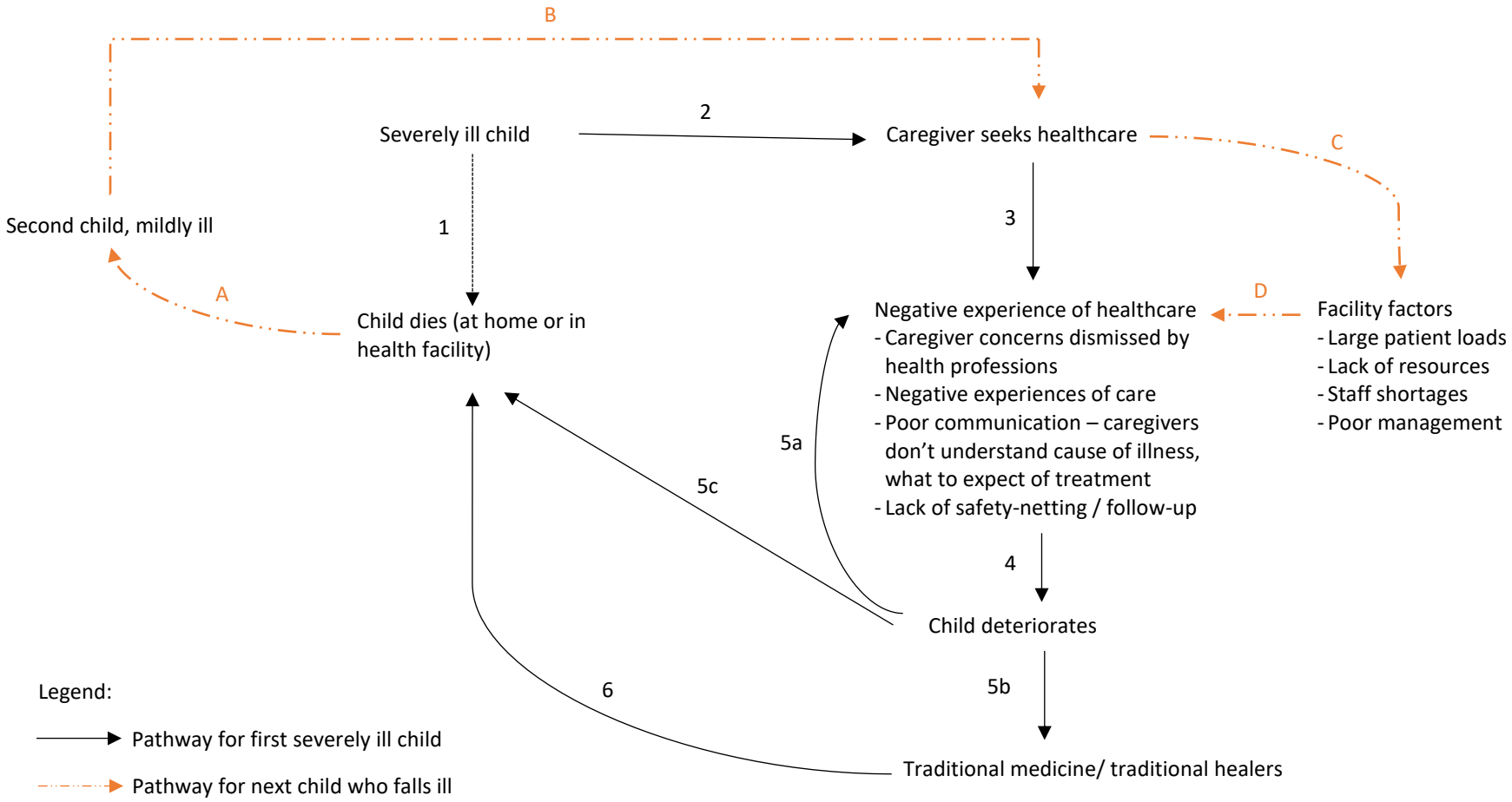


Figure 7.2: Modified model of the process of seeking and providing healthcare during childhood illness in rural South Africa.

Following this model, we start with a severely ill child (pathway indicated by black arrows). In some cases, caregivers lacking knowledge might not recognise the illness and so the child dies at home without care (indicated by arrow 1). However, in many cases the caregiver identifies signs of illness and appropriately seeks healthcare for the child (step 2). For a series of reasons, caregivers have a negative experience at the healthcare provider (step 3). When the child deteriorates (step 4) caregivers' responses may differ: some might re-seek care, though often going to a different provider (either to a different clinic, to a private GP or to a hospital) (step 5a). Some believe that the failure to improve having received allopathic treatment must indicate that this is a traditional problem and so seek out traditional healers (step 5b). Others are either unable to re-seek care, or believe that having seen a healthcare professional already, there is nothing more to be done (step 5c). Ultimately the child dies (whether at home or in a health facility) (steps 5c, 6).

In addition to more accurately describing the care pathway for fatal child illness in rural South Africa as experienced by caregivers, this model also offers insights into what follows a child's death in the context of poor caregiver knowledge of childhood illness, both in terms of identifying signs of severe illness and in terms of understanding why the child died (pathway indicated by orange dashed arrows). Following the death of their child, caregivers lose confidence in their ability to identify severe child illness (arrow A) and become reliant on healthcare workers to identify disease and guide treatment. This is true even for very mild childhood illness which could be adequately managed at home but instead caregivers rush their children to clinics for urgent assessment and treatment (arrow B). As a result, there is a growing burden on the health system, whereby mildly unwell children are also brought to the clinic, exacerbating the existing supply-side barriers to high quality care (staff shortages, resource limitations, poor management, long waiting times etc) (arrow C) and perpetuating negative experiences of care (arrow D).

7.5 Discussion

7.5.1 Summary of findings

This study aimed to better understand caregivers' care-seeking experiences and decision-making during a child's final illness. Analysis of interviews and focus group discussions showed that caregivers' knowledge of childhood illness varied – with some unable to identify severe illness in their child or appreciate the urgency of the need for healthcare. Traditional medicine was an important treatment avenue utilised by caregivers, though rarely as a first port-of-call. When used as part of home care, caregivers suggested that they turned to traditional medicines as something familiar, but not necessarily that they clearly identified a traditional cause of illness. Most of those who engaged traditional healers did so if the child failed to improve after being seen at a formal allopathic healthcare provider - the assumption being that a failure to improve indicates that the illness is caused by a "traditional" illness. Transport barriers remain significant: cost, limited taxi times and having to arrange to hire or borrow private cars caused delays in accessing healthcare.

Finally, caregivers generally held low expectations of the healthcare system. This coloured their experiences of seeking healthcare during their child's final illness, often lending a positive lens to the experience where it exceeded the lowest of expectations. However, many still experienced the healthcare system negatively, with care-seeking interactions characterised by disrespectful and dismissive staff – even where caregivers clearly recognized that their child was ill - a lack of explanation of the child's illness, treatments and safety-netting advice and long waiting times especially for ambulances.

7.5.2 Adapted model of care-seeking during fatal child illness in rural South Africa

By considering the impact of each of the barriers caregivers identified at the different stages of seeking and providing care during a child's final illness, I was able to propose an adapted model of the care-seeking process to reflect the care pathways in rural South African communities (figure 7.2), clearly highlighting deviations from the more linear Pathways to Survival Framework. This model also demonstrates how caregivers modify their behaviours when another child becomes unwell, feeding a cycle that drives lower quality healthcare both within and outside the home. As such, the adapted model can be used as the basis for further research and intervention development, particularly where work is focused on home deaths in children under-5 in this and similar settings.

Core to the understanding and application of this new model is a recognition of the "socialised nature of healthcare" (5). When understood as a series of relationships or interactions (e.g. between patients and healthcare professionals or patient-patient interactions), the concepts of social exclusion and social capital are critical in understanding how such interactions are experienced and managed.

7.5.3 Social exclusion

Amartya Sen's writings on social exclusion highlight the relational nature of poverty. He argues that impoverishment extends beyond the material and includes non-material elements which are critical to the freedom to access opportunities. He refers to such non-material dimensions of impoverishment as capability deprivation. Viewed through this lens, impoverishment is defined not

merely as a lack of wealth or income but as a loss of the ability to claim essential services and to participate in social relationships (6).

When applied to the South African public healthcare context, the concept of social exclusion helps to explain caregivers' responses to seeking healthcare. As has been described in previous chapters, the populations in which this research was conducted are poor. The quality of basic education is low, unemployment rates are high, and the communities are still experiencing the many legacies of Apartheid related to spatial segregation, such as limited access to piped water and high levels of temporary labour migration. Negative engagements with health professionals - be that in the form of disrespectful staff, lack of medications, long waiting times or poor communication - which occur in the context of disadvantage or poverty - undermine caregivers' ability to claim a minimum standard of healthcare by reinforcing perceptions of social exclusion which feed into the lived experience of poverty. This also helps explain the persistently low expectations of the healthcare system that were implicit in many of the respondents' comments.

The effect of social exclusion and capability deprivation in healthcare interactions is further exaggerated when located in the context of paternalistic healthcare systems, as is common in South Africa. There is an inherent power differential between health professionals and their patients: health professionals hold more knowledge about a given medical condition than their patients and have the power to recommend and prescribe treatment. This power differential is further exaggerated in settings where patients perceive that healthcare professionals also have the power to deny treatment or somehow harm the patient if they so desire, as was described by participants in this study. Such findings have also been noted elsewhere in Africa (31). In an already hierarchical

relationship, poor communication and negative care-seeking experiences further disempower patients to exert a claim on quality healthcare.

Finally, the sense of capacity deprivation and social exclusion driven by the negative experiences of care-seeking and the death of their child contributes to an internalisation of self-doubt and blame for the child's death. One caregiver exemplified this, referring to their child's death as "their mistake", rather than recognising that there were multiple failures throughout the healthcare system that contributed to the child's death. Caregivers lost confidence in their assessment of illness severity. Instead of doubting the healthcare system, or even turning away from it, caregivers delegated more of their parental authority in the assessment and management of their children to health professionals, reinforcing the unequal power relations and the paternalistic nature of the patient-provider relationship.

This behaviour is described elsewhere in the South African healthcare system in relation to maternal care seeking and institutional delivery. Verbal and physical abuse of labouring mothers by nursing staff is well documented across South Africa (32). And yet mothers have come to normalise nurses' aggressive language as a means of coping with the situation, and as a result may no longer feel that it is unacceptable or offensive (33). Such seemingly counter-intuitive behaviours reflect societal power dynamics of race, class and poverty that play out in healthcare interactions whereby healthcare staff feel the need to "control" patients, and this becomes an accepted and institutionalised modus operandi (33).

7.5.4 Social Capital

As a contrast to the social exclusion narrative, some caregivers relied on social capital to negotiate access to healthcare services and experienced care-seeking more positively. The precise definition of social capital is contested, but those used most commonly in relation to healthcare have in common a sense of shared networks and social infrastructure accessed by individuals by virtue of being members of a group or community and understanding the shared values and unspoken rules of this group (7,34). Social capital therefore becomes a form of currency, which grants members of the group access to opportunities which those outside the group may find it more difficult to access.

In this study, those with family members or friends who worked at the clinics could draw on those relationships to ensure better care. This may occur consciously, for example the description of HIV positive women actively fostering relationships with nursing staff to ensure that they receive medications even if stock is limited, or unconsciously, as was the case for participants 4 and 37 who believed that they received better treatment from nurses because they knew that she was related to another staff member. Social capital was therefore a source of influence which caregivers used to navigate their interactions with the healthcare sector. However, the corollary is that for those who lack social capital in these circles, this is yet another example of power imbalances colliding and coinciding to allow some people to be taken more seriously and experience the system more positively than others.

So where does this leave us? Building social capital may be a way of empowering caregivers to confidently assert their claim for quality healthcare. Possible interventions to this effect will be discussed in the following chapter notably participatory action groups within the community.

7.5.5 Traditional medicine

The motivations that seem to underpin traditional medicine use by participants in this study partly reflect a familiarity with these treatment methods and a trust in their value based on a shared world view. Traditional treatments such as enemas were part of a repertoire of home treatments upon which caregivers drew when their child was ill. And similarly, in the scenario where the child was not improving after seeking formal medical care, traditional healers were another avenue for caregivers to try. There was a sense of desperation in caregivers' desire to try any and all options to help their child.

This understanding has significant implications for interventions: it is clearly not a question of blame – caregivers' intentions were to help the child, not to harm. This was true even when administering enemas which can be dangerous particularly in very young children, leading to diarrhoea, severe dehydration and poisoning (35,36). Enemas are a common traditional treatment in South Africa used in both preventative and curative traditional healthcare (37,38) and so without providing an alternate home care recommendation, caregivers may be left feeling helpless and are less likely to listen to healthcare workers who discourage their use. Health education interventions to improve caregivers' knowledge of child illness and offer support in providing home care may be of value and are discussed further in chapter 8.

In this study, caregivers did not clearly identify or name a specific traditional cause of disease that they were trying to treat, though other work in South Africa and sub-Saharan Africa found that many

caregivers believe in alternate traditional explanations for specific disease symptoms - such as convulsions associated with cerebral malaria - and so preferentially seek traditional care when such illnesses are identified (39–41). This would have significant implications for future interventions to address traditional medicine use - further research would be valuable in better understanding the differences in the findings, and how this impacts care-seeking decisions.

7.5.6 Strengths and limitations

This study had four important strengths, and corresponding limitations. First, all interviews and focus group discussions were conducted in participants' first language (isiZulu or Xitsonga). This encouraged participation of individuals who might otherwise have refused or been unable to participate in the study if all data collection had been in English. Participants were fluent and spoke more freely about their experiences during the child's final illness. However, interviews needed to be translated into English for analysis: it is possible that some of the subtilties of the meaning and tone of the conversation were lost during this process. Furthermore, by relying on translated transcripts, I was already working from data that has been filtered once by the interviewer, with greater chance for their individual biases and positionality to affect the data. The language requirement and power imbalances created by my position as a doctor also meant that I did not conduct the interviews myself and was therefore reliant on the interviewer to accurately capture notes on the context, and to probe appropriately. The lack of experience of some interviewers meant that they did not always probe when needed, and their familiarity with the context meant that they did not ask questions which would have been interesting to an outsider (for example about why people chose to use enemas, or whether they were given advice on when to return to a health facility). I tried to minimize the impact of working through interviewers by debriefing with each

interviewer after each interview before they did the next one, encouraging detailed case summaries, and recommending that they leave the original isiZulu or Xitsonga word in text where there was not an appropriate direct translation.

Second, interviews were conducted at least one year after the death of the children in question, but in some cases two to three years after the child's death. This was advantageous as it meant that caregivers had, for the most part, grieved the loss of their child and the risk of the study causing significant emotional distress was lower. However, this time delay also introduced the potential for recall bias. We tried to reduce the impact of this by concentrating on caregiver's impressions of healthcare services and how they felt about their care-seeking experiences and less on precise timings or particular medications prescribed. I was also reassured by the fact that the narratives were generally clear and consistent across the interview.

Third, our sampling strategy allowed us to capture a diverse set of opinions and included participants from households of varying sizes (from three to 28 members) and across socio-economic quintiles in both HDSS sites, though all households would fall into the lower socioeconomic bracket nationally and their experiences broadly represent those of poor, rural communities. Furthermore, although we did not purposively sample based on caregiver relationship to the child (i.e. mother, father, grandparent etc), our sample included fathers and traditional healers. Both are generally under-represented in research on childhood illness despite being important stakeholders, contributing to decision-making and caregiving, often holding positions of authority within the household and community and sometimes acting as gatekeepers to care. However, relatively few participants disclosed being HIV positive – although 21% of the respondents were known to be HIV positive from

the verbal autopsy or household surveys. The low disclosure rates may partly reflect the impact of stigma and fear of discrimination if participants revealed their status which may persist even though interviewers were trained to be non-judgemental and reminded participants that the interview was confidential. It might also reflect that some participants were grandmothers and may themselves have been HIV negative even if the biological mother of the deceased child was HIV positive.

I was not able to identify differences in experiences based on HIV status of the child or caregiver, maternal education level, household size or any of the other demographic factors used to purposively sample, despite having identified many of them as relevant factors in previous chapters. It was also difficult to get participants to think creatively about solutions to the problems in the healthcare sector. This was partly because participants were unwilling to hypothesise about explanations for population trends which I witnessed in the longitudinal data e.g. why HIV positive children more likely to die in a facility, saying that they did not want to comment on anything that they had not experienced directly. However, there were clear differences in the type of information collected from in-depth interviews and focus group discussions. Whereas in-depth interviews provided detailed narratives of the child's final illness, often describing multiple points of contact with the healthcare system, the focus group discussions generally provided a more communal perspective on the types of experiences caregivers have when seeking healthcare (both during the child's final illness and at other times – whether for the same child or a different child). The focus groups also served to validate the findings from in-depth interviews with participants often reaffirming the findings presented to them, and frequently adding additional insights and explanations as to why experiences might vary e.g. highlighting the importance of knowing a health worker at the clinic personally.

Finally, caregivers' accounts were used to modify the Pathways to Survival Framework to produce a care-seeking model for childhood illness in rural South Africa. This model contributes to the literature on theories of care-seeking and access to health care and can be used as a basis for further research on childhood illness and intervention development to reduce child mortality. However, the adapted model may be context-specific and may not be relevant in other African countries or in urban settings. It would require further validation in such settings before it can be applied more widely.

7.6 Conclusion

This study detailed caregivers' experiences of seeking and receiving healthcare during a child's final illness. It was clear from caregivers' accounts that barriers to accessing healthcare disrupt the workings of previously accepted care-seeking models, such as that presented in the Pathways to Survival Framework. By applying the concepts of social exclusion and capability deprivation, I was able to develop an alternate model that more realistically reflects care-seeking experiences and decision-making during severe childhood illness in rural South Africa. This model can be used as the basis for developing interventions to reduce under-5 mortality in rural South African settings by targeting deficits which drive the model. These include a lack of caregiver knowledge which delays care-seeking and contributes to the use of traditional medicines, transport barriers, and negative care-seeking experiences which disempower caregivers and limit their ability to claim a minimum standard of healthcare. These will be discussed in more detail in Chapter 8.

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Chapter 8: Discussion

8.1 Introduction

My thesis aims to better understand why children under five years of age die at home in rural South Africa. In this concluding chapter I will summarise the key findings from my doctoral work bringing together the quantitative and qualitative results and comparing them with the existing literature. I will show how these findings affect the processes of providing care within the home, and seeking and receiving healthcare outside the home during fatal childhood illness in rural South Africa and discuss policy recommendations to reduce under-5 deaths particularly at home. Finally, I will identify questions arising from my thesis which warrant further research.

There are five key findings from my thesis discussed in more detail is sections 8.2 – 8.6:

1. The proportion of children under five years that die at home has remained constant from 2000-2015 at 50%, despite a decline in the under-5 mortality rate.
2. Over 80% of the children who died at home were taken for formal healthcare during their final illness.
3. Modifiable factors that contributed to home deaths in children under-5 occurred within and outside the home.
    i. Within the home, a lack of caregiver knowledge contributed to poor recognition of illness, and failure to appreciate the severity of the illness.

ii. Outside the home, modifiable factors included a lack of transport, caregivers' negative experiences of seeking healthcare, a lack of safety-netting and follow-up and low referral rates from primary care providers to secondary level facilities.

4. Consulting traditional healers and use of traditional medicines was relatively uncommon, but when this did occur, caregivers' decisions seemed driven by a desperate need to help the child rather than a strongly held traditional belief about the underlying cause of the disease.
5. HIV-related deaths were less likely to occur at home than in health facilities after 2012, partly reflecting the social capital earned by HIV-positive caregivers through repeated contact with facilities and a familiarity with the health system.

8.2 Half of under-5 deaths occur at home

In chapter 5 I presented an analysis of longitudinal population-based data which clearly demonstrated that the proportion of children who died at home has remained constant from 2000 to 2015, around 50% of all deaths. This is despite the significant decline in the absolute number of deaths and the under-5 mortality rate since the mid-2000's. This is in keeping with the literature from across South Africa, which has underpinned the need for population-based research on child mortality, in addition to the established facility-based audits which miss those deaths which occur outside of health facilities (1–3).

8.3 Care-seeking rates are high for all under-5 deaths, including for those that die outside of facilities

My thesis has demonstrated definitively that the large majority of children who died under the age of five years (92%) were taken to a formal healthcare provider during their final illness, including over 80% of children who died at home. These high rates of care-seeking are in keeping with figures from elsewhere in sub-Saharan Africa presented in chapter 3. Furthermore, based on the findings from the social autopsy presented in chapter 6, a third of children who died in 2017 were taken to more than one formal healthcare provider.

By using a longitudinal dataset with over 3000 deaths between 2000-2015, I could determine changes over time in a) where children died and b) care-seeking behaviour, and identify factors associated with dying at home despite having sought healthcare (i.e. those factors associated with place of death independently of care-seeking). As discussed in detail in chapter 5, the main factors associated with death at home despite having sought healthcare were age, lack of maternal education, being of Mozambican descent (in Agincourt), traditional medicine use and HIV-related illness. First, early neonatal deaths are less likely to occur at home than older age groups. I suggest that this likely reflects the high in-facility delivery rates in South Africa (4).

Second, lower maternal education is associated with increased odds of dying at home despite having sought healthcare. This finding adds to the large body of literature that identifies low maternal education as a risk factor for child mortality (5,6), and was the first sign to emerge in this thesis of the importance of social capital theory (7,8) in affecting the outcomes of consultations with caregivers. In trying to explain how maternal education linked specifically to place of death despite seeking healthcare – and so not merely reflecting caregivers' failure to recognise illness – I argue

that mothers with higher levels of education may be better able to assert their concerns and demand to be taken seriously when engaging health workers (9). Health workers might also be more careful and take more time when examining children of more educated mothers who they see as their equal and believe are more likely to understand the information the healthcare worker provides (10). I raise the importance of social capital again in relation to HIV-related illness and have explored this in detail in my qualitative work (Chapter 7).

Third, being of Mozambican descent was associated with increased odds of home death despite seeking healthcare. In Agincourt, Mozambican descent is partly a proxy for low socioeconomic status, which is known to be a barrier to repeated care-seeking and acceptance of admission (11–14). Poorer households may also be burdened by practical motivations for caregivers preferring that their child die at home such as the much higher cost associated with transporting a dead body rather than taking the child home in a public taxi while still alive. The child may then be buried at home. There are also likely differences in cultural beliefs around illness and treatment-seeking between Mozambican and South African households (14). Of concern was that Mozambicans may be experiencing xenophobia at healthcare facilities, explaining the high proportion of home deaths despite seeking care (15,16). This is not supported by the qualitative work, though there were few Mozambican caregivers in the sample and this issue would require further dedicated research.

Fourth, traditional medicine use is associated with increased odds of home death despite seeking healthcare, though its use seems to be declining over the years. This issue was explored in greater detail in the social autopsy and qualitative work and is discussed fully in section 8.5 below. Finally, HIV-related deaths are associated with deaths at home despite seeking healthcare in the earlier

years (2000-2011) but were less likely to occur at home having sought healthcare in 2012-2015. This is one of the most unexpected findings from my thesis and is explored in more depth in section 8.6 below.

8.4 Modifiable factors

The concept of modifiable factors was introduced in chapter 6, and refers to any factor in the care of a child that can be changed and, had it been changed, the death could have been avoided (1). This includes events, actions, omissions or substandard care that contributed to the child's death (17). Assessment of "modifiability" is contextual, taking into account what is reasonable in a given setting: in order to be assessed as modifiable, factors should be able to be improved by means of "locally achievable interventions"(17).

Modifiable factors may occur at different levels: within the home, outside the home, at the level of the caregiver, the health facility or the wider community and structural environment. They may be supply-side factors, or demand-side factors. For the purposes of this discussion, modifiable factors have been split according to those which exist within the home, and those which occur outside the home. All modifiable factors identified in my thesis are based on the caregivers' perspectives. My work did not include inputs from healthcare providers and so I did not pass judgement on the quality of medical care provided other than to comment on the caregivers' experiences of seeking healthcare. Further research is required to fully assess quality of care as a modifiable factor.

Figure 8.1 demonstrates how each of the modifiable factors identified in this thesis act at specific stages of the care pathway, limiting access to healthcare and contributing to mortality.

8.4.1 Within the home

Modifiable factors within the home have become increasingly important. I first suggest this in chapter 5 where I show that almost half of the children that died at home in 2015 had not been taken outside the home for healthcare during their final illness. Even though the rate of under-5 deaths which occurred at home without having sought healthcare has remained constant at 2-5 per 1000 live births since 2000, they account for a growing percentage of home deaths as the overall under-5 mortality rate declines - from 8% of home deaths in 2004, to 49% of home deaths in 2015. Chapters 6 and 7 helped to identify factors within the home that contribute to this finding, namely a lack of caregiver knowledge of child illness driving poor recognition of illness and failure to appreciate the urgent need for care.

Lack of caregiver recognition of childhood illness

Both the quantitative and qualitative findings suggest that some caregivers lack adequate knowledge of childhood illness and are unable to recognise severe disease. In chapter 6, following the Pathways to Survival Framework for 48 deaths across the two study sites, six caregivers (13%) did not identify that their child displayed signs or symptoms of illness. In addition, nine children (19%) received home care despite having severe or possible severe symptoms and four caregivers (8% of all deaths) delayed seeking healthcare by more than 24 hours despite the child having at least one sign of severe or possibly severe illness. This suggests that caregivers might not fully appreciate the severity of the child's illness and the urgency of the care required.

This theory was supported by the qualitative data presented in chapter 7. Some interview participants commented that they were surprised when their child died as they did not realise that the symptoms the child displayed were abnormal or suggestive of severe disease needing immediate medical attention. In focus group discussions caregivers commented that they felt unable to distinguish mild and severe disease, with one participant noting "*whether the child is a bit or very ill, when a child is ill it is the same".*

Caregiver recognition of illness is a well-recognised factor that affects appropriate care-seeking behaviour in child illness (13,18), and recommendations for interventions to improve caregivers' knowledge and ability to recognise severe illness are discussed in section 8.7. However, based on the qualitative data, improving caregiver knowledge and recognition of illness is unlikely to be sufficient. In addition, caregivers need to be empowered to act on that knowledge and assert their claim on high quality healthcare services.

Decision-making: how our findings differed from the literature

I did not find evidence of delays in deciding to seek healthcare due to needing permission from male decision-makers, or the household head. This is in contrast to literature from elsewhere in South Africa and sub-Saharan Africa which highlight a lack of empowerment of mothers in the decision-making process as an important contributor to home delays (19,20). Rather, caregivers indicated that they partook in a process of advice-seeking from, and consultation with, other family members and neighbours on the severity of the child's symptoms and that there was joint decision-making when others were immediately available to provide input.

8.4.2 Outside the home

Lack of transport

A lack of transport has long been recognised as a significant barrier to accessing healthcare (21,22). The three delays model, first developed by Thaddeus and Maine in relation to avoidable maternal mortality, specifically identifies transport as a potential cause of significant delays in accessing healthcare (22). This model has subsequently been applied to under-5 mortality (23,24) and was used as one of the models of analysis in Chapter 6 to prioritise modifiable factors contributing to under-5 deaths in 2017. However based on the analysis in Chapter 6, it initially appeared that transport barriers were minimal in rural South Africa, with no caregivers reporting that their nearest facility was more than two hours away nor that they were unable to accept referral due to a lack of transport (the two metrics used to calculate transport delay (24)). As previously discussed, this was an unexpected, and somewhat unbelievable finding, contrasting starkly with literature from other South African contexts (19,25–27), and anecdotally from what patients regularly report.

My qualitative data (chapter 7) confirmed that the quantitative findings conflicted with other information characterising caregivers' experiences, with many having faced transport challenges when trying to access healthcare during their child's final illness. Caregivers reported having to borrow money to hire private cars from neighbours or members of the community, struggling to cover taxi fares, or having to wait until a family member with a car came home to take them to a health facility. They also noted that transport difficulties were exacerbated if the child needed to be taken to a health facility after hours (either at night or on a weekend), as taxis did not run at those times, and only one or two facilities were open 24 hours, which were typically much further away.

The differences between the quantitative and qualitative findings related to transport highlight the importance of asking the right question in quantitative data collection to accurately capture the metric in which one is interested. In the case of transport barriers, the metrics used in the standard WHO Verbal Autopsy questionnaire (which provided data on transport delays analysed in Chapter 6), are inappropriate to the South African context. Few households live more than two hours from their nearest health facility – though many might live more than 30 minutes from a facility, and research has shown that even small distances can limit access to care (28). In addition, while most families eventually managed to obtain money to cover transport costs, or found someone to assist with private transport (and therefore caregivers responded that they had not had to decline referral due to a lack of transport), they were still delayed by the process of having to find and negotiate use of transport, and it was still a significant stressor in the care-seeking experience.

Caregivers' negative experiences of seeking healthcare

I have highlighted negative experiences of seeking healthcare as an important theme arising from the interviews and focus group discussions with caregivers (chapter 7). Staff reportedly shouted at caregivers, blamed them for the child's death and failed to provide explanations for what was wrong with the child, the treatment or medical procedures they were performing, or offer adequate safety-netting or follow-up advice. Even where caregivers clearly identified that their child was severely ill, medical staff were sometimes dismissive, and caregivers did not feel empowered to assert their concerns during consultations and demand appropriate medical attention.

Negative experiences of care-seeking were so common-place that caregivers had lowered their expectations of the healthcare system, such that the *absence* of poor care was interpreted as a

positive experience. However, surprisingly such experiences did not turn people away from the formal healthcare system. This contrasts with research by Sharkey et al (2011) interviewing caregivers of children under-5 years, which suggested that poor staff attitudes and negative treatment of caregivers are factors that drove them away from formal healthcare systems and towards traditional healers and other informal providers (19). Using Amartya Sen's concept of social exclusion (29), I argue that caregivers come to internalise the experience of a child's death as a personal failure rather than a health-system failure and feel further disempowered to manage future childhood illness. Acceptance and normalisation of the poor staff attitudes and behaviours has also been demonstrated in literature on maternal care-seeking in South Africa, whereby expectant mothers accept abusive treatment from nurses and midwives during and after labour as an institutionalised culture reflecting paternalistic health systems, and complex societal power dynamics related to race, class and gender (30). As a result, despite previous negative care-seeking experiences, and the expectation of further negative experiences, caregivers continue to seek healthcare from the formal healthcare system. This cycle was described in Figure 7.2 in Chapter 7.

Low referral rates by healthcare workers to secondary facilities

In chapter 3, I identified low referral rates as a potential modifiable factor contributing to under-5 mortality across sub-Saharan Africa. Chapter 6 confirmed that referral was also a concern in South African settings, though with significant variability across the two study sites (being much lower in AHRI than in Agincourt. In AHRI, only 20% of children who left the first healthcare provider alive were referred for further care). It remains unclear why children were not referred: a recent review of care-seeking experiences in Cape Town suggested that caregivers perceived the quality of care to be better in hospitals and frequently requested referral from primary care clinics to higher-level facilities (31). However, caregivers who participated in my qualitative study (chapter 7) did not

express a clear preference for hospital-level care over primary healthcare facilities. Differences in geography are suggested as a possible barrier to referral – specifically the need to travel through a nature reserve with wild animals and poor lighting if patients from AHRI were to go to the district hospital. In addition, many caregivers commented on the lack of availability of private transport and delays caused by waiting for ambulances which may disincentivise referral. However, this thesis was not well placed to investigate supply-side barriers to referral and further work is required in this area.

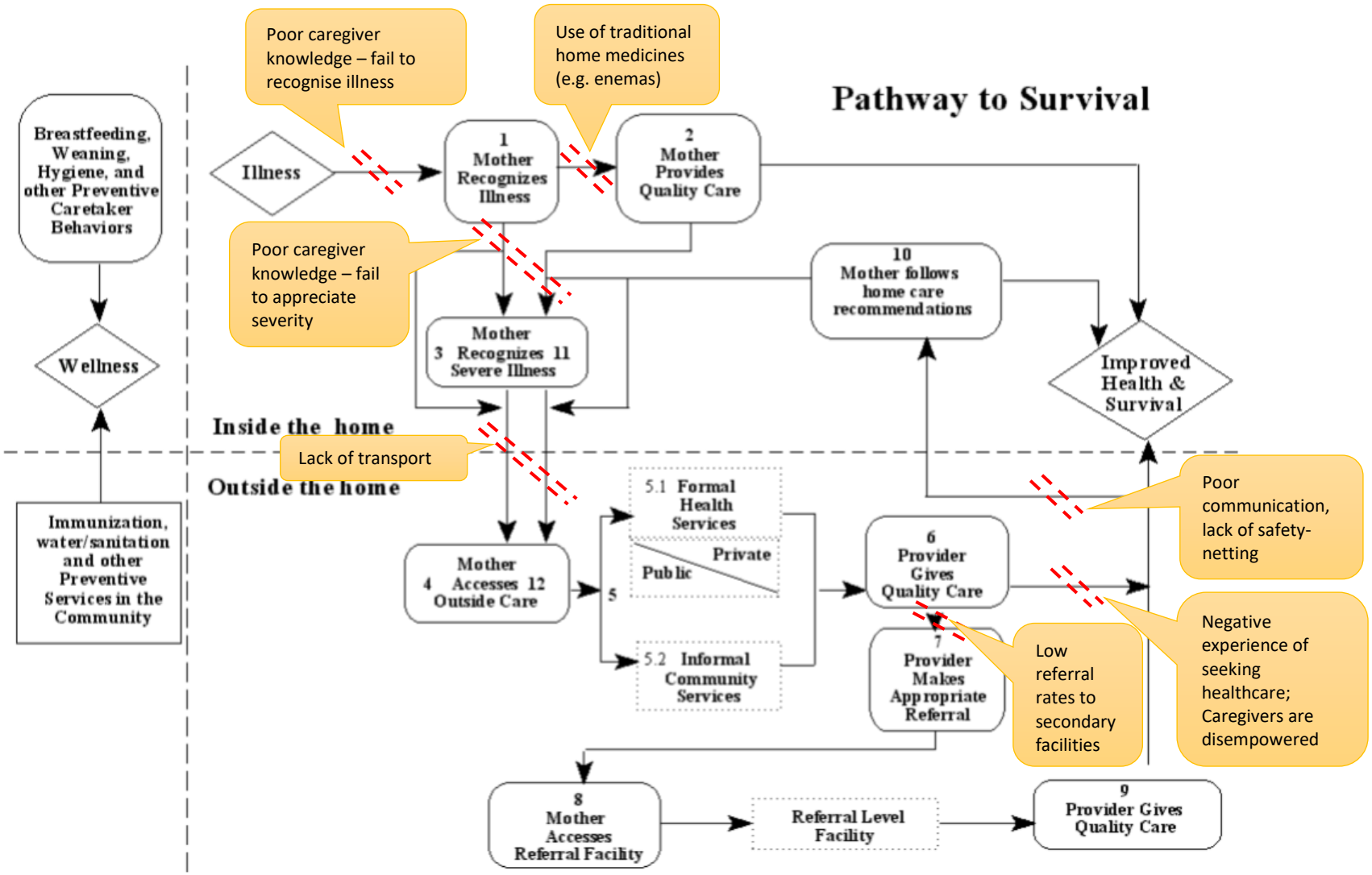


Figure 8.1: Adaptation of the Pathways to Survival Framework showing those modifiable factors identified in this thesis within and outside the home, and the stage of the pathway at which each factor acts.

8.5 Traditional medicine and consulting traditional healers

Traditional medicine and consulting traditional healers is common in South Africa, though typically it is used in parallel with western medical care – what is referred to as 'medical pluralism' (32,33). Traditional healers are widely available to communities in both rural and urban areas (34,35), and are seen as providing a valuable service in the community, offering patients more time, listening to them, acknowledging their concerns, and operating from a shared world view (19,34,36). However, some practices are dangerous from a medical standpoint: of note in the case of child illness are the use of enemas, oral ingestion of 'muti' (traditional remedies) which might include toxic substances and lead to poisoning, and infections related to scarification rituals, including the transmission of HIV if rituals are not performed with sterilised equipment (37,38). It is important to understand why traditional medicines and traditional healers are used if one is to limit the medical harms and maximise the benefits of medical pluralism.

This thesis has highlighted three important insights relating to traditional medicines use and the consulting of traditional healers: first, traditional medicine use appears to be declining over time, at least during fatal childhood illness. Second, despite having noted a decline in traditional medicine use over time, quantitative data collection methods tend to under-estimate traditional medicine use compared to qualitative data collection (39,40). Third, traditional medicine use and consulting traditional healers seems driven by caregivers' desperate desires to try all available options to help their child rather than by a belief in a traditional cause of the disease.

Decline in traditional medicine use over time

Quantitative data from chapters 5 and 6 suggest that use of traditional medicines in fatal childhood illness has declined significantly, so much so that, based on verbal and social autopsy data, only one child was given traditional medicine during their final illness in 2017 and not a single child who died in 2017 was reportedly taken to a traditional healer during their final illness. This is in line with findings on adult care-seeking behaviours in South Africa and across other middle income countries as reported in the WHO-SAGE study (41). Given that the data collection instrument used to collect information on traditional medicine use across the two study sites has remained constant over time (with the same question being included in updated verbal autopsy tools), this decline in traditional medicine use likely reflects a real reduction and is not solely explained by desirability bias (i.e. that participants under-report traditional medicine use because they fear being criticised for the practice).

Differences between quantitative and qualitative data on traditional medicine use

Despite some evidence that there has been a genuine decline in traditional medicine use, it is also clear that quantitative data collection tools underestimate the use of traditional medicines and healers. This was evident in the mismatch of reporting between the social autopsy study and the qualitative interviews and focus group discussions. One caregiver (2%) admitted to using traditional medicines at home in the social autopsy, and all denied taking their child to a traditional healer. In contrast, eight of the same caregivers who participated in the qualitative study (21%) said that they used traditional medicines, traditional healers or faith healers during the child's final illness. While this is clearly still much lower than the rates recorded from verbal autopsy data in 2000 when 62% of caregivers reported using traditional medicines or consulting a traditional healer during the

child's final illness (chapter 5), it demonstrates that qualitative research can access important insights in fully describing the treatment options used by caregivers.

The difference in reporting in qualitative and quantitative methods might reflect the impact of social desirability bias, defined above. Qualitative researchers can spend more time building rapport with participants than verbal autopsy fieldworkers would ordinarily be able to do when completing the close-ended verbal and social autopsy questionnaire. Qualitative research questions are often more open-ended allowing for anticipated and unanticipated themes to emerge. In addition, qualitative researchers were specifically selected to be non-medical and were from the same cultural background as the participants. This might have encouraged participants to be more open and honest about their treatment choices, as they felt less judged and less fearful of criticism. By contrast, verbal autopsy fieldworkers in AHRI are nursing staff, and fieldworkers in Agincourt are still conducting a very medicalised autopsy interview asking about specific medical symptoms in an interview that is framed around identifying biological cause of death.

Motivations underlying caregivers' use of traditional medicines and traditional healers

Based on the qualitative work presented in Chapter 7, one of the main motivations driving traditional medicine and traditional healer use seemed to be caregivers' desperate desire to help their child get better. Within the home, some caregivers administered enemas as part of a routine to promote general well-being or treat symptoms of mild child illness. In some cases, caregivers were just desperate to do *something*, and this was a practice with which they were familiar. This is in keeping with literature that shows that enemas are commonly used by caregivers in South African communities as part of preventative healthcare (often given to children routinely to clean out the

gut) and as part of treatment for diseases such as fever or diarrhoea (35,42). The use of enemas did not appear to delay access to formal healthcare and was clearly not driven by malicious intent. However, traditional enemas can be dangerous causing severe diarrhoea, dehydration and even poisoning (37,38). Strategies to eliminate their use as a treatment modality in child illness are therefore important and warrant further research.

The desperate need to help their child also appeared to underpin caregiver's motivation for consulting traditional healers. Many caregivers did not have a clear idea of what was causing the child's illness; of those who consulted a traditional healer, most participants in the qualitative study (chapter 7) started with using allopathic treatment options, and attending formal healthcare facilities, but felt that they should try traditional treatment approaches if the child did not improve as this was seen as an indication that the illness might have a traditional cause. This contrasts with research that has shown that caregivers seek out traditional treatments as they identify a specific traditional cause of disease (39,40).

The motivations for use of traditional medicines and healers identified in my thesis are relevant in interpreting the quantitative results that traditional medicine use and consulting traditional healers was associated with greater odds of dying at home despite seeking healthcare. It seems unlikely that this is a causal association. Rather traditional medicine use is a confounder, demonstrating the severity of a child's illness and their failure to respond to initial treatment either at home or in a formal health facility. Traditional medicines and healers were used as part of caregiver's attempts to follow all available treatment avenues. Traditional medicine use is compounded by poor caregiver

knowledge, negative care-seeking experiences, a lack of referral and inadequate safety-netting, all of which are more readily linked to home deaths despite seeking healthcare.

8.6 HIV-related deaths

No thesis on South African healthcare is complete without due consideration paid to the question of HIV. The HIV/AIDS epidemic is arguably the single largest influence on the issue of under-5 mortality in South Africa over the past 2 decades, accounting for most of the increase in mortality that occurred over the 1990s and into the early 2000s, and with HIV-treatment programmes (including the introduction and scaling of prevention of mother-to-child transmission (PMTCT) and antiretroviral treatment (ART) programmes) credited with the subsequent decline in under-5 mortality since 2003 (43). South Africa reduced the rate of paediatric HIV infection by more than 80% between 2009-2015, and the rate of mother-to-child transmission was just 2% by 2016 (44). However, research looking at experiences of people living with HIV remains largely negative highlighting the ongoing challenges of stigma and discrimination (45–49). In addition, one cannot forget the generation of orphans left behind as mothers and fathers died from HIV-related illnesses, to be raised by grandparents or extended family members (50,51). Nor can we ignore the evidence showing that maternal death increases the risk of a child dying both in the months preceding and in the months following her death (52). The lasting negative experiences of families, children and caregivers living with or affected by HIV made the findings from this thesis unexpected: my findings suggest that the model of care provided to HIV-positive children in recent years may provide lessons which can be applied more generally to the care of all infants and young children.

This thesis showed that in recent years (from 2012 onwards), HIV-related deaths were less likely to occur at home compared to HIV-unrelated deaths where healthcare was sought. I did not find a consistent pattern in place of death across the remaining top causes of death. I also showed that while the proportion of HIV-unrelated under-5 deaths occurring at home was constant over time at approximately 50%, the proportion of HIV-related deaths occurring at home fell from 60% in 2000-2011, to 39% in 2012-2015. Clearly there is something different about the way these caregivers engaged with formal healthcare services, compared to caregivers of children who did not die of an HIV-related cause.

This question was explored further during the qualitative work. Although respondents were not able to fully explain the association found between HIV-related illness and place of death, some commented that there were differences in the way that HIV-positive caregivers were treated at antenatal clinics and HIV-positive children when seeking healthcare. HIV-positive mothers were often friendlier with staff, more familiar with the system. One participant suggested that HIV-positive mothers made a conscious effort to befriend clinic staff as it was to their advantage to have personal relationships with staff should medications run short as they would be prioritised. While more research is needed with HIV positive caregivers, and with clinic staff, the data from this thesis suggests that HIV positive mothers, or caregivers of HIV positive children, gain social capital as a result of their closer relationship with the healthcare system: frequent check-ups and additional healthcare needs mean they develop a familiarity with the system, and get to know clinic staff. Perhaps the additional emphasis placed on health promotion with HIV-positive caregivers and children, relating to adherence to antiretroviral treatment, feeding practices, growth measurement and signs of illness, means they feel more empowered to express their concerns when a child is ill.

8.7 Policy recommendations

Although there has been work to demonstrate which interventions are most effective at reducing under-5 mortality overall (including extended vaccination schedule, access to PMTCT and ART, antibiotic treatment for pneumonia, oral rehydration solution for diarrhoea, exclusive breastfeeding campaigns and vitamin A supplementation), these policies do not focus specifically on deaths at home. I therefore suggest policies which focus on those modifiable factors identified through my doctoral work as contributing to home deaths in particular. These recommendations include interventions implemented at a community level and at facility levels. Finally, I recommend adjustments to standardised data collection tools to scale the investigation of social circumstances of death in other settings which will strengthen information on strategies to reduce child mortality.

8.7.1 Community-level recommendations

Many community level interventions have been shown to be effective in improving caregiver knowledge of danger signs of severe child illness and prompting care-seeking during child illness (both modifiable factors which I highlighted as contributing to under-5 deaths at home). These include home visits of pregnant and recently-delivered women by community health workers (CHWs), and community mobilisation through participatory action groups.

Recommendation 1: All pregnant and recently delivered women should receive routine home visits by community health workers during the antenatal and postnatal period.

Home visits by CHWs for mothers and their newborn children serve to decentralise the provision of healthcare in the postnatal period and offer regular opportunities to deliver health promotion and health education to mothers and family members (particularly husbands and grandmothers). CHWs may also recognise dangers signs in the child, encourage referral where signs of severe illness are present, and treat certain conditions syndromically such as pneumonia, diarrhoea and growth faltering (53). The Good Start trial in KwaZulu-Natal, demonstrated that postnatal home visits by CHWs were effective in increasing knowledge of newborn danger signs, attendance of the one-week postnatal clinic visit, and greater length-for-age (suggesting that infants of mothers who received home visits were better nourished) (54). In keeping with findings from my systematic review in Chapter 2, parental acceptance of referral by a CHW to a primary healthcare facility was high, and the intervention was deemed acceptable, feasible and effective (55).

A Cochrane review on community-based intervention packages further highlighted the educational benefits of home visits in increasing rates of exclusive breastfeeding and improving caregiver knowledge of developmental milestones (56) and another review of CHW programmes in south Asia demonstrated an overall reduction in neonatal mortality (57). The Newhints trial is the only trial conducted in sub-Saharan Africa that evaluated the impact of home visitation on neonatal mortality specifically, in addition to care-seeking behaviours or newborn care practices (58). This study did not demonstrate a significant reduction in mortality despite showing improved illness recognition and referral of neonatal illness. However, investigators argued that the study was underpowered to detect reductions in neonatal mortality below 25%, but that the trial's results were similar to those

findings from south Asia. When meta-analysed with previous trials from south Asia home visits reduce neonatal mortality by 12% (95% CI 5-18%) (58).

As of 2009, the WHO and UNICEF recommended that every pregnant woman should receive at least two antenatal home visits, and two postnatal home visits – the first should be within the first 24 hours after birth (59).

However, key features of a successful CHW programme include appropriate training, adequate supervision, appropriate linkage to other parts of the healthcare system and sufficient resources to pay CHWs and provide the supplies and equipment necessary for their work. Currently, South Africa's CHW training is inadequate. Compulsory training before starting in the field is only a two-week course (level 1 training) and does not include disease-specific modules. Level 2 training is supposed to be co-ordinated by the supervisors and requires accompanied home visits to evaluate the CHW's work. However, where supervision is lacking, or where CHWs are in rural areas far from centres where more advanced training courses are run, this additional training does not occur (60).

The second edition *of Disease Control Priorities in Developing Countries* (DCP2) recommends a supervision ratio of a least one supervisor to 20 CHWs suggesting that this is a key difference between those CHW programmes which are effective in improving maternal and child health outcomes and those which are not (61). Current policy in South Africa includes CHWs as part of ward-based outreach teams (WBOTs). WBOTs are supposed to include one outreach team leader, six to ten CHWs and one data capturer, with an ideal ratio of one WBOT per 6000 community

members (62). In pilot studies, the team leader role was ideally filled by a professional nurse (a senior nurse with 4 years of training, often with additional diplomas in primary health care, HIV, maternal and child health, and with many years of experience who is to act as supervisor (63)), however a revision of the policy now suggests that this role can be filled by enrolled nurses (junior nurses with 2 years of training) who have received additional training in community health nursing (62) . WBOTs are not yet operational in all provinces, and where they exist, they often lack adequate supervision and necessary resources to perform even the most basic health checks. Research following the pilot of WBOTs in Gauteng province showed that many WBOTS relied on an enrolled nurse in place of a professional nurse, but that supervision was much more effective when conducted by a professional nurse (63).

Linkage to care also varies across different structures of the WBOT: it is dependent on the seniority of the supervisor and their location either in the main primary care clinic or in the community (at a health post). Research suggests that the optimal structure includes having a professional nurse as the supervisor, who is based in the main primary care clinic serving the community (63). However, a lack of transport for CHWs can limit access to supervisors and reduce the likelihood of nurses joining CHWs on supervised home visits (64). Inadequate resourcing extends beyond a lack of transport: CHWs are poorly paid, and this contributes to low job satisfaction, poor morale and a lack of motivation (65).

While South Africa has had a policy that outlines the inclusion of CHWs as part of a revised primary healthcare system since 2011, the implementation of this policy leaves much to be desired. A recent analysis of CHW programmes as a method of delivering key child health interventions using the Lives

Saved Tool (LiST) suggests that using CHWs is increasingly cost-effective in South Africa (66). However, as the country considers expansion of the WBOT programme, health departments must be sure to build on existing guidelines around optimal supervision ratios, linkage to care and ensure adequate resources for the programme.

Recommendation 2: Develop and pilot Participatory Action Groups to increase caregivers' knowledge of childhood illness and their confidence to engage healthcare services more assertively.

Community mobilisation has been defined as "a capacity-building process through which community individuals, groups, or organisations, plan, carry out, and evaluate activities on a participatory and sustained basis to improve their health and other needs, either on their own initiative or stimulated by others " (67). Increasingly literature on community mobilisation strategies to improve neonatal and child health outcomes has highlighted women's groups as a tool to mobilise and empower women, deliver health education and prevention messages, improve newborn care and reduce neonatal mortality by approximately 20% (53,68,69). Women's groups use participatory action research and are led by appropriately trained facilitators (70). Women in the group work through a process of identifying the problems and their root causes, planning and implementing interventions and then reviewing progress (variably referred to as a community mobilisation action cycle (71), or as a participatory learning and action cycle (68)). These groups have also been shown to be most effective at improving neonatal health outcomes when at least 30% of women in the group are pregnant (68). Furthermore, the effect of reducing mortality and improving care-seeking practices are increased when combined with home visits by community health workers (68,72).

Community mobilisation through participatory learning and action cycles are particularly appealing in the South African context where capability deprivation and the lived experience of poverty, as described by Amartya Sen (29), serve to disempower caregivers in their interactions with healthcare providers (chapter 7). In these settings, health education is more empowering and effective when it is participatory, involving problem solving and dialogue, rather than message giving (68). This serves to better address the challenge I articulated in Chapter 7, whereby even when caregivers identified that their child was ill, and had sought care, they were unable to assert themselves during the consultation with a healthcare provider.

Women's groups have not been utilised extensively in South Africa: in the 1970s Erika Sutter and Selina Maphorogo established Care Groups in what is now Limpopo province to offer health education to prevent trachoma infection and subsequent blindness. This project was incredibly successful, and these Care Groups still operate in the region, having shifted focus to broader health promotion issues (73). More recently, participatory action research is being shown to empower the communities in Mpumalanga to address drivers of child mortality. The Verbal Autopsy Participatory Action Research (VAPAR) project in Agincourt has developed a model linking key stakeholders from government, health facilities and the community to identify and prioritise drivers of under-5 mortality and develop solutions which can be implemented at local levels and may be generalisable to rural areas across the country (74,75). Further piloting of this style of community engagement and empowerment may be of value and should be considered as a possible strategy for improving caregiver knowledge and building caregivers' confidence in assessing their child's illness and seeking healthcare.

8.7.2 Facility level recommendations

Recommendation 3: Improve data sharing on identified child deaths between health and demographic surveillance systems and health facilities so that home deaths can be included in facility-based mortality reviews especially if the child was taken to a healthcare provider during their final illness.

Facility-based mortality reviews have been shown to reduce perinatal and under-5 mortality by driving improvements in the quality of care provided (76). Expanding facility-based death reviews to incorporate deaths which occur outside of the health facility would be valuable given that most children who died at home were taken to formal healthcare providers shortly before death. Routine identification of all deaths is already underway in existing health and demographic surveillance system (HDSS) sites and will occur in the additional HDSS sites to be established over the coming 10 years as part of the South Africa Population Research Infrastructure Network (SAPRIN). Therefore, formal communication channels should be established between researchers from the HDSS sites and health facilities to notify facilities of home deaths and share relevant information captured through verbal and social autopsies. Facilities could then follow-up those deaths not already included in the Perinatal Problem Identification Programme (PPIP) or the Child Health Problem Identification Programme (Child PIP) to identify additional learnings. This would also allow greater opportunities to include caregivers and community member feedback as part of the review, as was done in confidential enquiries in Mali and Uganda (77).

By logical extension, where PPIP and Child PIP coverage is incomplete, efforts should be undertaken to increase coverage. Coverage of Child PIP is of particular concern at only 61% of hospitals nationally (78). Where required, additional training and support should also be provided to ensure optimal facilitation of death reviews and close the communication loop between those analysing

the data on modifiable factors, and facilities who need to design and implement policies to address areas of concern. This is critical to the success of PPIP and Child PIP, as alone they have not reduced in-hospital mortality (79,80). Participatory learning and action cycles can be used within facilities to identify modifiable factors (as part of the audit process), prioritise problems, develop and trial interventions, and re-evaluate their effect as a regular, ongoing process. Similar strategies have been employed with great success as part of Lean Management strategies piloted in several South African healthcare facilities to tackle inefficiencies which hinder delivery of high-quality care (81,82).

Recommendation 4: Implement clear guidelines for safety-netting and follow-up.

Healthcare workers in South Africa should be made aware that a large proportion of children who die are seen by medical staff during their final illness and sent home. They should therefore consider clear safety-netting advice for caregivers, with instructions for what should prompt re-presentation. Much of this advice is laid out in the IMCI guidelines (83), and in the standard treatment guidelines for Primary Care Facilities (84), but safety-netting takes additional time and requires good communication, using descriptions of danger signs that caregivers can understand. In settings where communication is poor and time is limited, safety-netting may not be prioritised. While further research is needed to confirm the barriers to safety-netting from healthcare workers' perspectives, my thesis demonstrates clearly that from caregivers' perspectives safety-netting information is lacking.

Recommendation 5: Pilot participatory learning workshops with healthcare workers to identify reasons for negative staff attitudes and attempt to address them.

Reports of mistreatment of patients by healthcare workers, including physical, verbal, emotional and even sexual abuse, have been documented for over 25 years in South Africa (30,85). However, there are few interventions which have specifically targeted improving the provider-patient relationship. As described in chapter 7, healthcare workers' behaviours have become normalised, reinforced by existing gender, race and class power imbalances. Therefore, one approach to consider in addressing poor provider-patient relationships is to use participatory learning in workshops with healthcare workers to sensitise staff to these social norms and how they affect the quality of patient care (86).

Healthcare Workers for Change, a programme piloted in South Africa in the early 2000s, focused on improving gender sensitivity amongst nurses (87). The research team produced workshop outlines and activities to prompt nurses to reflect on their practices, the impact that this has on patient care and the underlying beliefs which drive discriminatory practices against women. These workshops made staff aware of their own biases against women, particularly those who lacked education, with staff commenting that they purposely did not give such women information about their diagnosis or treatment options believing they would not be able to understand (10). A second example of participatory learning workshops focused on gender-based violence. These workshops involved both male and female nurses and demonstrated that in addition to perpetuating gender-based violence (physical, emotional and psychological) against patients, many nurses were themselves victims of gender-based violence. Understanding the context from which nurses come and to which they return at the end of their working day, is important in trying to create supportive environments to break a cycle of violence and encourage better patient interaction and improve quality of care (88).

Regular participatory learning workshops with healthcare workers prompt staff to reflect on how their beliefs and behaviours have changed and limit a reversion back to old habits. Further research would be valuable to assess the feasibility of such workshops at scale and the impact of complex interventions – combining facility-based participatory learning workshops with community-level interventions to empower women and build their confidence in accessing healthcare services - on the patient-provider relationships.

8.7.3 Data collection instruments

Recommendation 6: Social autopsy questions addressing the social circumstances of death should be included in the standardised WHO Verbal Autopsy tools.

Chapter 6 demonstrated the value of the addition of a select number of social autopsy questions to the standardised WHO VA tools to investigate social circumstances of death. By integrating the social autopsy (table 6.1 chapter 6) into the existing WHO VA questionnaires, only 7 additional questions were required to ensure that there was at least one data point for each stage of the care pathways as defined by the Pathways to Survival Framework. This substantially reduced the total time required to collect data on the circumstances of death compared to conducting a separate social autopsy interview which would repeat many of the questions already asked in the WHO standardised verbal autopsy (as in envisioned in the full INDEPTH Network Social Autopsy tools included as appendices 6.1 and 6.2). The additional costs were also low as no additional staffing or data collection equipment was required.

Recommendation 7: Questions used to identify transport delays should be adapted to the local context.

It is clear from the inconsistency in the quantitative and qualitative data on the lack of access to transport in chapters 6 and 7 respectively, that the verbal autopsy questions on transport access used in the quantitative analysis need to be adapted to more sensitively identify transport barriers in South Africa. The question currently reads "Does it take more than 2 hours to get to the nearest hospital or health facility?" The question clearly establishes a two-hour cut-off as an assessment of the significance of transport as a barrier to accessing healthcare. This is likely too long for South African settings where nationally few households are further than 10km from the nearest facility, and the average distance of households to a healthcare facility was only 3km in both Agincourt and AHRI. A cut-off of one hour may be a more appropriate metric nationally, and where regional data suggests smaller distances (as is likely the case in urban areas), a thirty-minute cut-off may be more appropriate. It is also worth piloting an alteration of the wording of the question to ask caregivers how long they waited for transport – or spent trying to arrange transport, or whether they had difficulty in reaching the health facility in time – rather than only asking how long it takes to get to the nearest facility as in the current wording. This would more accurately capture the full extent of delays in accessing healthcare attributable to lack of transport.

Recommendation 8: Questions on use of traditional medicines or traditional healers should be developed with traditional healers, healthcare workers and community members so that the phrasing and contextualisation is appropriate and more likely to accurately identify these health behaviours.

Traditional medicine use was also inconsistently reported across quantitative and qualitative data. Given the importance of accurately measuring traditional medicine use, and the extent of medical pluralism, quantitative data collection tools on traditional medicine use should be developed in consultation with individuals who navigate the allopathic and traditional medicine worlds concurrently e.g. medical practitioners who have also trained as sangomas, nurses who live and

work in communities where traditional medicine use is common, caregivers who attend the clinic and also engage in traditional practices, and traditional healers themselves. These changes need to be supported concurrently with additional training for fieldworkers conducting verbal autopsy interviews, to try encourage better rapport and non-judgementalism with reminders that they are interested in understanding what happened and will not criticise respondents for use of traditional treatment choices. Where one is especially interested in accurate data collection on traditional medicine use, interviewers should not themselves be nurses, or affiliated to specific healthcare facilities.

8.8 Recommendations for future research

My doctoral thesis has identified four key questions that require further research. First: additional research with healthcare providers is critical in fully exploring modifiable factors related to under-5 deaths at home given the high rates of care-seeking during the child's final illness. It is important to assess the quality of care provided to children who died at home after seeking healthcare, and to identify opportunities for improvements where substandard care or delays contributed to death. Understanding healthcare workers' perspectives on caregivers' experiences of seeking healthcare would also be valuable for the development of interventions to improve the provider-patient relationship. Such interventions should in turn be piloted to evaluate their impact and feasibility.

Second, while it is clear that referral rates from primary healthcare providers to higher levels of care are low, research is required to identify the barriers faced by healthcare workers when trying to refer children to higher levels of care. Barriers likely exist at individual, facility and health systems levels and so mixed-methods approaches will be well suited to answer this question.

Third, use of traditional medicines and traditional healers was identified as an important issue throughout my thesis. The use of mixed methods provided a better understanding of the practices and motivations behind treatment choices in these two rural communities, however I did not set out to explore this issue fully in my thesis and many questions remain unanswered. Further research is required to understand particular issues around the use of enemas and to develop strategies which effectively reduce their use as it is clear from the data that having nurses and doctors tell patients not to use them (and subsequently shouting at them and shaming them for administering an enema) does not work. Accurately recording the prevalence and patterns of traditional medicine use (whether before, after or in parallel with allopathic medicine, or for particular symptoms) and the social determinants which affect usage patterns will help in targeting interventions to limit the harms of traditional medicines while still maximising the benefits of medical pluralism.

Fourth, longitudinal analysis in chapter 5 demonstrated a significant association between place of death and HIV, with HIV-related deaths being more likely to occur in a healthcare facility since 2012 compared to HIV-unrelated deaths. I argue that this reflects social capital earned by caregivers who are themselves HIV positive or who care for HIV-positive children, through more regular contact with healthcare staff and a familiarity and comfort with the operations of the healthcare system. This contrasts with the many negative experiences of stigma experienced by people living with HIV. It is also possible that this group of caregivers receive more attention from clinic staff during routine postnatal visits and child-wellness check-ups with a greater emphasis on health promotion and education of the caregiver, and that when an HIV-positive or HIV-exposed child is sick and brought to the clinic, their caregivers' concerns are taken more seriously by nursing staff. All of these

hypotheses require further research. Furthermore, should a particular package of care be identified that is provided for HIV-positive caregivers and children, researchers should consider whether similar packages of care should be made available to all children under-5 as a means of reducing the proportion of children who die at home.

8.9 Conclusion

Home deaths accounted for almost half of all under-5 deaths in South Africa in 2015. Yet to date, very little research has been undertaken to explain this phenomenon. Sustainable Development Goal three aims to end all preventable newborn and under-5 deaths. As South Africa attempts to meet the neonatal and under-5 mortality targets by 2030, the call for further information on deaths of children at home has grown louder, recognising that interventions to reduce facility-based deaths may not be effective at reducing home deaths.

My doctoral work has helped to understand why children under-5 die at home in rural South Africa, and to recommend interventions which specifically target a reduction in home deaths in rural communities. My research was undertaken in high HIV-burden settings, in rapidly transitioning rural populations, in two of the nine provinces of South Africa. These are poor communities with high rates of unemployment, labour migration, and dependency on social grants. By locating this research within existing health and demographic surveillance systems, I was able to conduct population-based research critical to investigating the circumstance of home deaths, drawing on longitudinal data and combining quantitative and qualitative primary data collection methods.

I confirmed that approximately 50% of under-5 deaths continue to occur outside of health facilities – mostly at home – despite a decline in the overall under-5 mortality rate. Furthermore, I showed that over 90% of all children who died below the age of five years had been taken outside the home for formal healthcare during their final illness, including over 80% of children who died at home. This clearly indicates that home deaths are not purely a function of caregivers' failure to recognise illness or access healthcare services. I identified modifiable factors contributing to home deaths within and outside the home and made recommendations for policy interventions to address these factors. I have also recommended improvements to existing data collection tools used to research under-5 deaths at home in South Africa and elsewhere, which will strengthen information on strategies to reduce child mortality.

Finally, I have highlighted the need for further research to evaluate the quality of care provided to children who died at home after seeking healthcare, identify barriers health workers face in referring patients to higher facilities and assess which aspects of the current HIV care package confer protection on HIV positive children, reducing their odds of dying at home, and what the implications would be for providing similar services to all children under five years. Engaging traditional healers, community members and health practitioners to further understand the role of traditional medicines and healers in fatal child illness offers opportunities to maximise the benefits of medical pluralism and reduce the harms.

Home deaths in children under-5 result from multiple failings along the care pathway. Engaging caregivers, healthcare providers and the broader community in trying better to understand the

ongoing challenges which act as barriers to seeking and receiving high-quality healthcare will better enable South Africa to reduce under-5 mortality at home and overall.

8.10 References

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Appendices

Appendix 3.1: Data extraction template

Study title, author	title a, AA	title b, BB	title c, CC
Identifier	AA, date	BB, date	CC, date
Country	Country x	Country y	Country z
Age group (1=neonatal, 2=1-59 months, 3=0-59 months)	1	2	3
Age	0-28	1-59	0-59
All-cause mortality or specific cause (specify)	all cause	all cause	malaria
N	590	620	320
Female		316	156
Died at home:	284	470	
Died in any formal health facility:	306	115	
Died in formal PHC:	64		
Died in other health facility (not hospital but further details unspecified)		63	
Died in hospital:	200	52	
Died in private clinic:	42		
Died elsewhere	0	10	
Died on route		24	
Number tracked through care pathway	590	601	320
Illness recognition		601	
Severe illness recognized		578	
No care given/no home care and did not attempt to seek care.		71	38
Home care given		68	73
Care sought/attempted to seek care outside the home (Note does not require that arrived at care alive)	426	498	282
Sought/attempted to seek formal care (Note does not require that arrived at care alive)	365	477	
Died before setting out for formal care/ on route/could not reach ANY formal provider		102	
Sought/attempted to seek Informal care	61	37	
Arrive alive at formal healthcare facility		375	
Total number who leave the first health facility alive (proportion to be calculated of those who arrived alive):		306	
Number not referred from facility		248	
Number referred from facility		58	
Acceptance of referral (was taken and died on the way OR arrived alive at the intended destination)		40	

Appendix 3.2: Quality assessment of included studies

Table 3.2.1: Adapted quality assessment tool

Quality indicator	Full question included in the quality assessment tool
1.	Were the aims and objectives of the study clear and relevant to our review?
2.	Was the sample size justified?
3.	Was the target/ reference population clearly defined?
4.	Was the sample frame taken from an appropriate population base so that it closely represented the target/reference population under investigation?
5.	Were measures taken to address and categorise non-responders where appropriate?
6.	Were the data collected using instruments/ measures that had been trialed, piloted or published previously?
7.	Were the methods sufficiently described (including statistical methods) to allow them to be repeated?
8.	Were the demographic data adequately described?
9.	Is the response rate unconcerning (i.e. >=90%)
10.	If appropriate, was information about non-responders described?
11.	Were the results presented for all the analyses described in our methods?
12.	Were the limitations of the study discussed?
13.	Was the research free from any funding sources or conflicts of interest that may affect the authors' interpretation of the results?
14.	Was there ethical approval or consent of participants? (Yes=1, No/unspecified=0)

Table 3.2.2: Quality assessment of included studies

Study no:	Author	Quality indicator*														Quality score:
		1	2	3	4	5	6	7	8	9	10	11	12	13	14	
1	Snow et al	0	1	1	1	1	0	0	1	1	1	0	1	1	1	0.71
2	Sodemann et al	0	1	1	1	0	0	1	1	0	0	0	0	1	1	0.50
3	Garg et al	1	1	1	1	0	0	0	0	1	1	0	1	1	0	0.57
4	Armstrong et al	1	1	1	1	1	0	0	1	1	1	0	0	1	1	0.71
5	Schumacher et al	1	1	1	1	1	1	1	1	1	1	0	1	1	1	0.93
6	Hinderaker et al	0	1	1	1	0	1	0	0	1	1	0	0	1	1	0.57
7	Muller et al	1	1	1	1	1	0	0	0	1	1	0	0	1	1	0.64
8	de Savigny et al	1	1	1	1	1	1	1	1	1	1	0	1	1	1	0.93
9	Beiersmann et al	0	0	1	1	0	0	0	0	0	0	0	0	1	1	0.29
10	Kamugisa et al	0	1	1	1	1	1	1	0	1	1	0	1	1	1	0.79
11	Edmond et al	0	1	1	1	0	1	1	0	1	1	0	1	1	1	0.71
12	Hildenwall et al	0	1	1	1	0	1	1	1	1	1	0	1	1	1	0.79
13	Kallander et al	1	1	1	1	1	0	1	0	1	1	1	1	1	1	0.86
14	Kaatano et al	0	0	1	1	0	1	1	0	0	0	0	1	1	1	0.50
15	Waiswa et al	1	1	1	1	1	1	1	0	1	1	0	1	1	1	0.86
16	Kallander et al	1	1	1	0	0	1	1	1	0	0	1	1	1	1	0.71
17	Manortey et al	0	1	1	1	1	1	1	1	1	1	0	1	1	1	0.86
18	Mrisho et al	1	0	1	1	0	1	1	1	1	1	0	0	1	1	0.71
19	Olack et al	0	1	1	1	0	0	1	1	0	0	0	1	1	1	0.57
20	Rahman et al	0	0	1	0	0	0	0	0	0	0	0	1	1	0	0.21
21	Koffi et al	1	1	1	1	1	1	1	1	0	0	1	1	1	1	0.86
22	Koffi et al	1	1	1	1	0	1	1	1	0	0	1	1	1	1	0.79
23	Assefa et al	0	1	1	1	1	1	1	0	1	1	0	1	1	1	0.79
24	D'Ambruoso et al	0	1	1	1	0	1	1	1	1	1	0	1	1	1	0.79
25	Kalter et al	0	1	1	1	0	1	1	1	1	1	1	1	1	1	0.86
26	Koffi et al	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1.00
27	Obor et al	0	1	1	1	0	1	0	0	1	1	0	0	0	0	0.43
28	Rosario et al	0	1	1	1	1	1	1	1	0	1	0	1	1	1	0.79
29	Bogale et al	1	1	1	1	1	1	1	0	1	1	0	1	1	1	0.86
30	Koffi et al	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1.00
31	Koffi et al	1	1	1	1	1	1	1	0	1	1	1	1	1	1	0.93
32	Navale et al	0	1	1	1	0	1	0	1	0	0	0	1	1	1	0.57
33	Kagabo et al	1	1	1	1	1	1	1	1	1	1	0	1	1	1	0.93
34	Willcox et al	1	1	1	1	0	1	1	0	0	0	1	0	1	1	0.64

*See Table 3.2.1 for list of questions associated with each quality indicator.

Appendix 3.3: Suggested definitions for each stage of the care pathway

Table 3.3.1: Suggested definitions for each stage of the care pathway

Stage of care pathway	**Definition**
Died at home	# who died at home / total deaths
Died in any formal health facility	# who died in a health facility (primary, secondary or tertiary level) / total deaths
Died on route to a health facility	# who died eon route to a health facility (primary, secondary or tertiary level) / total deaths
Died elsewhere	Place of death not at home, in a health facility or on route to a health facility / total deaths
Illness recognition	# Any signs or symptoms of illness reported/total deaths
Severe illness recognised	# of deceased children whose caregivers reported one or more possibly severe or severe signs or symptoms/total death Severe illness was defined by the caretakers' mention of at least one of the danger signs defined by the Integrated Management of Childhood Illness (IMCI) guidelines. These include convulsions, chest indrawing, nasal flaring, grunting, bulging fontanelle, umbilical redness extending to the skin, many or severe skin pustules, lethargic or unconscious or less than normal movement, not able to drink or breastfeed, vomits everything, convulsions, loose stools/diarrhea > 2 days, heavy bleeding
No care given or did not attempt to seek care	# with no home care and no attempt to seek care outside the home / total deaths
Home care given	# Home care given / total deaths (Note: no judgment made of appropriateness of home care)
Care sought or attempted to seek care outside the home	Sought or attempted to see any Care outside the home for the child's fatal illnesses / total death (Note this includes formal and informal sources of care)
Sought or attempted to seek formal care	Sought or attempted to seek formal care / total deaths
Died before setting out for formal care or on route or could not reach ANY formal provider	Died before setting out or on route to formal provider / total deaths
Sought or attempted to seek Informal care	Sought or attempted to seek informal care / total deaths
Proportion who leave the first health facility alive	# of children leaving the health facility alive / total deaths

Appendix 3.4: Summary of results, stratified by national income status

Table 3.4.1: Summary of results, stratified why national income status

Outcome	Low income				Lower middle income				Upper middle income		
	Number of studies*	Number of deaths	Proportion (95% CI)	I^2	Number of studies*	Number of deaths	Proportion (95% CI)	I^2	Number of studies*	Number of deaths	Proportion (95% CI)
Died at home	22	5980	53.3 (44.0-62.5)	98.0	4	3196	55.4 (37.9-72.1)	98.6	0	-	-
Died in a health facility	17	5330	35.2 (26.4-44.6)	97.9	4	3196	34.9 (20.8-50.4)	98.3	0	-	-
Died on route to a health facility	7	1718	5.7 (2.6-9.9)	88.2	3	2856	3.5 (2.6-4.6)	-	0	-	-
Died elsewhere	12	3562	4.7 (1.7-9.1)	96.0	4	3196	5.8 (1.8-11.6)	96.1	0	-	-
Signs/Symptoms of illness	10	3736	98.0 (93.6-100.0)	97.7	3	2793	100.0 (100.0-100.0)	-	1	110	95.5 (89.8-98.0)
Signs/Symptoms of severe illness	9	3307	87.4 (74.8-96.2)	98.8	3	2793	97.0 (96.3-97.6)	-	0	-	-
Died immediately/no care given	15	4033	15.2 (7.7-24.4)	98.1	3	2793	18.2 (4.9-37.3)	-	0	-	-
Home care given	12	3969	44.9 (27.5-63.0)	99.1	3	2793	28.9 (16.1-43.7)	-	0	-	-
Sought/attempted to seek care outside the home	27	6949	71.2 (62.7-79.1)	98.2	3	2793	73.3 (54.3-88.6)	-	0	-	-
Sought/attempted to seek formal care	23	6136	61.1 (51.0-70.7)	98.3	3	2793	61.2 (39.4-80.8)	-	1	110	61.8 (52.5-70.4)
Sought/attempted to seek informal care	13	4610	16.2 (8.1-26.4)	98.6	3	2793	22.1 (9.6-38.0)	-	1	110	17.3 (11.3-25.4)
Died before setting out/on route to provider	8	2527	8.8 (4.8-13.7)	91.7	3	2793	9.6 (2.6-20.3)	-	0	-	-
Arrived alive at formal health facility (out of all deaths)	9	2857	50.3 (38.9-61.7)	97.0	3	2793	50.0 (24.9-75.2)	-	0	-	-
Arrived alive at formal health facility (of those who sought formal care)	9	1679	87.9 (79.3-94.6)	94.1	3	1852	83.4 (63.7-96.5)	-	0	-	-

Left formal health facility alive (out of all deaths)	6	2484	33.0 (21.0-46.1)	97.7	3	2793	35.5 (14.5-60.1)	-	0	-	-
Left formal health facility alive (of those who arrived alive)	6	1245	67.7 (51.5-82.0)	96.9	3	1406	71.4 (58.6-82.6)	-	0	-	-
Referred for further care (out of all deaths)	9	2985	16.7 (8.9-26.1)	97.3	3	2793	5.8 (1.5-12.3)	-	0	-	-
Referred for further care (of those who left the facility alive)	4	721	31.0 (6.5-63.3)	98.5	3	967	15.1 (9.8-21.2)	-	0	-	-
Accepted referral (of all deaths)	8	2888	10.6 (5.3-17.4)	96.1	3	2793	4.4 (1.1-9.7)	-	0	-	-
Accepted referral (of those referred)	8	521	63.0 (51.9-73.6)	77.3	3	140	83.2 (75.9-89.6)	-	0	-	-

*Note: In cases where data was collected from more than one country as part of the same study, each country was counted as a separate study for the purpose of the meta-analysis
Only 1 study therefore I^2 not reported.
Figures in red: significant at P<0.05; figures in orange: significant at p<0.1

Appendix 3.5: Summary of results, stratified by whether or not user-fees are charged for health services

Table 3.5.1: Summary of results, stratified why user-fee policy

Outcome	User fees				No user fees			
	Number of studies*	Number of deaths	Proportion (95% CI)	I^2	Number of studies*	Number of deaths	Proportion (95% CI)	I^2
Died at home	9	3630	69.1 (56.2-80.6)	98.4	16	3364	43.8 (34.3-53.5)	96.7
Died in a health facility	8	3533	24.9 (14.6-36.9)	98.3	11	2811	44.8 (33.5-56.5)	97.3
Died on route to a health facility	2	799	3.6 (2.4-5.0)	-	6	1593	5.2 (1.9-9.7)	89.6
Died elsewhere	6	2470	5.6 (0.8-13.9)	97.9	8	2106	3.9 (1.9-6.5)	84.3
Signs/Symptoms of illness	5	2250	96.9 (89.6-100.0)	97.8	8	2333	99.1 (95.1-100.0)	96.9
Signs/Symptoms of severe illness	5	1962	89.6 (70.9-99.4)	99.0	6	2082	89.6 (76.3-97.9)	98.4
Died immediately/no care given	8	2120	19.4 (9.1-32.4)	97.4	8	2536	15.2 (4.9-29.7)	98.7
Home care given	5	1846	38.9 (27.0-51.5)	95.7	9	2587	44.9 (22.6-68.2)	99.3
Sought/attempted to seek care outside the home	11	3942	67.9 (52.5-81.5)	98.9	17	3630	70.9 (60.7-80.2)	97.5
Sought/attempted to seek formal care	12	3945	53.1 (39.0-66.9)	98.6	13	2915	65.0 (51.6-77.3)	98.0
Sought/attempted to seek informal care	6	3037	25.2 (14.4-37.8)	98.2	10	2420	11.3 (4.2-21.0)	97.5
Died before setting out/on route to provider	4	1516	7.6 (3.8-12.6)	84.0	5	1634	8.0 (2.8-15.5)	94.7
Arrived alive at formal health facility (out of all deaths)	5	1846	45.4 (27.9-63.5)	98.0	5	1634	49.6 (32.0-67.3)	97.9
Arrived alive at formal health facility (of those who sought formal care)	5	1185	92.1 (80.5-99.2)	95.2	5	940	84.8 (73.3-93.6)	93.3
Left formal health facility alive (out of all deaths)	3	1499	40.0 (22.4-59.0)	-	4	1608	26.7 (11.7-45.0)	98.3
Left formal health facility alive (of those who arrived alive)	3	898	78.2 (75.4-80.9)	-	4	758	65.4 (39.0-87.6)	97.9
Referred for further care (out of all deaths)	4	1596	12.3 (4.1-23.8)	96.7	7	2126	16.3 (7.4-27.6)	97.3

Referred for further care (of those who left the facility alive)	3	700	34.4 (4.5-73.9)	-	4	498	34.5 (7.6-68.4)	97.8
Accepted referral (of all deaths)	3	1499	9.1 (3.0-17.9)	-	7	2126	9.5 (4.3-16.4)	94.9
Accepted referral (of those referred)	3	278	73.5 (58.0-86.7)	-	7	315	62.3 (48.0-75.7)	77.6

*Note: In cases where data was collected from more than one country as part of the same study, each country was counted as a separate study for the purpose of the meta-analysis

Figures in red: significant at P<0.05; figures in orange: significant at p<0.1

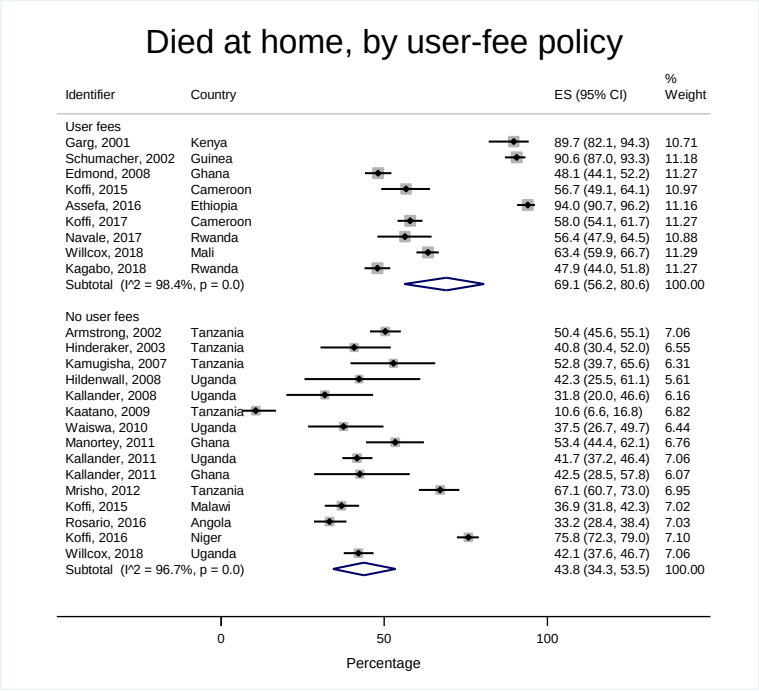


Figure 3.5.1: Proportion of children who died at home, by user-fee policy

Appendix 5.1: Model building process for neonatal deaths

Table 5.1.1: Model building process for neonatal deaths

Variable	Model 1			Model 2 (Model 1 + Socioeconomic variables)			Model 3 (Model 2 + environmental/household variables)			Model 4 (Model 3 + individual level variables)		
	OR*	95% CI	P value	OR*	95% CI	P value	OR*	95% CI	P value	OR*	95% CI	P value
Distal Determinants:												
Year of death (reference: 2012-2015)	1	-	0.004	1	-	0.004	1	-	0.004	1		0.091
2000-2003	0.66	0.18-2.50	-	0.66	0.18-2.50	-	0.66	0.18-2.50	-	0.62	0.15-2.45	
2004-2007	1.51	0.43-5.30	-	1.51	0.43-5.30	-	1.51	0.43-5.30	-	0.95	0.25-3.58	
2008-2011	3.49	1.12-10.84	-	3.49	1.12-10.84	-	3.49	1.12-10.84	-	2.13	0.656.97	
Study site (reference: AHRI)	0.40	0.19-0.85	0.017	0.40	0.19-0.85	0.017	0.40	0.19-0.85	0.017	0.46	0.21-1.01	0.053
Socioeconomic Position:												
Socioeconomic status (reference: quintile 1 - poorest)				-	-	-	-	-	-	-	-	-
Quintile 2 - poor				-	-	-	-	-	-	-	-	-
Quintile 3 – medium				-	-	-	-	-	-	-	-	-
Quintile 4 – rich				-	-	-	-	-	-	-	-	-
Quintile 5 - richest				-	-	-	-	-	-	-	-	-
Maternal education (reference none)				-	-	-	-	-	-	-	-	-
Started/completed primary school				-	-	-	-	-	-	-	-	-

Started/completed secondary school		-	-	-	-	-	-	-	-	-
Started/completed tertiary education		-	-	-	-	-	-	-	-	-
Mother temporary migrant		-	-	-	-	-	-	-	-	-
Mother working		-	-	-	-	-	-	-	-	-
Household head working		-	-	-	-	-	-	-	-	-
Number of household members working		-	-	-	-	-	-	-	-	-
Environmental and household factors:										
Household size (reference 1-5 members)					-	-	-	-	-	-
6-10 members					-	-	-	-	-	-
10-15 members					-	-	-	-	-	-
>15 members					-	-	-	-	-	-
Number of children aged 0-4 in the household					-	-	-	-	-	-
Household head female					-	-	-	-	-	-
Distance to clinic					-	-	-	-	-	-
Maternal conditions:										
Mother deceased								-	-	-
Young mother (<20 years)								-	-	-
Mother relationship status (reference: single)								-	-	-
Married/cohabiting								-	-	-
Divorced/separated								-	-	-
Widowed								-	-	-
Child conditions:										
8-27 days (reference 0-7 days)								5.56	2.68-11.55-	<0.001
Female child								0.47	0.22-0.99	0.047
Traditional medicine								-	-	-

Table 5.1.2: Model building process for deaths of infants and young children

Variable	Model 1			Model 2 (Model 1 + Socioeconomic variables)			Model 3 (Model 2 + environmental/household variables)			Model 4 (Model 3 + individual level variables)		
	OR	95% CI	P value	OR*	95% CI	P value	OR*	95% CI	P value	OR*	95% CI	P value
Distal Determinants:												
Year of death (reference: 2012-2015)	1	-	<0.001	1		<0.001	1		<0.001	1	-	-
2000-2003	0.97	0.74-1.28		0.58	0.42-0.81		0.58	0.42-0.81		0.85	0.52-1.41	-
2004-2007	1.56	1.19-2.04		1.36	0.98-1.87		1.36	0.98-1.87		1.01	0.66-1.55	-
2008-2011	1.40	1.06-1.84		1.44	1.07-1.93		1.44	1.07-1.93		1.05	0.73-1.51	-
Study site (reference: AHRI)	0.96	0.81-1.14	0.654	1.18	0.95-1.47	0.144	1.18	0.95-1.47	0.144	0.65	0.50-0.84	0.001
Socioeconomic Position:												
Socioeconomic status (reference: quintile 1 - poorest)				-	-	-	-	-	-	-	-	-
Quintile 2 - poor				-	-	-	-	-	-	-	-	-
Quintile 3 – medium				-	-	-	-	-	-	-	-	-
Quintile 4 – rich				-	-	-	-	-	-	-	-	-
Quintile 5 - richest				-	-	-	-	-	-	-	-	-
Maternal education (reference none)				1	-	<0.001	1	-	<0.001	1	-	<0.001
Started/completed primary school				0.80	0.52-1.23	-	0.80	0.52-1.23	-	0.82	0.50-1.34	-
Started/completed secondary school				0.54	0.36-0.80	-	0.54	0.36-0.80	-	0.51	0.33-0.80	-
Started/completed tertiary education				0.39	0.20-0.74	-	0.39	0.20-0.74	-	0.36	0.18-0.74	-
Mother temporary migrant				-	-	-	-	-	-	-	-	-
Mother working				-	-	-	-	-	-	-	-	-

Household head working		-	-	-	-	-	-	-	-	-
Number of household members working		-	-	-	-	-	-	-	-	-
Environmental and household factors:										
Household size (reference 1-5 members)					-	-	-	-	-	-
6-10 members					-	-	-	-	-	-
10-15 members					-	-	-	-	-	-
>15 members					-	-	-	-	-	-
Number of children aged 0-4 in the household					-	-	-	-	-	-
Household head female					-	-	-	-	-	-
Distance to clinic					-	-	-	-	-	-
Maternal conditions:										
Mother deceased								-	-	-
Young mother (<20 years)								-	-	-
Mother relationship status (reference: single)								-	-	-
Married/cohabiting								-	-	-
Divorced/separated								-	-	-
Widowed								-	-	-
Child conditions:										
29 days-1 year (reference 1-4 years)								-	-	-
Female child								-	-	-
Traditional medicine								-	-	-
HIV/AIDS*time (ref category 2012-2015)								2.43	1.83-3.22	<0.001
HIV*time (2000-2003)								1	-	0.009
HIV*time (2004-2007)								1.59	0.73-3.48	-
HIV*time (2008-2011)								2.66	1.29-5.48	-
HIV/AIDS in 2012-2015 (reference period)								2.96	1.49-5.87	-

Appendix 5.2: Place of death and care-seeking, disaggregated by study site.

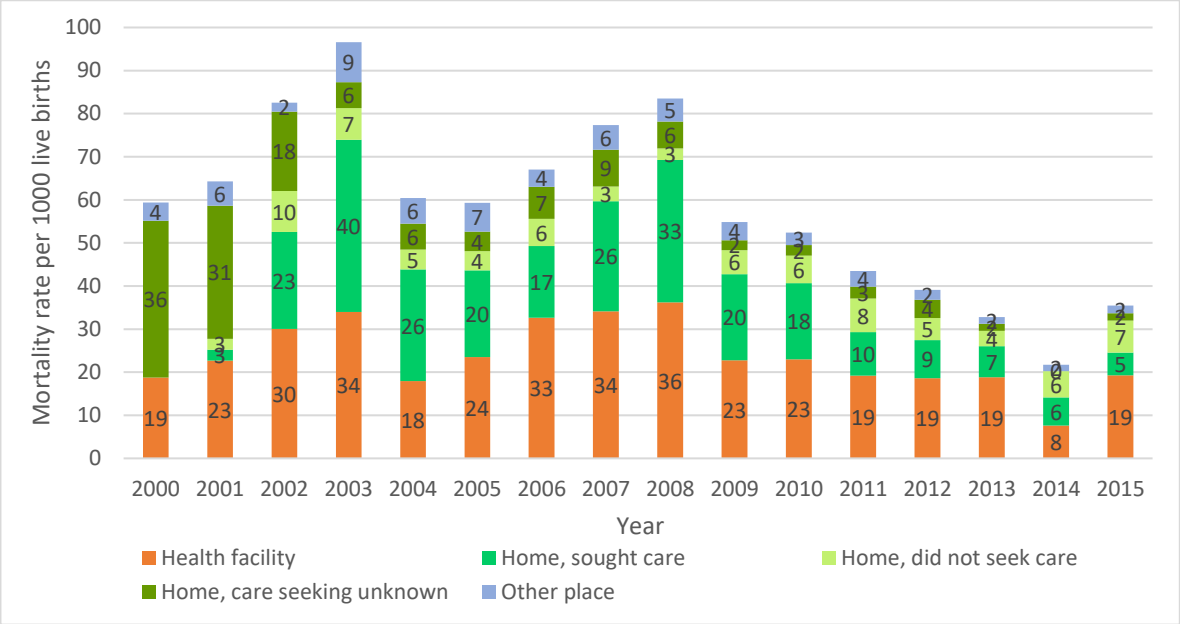


Figure 3.2.1: Place of death and care-seeing, Agincourt, 2000-2015

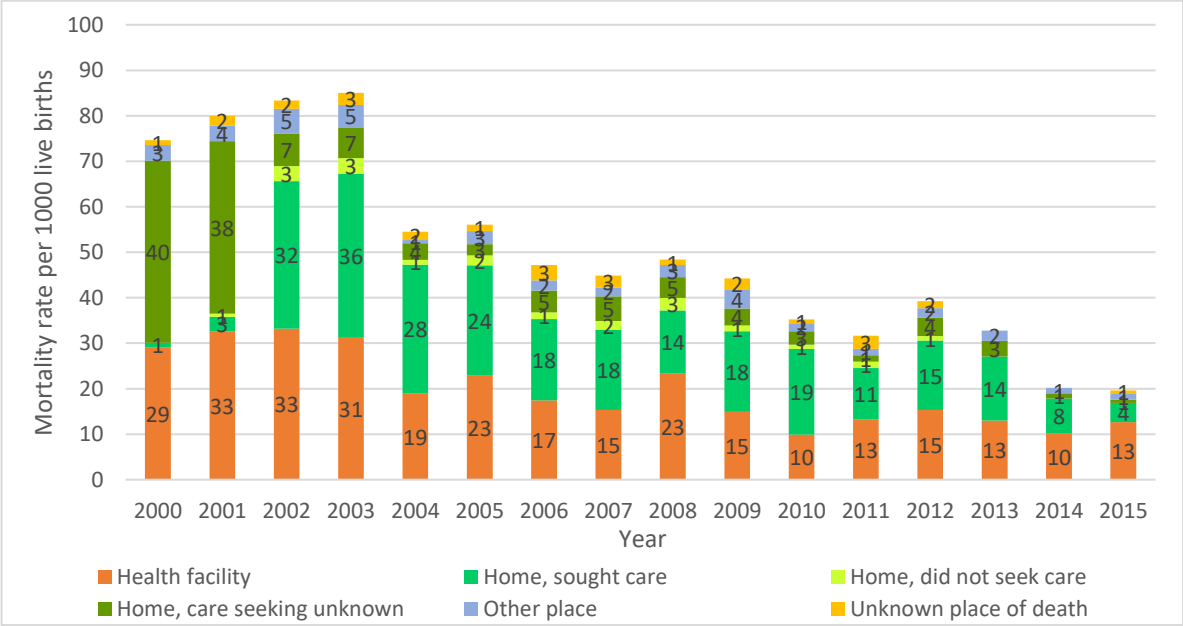


Figure 5.2.2: Place of death and care-seeking, AHRI, 2000-2015

Appendix 6.1: INDEPTH Network Social Autopsy Tool for Newborn Deaths

SOCIAL AUTOPSY TOOL FOR NEWBORN DEATHS (0-28 DAYS) AN INDEPTH TOOL

OPEN HISTORY QUESTION

Instructions to interviewer - Allow the respondent to tell you about the illness in his or her own words. Do not prompt except for asking whether there was anything else after the respondent finishes. Keep prompting until the respondent says there was nothing else. While recording, underline any unfamiliar terms.

PROBE FOR:

Recognition in the home (first symptoms recognised, other symptoms, when did they realise it was severe, who recognized the first and severe symptoms)

Timing (how long it took from first symptoms to realising it was severe)

Actions taken in home and outside the home (how long after first symptom and severe symptoms, what actions, what treatment, who made the decision, reason for this action, if not going outside for care – why?)

Provider behaviour (advice given, treatment given, referral, referral experience, timing of referral, reasons for not going or delaying referral)

ASK :

Could you tell me about the illness that led to the child's death?

Is there anything that you or anyone else could have done differently to prevent this death? Why?

_____

_____

_____

_____

_____

_____

_____

_____

_____

_____

1. TREATMENT AND HEALTH SERVICE USE FOR THE FINAL ILLNESS			
1.1. DID THE MOTHER RECEIVE ANTENATAL CARE?	YES 1 NO 2 DON'T KNOW 8	→1.4 →1.4	ANC
1.2. HOW MANY TIMES DID THE MOTHER ATTEND ANC?	TIMES ☐☐ 99 DON'T KNOW		TANC
1.3. HOW OLD WAS THE PREGNANCY AT THE FIRST ANC VISIT?	WEEKS ☐☐ MONTHS ☐☐ 99 DON'T KNOW		OANC
1.4. DID THE MOTHER TAKE ANY MALARIA PROPHYLAXIS DURING THE PREGNANCY (IPTP)?	YES 1 NO 2 DON'T KNOW 99		IPTP
1.5. DID THE MOTHER SLEEP UNDER A BED NET DURING THE PREGNANCY?	YES 1 NO 2 DON'T KNOW 99		MBED
1.6. WAS THE MOTHER TESTED FOR HIV?	YES 1 NO 2 DON'T KNOW 99		HIVT
1.7. WAS THE MOTHER GIVEN FOLATE AND IRON SUPPLEMENTS?	YES 1 NO 2 DON'T KNOW 99		FOLIR
1.8. WAS THE MOTHER GIVEN DEWORMING TABLETS?	YES 1 NO 2 DON'T KNOW 99		WORM
1.9. DID THE BABY SLEEP UNDER A BED NET?	YES 1 NO 2 DON'T KNOW 99		BBED
1.10. HOW SOON AFTER LABOUR STARTED DID THE MOTHER REACH DELIVERY CARE?	HOURS ☐☐ 99 DON'T KNOW		REACH
1.11. WHAT MATERIAL WAS USED FOR CUTTING THE CORD?	NEW RAZOR BLADE 1 USED RAZOR BLADE 2 SCISSORS 3 OTHER (SPECIFY) 4 DON'T KNOW 99		CCORD
1.12. WHAT MATERIAL WAS USED FOR TYING THE CORD?	CLEAN PIECE OF THREAD 1 UNCLEAN PIECE OF THREAD 2 CORD CLAMP 3 OTHER (SPECIFY) 4 DON'T KNOW 99		TCORD

1.13. ON WHAT SURFACE DID THE MOTHER DELIVER?	MATRASS 1 FLOOR WITH MACKINTOSH/COVER 2 DIRECTLY ON THE FLOOR 3 OTHER (SPECIFY) 4 DON'T KNOW 99		SURF
1.14. DID THE BIRTH ATTENDANT USE GLOVES?	YES 1 NO 2 DON'T KNOW 99		GLOV
1.15. DID THE BIRTH ATTENDANT WASH HIS/HER HANDS?	YES 1 NO 2 DON'T KNOW 99		WASH
1.16. DID THE BIRTH ATTENDANT CLEAN THE PERINEUM OF THE MOTHER?	YES 1 NO 2 DON'T KNOW 99		PERI
1.17. HOW WAS THE BABY CLEANED ON THE FIRST DAY AFTER BIRTH?	BATHING WITH COLD WATER 1 BATHING WITH WARM WATER 2 WIPING WITH FABRIC 3 NOT CLEANED 4 OTHER (SPECIFY) 5 DON'T KNOW 99		CLEAN
1.18. HOW WAS THE BABY KEPT WARM ON THE FIRST DAY AFTER BIRTH?	WRAPPING 1 SKIN-TO-SKIN 2 INCUBATOR 3 OTHER (SPECIFY) 4 DON'T KNOW 99		WARM
1.19. WAS THE CHILD EVER BREASTFED? 1.20. HOW SOON AFTER BIRTH WAS BREAST FEEDING INITIATED?	YES 1 NO 2 DON'T KNOW 99 HOURS ☐☐ DON'T KNOW 99	 →1.22 →1.22	BFED HBFE
1.21. WAS ANY OTHER FEEDS ADMINISTERED BEFORE BREAST MILK FLOW STARTED?	YES (SPECIFY) 1 NO 2 DON'T KNOW 99		OFEED
1.22. HOW SOON AFTER BIRTH WAS THE BABY DISCHARGED?	HOURS ☐☐ DAYS ☐☐ DON'T KNOW 99		BDIS
1.23. WAS THE BABY EXAMINED BY A HEALTH WORKER PRIOR TO DISCHARGE?	YES 1 NO 2 DON'T KNOW 99		BEXAM
1.24. DID YOU RECEIVE ANY COUNSELLING BY A HEALTH WORKER PRIOR TO DISCHARGE?	YES 1 NO 2 DON'T KNOW 99		COUNS

1.25. WHAT WERE YOU COUNSELLED ON?	BREAST FEEDING 1 IMMUNIZATION 2 POST-NATAL CARE ATTENDANCE 3 DANGER SIGNS 4 OTHER (SPECIFY) 5 DON'T KNOW 99		COUND
1.26. WAS THE CHILD GIVEN ANY OF THE FOLLOWING VACCINES IN THE FIRST WEEK OF LIFE?	BCG (TB) 1 OPV (POLIO) 2 DON'T KNOW 99		VACC
1.27. WAS THE MOTHER GIVEN ANY VITAMIN A JUST BEFORE OR AFTER DELIVERY?	YES 1 NO 2 DON'T KNOW 99		VITA
1.28. WHEN DID THE BABY FIRST COME IN CONTACT WITH A HEALTH FACILITY?	DAYS ☐☐ DON'T KNOW 99		CONT
1.29. SYMPTOMS IN CHRONOLOGICAL ORDER (DAYS AFTER BIRTH)	**SYMPTOM** 1: 2: 3: 4: 5:	**DAY AFTER BIRTH** DAY: DAY: DAY: DAY: DAY:	S1/D1 S2/D2 S3/D3 S4/D4 S5/D5
1.30. HOW LONG AFTER YOU RECOGNISED THE FIRST SYMPTOM DID THE BABY DIE?	DAYS ☐☐ DON'T KNOW 99		DITI

Appendix 6.2: INDEPTH Network Social Autopsy Tool for Child Deaths

SOCIAL AUTOPSY TOOL FOR CHILD DEATHS (29 DAYS TO 14 YEARS) AN INDEPTH TOOL

OPEN HISTORY QUESTION

Instructions to interviewer - Allow the respondent to tell you about the illness in his or her own words. Do not prompt except for asking whether there was anything else after the respondent finishes. Keep prompting until the respondent says there was nothing else. While recording, underline any unfamiliar terms.

PROBE FOR:

Recognition in the home (first symptoms recognised, other symptoms, when did they realise it was severe, who recognized the first and severe symptoms)

Timing (how long it took from first symptoms to realising it was severe)

Actions taken in home and outside the home (how long after first symptom and severe symptoms, what actions, what treatment, who made the decision, reason for this action, if not going outside for care – why?)

Provider behaviour (advice given, treatment given, referral, referral experience, timing of referral, reasons for not going or delaying referral)

ASK :

Could you tell me about the illness that led to the child's death?

Is there anything that you or anyone else could have done differently to prevent this death? Why?

_____

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1. TREATMENT AND HEALTH SERVICE USE FOR THE FINAL ILLNESS				
1.1. SYMPTOMS IN CHRONOLOGICAL ORDER (AFTER ILLNESS STARTED)	**SYMPTOM** 1:_____ __ 2:_____ __ 3:_____ __ 4:_____ __ 5:	**DAY RECOGNISED** DAY: **1** DAY: DAY: DAY: DAY:		S1/D1 S2/D2 S3/D3 S4/D4 S5/D5
1.2. HOW LONG AFTER YOU RECOGNISED THE FIRST SYMPTOM DID THE CHILD DIE?	DAYS_____ ☐☐ DON'T KNOW _____ 99			DITI
1.3. DID THE CHILD USUALLY SLEEP UNDER A BED NET?	YES_____ 1 NO _____ 2 DON'T KNOW _____ 99			CBED
1.4. DID S/HE RECEIVE ANY TREATMENT BEFORE S/HE DIED?	YES_____ 1 NO _____ 2 DON'T KNOW _____ 99		→1.33 →END	ANYT
1.5. WHY DID THE CHILD NOT RECEIVE ANY TREATMENT?	_____ ___ _____ ___ _____ ___		→END	NTRE
1.6. HOW WAS S/HE TREATED AT HOME?	NO HOME TREATMENT _____ 1 WITH DRUGS_____ 2 WITH HERBS _____ 3 OTHER (SPECIFY) _____ 4 DON'T KNOW _____ 99		→1.36 →1.36	HOTR
1.7. WHAT TYPE OF TREATMENT WAS GIVEN TO THE CHILD?	MALARIA DRUG (SPECIFY)_____ 1 ANTIBIOTIC (SPECIFY) _____ 2 PARACETAMOL_____ 3 OTHER (SPECIFY) _____ 4 DON'T KNOW _____ 99			TYTRH
1.8. HOW MUCH TIME AFTER ILLNESS STARTED WAS CARE INITIALIZED AT HOME?	DAYS_____ ☐☐ DON'T KNOW _____ 99			DCAH
1.9. WAS THE CHILD BROUGHT OUTSIDE THE HOME FOR CARE WHILE SHE HAD THIS ILLNESS?	YES_____ 1 NO _____ 2 DON'T KNOW _____ 99		→1.38 →1.52	CSLOC
1.10. WHY DID YOU NOT TAKE THE CHILD FOR OUTSIDE CARE?	_____ ___ _____ ___ _____ ___		→1.52	NOUT

1.11. ON WHICH DAY AFTER THE FIRST SYMPTOM WAS THE CHILD BROUGHT OUTSIDE THE HOME FOR CARE?	DAYS ☐☐ DON'T KNOW 99		DCARS
1.12. WHERE DID YOU GO TO SEEK TREATMENT? **(CIRCLE ALL THAT APPLY – PROBE BY SAYING "ANYWHERE ELSE")**	HOSPITAL 1 HEALTH CENTRE 2 PRIVATE CLINIC 3 DRUG SHOP 4 TRADITIONAL HEALER 5 OTHER (SPECIFY) 6 DON'T KNOW 99		WHITR
1.13. CARE SOUGHT IN CHRONOLOGICAL ORDER **TYPE OF PROVIDER** - USE CODES ABOVE **WHEN** – DAYS AFTER ILLNESS STARTED			

TYPE OF PROVIDER:	**WHEN?**	**FACILITY NAME:**	**VILLAGE:**	**DISTRICT:**		
1:_____	DAY:_____	_____	_____	_____		P1/W1
2:_____	DAY:_____	_____	_____	_____		P2/W2
3:_____	DAY:_____	_____	_____	_____		P3/W3
4: _____	_ DAY:					P4/W4

1.14. HOW DID YOU TAKE THE CHILD TO THE FIRST AND LAST CARE PROVIDER?		**1ST SOURCE**	**LAST SOURCE**		
	PRIVATE CAR 1	☐	☐		TRAN1
	BICYCLE 2	☐	☐		TRAN2
	MOTORCYCLE 3	☐	☐		
	TAXI 4	☐	☐		
	ON FOOT 5	☐	☐		
	OTHER (SPECIFY) 6	☐	☐		
	DON'T KNOW 99				
1.16. HOW MUCH TIME DID IT TAKE TO GO TO THE FIRST AND LAST PROVIDER?	HOURS 1 DON'T KNOW 99	☐☐ ☐	☐☐ ☐		TIPR1 TIPR2
1.17. WHAT KIND OF TREATMENT WAS GIVEN TO THE CHILD AT THE FIRST AND LAST CARE PROVIDER?	TABLETS (SPECIFY) 1 SYRUP (SPECIFY 2 BLOOD TRANSFUSION 3 IV FLUID/ORS/INJECTION 4 OXYGEN 5 NO TREATMENT 6 OTHER (SPECIFY) 7 DON'T KNOW 99	☐ ☐ ☐ ☐ ☐ ☐ ☐	☐ ☐ ☐ ☐ ☐ ☐ ☐		TRE1 TRE2
1.18. HOW LONG AFTER YOU ARRIVED AT THE CARE PROVIDER WAS TREATMENT OBTAINED?	IMMEDIATELY 1 HOURS 2 DON'T KNOW 99	☐ ☐☐ ☐	☐ ☐☐ ☐		TITRE1 TITRE2
1.19. DID YOU HAVE TO PAY FOR THE TREATMENT THAT WAS GIVEN TO YOU?	YES 1 NO 2 DON'T KNOW 99				PATRE
1.20. WAS THE CHILD EVER HOSPITALIZED DURING THE FINAL ILLNESS?	YES 1 NO 2 DON'T KNOW 99				HOSPI
1.21. WAS THE CHILD EVER REFERRED TO ANOTHER PLACE OF CARE DURING THE FINAL ILLNESS?	YES 1 NO 2 DON'T KNOW 99			→1.52	REF

		→1.52	
1.22. WHERE DID THE PROVIDER TELL YOU TO TAKE THE CHILD FOR REFERRAL?	HOSPITAL 1 HEALTH CENTRE 2 PRIVATE CLINIC 3 DRUG SHOP 4 TRADITIONAL HEALER 5 OTHER (SPECIFY) 6 DON'T KNOW 99		WHRE
1.23. WHAT WAS THE REASON FOR THE REFERRAL?	LACK OF EQUIPMENT 1 FOR BETTER CARE 2 LACK OF BLOOD 3 LACK OF DRUGS 4 LACK OF OXYGEN 5 OTHER (SPECIFY) 6 DON'T KNOW 99		RERE
1.24. WAS THE CHILD TAKEN TO THE PLACE WHERE SHE/HE WAS REFERRED?	YES 1 NO 2 DON'T KNOW 99	→1.52	TARE
1.25. WHY DID YOU NOT TAKE THE CHILD FOR REFERRAL CARE?	CHILD DIED BEFORE REACHING 1 THOUGHT IT WASN'T NECESSARY 2 HOPED/WAITED FOR IMPROVEMENT 3 LACK OF MONEY 4 LACK OF TRANSPORT 5 OTHER (SPECIFY) 6 DON'T KNOW 99		REFNO
1.26. HOW MUCH DID YOU PAY FOR TRANSPORT DURING THE FINAL ILLNESS EPISODE?	☐☐☐☐☐☐☐☐ UGS		COSTR
1.27. HOW MUCH DID YOU PAY FOR TREATMENT AND OTHER COSTS RELATED TO CARE OF THE BABY (INCL. FEES FOR ADMISSION, CONSULTATION, LAB TESTS, CONSUMABLES ETC)?	☐☐☐☐☐☐☐☐ UGS		COSTP
1.28. HOW MUCH DID YOU PAY FOR OTHER COSTS (INCL. ACCOMODATION, FEEDING ETC)?	☐☐☐☐☐☐☐☐ UGS		COSTO

Appendix 6.3: Findings from full INDEPTH Social Autopsy questionnaire for neonatal and child deaths in Agincourt in 2017

Table 6.3.1 summarises the additional information collected in Agincourt from the full INDEPTH Network Social Autopsy modules for neonatal and child deaths in 2017. As indicated in the left column, additional details were obtained on the order and timing of symptoms (this supplements the verbal autopsy which collects data on the presence of symptoms but not the order in which they appeared), the specific treatments given to the child at home, the timings of various stages of the care pathway and associated costs incurred at each stage of seeking and receiving care. As is shown in the table, fever and difficult breathing were the most common symptoms reported. In general, processes appear to happen quickly at all stages of the care pathway (from illness recognition, travel to the facility and receiving care after arrival at the facility). The main cost incurred was transport, though only a quarter of those who sought care reported needing to pay for transport at all.

While this additional detail is interesting, it is unlikely to change the recommendations for policy interventions. Furthermore, it seems clear that this method is not adequate in collecting data particularly around transport costs. While it might well be the case that increased availability of private cars has led to a reduction of the direct cost of transport during a given illness episode, evidence still suggests that accessing transport is a key barrier to accessing health care (as noted in the main text of the chapter). This might be because of delays in finding or negotiating use of a private care from a neighbour or friend, or difficulties in finding money for public transport where it was used. Another explanation is that caregivers do not accurately recall what was spent on transport during the illness episode, particularly when the verbal and social autopsy is conducted up to a year after the child's death; or that they are embarrassed to admit that they were unable to afford transport and don't report these costs as negatively impacting on the financial security of the household.

Similar concerns about recall bias and accuracy have been raised by Kallander et al (2011) with regards to events at each provider. When designing the INDEPTH Network VASA tools for neonatal and child deaths, questions were specifically limited to the first and last provider to optimise accurate recall of relevant details (1).

Table 6.3.1: Summary of additional findings using full INDEPTH Network social autopsy tools for neonatal and child deaths in Agincourt

Stage of care pathway	**Response**
Illness recognition	
First symptom:	Fever/ "hot body" - 11 caregivers Difficulty breathing - 6 caregivers Weakness – 3 caregivers Sore stomach – 3 caregivers Diarrhoea – 2 caregivers Chest pain - 1 caregiver Crying uncontrollably – 1 caregiver Loss of appetite – 1 caregiver Swollen stomach – 1 caregiver Rash over whole body including the face – 1 caregiver Vomiting – 1 caregiver Burns to the chest and stomach -1 caregiver. None -6 caregivers.
Median delay in days to recognition of first symptom from onset of illness (IQR, range)	0 (0-0, 0-14)
Second symptom:	Difficulty breathing - 6 caregivers Fever/ "hot body" -4 caregivers Weakness – 2 caregivers Vomiting – 1 caregiver White patches in the mouth – 1 caregiver Stiff tongue - 1 caregiver
Median delay in days to recognition of second symptoms from onset of illness (IQR, range)	0.5 (0-2, 0-9)
Third Symptom:	Difficulty breathing – 3 Vomiting -1 Weakness -1 Swollen face -1 Sweating – 1
Fourth Symptom:	Fever/ "hot body" – 1 Frothing at the mouth – 1
Care in the home:	Paracetamol syrup – 4 Oral Rehydration Solution - 2 Left over antibiotics -1
Sought/Attempted to seek care outside the home:	

Mode of transport used to reach health facility	Private cars - 9/24 (38%) Minibus taxis - 6/24 (25%) Motorcycles - 1/24 (4%) Walked - 5 caregivers (21%) Other - 1 (4%)
Mean travel time to reach nearest healthcare provider, in minutes	25 +/-12
Median transport costs, in Rands (IQR, range)	0 (0-10, 0-300)**
Received (quality) care from healthcare provider:	
Median delay to receiving treatment after arriving at a formal healthcare provider, in minutes (IQR, range)	0 (0-10, 0-30)
Median treatment costs, in Rands (IQR, range)	0 (0-0, 0-350)***

* only 13/23 (57%) were able to provide an estimate of timing while 10 (43%) did not know.
** only 6 respondents reported having to pay for transport at all

*** only 2/29 caregivers paid for treatment.

Reference:

1. Kallander K, Kadobera D, Williams TN, Nielsen RT, Yevoo L, Mutebi A, et al. Social autopsy: INDEPTH Network experiences of utility, process, practices, and challenges in investigating causes and contributors to mortality. Popul Health Metr. 2011 Aug;9:44.

Appendix 6.4: Training Scenarios for Verbal and Social Autopsy

The interviewer needed to accurately obtain the history from the respondent to complete the verbal and social autopsy interview.

Scenario 1:

You are the mother of the child:

4 year old male, born on 01.08.2013, died on 13.08.2017

He was a well child before the final illness
He started coughing 2 weeks before he died. He had a fever that was on and off, and got very very hot. Then a week before he died he started to complain of a headache, and got a stiff neck. He didn't want to eat or drink and didn't play anymore.

The day before he died he had a fit when his temperature got very high. He didn't ever wake up after the fit. When he had the fit his whole body shook. The fit lasted for 20 minutes.

Mom took him to the clinic 3 days after he started coughing but they said it was just the flu and gave him some panado syrup for the fever.

Then when he had the fit they took called an ambulance and they were taken to the clinic, and then transferred tinstwalo hospital. The doctors gave him a drip with antibiotics. He died the next day in hospital.

The family did not use traditional medicine.

Pregnancy and birth history:

- The pregnancy was normal and lasted 9 months. Mom tested HIV negative. She had 4 ANC visits starting from 15 weeks pregnant.
- Mom was healthy in the pregnancy up till the last week when she developed high blood pressure. She had a caesarean section to deliver the baby (it was an elective Caesar, meaning she did not go into labour) at Tinstwalo hospital.
- This was her first pregnancy.
- The baby was fine at birth. There were no problems.
- The baby was breastfed.
- The baby got all his vaccinations but mom does not have the Road to Health Card with her.

The death was registered but the death certificate is in Johannesburg with the father.

Scenario 2:

You are the husband of the deceased:

35 year old women, born in July 1985 (unsure of the day), died on 01.08.2017

She was 7 months pregnant. She died in a car accident. She was in a taxi travelling to Johannesburg and there was a crash on the highway outside Nelspruit and she died.
The taxi crashed into another car. You don't know anything about the other car, or about the driver of the taxi. She died at the site of the accident.

Medical history:
She has diabetes, and high blood pressure from before the pregnancy.
She had regular periods with no bleeding in between periods.
She had not gone through menopause yet.

Pregnancy:
She was 7 months pregnant. This was her 4th pregnancy – she has 2 other children who are alive and had one miscarriage before this pregnancy.
She was also diagnosed as HIV positive in this pregnancy and started on ARV's.
The pregnancy was going well. She had some vaginal bleeding in the first 2 months of the pregnancy but that had stopped and the clinic said the baby was still fine.
She had 3 ANC visits so far. Her first visit was at 7 weeks of the pregnancy.

She did not smoke or drink alcohol or use other drugs.

She was generally an active person. She was employed at a game lodge near by.

Scenario 3:

You are the daughter-in-law of the deceased (same household)

75 year old male. Born in 1942 (uncertain of the month or the day), died on 30 July 2017

He started coughing 2 weeks before he died. He was coughing a lot, with blood coming up too.
He had a fever that started 2 days after he started coughing. The fever was worst at night and it continued until he died.
He was sweating at night.
He started to have diarrhoea 1 week before he died. No blood in the stool.
The diarrhoea continued until death.
He also had urine problems for 1 weeks – the doctors said he had a kidney infection. He would go to the toilet very often (and couldn't hold in his urine).

The family took him to the clinic when he started having diarrhoea. The nurses said his temperature was very high and so they transferred him to the hospital. In the hospital they gave him a drip, and antibiotics. They also said his blood was low and he needed a blood transfusion.
He stopped waking up one day before he died.
The doctors say he died from infection all over the body.

Medical history:

Known with high blood pressure, heart failure and a previous stroke – he was weak on the right side.

He was breathless for many years (uncertain how long). It was worse when he would lie flat, and he could not walk more than a few steps without stopping to take a breath. He also had swollen legs (both legs) for many years.

Risk factors:

He drank alcohol (beer) – 1 case per weekend.
He smoked 1 pack per day (20 cigaretters per pack) for 50 years.
He did not take other drugs

He worked in a gold mine when he was younger. He retired when he was 60 years old. He worked in the mine for 40 years.

Appendix 6.5: Individual care pathways for child deaths in AHRI and Agincourt

Table 6.5.1: Individual care pathways for child deaths in AHRI

Individual ID	Age	Place of death	Home care	Care outside the home	Reason for not taking the child outside the home for care	Provider 1	Provider 2	Provider 3	Provider 4	Total number of healthcare visits	Was the patient referred?	Did the patient reached the referral facility?
1	7m	Home	No	No	Sudden death. No time for treatment	None	.	.	.	.	.	.
2	5m	Home	No	No	Didn't look ill	None	.	.	.	.	.	.
3	27d	Home	No	No	Sudden death	None	.	.	.	.	.	.
4	3y	Home	No	Yes		PHC/CHC	None	.	.	1	.	.
5	2y	Home	No	Yes		PHC/CHC	None	.	.	1	.	.
6	1m	Home	No	Yes		PHC/CHC	None	.	.	1	.	.
7	2y	Home	Yes	Yes		PHC/CHC	Private GP	.	.	2	.	.
8	1y	Home	Yes	Yes		PHC/CHC	.	.	.	1	.	.
9	1y	Home	Yes	Yes		PHC/CHC	None	.	.	1	.	.
10	4y	Hospital	No	Yes		Private hospital	None	.	.	1	.	.
11	1y	Hospital	No	Yes		Govt hospital	None	.	.	1	.	.
12	0d	Hospital	No	Yes		Govt hospital	None	.	.	1	.	.
13	6m	Hospital	No	Yes		PHC/CHC	Govt hospital	None	.	2	Yes	Yes
14	1d	Hospital	No	Yes		Govt hospital	PHC/CHC	Govt hospital	Govt hospital	4	.	.
15	1d	Hospital	No	Yes		Govt hospital	Govt hospital	None	.	2	.	.
16	2d	Hospital	No	Yes		Govt hospital	None	.	.	1	.	.
17	3y	Hospital	Yes	Yes		PHC/CHC	Govt hospital	None	.	2	Yes	Yes
18	1m	Other health facility	No	Yes		Don't know	.	.	.	.	.	.
19	0d	Other health facility	No	Don't know		None	.	.	.	.	.	.
20	9m	En route	No	Yes		Private hospital	None	.	.	1	.	.

Excluded from analysis as no information on care pathway available												
21	2y	Other	No	No	The family is uncertain if the child is dead or alive	None	.	.	.	.	.	.
22	2y	Hospital	.	.		.	.	.	.	.	.	.
23	1y	.	.	.		.	.	.	.	.	.	.
24	0d	Refused to answer	.	.		.	.	.	.	.	.	.

*Age presented in d=days, m=months, y=years

** PHC=primary health centre; CHC=community health centre. Both are government-run primary care centres.

Table 6.5.2: Individual care pathways for child deaths in Agincourt

Individual ID	Age	Place of death	Home care	Care outside the home	Reason for not taking the child outside the home for care	Provider 1	Provider 2	Provider 3	Provider 4	Total number of healthcare visits	Was the patient referred?	Did the patient reached the referral facility?
Agincourt												
Children tracked through care pathway												
25	4y	Home	No	No	He died same time	None	.	.	0	.	.	
26	4y	Home	No	Yes		PHC/CHC	None	.	1	No	.	
27	1m	Home	No	Yes		PHC/CHC	Govt hospital	PHC/CHC	3	Yes	Yes	
28	2m	Home	Yes	No	Left over treatment from clinic was given	None	.	.		.	.	
29	6m	Home	Yes	No	The mother was planning to take his child to the clinic the next day	None	.	.	0	.	.	
30	2y	Home	Don't know	No	Sudden death they didn't see any symptoms	None	.	.	0	.	.	
31	10m	Hospital	No	Yes		Govt hospital	.	.	1	No	.	
32	4y	Hospital	No	Yes		PHC/CHC	PHC/CHC	Govt hospital	3	Yes	Yes	
33	1y	Hospital	No	Yes		PHC/CHC	Govt hospital	None	2	Yes	Yes	
34	2y	Hospital	No	Yes		Govt hospital	none	.	1	No	.	
35	2y	Hospital	No	Yes		Private GP	PHC/CHC	Govt hospital	3	Yes	Yes	
36	2y	Hospital	No	Yes		Govt hospital	None	.	1	No	.	

37	9m	Hospital	No	Yes		None	.	.	0	No	.	
38	6m	Hospital	No	Yes		PHC/CHC	Govt hospital	.	2	Yes	Yes	
39	1m	Hospital	No	Yes		PHC/CHC	Govt hospital	None	2	No	.	
40	1y	Hospital	No	Yes		Govt hospital	None	.	1	No	.	
41	2d	Hospital	No	Yes		Govt hospital	None	.	1	No	.	
42	2m	Hospital	No	Yes		PHC/CHC	Govt hospital	.	2	Yes	Yes	
43	5d	Hospital	No	Yes		Govt hospital	None	.	1	No	.	
44	26d	Hospital	Yes	Yes		Private GP	Govt hospital	None	2	Yes	Yes	
45	6m	Hospital	Yes	Yes		PHC/CHC	Govt hospital	.	2	Yes	Yes	
46	1y	Hospital	Yes	Yes		PHC/CHC	Govt hospital	None	2	Yes	Yes	
47	3y	Other health facility	No	Yes		PHC/CHC	PHC/CHC	None	2	Yes	No	
48	1y	Other health facility	Yes	Yes		PHC/CHC	None	.	1	No	.	
49	11m	En route	No	Yes	Died on the way to hospital	None	.	.	0	.	.	
50	2y	En route	No	Yes		None	.	.	0	No	.	
51	26d	En route	Yes	Yes		Private GP	None	.	1	Yes	Yes	
55	10m	Other	No	Yes		PHC/CHC	None	.	1	No	.	
Excluded from analysis as born and died in hospital without discharge												
53	0d	Hospital	No	No	The baby was in the hospital	Govt hospital	None	.	1	.	.	

*Age presented in d=days, m=months, y=years

** PHC=primary health centre; CHC=community health centre. Both are government-run primary care centres.

Appendix 7.1: Participant information sheet and consent forms

Research Study Title: Caregivers' experiences of seeking care and barriers to access in child illness that led to death in rural South Africa

Information Sheet and consent form: Individual Interview

To be provided to, and discussed with the following people:

- **Caregivers of children who died under the age of 5 years**
- **Participants over the age of 18**

Study introduction and overview

Hello – my name is XXXX. I work for the MRC/Wits Rural Public Health and Health Transitions Research Unit (Agincourt). I would like to invite you to take part in a research study, conducted by the Agincourt Unit and the University of Oxford. This study forms part of Dr Jessica Price's PHD, who is studying at the University of Oxford.

The study today involves an interview which I will explain. It is up to you to decide whether you wish to take part. Please consider this information carefully, discuss it with others if you wish, and take the time you need to make a decision. I will be happy to answer any questions. Please ask if there is anything that is not clear, or if you would like more information. If you agree to take part in the study, you can decide to withdraw at any time, without giving any reason. This information sheet is yours, and you may keep it.

Who will be asked to take part in this study?

I am asking primary caregivers, over the age of 18 years, who completed the interview for a child who died below the age of 5 years and who live in the study area, to take part.

Study overview

This study builds on the Social Autopsy interview that you already participated in when a fieldworker visited your house to ask questions about the child's final illness. The research team hope to better understand the process of accessing healthcare services for children in the community during their final illness. By better understanding these experiences and the problems you faced, we can make recommendations to improve access to healthcare.

Therefore during this interview I will ask you about:

- Your experiences of seeking care during your child's final illness
- Any problems you faced in accessing formal healthcare services

The interview will last about 1 hour. With your permission, I will record the interview using a digital voice recorder and will then type everything you said into a computer. I will also take a few notes while you speak to help with the transcription process (which I will explain in a moment).

What are the risks involved in the study?

This study will involve an interview about the period of illness leading up to the death of your child. I am interested in understanding your experiences of seeking care, and the challenges you faced in accessing formal health services. I am aware that discussing this may be distressing. If you find the interview too upsetting at

any stage, you are free to stop the interview. You can also decide whether you'd like to continue the interview (either after a short break, or re-arranged for another day), or whether you'd like to stop the interview altogether. When you pause the interview, I will turn off the audio recording.

What are the benefits of being involved in the study?

You may find it comforting to discuss your child's final illness. We hope that recommendations from this study made to the Department of Health will increase access to healthcare in the community and improve the experience of seeking care.

What if you do not want to take part in the study?

Taking part in the study is voluntary. You are free to refuse to be interviewed, and/or you can decline to answer specific questions during the interview. You are also free to withdraw from the study at any point, including stopping the interview at any point, in which case all data and audio recordings up till that point will be discarded. If you decline or choose to stop the interview, you will not be penalised and nothing bad will happen.

Who will see the information that is collected?

All the information collected is kept private and confidential. The recording of the interview will be downloaded onto a secure computer immediately after the interview. During the transcription process, whereby a written copy of the interview is produced, all names mentioned (including your own and the name of your child) will be removed. I will not share your name with anyone else. The audio recording and the written copy of the interview will be stored securely at the Agincourt Unit offices as part of the MRC/Wits Rural Public Health and Health Transitions Research Unit (Agincourt) database. The audio recording will be stored for 10 years. The anonymised written copy of the interview will be kept indefinitely. The anonymised findings from this study will be included in a DPhil thesis at the University of Oxford (which will be publicly available) and written up in articles for scientific journals to share the information that I learn with researchers, doctors and others in South Africa and the world.

The ethics committee

This study has been approved by the University of Witwatersrand (Wits) Human Research Ethics Committee and University of Oxford Tropical Research Ethics Committee. Contact details for the Wits Human Research Ethics committee are at the end of the page. The Ethics Committees may look at the information from the study to check that procedures are being correctly and safely followed.

Communication of our research findings

Periodically, we will inform the Department of Health at district, provincial and national levels and the local community about the findings of the study overall, but not the results of you specifically.

Who to contact if you want to know more, or if you have a problem or complaint at any time?

If you ever have questions about this study, or in case you are harmed as a result of participation in the study, you should contact the study team:

Dr Xavier Gomez-Olive (Research Manager): Tel: 013 795 5076, Cell: 076 378 8255, email: F.Gomez-OliveCasas@wits.ac.za ; Ms Audrey Khosa, for Shangaaan speakers (Project Co-ordinator) at the MRC/Wits-Agincourt Unit office: Tel: 013 795 5076; Cell: 083 581 7613; Email: Audrey.Khosa@wits.ac.za.

You can also contact the Wits Human Research Ethics Committee: Professor Clement Penny (Chair): Tel 011 717 1234/2301; Email: Clement.Penny@wits.ac.za

PARTICIPANT CONSENT FORM

HREC Approval Reference: M180102

Caregivers' experiences of seeking care and barriers to access in child illness that led to death in rural South Africa

Please tick the box if you agree with the corresponding statement:

1	I confirm that I have read and understand the information sheet for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.	☐
2	I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, and without any adverse consequences.	☐
3	I understand that research data collected during the study may be looked at by designated individuals from the University of Witwatersrand and the University of Oxford where it is relevant to my taking part in this study. I give permission for these individuals to access my data.	☐
4	I understand that this project has been reviewed by, and received ethics clearance through the University of Witwatersrand Human Research Ethics Committee and the University of Oxford Tropical Research Ethics Committee.	☐
5	I understand who will have access to personal data provided, how the data will be stored and what will happen to the data at the end of the project.	☐
6	I understand how this research will be written up and published.	☐
7	I understand how to raise a concern or make a complaint.	☐
8	I consent to being audio recorded.	☐
9	I agree to take part in the study.	☐

_____ _____ _____

Participant's name (print) Participant's signature (*1) Date

(*1) FOR PERSONS WHO CANNOT WRITE MARK WITH 'X'

_____ _____ _____

Name of fieldworker who took consent (print) Staff member's signature Date

_____ _____ _____

Witness' name (print) (*2) Witness' signature Date

(*2) WITNESS ONLY IN CASE IF THE PARTICIPANT CANNOT WRITE OR IN CASE THE PARTICIPANT ASKS FOR A WITNESS. WITNESS MUST BE NEITHER CHILD NOR STUDY STAFF.

Research Study Title: Caregivers' experiences of seeking care and barriers to access in child illness that led to death in rural South Africa

Information Sheet and consent form: Focus Group

To be provided to, and discussed with the following people:

- **Caregivers of children who died under the age of 5 years**
- **Participants over the age of 18**

Study introduction and overview

Hello – my name is XXXX. I work for the MRC/Wits Rural Public Health and Health Transitions Research Unit (Agincourt). I would like to invite you to take part in a research study, conducted by the MRC Wits/Agincourt Research Unit and the University of Oxford. This study forms part of Dr Jessica Price's PHD, who is studying at the University of Oxford.

The study today involves a focus group discussion which I will explain. It is up to you to decide whether you wish to take part. Please consider this information carefully, discuss it with others if you wish, and take the time you need to make a decision. I will be happy to answer any questions. Please ask if there is anything that is not clear, or if you would like more information. If you agree to take part in the study, you can decide to withdraw at any time, without giving any reason. This information sheet is yours, and you may keep it.

Who will be asked to take part in this study?

I am asking primary caregivers over the age of 18 years who completed the interview for a child who died below the age of 5 years and who lives in the study area, to take part.

Study overview

This study builds on the Social Autopsy interview that you already participated in when a fieldworker visited your house to ask questions about the child's final illness. The research team hope to better understand the process of accessing healthcare services for children in the community during their final illness. By better understanding these experiences and the problems you faced, we can make recommendations to improve access to healthcare.

Therefore during this focus group discussion I will ask you about:

- Your experiences of seeking care during your child's final illness
- Any problems you faced in accessing formal healthcare services
- Whether you think our findings from interviews in the community are reasonable and relatable.

The focus group will last about 1 hour. With your permission, I will record the discussion using a digital voice recorder and will afterwards type everything that is said into a computer. I will also take a few notes while the discussion takes place to help with the transcription process (which I will explain in a moment). I ask that all participants in the focus group discussion respect confidentiality and that you do not share what was discussed in the group with others once you leave; however, this cannot be guaranteed.

What are the risks involved in the study?

This study will involve a discussion about the care seeking during your child's final illness. I am interested in understanding your experiences of seeking care, and the challenges you faced in accessing formal health services, and whether others in the group had similar or different experiences I are aware that discussing this may be distressing. If you find the discussion too upsetting at any stage, you are free to leave the discussion.

You can also decide whether you'd like to rejoin the group, or whether you'd like to conclude the discussion altogether.

What are the benefits of being involved in the study?
You may find it comforting to discuss your child's final illness. We hope that recommendations from this study made to the Department of Health will increase access to healthcare in the community and improve the experience of seeking care.

What if you do not want to take part in the study?
Taking part in the study is voluntary. You are free to refuse to participate, and/or you can decline to answer specific questions during the discussion. You are also free to withdraw from the study at any point, including leaving the focus group at any point, however I would include your contributions until that point in the written anonymised copy of the focus group discussion. If you refuse to participate or withdraw during the discussion, you will not be penalised and nothing bad will happen.

Who will see the information that is collected?
I will keep the information collected private and confidential. However, other members of the focus group discussion will hear what you say, and so I cannot guarantee confidentiality. The recording of the focus group discussion will be downloaded onto a secure computer immediately after the interview. During the transcription process, whereby a written copy of the interview is produced, all names mentioned (including your own and the name of your child) will be removed. I will not share your name with anyone else. The audio recording and the written copy of the interview will be stored securely at the Agincourt Unit offices as part of the MRC/Wits Rural Public Health and Health Transitions Research Unit (Agincourt) database. The audio recording will be stored for 10 years. The anonymised written copy of the interview will be kept indefinitely. The anonymised findings from this study will be included in a DPhil thesis at the University of Oxford (which will be publicly available) and written up in articles for scientific journals to share the information that I learn with researchers, doctors and others in South Africa and the world.

The ethics committee
This study has been approved by the University of Witwatersrand (Wits) Human Research Ethics Committee and the University of Oxford Tropical Research Ethics Committee. Contact details for the Wits Human Research Ethics committee are at the bottom of the page. The Ethics Committees may look at the information from the study to check that procedures are being correctly and safely followed.

Communication of our research findings
Periodically, we will inform the Department of Health at district, provincial and national levels and the local community about the findings of the study but not information given by you individually.

Who to contact if you want to know more, or if you have a problem or complaint at any time?
If you ever have questions about this study, or in case you are harmed as a result of participation in the study, you should contact the study team:

Dr Xavier Gomez-Olive (Research Manager): Tel: 013 795 5076, Cell: 076 378 8255, email: F.Gomez-OliveCasas@wits.ac.za; Ms Audrey Khosa, for Shangaaan speakers (Project Co-ordinator) at the MRC/Wits-Agincourt Unit office: Tel: 013 795 5076; Cell: 083 581 7613; Email: Audrey.Khosa@wits.ac.za.

You can also contact the Wits Human Research Ethics Committee: Professor Clement Penny (Chair): Tel 011 717 1234/2301; Email: Clement.Penny@wits.ac.za

PARTICIPANT CONSENT FORM

HREC Approval Reference: M180102

Caregivers' experiences of seeking care and barriers to access in child illness that led to death in rural South Africa

Please tick the box if you agree with the corresponding statement:

1	I confirm that I have read and understand the information sheet for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.	☐
2	I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, and without any adverse consequences.	☐
3	I understand that research data collected during the study may be looked at by designated individuals from the University of Witwatersrand and the University of Oxford where it is relevant to my taking part in this study. I give permission for these individuals to access my data.	☐
4	I understand that this project has been reviewed by, and received ethics clearance through the University of Witwatersrand Human Research Ethics Committee and the University of Oxford Tropical Research Ethics Committee.	☐
5	I understand who will have access to personal data provided, how the data will be stored and what will happen to the data at the end of the project.	☐
6	I understand how this research will be written up and published.	☐
7	I understand how to raise a concern or make a complaint.	☐
8	I consent to being audio recorded.	☐
9	I agree to take part in the study.	☐

_____ _____ _____

Participant's name (print) Participant's signature (*1) Date

(*1) FOR PERSONS WHO CANNOT WRITE MARK WITH 'X'

_____ _____ _____

Name of fieldworker who took consent (print) Staff member's signature Date

_____ _____ _____

Witness' name (print) (*2) Witness' signature Date

(*2) WITNESS ONLY IN CASE IF THE PARTICIPANT CANNOT WRITE OR IN CASE THE PARTICIPANT ASKS FOR A WITNESS. WITNESS MUST BE NEITHER CHILD NOR STUDY STAFF.

Research Study Title: Caregivers' experiences of seeking care and barriers to access in child illness that led to death in rural South Africa

Information Sheet and consent form: Individual Interview

To be provided to, and discussed with the following people:

- **Caregivers of children who died under the age of 5 years**
- **Participants over the age of 18**

Study introduction and overview

Hello – my name is XXXX. I work for the Africa Health Research Institute (AHRI).

I would like to invite you to take part in a research study, conducted by AHRI and the University of Oxford. This study forms part of Dr Jessica Price's PHD, who is studying at the University of Oxford.

The study today involves an interview which I will explain. It is up to you to decide whether you wish to take part. Please consider this information carefully, discuss it with others if you wish, and take the time you need to make a decision. I will be happy to answer any questions. Please ask if there is anything that is not clear, or if you would like more information. If you agree to take part in the study, you can decide to withdraw at any time, without giving any reason. This information sheet is yours, and you may keep it.

Who will be asked to take part in this study?

I am asking primary caregivers, over the age of 18 years, who completed the interview for a child who died below the age of 5 years and who live in the study area, to take part.

Study overview

This study builds on the Verbal and Social Autopsy interview that you already participated in when a fieldworker visited your house to ask questions about the child's final illness. The research team hope to better understand the process of accessing healthcare services for children in the community during their final illness. By better understanding these experiences and the problems you faced, we can make recommendations to improve access to healthcare.

Therefore during this interview I will ask you about:

- Your experiences of seeking care during your child's final illness
- Any problems you faced in accessing formal healthcare services

The interview will last about 1 hour. With your permission, I will record the interview using a digital voice recorder and will then type everything you said into a computer. I will also take a few notes while you speak to help with the transcription process (which I will explain in a moment).

What are the risks involved in the study?

This study will involve an interview about the period of illness leading up to the death of your child. We are interested in understanding your experiences of seeking care, and the challenges you faced in accessing formal health services. I am aware that discussing this may be distressing. If you find the interview too upsetting at any stage, you are free to stop the interview. You can also decide whether you'd like to continue the interview (either after a short break, or re-arranged for another day), or whether you'd like to stop the interview altogether. When you pause the interview, I will turn off the audio recording. The study team is supported by a social worker and a psychologist who are also available to you if you feel distressed and would like further assistance.

What are the benefits of being involved in the study?
You may find it comforting to discuss your child's final illness. We hope that recommendations from this study made to the Department of Health will increase access to healthcare in the community and improve the experience of seeking care.

What if you do not want to take part in the study?
Taking part in the study is voluntary. You are free to refuse to be interviewed, and/or you can decline to answer specific questions during the interview. You are also free to withdraw from the study at any point, including stopping the interview at any point, in which case all data and audio recordings up till that point will be discarded. If you decline or choose to stop the interview, you will not be penalised and nothing bad will happen.

Who will see the information that is collected?
I will keep the information collected private and confidential. The recording of the interview will be downloaded onto a secure computer immediately after the interview. During the transcription process, whereby a written copy of the interview is produced, all names mentioned (including your own and the name of your child) will be removed. We will not share your name with anyone else. The audio recording and the written copy of the interview will be stored securely at the AHRI offices as part of the AHRI database. The audio recording will be stored for 10 years. The anonymised written copy of the interview will be kept indefinitely. The anonymised findings from this study will be included in a DPhil thesis at the University of Oxford (which will be publicly available) and written up in articles for scientific journals to share the information that we learn with researchers, doctors and others in South Africa and the world.

The ethics committee
This study has been approved by the University of Kwa-Zulu Natal (UKZN) Biomedical Research Ethics Committee and University of Oxford Tropical Research Ethics Committee. Contact details for the UKZN Biomedical Research Ethics committee are at the end of the page. The Ethics Committees may look at the information from the study to check that procedures are being correctly and safely followed.

Communication of our research findings
Periodically, we will inform the Department of Health at district, provincial and national levels and the local community about the findings of the study overall, but not the results of you specifically.

Who to contact if you want to know more, or if you have a problem or complaint at any time?
If you ever have questions about this study, or in case you are harmed as a result of participation in the study, you should contact Dr Jessica Price (Principal Investigator) or Dr Janet Seely (Head: Social Sciences and Research Ethics) at the Africa Health Research Institute (AHRI) (035 550 7500) or Ms Ncengani Mthethwa of our Community Engagement Office (0800 203 695) during working hours (0800-1630 Monday to Friday).

PARTICIPANT CONSENT FORM

BREC Approval Reference:

Caregivers' experiences of seeking care and barriers to access in child illness that led to death in rural South Africa

Please tick the box if you agree with the corresponding statement:

1	I confirm that I have read and understand the information sheet for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.	☐
2	I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, and without any adverse consequences.	☐
3	I understand that research data collected during the study may be looked at by designated individuals from the University of Kwa-Zulu Natal and the University of Oxford where it is relevant to my taking part in this study. I give permission for these individuals to access my data.	☐
4	I understand that this project has been reviewed by, and received ethics clearance through the University of Kwa-Zulu Natal Biomedical Research Ethics Committee and the University of Oxford Tropical Research Ethics Committee.	☐
5	I understand who will have access to personal data provided, how the data will be stored and what will happen to the data at the end of the project.	☐
6	I understand how this research will be written up and published.	☐
7	I understand how to raise a concern or make a complaint.	☐
8	I consent to being audio recorded.	☐
9	I agree to take part in the study.	☐

_____ _____ _____

Participant's name (print) Participant's signature (*1) Date

(*1) FOR PERSONS WHO CANNOT WRITE MARK WITH 'X'

_____ _____ _____

Name of fieldworker who took consent (print) Staff member's signature Date

_____ _____ _____

Witness' name (print) (*2) Witness' signature Date

(*2) WITNESS ONLY IN CASE IF THE PARTICIPANT CANNOT WRITE OR IN CASE THE PARTICIPANT ASKS FOR A WITNESS. WITNESS MUST BE NEITHER CHILD NOR STUDY STAFF.

Research Study Title: Caregivers' experiences of seeking care and barriers to access in child illness that led to death in rural South Africa

Information Sheet and consent form: Focus Group

To be provided to, and discussed with the following people:

- **Caregivers of children who died under the age of 5 years**
- **Participants over the age of 18**

Study introduction and overview:
Hello – my name is XXXX. I work for the Africa Health Research Institute (AHRI).

I would like to invite you to take part in a research study, conducted by AHRI and the University of Oxford. This study forms part of Dr Jessica Price's PHD, who is studying at the University of Oxford.

The study today involves a focus group discussion which I will explain. It is up to you to decide whether you wish to take part. Please consider this information carefully, discuss it with others if you wish, and take the time you need to make a decision. I will be happy to answer any questions. Please ask if there is anything that is not clear, or if you would like more information. If you agree to take part in the study, you can decide to withdraw at any time, without giving any reason. This information sheet is yours, and you may keep it.

Who will be asked to take part in this study?
I am asking primary caregivers over the age of 18 years who completed the interview for a child who died below the age of 5 years and who lives in the study area, to take part.

Study overview
This study builds on the Verbal and Social Autopsy interview that you already participated in when a fieldworker visited your house to ask questions about the child's final illness. The research team hope to better understand the process of accessing healthcare services for children in the community during their final illness. By better understanding these experiences and the problems you faced, we can make recommendations to improve access to healthcare.

Therefore during this focus group discussion I will ask you about:

- Your experiences of seeking care during your child's final illness
- Any problems you faced in accessing formal healthcare services
- Whether you think our findings from interviews in the community are reasonable and relatable.

The focus group will last about 1 hour. With your permission, I will record the discussion using a digital voice recorder and will afterwards type everything that is said into a computer. I will also take a few notes while the discussion takes place to help with the transcription process (which I will explain in a moment). I ask that all participants in the focus group discussion respect confidentiality and that you do not share what was discussed in the group with others once you leave; however, this cannot be guaranteed.

What are the risks involved in the study?
This study will involve a discussion about the care seeking during your child's final illness. I am interested in understanding your experiences of seeking care, and the challenges you faced in accessing formal health services, and whether other in the group had similar or different experiences I am aware that discussing this may be distressing. If you find the discussion too upsetting at any stage, you are free to leave the discussion. You can also decide whether you'd like to rejoin the group, or whether you'd like to conclude the discussion

altogether. The study team is supported by a social worker and a psychologist who are also available to you if you feel distressed and would like further assistance.

What are the benefits of being involved in the study?

You may find it comforting to discuss your child's final illness. We hope that recommendations from this study made to the Department of Health will increase access to healthcare in the community and improve the experience of seeking care.

What if you do not want to take part in the study?

Taking part in the study is voluntary. You are free to refuse to participate, and/or you can decline to answer specific questions during the discussion. You are also free to withdraw from the study at any point, including leaving the focus group at any point, however I would include your contributions until that point in the written anonymised copy of the focus group discussion. If you refuse to participate or withdraw during the discussion, you will not be penalised and nothing bad will happen.

Who will see the information that is collected?

I will keep the information collected private and confidential. However, other members of the focus group discussion will hear what you say, and so I cannot guarantee confidentiality. The recording of the focus group discussion will be downloaded onto a secure computer immediately after the interview. During the transcription process, whereby a written copy of the interview is produced, all names mentioned (including your own and the name of your child) will be removed. We will not share your name with anyone else. The audio recording and the written copy of the interview will be stored securely at the AHRI offices as part of the AHRI database. The audio recording will be stored for 10 years. The anonymised written copy of the interview will be kept indefinitely. The anonymised findings from this study will be included in a DPhil thesis at the University of Oxford (which will be publicly available) and written up in articles for scientific journals to share the information that we learn with researchers, doctors and others in South Africa and the world.

The ethics committee

This study has been approved by the University of Kwa-Zulu Natal (UKZN) Biomedical Research Ethics Committee and the University of Oxford Tropical Ethics Research Committee. Contact details for the UKZN Biomedical Research Committee are at the bottom of the page. The Ethics Committees may look at the information from the study to check that procedures are being correctly and safely followed.

Communication of our research findings

Periodically, we will inform the Department of Health at district, provincial and national levels and the local community about the findings of the study but not information given by you individually.

Who to contact if you want to know more, or if you have a problem or complaint at any time?

If you ever have questions about this study, or in case you are harmed as a result of participation in the study, you should contact Dr Jessica Price (Principal Investigator) or Dr Janet Seely (Head: Social Sciences and Research Ethics) at the Africa Health Research Institute (AHRI) (035 550 7500) or Ms Ncengani Mthethwa of our Community Engagement Office (0800 203 695) during working hours (0800-1630 Monday to Friday).

PARTICIPANT CONSENT FORM

BREC Approval Reference:

Caregivers' experiences of seeking care and barriers to access in child illness that led to death in rural South Africa

Please tick the box if you agree with the corresponding statement:

1	I confirm that I have read and understand the information sheet for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.	☐
2	I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, and without any adverse consequences.	☐
3	I understand that research data collected during the study may be looked at by designated individuals from the University of Kwa-Zulu Natal and the University of Oxford where it is relevant to my taking part in this study. I give permission for these individuals to access my data.	☐
4	I understand that this project has been reviewed by, and received ethics clearance through the University of Kwa-Zulu Natal Biomedical Research Ethics Committee and the University of Oxford Tropical Research Ethics Committee.	☐
5	I understand who will have access to personal data provided, how the data will be stored and what will happen to the data at the end of the project.	☐
6	I understand how this research will be written up and published.	☐
7	I understand how to raise a concern or make a complaint.	☐
8	I consent to being audio recorded.	☐
9	I agree to take part in the study.	☐

_____ _____ _____

Participant's name (print) Participant's signature (*1) Date

(*1) FOR PERSONS WHO CANNOT WRITE MARK WITH 'X'

_____ _____ _____

Name of fieldworker who took consent (print) Staff member's signature Date

_____ _____ _____

Witness' name (print) (*2) Witness' signature Date

(*2) WITNESS ONLY IN CASE IF THE PARTICIPANT CANNOT WRITE OR IN CASE THE PARTICIPANT ASKS FOR A WITNESS. WITNESS MUST BE NEITHER CHILD NOR STUDY STAFF.

Appendix 7.2: Interview Guide

*Note: Consent to be taken before starting the interview. Interviewer to then start by introducing themselves, reminding the participant they will be audio-recorded, they can refuse to answer any questions and/or pause the interview.

1. Family setup: Can you tell me about your household? – How many people, what are their roles? Anyone working? Income sources? Number of children in the household? Any previous deaths in the household?
2. Interaction with community: supportive or not? What do they mean that they have a good or bad relationship with the community?
3. Church/Religion – and role in supporting during illness/bereavement
4. Can you tell me about your child's final illness? (allow participant to finish their story without interruption. If not supplied, then probe for symptoms recognised, what they did in response to those symptoms, where they sought care and when, did they refer to the RTHC for information/guidance – can they understand the information given that it is in English)
5. How did you decide to seek care? Who made that decision? Was it discussed with anyone?
6. Can you tell me about your experience of seeking care? How did the staff treat them?

(Probe for positive and negative experiences, how did the staff treat them, were they made to wait, were they allowed to stay with their children during any treatments/procedures – and did they like this or not?)

*If they didn't seek care, explore issues around why they didn't access care.

*any causes of major delays in seeking care

*use of traditional medicine

7. Why did you go to your chosen healthcare provider?
8. What treatment did you get from the provider? What advice did the provider give you?

(explore whether they completed/complied with the treatment, why or why not)

(if died at home after seeking care, why did they not go back to care when the child was not getting better?)

9. Can you tell me about any challenges you faced in accessing healthcare? Is there anything that made is difficult to get healthcare?
10. How did you overcome those difficulties?

11. Were you satisfied with the care you were offered? Is there anything that could have been done better?
12. Who told you the child had died? What did they say? Do you know what was the cause of the death (was this explained)?
13. What about the burial? When, where, what rituals?
14. Death registered? Child care grant cancelled?