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Assessing the burden and risk factors of sudden infant death syndrome (SIDS) and other sleep related infant deaths in Africa: a case study of Zambia

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BOSTON UNIVERSITY
SCHOOL OF PUBLIC HEALTH

Dissertation

**ASSESSING THE BURDEN AND RISK FACTORS OF SUDDEN INFANT
DEATH SYNDROME (SIDS) AND OTHER SLEEP RELATED INFANT
DEATHS IN AFRICA: A CASE STUDY OF ZAMBIA**

by

GODWIN KOFI OSEI-POKU

BSc., University of Ghana, 2005
MBChB, University of Ghana Medical School, 2008
M.P.H., Boston University, 2015

Submitted in partial fulfillment of the
requirements for the degree of
Doctor of Public Health

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Approved by

First Reader

Christopher J. Gill, M.D.
Associate Professor of Global Health

Second Reader

William B. MacLeod, Sc.D.
Research Associate Professor of Global Health

Third Reader

Patricia A. Elliot, DrPH
Clinical Associate Professor of Community Health Sciences

Fourth Reader

Somwe Wa Somwe M.D.
Consultant Paediatrician – Department of Paediatrics and Child Health
University of Zambia

DEDICATION

To my wife, Sefarkor and children, Kwaku, Kwame and Akua for your love, support, and sacrifice throughout this process. You inspire me daily to keep challenging myself.

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Boston University School of Public Health, 2022

Major Professor: Christopher J. Gill, M.D., Associate Professor of Global Health

ABSTRACT

Background: In wealthier countries, sudden infant death syndrome (SIDS) is consistently mentioned as a leading preventable cause of infant mortality. However, in Africa, little is known about SIDS. The general view in the Global Health community is that SIDS is not a significant cause of infant mortality in low resource settings. But is this assumption correct? It seems illogical that SIDS would only be confined to high-income settings. An alternative hypothesis is that we are in a situation where SIDS in Africa has historically not been a priority area for research. Consequently, we may have fallen into the common trap where the absence of evidence is misconstrued as evidence of absence. The focus of this thesis is to challenge these assumptions.

Methods: We do this in stages. First, we present results of a systematic review of published studies about SIDS in Africa. Second, we analyze a recently collected unique data set consisting of verbal autopsy data from the next of kin of several hundred deceased infants to attempt to quantify the burden of apparent SIDS deaths. Third, we assess the burden of canonical risk factors for SIDS using prospectively collected survey data. And fourth, we analyze individual attitudes, knowledge, and experience with SIDS collected via focus groups and in-depth interviews to better understand awareness of SIDS and its

risk factors, and the potential that these could be modified.

Results: The systematic review confirmed that SIDS is poorly studied in Africa. Most of the research on SIDS in Africa comes from South Africa. The incidence of SIDS was high, with reported incidence rates of between 3.01 to 3.70 per 1000 live births in South Africa compared to 0.3 per 1000 live births in the U.S. Bedsharing and prone/lateral sleeping were universally prevalent in countries where these were assessed. In Zambia, 7.4% of decedent infants who died at home died suddenly and unexpectedly, with 5.4% presumably dying of SIDS. In surveys, nearly all infants (89.5%) shared a bed with an adult during sleep, and nearly two-thirds slept (73%) in the lateral position. Infants rarely slept in the recommended supine/back position. In focus group discussions, mothers indicated that they felt the supine sleep position posed an aspiration risk to the infant. Most cited health care workers and experienced women in the community as sources of information on sleep practices.

Conclusion: Contrary to the prevailing view of SIDS in low to middle-income countries, in Africa and Zambia specifically, SIDS may be a significant cause of infant mortality, but it is going unrecognized or unreported. Public health interventions in Africa and Zambia are overlooking SIDS as an important cause of infant mortality. Interventions to prevent SIDS, such as laying the infant to sleep on the back, are low cost and will be worthwhile in reducing the high infant mortality rates in these settings.

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LIST OF ABBREVIATIONS

<i>AAP</i>	American Association of Pediatrics
<i>AIDS</i>	Acquired Immune Deficiency Syndrome
<i>AIR</i>	American Institute of Research
<i>ASSB</i>	Accidental Suffocation and Strangulation in Bed
<i>B19</i>	Parvovirus B19
<i>BCG</i>	Bacille Calmette-Guérin
<i>BID</i>	Brought in Dead
<i>BU</i>	Boston University
<i>CDC</i>	Centers for Disease Control and Prevention
<i>CMV</i>	Cytomegalovirus
<i>CPD</i>	Continuous Professional Education
<i>CSDH</i>	Commission on Social Determinants of Health
<i>DFID</i>	Department for International Development
<i>DHMO</i>	District Health Management Office
<i>DHS</i>	Demographic and Health Surveys
<i>DrPH</i>	Doctor of Public Health
<i>EBF</i>	Exclusive Breastfeeding
<i>EPI</i>	Expanded Programme on Immunization
<i>EV</i>	Enterovirus
<i>FCDO</i>	Foreign Commonwealth & Development Office (FCDO)
<i>FFPE</i>	Formalin Fixed, Paraffin-embedded
<i>FGD</i>	Focus Group Discussion
<i>GALT</i>	Galactose-1-Phosphate Uridylyl transferase
<i>GBD</i>	Global Burden of Disease Study

<i>GRZ</i>	Republic of Zambia
<i>GTZ</i>	German Technical Corporation
<i>HCoV</i>	Human Coronavirus
<i>HIV</i>	Human Immunodeficiency Virus
<i>HMPV</i>	Human Metapneumovirus
<i>HRV</i>	Human Rhino Virus
<i>ICU</i>	Intensive Care Unit
<i>IDI</i>	In Depth Interview
<i>IHC</i>	Immunohistochemistry
<i>IHME</i>	Institute for Health Metrics and Evaluation
<i>IMCI</i>	Integrated Management of Childhood Illness
<i>IRB</i>	Institutional Review Board
<i>LMIC</i>	Low-to-Middle-Income Country
<i>LQTS</i>	Long QT Syndrome
<i>MICS</i>	Multiple Indicator Cluster Surveys
<i>MOH</i>	Ministry of Health
<i>NGO</i>	Non-Governmental Organization
<i>NHRA</i>	National Health Research Authority
<i>NICHD</i>	National Institute of Child Health and Human Development
<i>OPV</i>	Oral Polio Vaccine
<i>OR</i>	Odds Ratio
<i>PASS</i>	Prenatal Alcohol in SIDS and Stillbirth Network
<i>PCR</i>	Polymerase Chain Reaction
<i>PHMRC</i>	Population Health Medical Research Council
<i>PI</i>	Principal Investigator

<i>PIV3</i>	Parainfluenza Virus Type 3
<i>PR</i>	Prevalence Ratio
<i>PRISMA</i>	Preferred Reporting Items for Systematic Reviews and Meta-Analyses
<i>RA</i>	Research Assistant
<i>RR</i>	Relative Risk
<i>RSV</i>	Respiratory Syncytial Virus
<i>RVD</i>	Retroviral Disease
<i>SAS</i>	Statistical Analysis System
<i>SCN10A</i>	Sodium Voltage-Gated Channel Alpha Subunit 10
<i>SCN5A</i>	Sodium Voltage-Gated Channel Alpha Subunit 5
<i>SDOH</i>	Social Determinants of Health
<i>SIDS</i>	Sudden Infant Death Syndrome
<i>SUDI</i>	Sudden Unexpected Death in Infancy
<i>SUID</i>	Sudden Unexpected Infant Death
<i>SVD</i>	Spontaneous Vaginal Delivery
<i>UNICEF</i>	United Nations International Children’s Education Fund
<i>UNZA</i>	University of Zambia
<i>UNZABREC</i>	University of Zambia Biomedical Research Ethics Committee
<i>USAID</i>	United States Agency for International Development
<i>USID</i>	Unclassified Sudden Infant Death
<i>UTH</i>	University Teaching Hospital
<i>VA</i>	Verbal Autopsy
<i>WHO</i>	World Health Organization
<i>ZPRIME</i>	Zambia Pertussis and RSV Infant Mortality Estimation Study

CHAPTER 1: INTRODUCTION

1.1 Chapter Overview

This chapter outlines the dissertation's rationale and public health significance. It introduces sudden infant death syndrome (SIDS), a leading preventable cause of infant mortality in high-income countries as the focus of this dissertation. The epidemiology, definitions, pathophysiology, and key risk factors of SIDS are presented as background information to guide the dissertation. The chapter concludes with an overview of the problem statement, research purpose, study questions, and study aims.

1.2 Rationale and public health significance

Infant mortality continues to be a significant public health issue in Africa. In the last few decades, significant progress has been made globally in reducing infant mortality.[1] Despite this progress, an estimated 4 million children under 1 year of age died in 2018, constituting nearly 75% of the global under-5 mortality.[1] Nearly half of the global infant mortality occurred in sub-Saharan Africa in 2018.[1] The probability of an African child dying before the first birthday was over six times higher than that of a child in Europe.[1]

In developed or wealthier countries, sudden infant death syndrome (SIDS) is a leading cause of infant mortality. In the United States (U.S.) for instance, SIDS was the leading cause of post-neonatal mortality in 2017.[2] On the other hand, in Africa and most developing countries, SIDS is rarely discussed as a cause of infant mortality, and yet there is no reason to believe that SIDS does not occur in these countries. The risk factors for SIDS and other sleep-related infant deaths are very similar [3] and include, sleeping in the lateral or prone position, co-sleeping with an adult, little or no prenatal care, maternal age

less than 20 years, prematurity or low birth weight and maternal smoking.[4,5] More importantly, recent evidence suggest a strong association of SIDS with low socioeconomic status, low maternal education and single marital status,[6] risk factors that are prevalent in most African countries.[7] Moreover, Ibeziako et al reported a high incidence of the prone sleeping position and bed sharing in a cohort of babies in South Eastern Nigeria.[8] In spite of this, the global health community has largely ignored SIDS as a cause of infant mortality in Africa and most developing countries, focusing instead on infectious causes of infant mortality. For instance, a search on the World Health Organizations (W.H.O) website for “SIDS” leads to a series of articles on “Small Island Developing States” with very few on the clinical entity sudden infant death syndrome.

Public health campaigns in high income countries in the 1990’s led to significant reductions in infant mortality by targeting major risk factors of SIDS such as bed-sharing, prone sleeping, and prenatal exposure to tobacco smoke. However, such campaigns or programs are missing in Africa. Currently, South Africa is the only African country to have launched a sudden infant death awareness campaign¹. [9] In addition, accurately classifying SIDS remains a challenge in most African countries due to the lack of national protocols for infant death scene investigation and generally low autopsy rates.[10,11] A consequence of this is that many infant deaths are incorrectly attributed to infections and other causes of infant mortality, making it difficult to estimate the true burden of SIDS. The paucity of

¹ The first sudden infant death awareness campaign in South Africa, dubbed Snuggle Time Safe Sleep Campaign was launched on the 9th of September 2003 by Baby Talk South Africa and Baby City Stores South Africa. To the best of our knowledge, this is the first and only SIDS awareness campaign in Africa.

information on the burden of SIDS and other sleep-related infant deaths delays the implementation of interventions that target the risk factors of SIDS. Interventions to prevent SIDS are low cost and would be impactful in low to middle income countries (LMICs) with limited resources such as found in Africa.

1.3 Background

1.3.1 Definition of SIDS

The sudden death of an apparently healthy infant during sleep is not new. There are recorded episodes of sudden infant death in several ancient texts including the bible².^[12] The first use of the term sudden infant death syndrome or SIDS was in 1969.^[13] It was used to describe a subgroup of unexplained infant deaths that presented with similar clinical, and pathological features.^[7,13] The 1969 definition proposed by Beckwith and colleagues identified SIDS as “the sudden death of any infant or young child, which is unexpected by history, and in which a thorough post-mortem examination fails to demonstrate an adequate cause of death”.^[7] This definition remained largely unchanged until 1989 when a more restrictive age limit and explicit criteria were included.

The 1989 definition proposed by an expert panel of the National Institute of Child Health and Human Development (NICHD) states that SIDS is “the sudden death of an infant under one year of age, which remains unexplained after a thorough case investigation, including performance of a complete autopsy, examination of the death scene, and a review of the clinical history”.^[14] The 1989 definition built on the 1969

² King Solomon dealt with an argument between two mothers in 1 Kings 3:16–28, in which one of their babies was apparently laid on and found dead in the middle of the night.

definition by restricting SIDS to infants under 1 year of age and mandated the performance of a death scene investigation to get a complete picture of the circumstances of the infant's death. Following suggestions to stratify SIDS cases into categories for diagnostic purposes, a panel met in San Diego and proposed a definition for SIDS as "the sudden unexpected death of an infant less than 1 year of age, with onset of the fatal episode apparently occurring during sleep, that remains unexplained after a thorough investigation including performance of a complete autopsy and review of the circumstances of death and clinical history". [15] This definition included an association with sleep in addition to broadening the requirement for a death scene investigation to include an evaluation of the circumstance of the infant's death.[13] Under the San Diego definition, three subcategories were proposed (See appendix A). SIDS is thus a diagnosis of exclusion, typically involves a sleep period and has no distinctive diagnostic features. SIDS is assigned when reasonable attempts to identify an alternative explanation have been excluded.

1.3.2 Burden of SIDS

Current global estimates of the burden of SIDS are difficult to ascertain. However, in 2013, the global burden of disease study (GBD) reported an age-standardized SIDS mortality rate of 0.3 per 100,000 (UI: 0.1 to 0.3).[16] This is likely to be an underestimate of the true global SIDS burden due to wide variations in coding practices across countries.[13] For instance, Taylor et al in a study comparing SIDS coding practices across eight high income countries noted that the proportion of sudden infant death cases coded as SIDS ranged from 32.6% in Japan to 72.5% in Germany.[17] Moreover, in developing countries, infant mortality statistics rarely give estimates about the SIDS incidence rate. In

Nigeria for instance, autopsies and death scene investigations are rarely performed in sudden infant death cases. [10] This is true for most developing countries especially in Africa. On the other hand, infant mortality statistics from developed or high-income countries often include rates on the burden of SIDS. Based on data from these high income countries, the SIDS rate in 2015 ranged from 0.09 in Denmark [18] to 0.39 deaths per 1000 live births in the U.S.[19] In 2019, the SIDS rate in the U.S. was reported as 0.33 per 1000 live births. Similarly, the SIDS rate (unexplained infant death) in England and Wales for 2018 was reported as 0.3 per 1000 live births.[20]

SIDS rates in these countries were not always this low. SIDS rates before the “back to sleep” campaigns in the 1990s, ranged from 0.3 to 2.90 per 1000 live births.[21] A decade later in 2000, the SIDS rates ranged from 0.12 to 1.10 deaths per 1000 live births with a percent decrease ranging from 10% to 79% across several countries.[22] The greatest declines were noted in the first few years of these campaigns. For instance, following the back to sleep campaign in the U.S., the SIDS rate declined by 41% from 1.30 to 0.77 deaths per 1000 live births between 1991 and 1998.[23] Less dramatic declines were noted in subsequent years (Between 1998 and 2001, the SIDS rate declined by only 22% from 0.77 to 0.61 per 1000 live births).[23] Given that there are no safe sleep campaigns in most African countries, SIDS rates in these countries are likely to approximate those of high income countries in the pre “back to sleep” era.

1.3.3 SIDS and SUID

The less dramatic declines in the SIDS rate in high income countries in recent years have been attributed to a shift in diagnosis of SIDS cases.[22] Improvements in death scene

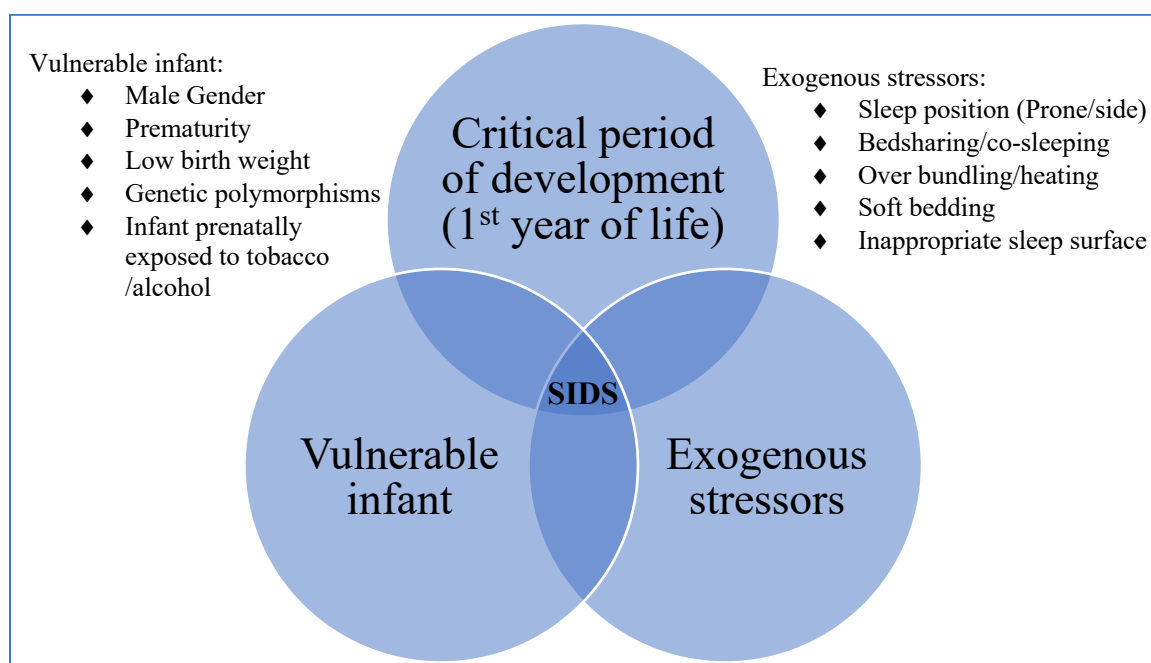
investigations means several cases which were previously classified as SIDS deaths are now classified as accidental suffocation or strangulation deaths (ASSB). In the U.S and other countries for instance, while the SIDS rate has declined, the number of deaths that are attributed to ASSB has increased. [23,24] Moreover, some pathologists adhere strictly to the 1989 definition of SIDS and would not classify a sudden infant death as SIDS without a death scene investigation or detailed postmortem investigation. Related to this, the term sudden unexpected infant death (SUID) or sudden death in infancy (SUDI) (Europe and UK) is used to denote SIDS, ASSB and other unexplained infant deaths since these deaths are often unwitnessed and it is difficult to ascertain if the death was due to asphyxia or suffocation.[25] SUID or SUDI is now preferred for research purposes and consistency across countries.

1.3.4 Overview of risk factors of SIDS/SUID

SIDS has long been thought to be multifactorial in origin due to the interaction of a variety of factors. [26–28] The Triple Risk model proposed by Filiano and Kinney in 1994, is currently the most widely accepted model to explain the pathogenesis of SIDS. It also serves as a conceptual framework to guide research on SIDS. It posits that SIDS occurs due to the intersection of an infant in a critical period of development, the presence of an underlying vulnerability and exposure of the infant to an exogenous stressor. [13,29] **(Figure 1)** Vulnerability of the infant is explained by factors intrinsic to the infant such as gender, while extrinsic factors such as the position the infant is laid to sleep explains the presence of exogenous stressors at the time of death.[30] Due to years of research, additional risk factors including young maternal age and other socio-economic factors have

been identified as important risk factors of SIDS. However, in nearly all cases of SIDS, at least one intrinsic or extrinsic factor is present.[30] This model is extremely helpful because it focuses our attention on those factors that are extrinsic to the infant and that can be readily modified, such as sleep position, co-sleeping, and the selection of bedding.

Figure 1: Triple risk model for SIDS



Source: Trachtenberg FL, Haas EA, Kinney HC, Stanley C, Krous HF. Risk factor changes for sudden infant death syndrome after initiation of Back-to-Sleep campaign. *Pediatrics*. 2012;129(4):630–8. <https://doi.org/10.1542/peds.2011-1419>. [30]

1. Risk factors intrinsic to the infant

Risk factors intrinsic to the infant are often non-modifiable and affects the infant's vulnerability. These include age, gender, prematurity, low birth weight, and genetic polymorphisms. Prenatal exposure to tobacco and alcohol have also been suggested as intrinsic risk factors since these occur during pregnancy. Postnatal exposure to tobacco is however seen as a maternal risk factor.

Age and gender. Younger infants are more vulnerable to SIDS than older infants. SIDS typically peaks at age 2–3 months with nearly 80% occurring during the first four months after birth. [23,24,31–33] SUID deaths are also more common among younger infants. In the U.S, 76–86% of SUID deaths occur between 0–4 months of age, peaking at 1–2 months.[34] Male gender is also strongly associated with the risk of SIDS. There is a 60:40 male to female ratio in the distribution of SIDS with males at significantly increased risk of SIDS. [31,35]

Prematurity and low birth weight. Preterm and low birth weight infants are also at increased risk of SIDS. Previous research suggest a more than fourfold increased risk of SIDS for preterm infants [36] or those with low birth weight.[37] For instance, Jonville-Bera et al found that the risk of SIDS was 6.53 times higher (95% CI: 2.29, 18.9) in low birth weight infants compared to those with normal weight.[37]

Genetic polymorphisms. Prior genetic studies have also identified several genes, most associated with cardiac ion channelopathies, cardiomyopathies and/or metabolic disorders in the etiology of SIDS, estimating that roughly 35% of SIDS cases could have a genetic etiology.[38] The genetic argument is strengthened when there are multiple SIDS deaths in the same family. In one study, infants with a sibling who died of SIDS had a 5.8 (95% CI, 2.1, 13.2) relative recurrence risk of SIDS.[39] Yet at the same time, most infants who died of SIDS lack such mutations and efforts to reduce SIDS rates through genetic screening programs have had minimal impact. That is consistent with the triple risk model since even in the presence of a rare genetic variant, a proximal stressor, such as sleeping face down, is still necessary for the tragic outcome to emerge. With that understanding,

and because genetic defects cannot be corrected, the focus on reducing SIDS deaths is on sleep practices: putting babies on their back, avoiding co-sleeping with parents, or using some sort of barrier device to separate parents from the infant when co-sleeping, such as a cardboard baby box.

Prenatal exposure to tobacco. The association between maternal smoking and SIDS has long been established by several epidemiological studies.[40,41] In fact, in one meta-analysis, the pooled relative risk of maternal smoking and SIDS was nearly fourfold (RR: 3.93, 95% CI: 3.78, 4.08).[41] In another earlier meta-analysis of 34 studies, the unadjusted pooled odds ratio for maternal smoking was more than twofold (OR: 2.77, 95% CI 2.45 to 3.13).[42] The risk of SIDS is also dose dependent and increases linearly with the number of cigarettes smoked.[40] The mechanism of how maternal smoking increases the risk of SIDS is thought to be due to impaired arousal patterns in sleeping infants [43], changes in autonomic function [44] and cardiovascular reflexes [45,46] increasing an infant's vulnerability to SIDS. Postnatal exposure to secondhand cigarette smoke especially combined with bed-sharing further increases an infant's risk of SIDS.[40]

Prenatal exposure to alcohol. Several epidemiological studies have also found a strong association between maternal alcohol use and SIDS. In one study, the authors estimated that maternal alcohol use during pregnancy accounted for at least 16.4% of SIDS deaths. [47] The risk of SIDS was nearly sevenfold when a maternal alcohol diagnosis was made during pregnancy (adjusted Hazards Ratio 6.92, 95% CI: 4.02, 11.90).[47] In another study, periconceptional maternal alcohol use (aOR, 6.2; 95% CI, 1.6–23.3) and first trimester binge drinking (aOR, 8.2; 95% CI: 1.9–35.3) were significantly associated with

an increased odds of SIDS.[48]

2. Extrinsic or exogenous risk factors

The sleep environment and other physical stressors at the time of death are often described as factors extrinsic to the infant. These include sleep position, bedsharing, over bundling, soft bedding, and other inappropriate sleep surfaces.

Sleep position. The prone sleeping position is the most significant extrinsic risk factor of SIDS [13] and has been targeted in several safe sleep campaigns. Much of the progress that has been made in reducing the rates of SIDS coincided with reductions in the rates of prone sleeping. The risk of SIDS is estimated to increase by more than twofold when an infant is placed in the prone position. [49,50] The side or lateral position is also associated with a twofold increased risk of SIDS.[51] The mechanism of this is thought to be due to rebreathing of expired gases leading to hypoxia and hypercapnia, overheating, and altered autonomic control of the infants cardiovascular system during sleep. [52–55]

Bedsharing or co-sleeping. Sharing a sleep surface also places the infant at increased risk of SIDS due to overlaying, suffocation and/or overheating. In one metanalysis, the pooled risk was nearly three times higher when an infant bedshares with another person (OR, 2.88; 95% CI, 1.99–4.18).[56] The risk is even higher when the infant is preterm or low birth weight, younger than 4 months, sleeps with a mother who smokes, drinks alcohol or uses other substances, and shares the sleep surface with more than one adult. [56–58]

Soft or loose bedding and bundling. Soft bedding is also thought to increase the risk of SIDS. A soft sleep surface may indent or conform to the infants head and may increase the risk of rebreathing or suffocation when the infant is placed prone or accidentally rolls

into the prone position.[59] Moreover, soft objects and other loose bedding such as thick blankets, and pillows are associated with an increased risk of suffocation and rebreathing leading to SIDS. [53,59] In fact, the risk of SIDS is increased fivefold when there is soft bedding in the infants sleep environment.[49] Overheating due to over-bundling or covering of the face or head of the infant is also thought to play a role in SIDS. One study found that 36% of SIDS cases were found to be sweating profusely at the time of death.[60]

3. Socio-economic and other risk factors

Several other risk factors have been reported including climate, ethnicity, maternal age, single marital status, inadequate prenatal care, twin births and history of mental illness in either parent. [35,61] Young maternal age, high birth order, single motherhood, low maternal or paternal education and maternal or paternal unemployment were associated with a doubling of the risk of SIDS.[62] Parental psychiatric admission is also associated with a sixfold increase in the risk of SIDS (RR 6.9; 95% CI, 4.1–11.6).[63]

1.4 Problem Statement

SIDS and/or SUID is the leading cause of preventable infant death in wealthier or high-income countries, accounting for nearly 33 to 50% of all post-neonatal mortalities in Germany, Australia, UK, Japan, and the U.S. Even in the Netherlands where SUID rates are low, SUID accounts for 18% of post neonatal mortalities.[22] On the other hand, in Africa, the contribution of SIDS to infant mortality has not been well characterized. There is a seeming lack of interest in SIDS by African researchers and the larger global health community [8,10] and yet it is remarkable to think SIDS doesn't contribute to infant mortality in Africa as it has been wherever else it has been studied. In fact, what little is

known about SIDS in Africa rests predominantly on quite recent studies conducted in South Africa.[11] However, demographically, South Africa is an outlier compared to the rest of the continent with relatively better socioeconomic conditions, which supports the need to study the problem in other more representative African settings. Yet, in a recent postmortem study in Zambia conducted by members of my thesis committee, 11.3% of infants died under circumstances that suggested SIDS [64], contrary to previous expectations that SIDS may not be contributing to infant mortality in countries outside of South Africa. The question that arises is whether the apparent absence of evidence about the burden of SIDS in Africa is an example where the absence of evidence has been misconstrued as evidence of absence?

1.5 Research purpose, questions and aims

1.5.1 Research purpose

This study sought to explore SIDS/SUID by conducting a formal systematic review of studies on SIDS/SUID pertaining to African populations. In addition, the study explored the burden of SIDS and the prevalence of its risk factors in a representative African country, Zambia. The study was conducted in Zambia, justified by the following considerations: Zambia is representative of many low and middle-income countries in having persistently high rates of infant mortality. In 2018, 69% of the country's child mortality occurred in children under 1 year of age.[65] The infant mortality rate in 2018 was 42 per 1000 live births.[65] Moreover, no study has explored SIDS and/or SUIDS in Zambia. This was the first study to explore SIDS and its risk factors in Zambia.

1.5.2 Research question and aims

This study thus answered the following questions:

What are the characteristics and range of research to address SIDS/SUID in Africa and what is the prevalence of SIDS/SUID, its risk factors and the determinants of these risk factors in Zambia?

Four research aims were explored to address these questions:

Aim 1: Systematically evaluate the literature on SIDS/SUID in Africa

Aim 2: Estimate the proportion of decedent infants who died from SIDS/SUID in Zambia

Aim 3: Determine the prevalence of the risk factors of SIDS/SUID in Zambia

Aim 4: Explore the perceptions of mothers and other care givers about the risk factors of SIDS/SUID in Zambia.

Briefly, to address the first aim, a systematic review of published and gray literature on SIDS/SUID in Africa was conducted. To address the second aim, verbal autopsy data from the Gate's foundation funded postmortem study in Zambia, ZPRIME³, was analyzed to estimate the proportion of decedent infants that died from SIDS/SUID in Zambia. Finally, the prevalence of the risk factors of SIDS/SUID was explored using a mixed methods analysis of data collected prospectively among groups of young mothers in Lusaka, including a sub-set of mothers who had lost an infant due to apparent SIDS.

³ ZPRIME, Zambia Pertussis and RSV Infant Mortality Estimation Study was a prospective postmortem study which aimed to estimate the proportion of decedent infants who died of RSV and/or Pertussis

CHAPTER 2: RESEARCH DESIGN AND METHODS

2.1 Chapter overview

This chapter outlines the methodology and research design for the study. The chapter is organized around each study aim and gives a high-level overview of the systematic review, analysis of the previously collected verbal autopsy data, and the prospective quantitative and qualitative risk factor analysis. The World Health Organization's conceptual framework for action on the social determinants of health is proposed as a framework for understanding SIDS in the context of low to middle income countries. The chapter concludes with dissemination plans for study findings.

2.2 Research question and study aims

The purpose of this study is to systematically review the literature on SIDS in Africa and to explore the burden, risk factors and determinants of SIDS in a low to middle income African country, Zambia. Details of the research aims, data collection, and analysis plans are presented in **Table 1**.

Table 1: Summary of data source, data collection and analysis plans for study aims

Aim	Data Source/ Target Audience	Purpose	Data collection method	Data analysis method
Aim 1: Systematically evaluate the literature on SIDS/SUID in Africa	- Embase, PubMed, Web of Science, Cochrane, Google Scholar	- Assess the characteristics and range of research on SIDS/SUID in Africa	- Systematic review	- Qualitative synthesis of relevant studies
Aim 2: Estimate the proportion of infant deaths	- Family (mother/father) of deceased infants	- To determine the proportion of decedent infants who	- Verbal autopsies with families of	- Quantitative coding of free text narratives

Aim	Data Source/ Target Audience	Purpose	Data collection method	Data analysis method
that are due to SIDS/SUID in Zambia		died of SIDS/SUID	deceased infants	
Aim 3: Determine the prevalence of the known risk factors of SIDS/SUID in Zambia	- Mothers of infants aged 1 year and below	- To estimate the prevalence of the known risk factors of SIDS/SUID	- Surveys with mothers of infants	- Frequencies, percentages, and logistic regression analysis
Aim 4: Explore the perceptions of mothers and other care givers about the risk factors of SIDS/SUID in Zambia	- Mothers and other care givers of infants aged 1 year and below - Mothers of infants who died of SUID	- To explore perceptions about the risk factors of SIDS/SUID - To explore SIDS risk factors among mothers of infants who died of SIDS/SUID	- Focus Group Discussions - In-depth interviews	- Thematic content analysis for qualitative data analysis

This study used a variety of study methods to address each study aim. Firstly, the systematic review of SIDS publications in Africa was conducted to estimate the burden of SIDS and its risk factors in Africa. Next, secondary analysis of verbal autopsy data from the Zambia Pertussis and RSV infant mortality estimation study (ZPRIME) was used to provide preliminary estimates on the prevalence of SIDS among decedent infants in Zambia. Finally, a mixed methods study design with primary data collection was employed to assess the risk factors of SIDS in Zambia. Primary data collection included surveys, FGDs and in-depth interviews with mothers and other caregivers of infants aged less than

1 year. A high-level overview of study methods for each study aim is presented below. More detailed descriptions of each study method are presented in chapters 3, 4, 5 and 6.

2.3 Study methods for Aim 1 - Systematic review

The systematic review qualitatively synthesized relevant studies conducted on SIDS/SUIDS in Africa to give estimates on the prevalence of SIDS/SUID and associated risk factors in Africa. Database search, title, abstract and full text review, and data extraction were independently conducted by two review authors, the study PI (DrPH candidate) and a research assistant (RA). The systematic review search strategy was executed on the 26th of December 2020. Title, abstract, full text review, data extraction and final reporting of review findings was conducted in the spring and summer of 2021.

Search strategy. Four databases (PubMed, Embase, Web of Science, and Cochrane) were searched using a search filter developed in collaboration with a librarian to identify peer reviewed articles on SIDS/SUID pertaining to African populations. Google scholar was additionally used to search for relevant gray literature. (See appendix A for filter). All articles up to December 26th were included.

Selection process. Title, abstract and full text review of search results were conducted in Covidence (Covidence.org, Melbourne Australia, <https://www.covidence.org>), a systematic review software. Articles were included for review if they were conducted in Africa (North Africa and sub-Saharan Africa), original articles or case reports/case series that specifically mentioned or reported data on sudden unexpected infant death (SUID) or sudden infant death syndrome (SIDS).

Data extraction. Author and institutional affiliation, source of funding and conflict of interest, year of publication, study design, study aim, country of the population studied, sample size including total number of infants studied, number and proportion of infants who died of SIDS and/or SUID, and reported prevalence of prone/lateral sleeping position, bed-sharing, maternal alcohol/smoking, prematurity, breastfeeding, genetic risk factors, viral infections in SUID cases, etc. were extracted using customized data extraction forms in Covidence.

Risk of bias assessment. Risk of bias of included studies was performed using the Newcastle Ottawa scale for observational studies or a modification. Studies were assessed on the three main domains of selection, comparability, and outcome and rated on a 9-point scale (case control, cohort, and cross-sectional/prevalence studies) or a 5-point scale (case reports or case series studies).

Statistical synthesis. Due to heterogeneity in study designs and a high risk of bias in most included studies, a meta-analysis was not conducted. Studies were qualitatively synthesized following the 27-item PRISMA checklist ⁴. The review addressed all the relevant PRISMA required elements.

⁴ PRISMA, Preferred Reporting Items for Systematic Reviews and Meta-Analyses is a minimum set of items required for the reporting of systematic reviews and meta-analyses. The 27 item PRISMA checklist can be accessed here:
http://prisma-statement.org/documents/PRISMA_2020_checklist.pdf

2.4 Research design and study methods for Aims 2, 3 & 4

Starting with the study setting and study sites for both ZPRIME and the mixed methods study, below is an overview of study methods for study aims 2, 3, and 4.

2.4.1 Study setting

Data collection for ZPRIME and the mixed methods study occurred across three sites in Lusaka, Zambia. Lusaka is the capital city of Zambia with a population of 1.7 million persons.[66] The city of Lusaka is surrounded by a series of unofficial peri-urban compounds/townships where most of the city's poor reside. The total population of Lusaka is thus estimated to be approximately 2.4 million individuals, or roughly 1/8th of the total population of Zambia itself.[66] Several primary health facilities provide health care to the population with the University Teaching Hospital (UTH) serving as the main referral facility.[64] The majority of health care facilities in Lusaka are managed by the Government of the Republic of Zambia (GRZ). Study sites were purposively sampled based on established relationships with the Boston University School of Public Health (BUSPH) and in consultation with in-country collaborators.

2.4.2 Study sites

University Teaching Hospital. The University Teaching Hospital's (UTH) morgue served as the study enrollment site for ZPRIME.[66] UTH is the largest hospital in Zambia with 1,655 beds and serves as the main training institution for doctors, nurses and other clinical officers in Zambia.[67,68] It serves as the main referral center for the roughly 2.4 million residents in Lusaka and the surrounding peri-urban townships. Clinical care is offered through four main departments of surgery, internal medicine, obstetrics and

gynecology and pediatrics.

Chilenje and Chawama Hospitals. Data collection for the mixed methods study occurred at two busy urban clinics in Lusaka: Chilenje and Chawama. Chilenje general attends to a wealthier and more advantaged population in Lusaka, whereas the Chawama township is one of the most densely populated and economically stressed parts of the city, with very high rates of poverty. Both the Chilenje and Chawama hospitals are called “first level” hospitals. These are essentially small community hospitals managed by the Government of the Republic of Zambia (GRZ).[69] **Table 2** provides summary data for each health facility. Participants were recruited from within the catchment area of each hospital.

Table 2: Health facility demographic information

Demographic features	Chawama	Chilenje
Facility Type (2020)	Level 1 Hospital	Level 1 Hospital
Epidemiological setting	Peri-urban	Urban
Catchment population (2012)	128,858	95,007
Distance of facility to DHMO (km) (2012)	10	7
Number of Beds (2012)	32	46

2.4.3 Study methods for Aim 2 - Analysis of ZPRIME verbal autopsy data

Verbal autopsy data collected as part of ZPRIME was analyzed qualitatively and quantitatively to give preliminary estimates on the burden of SIDS in Zambia. The ZPRIME project, a Bill and Melinda Gates sponsored project, was a postmortem community-based prevalence study designed to identify the proportion of decedents aged 4 days to less than 6 months that were attributable to *Bordetella pertussis* and *Respiratory Syncytial Virus* (RSV) in Lusaka, Zambia.[66] Despite the study’s focus on these two

pathogens, ZPRIME's data have proven valuable to understanding the circumstances of community infant mortality more generally. This is because each verbal autopsy includes a free-text narrative section, in which the next of kin were able to describe the circumstances of each death.

In reviewing these narratives, the study investigators first identified deaths that suggested SIDS. This initial observation led to the current detailed analyses of these narratives, supported by demographic and other data collected about the infants and their home environments. Data collection for ZPRIME occurred over three years from August 2017 to August 2020. Over its three years of data collection, ZPRIME collected data on > 2300 infants, of which roughly 60% occurred in the community and were paired with a verbal autopsy.

Recruitment and sampling. Data collectors stationed at the UTH morgue systematically recruited all infants who died at home and were brought in dead (BID) to a health facility. On notification of an infant death which met eligibility requirements, data collectors approached families of these infants for consent. VAs was conducted with families who gave consent for participation. Based on the recruitment strategy, VAs was conducted with approximately 80% of all BIDs who presented at UTH.

Data collection and analysis. Verbal autopsy interviews were conducted using an abbreviated verbal autopsy tool. For this study, our analysis centered on the open response narrative which allowed respondents to provide in depth descriptions of the circumstances leading to the infant's death. Textual points of interest that indicated a SIDS/SUID from free text narratives in the verbal autopsy were first coded qualitatively in excel and

subsequently analyzed quantitatively in SAS to provide estimates of the proportion of decedent infants that died from a SIDS or SUID. Frequencies, percentages, mean, standard deviation, odds ratios (OR) and 95% confidence intervals (CI) were calculated as appropriate. Logistic regression was used for both univariate and multivariate analysis.

2.4.4 Study methods for Aim 3 - Quantitative analysis of SIDS risk factors

Surveys with mothers at postnatal clinics were used to provide estimates on the prevalence of the known risk factors of SIDS. Bedsharing was assessed as the main primary outcome. The prone/side sleeping positions were assessed as secondary outcomes in addition to other risk factors such as prenatal or postnatal exposure to alcohol or tobacco.

Data source. Surveys targeted mothers of infants aged less than 1 year at each study site. To be eligible for surveys, mothers had to be aged between 18–49 years, resident in the catchment area of each study site and able to give either verbal or written informed consent for participation in the study.

Recruitment and sampling. Recruitment into surveys was based on a non-probability convenience sampling method. Designated nurses (gate keepers) identified eligible mothers for participation in the survey. All mothers who were eligible for the survey were invited to participate. The consent rate was much higher than expected, hence nearly all mothers who were approached agreed to participate in the study.

Data collection. Surveys were conducted using a 64-item questionnaire with 8 sections on the risk factors of SIDS. Questions centered on infant sleep practices, prenatal exposures to tobacco and alcohol, and maternal demographic factors. Surveys were administered in private rooms away from clinical services.

Sample size and statistical analysis. Sample size estimates for the surveys were based on previous work by Ibeziako et al.[8] Details of the sample size formula and considerations are provided in **Chapter 5**. Briefly, we estimated a required sample size of 480 mother baby-dyads based on an assumed bedsharing rate of 50% in Zambia and a 20% non-consent rate. Survey data was analyzed quantitatively in SAS 9.4. Frequencies, percentages, mean/standard deviation, and Prevalence ratios (PR) with 95% confidence intervals (95% CI) were calculated as appropriate. Log binomial regression was used for both univariate and multivariate analysis.

2.4.5 Study methods for Aim 4 - Qualitative analysis of SIDS risk factors

Focus Group Discussions were used to generate a rich understanding of the experiences and perspectives of mothers regarding infant sleep practices in Zambia. In depth interviews complemented surveys and FGDs by providing a more detailed view of these risk factors among mothers who lost infants in circumstances suggestive of SIDS.

Data source. FGDs were conducted with mothers and other caregivers of infants aged one year or younger while interviews targeted women in the community who had lost an infant to SUID. FGD participants were aged between 18–49 years, and resident within the catchment area of each hospital. Interview recipients had lost an infant suddenly and unexpectedly during sleep in the 5 years prior to the interview.

Recruitment and sampling. FGD participants were purposively sampled by designated nurses at each study site. Interview respondents were screened for participation using a question on the survey which asked if they had previously lost an infant suddenly and unexpectedly during sleep. Mothers who responded yes to this question and whose

description fit a SUID-like death were invited to participate in interviews. Written informed consent was obtained from all participants. Informed consent forms were provided in both English and Nyanja, the local language.

Data collection. FGDs used semi-structured interview guides and open-ended questions to allow participants to share their beliefs and experiences. Trained local data collectors facilitated these sessions, ensuring that concepts and themes were addressed appropriately. FGDs were conducted in Nyanja. In-depth interviews were similarly conducted in Nyanja and used a structured interview guide based on CDC's SUID reporting form which assessed the sleep environment of the infant at the time of death. Additional questions explored other risk factors that may have been present in the mother and thus predispose the infant to SIDS. FGDs and interviews were also conducted in private rooms at each study site.

Sample size and data analysis. Sample size estimates for FGDs and interviews were guided by considerations of thematic saturation. Thematic saturation occurs when more participants to a study do not yield new perspectives or information. Based on prior research[70], we determined that we would need to complete between 8–10 interviews and 6–8 individual focus group discussions consisting of 6–8 participants to reach thematic saturation. We ultimately conducted 8 in-depth interviews and 6 focus groups with 35 participants. The validity of our estimates was supported during data analysis when coding did not yield any new concepts or themes.

FGDs and interviews were audio recorded, translated, transcribed verbatim and analyzed using thematic content analysis. The thematic content analysis followed Nowell

and colleagues six steps for establishing trustworthiness.[71] (**Supplemental Table 2**) This six step approach ensured the study met the trustworthiness criteria established by Lincoln and Guba.[72] Briefly, the study PI (DrPH candidate) and research assistant (facilitator of the FGD's) independently reviewed a subset of transcripts and generated initial codes. Consensus was then reached on major themes through discussion.

2.4.6 Other study procedures for Aims 3 & 4

Data management and storage. To ensure confidentiality and anonymity of survey participants, participants were assigned a randomly generated ID as unique identifier. This ID was used on consent forms. Surveys were also administered on encrypted tablets using a secure platform, Qualtrics. FGD participants were each assigned a participant number at the start of each session and encouraged to avoid the use of names during sessions. Any identifying information that was accidentally included in audio recordings was removed from transcripts. Audio files, transcripts and other electronic files were stored on a password protected computer. Only study staff had access to these files. All consent forms and hand-written notes collected during the study period remained in Zambia and were stored in a locked cabinet, in a locked office at Right to Care, a Lusaka-based NGO. All audio recordings were erased after data analysis was completed.

Selection and training of study team. For all prospective data collection on the mixed methods study, we partnered with Right to Care to assist with field activities, including the recruitment of data collectors. The study team was made up of three quantitative data collectors, and one qualitative data collector, all native Zambians. Quantitative data collectors had prior experience in survey administration and were proficient in using

electronic survey platforms. The qualitative data collector had experience transcribing qualitative data and facilitating FGDs and conducting in depth interviews. All data collectors could speak English as well as the local languages Bemba and Nyanja. Data collectors received training on the overall objectives and aims of the study, including research ethics, obtaining informed consent and data management. The principal investigator conducted all trainings. Mock interviews and testing of the data collection tools were conducted as part of data collector training. Ethical oversight for data collectors was provided by the University of Zambia Biomedical Research Ethics Committee (UNZABREC).

Testing of data collection tools. Two rounds of testing of IRB approved data collection tools were conducted in Chawama hospital. This was to ensure that questions were relevant to the study, and culturally appropriate. Survey guides were pilot tested with four women while FGD and interview guides were pilot tested with two women. The necessary modifications were made to the tools in real time. Participants for pilot testing met inclusion criteria for each study type.

Site preparation. The appropriate institutional approvals were obtained in the first week of arrival in Zambia. The PI and study team members visited each study site to meet with the nurse-in-charge at each clinic to discuss study logistics. At these meetings, it was determined to align data collection with clinical services which often occurred between 8am to 1pm daily. The study team also made calls to the medical superintendent of Chilenje general hospital to introduce the study and obtain appropriate permissions for data collection.

Daily debrief. The study team met daily to discuss themes that emerged from the FGDs and Interviews and to implement real time changes to the survey. For instance, survey logic and phrasing of questions so that they were clearer, were made after the first day of debrief. The dates on which changes were made was noted to guide analysis of the data. The study team also assessed whether FGDs and interviews were approaching saturation. Daily debriefs were conducted in person while the PI was in Zambia and subsequently virtually via zoom or WhatsApp.

2.5 Conceptual framework

Previous recommendations to address SIDS/SUID have focused on individual behavioral interventions designed to change the knowledge, attitudes and behaviors of parents and caregivers.[3] This approach neglects the social determinants of health since, increasingly, there is evidence to suggest that SIDS is concentrated among socially disadvantaged families and communities.[33] To some extent, this means that SIDS is also a disease of poverty. For instance, Spencer and Logan in 2004 found a strong association between SUID and adverse social conditions in a systematic review of 52 studies.[73] In another study, infants of disadvantaged mothers were found to be at greater risk of dying from SIDS.[74] Although individual-level risk behaviors do influence the occurrence of a fatal outcome, these occur within the social and cultural context within which women/families live.[75]

Assessing the risk factors of SIDS within the context of a social vulnerability framework is the most relevant to the aims of this study. To address the socio-cultural, and economic context in which this research was conducted, the WHO's Social Determinants

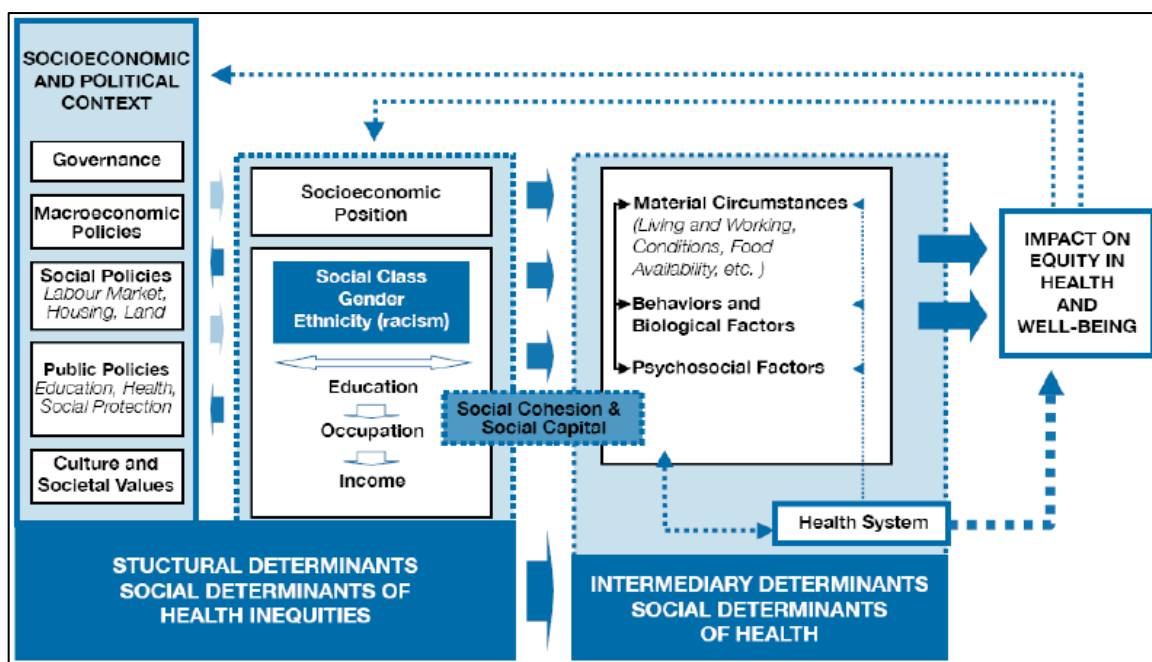
of Health (SDOH) conceptual framework was used to guide this study. This model demonstrates the complex intersection between social, economic, and political factors such as income, education, and occupation and how these influence health outcomes.[76] The model groups determinants of health into two broad categories of structural and intermediary determinants.

1. *Structural determinants* refers to an individual's socio-economic position in society determined by the economic and political context within which an individual is born and lives.[76] Proxies for structural determinants include income, education, occupation, social class, gender, and race/ethnicity
2. *Intermediary determinants* are those factors that determine an individual's likelihood of exposure to adverse health outcomes. There are three main categories of intermediary determinants: material, psychosocial, and biological factors[76]
 - a. *Material circumstances* include factors such as housing (overcrowding), neighborhood quality, and the physical work environment
 - b. *Psychosocial circumstances* include psychosocial stressors, stressful living circumstances and relationships and social support
 - c. *Behavioral and biological factors* include nutrition, tobacco, or alcohol consumption and genetic factors.

Concepts of social cohesion and social capital⁵ were included in this model as bridges between structural and intermediary determinants.

⁵ Kawachi and Berkman define social capital as the “resources accessed by individuals as a result of their membership of a network or group”.[77] These resources may include the exchange of information and social support

Figure 2: WHO CSDH Conceptual framework



Source: Solar O, Irwin A. *A Conceptual Framework for Action on the Social Determinants of Health. Social Determinants of Health Discussion Paper 2 (Policy and Practice)*. World Health Organization; 2010.

Our analysis centered on age, education, occupation, and residence as structural determinants while we focused on material, behavioral and biological factors as intermediary determinants. The risk factors of SIDS/SUID were assessed in a systematic manner across these structural and intermediary determinants to facilitate data collection across individual influences. Determinants and considerations explored in this research study are summarized in **Table 3** below:

Table 3: Determinants and considerations for data collection

Determinant	Definition	Considerations
Structural	Factors that determine an individual's socio-economic position and is based on the societal, economic, and political context within the individual was born and lives	Socio-economic position <ul style="list-style-type: none"> - Young maternal age - Marital status - Educational attainment - Occupation - Residence (study site)
Intermediary	Factors that influence an individual's likelihood of exposure or engagement in health compromising conditions.	Material <ul style="list-style-type: none"> - Housing: number of adults bedsharing with infant, overcrowding, number of children in household (parity), exposure to solid fuels from cooking - Consumption potential (financial means to buy baby cot or bassinet or other separate sleep surface for infant) - Access to health care (adequacy of prenatal care), access to information on recommended infant sleep practices - Nutrition (adequacy of breastfeeding and other infant feeding practices) Behavioral <ul style="list-style-type: none"> - Sleeping position - Use of blankets - Parental smoking and alcohol use Biological <ul style="list-style-type: none"> - Birth defects - Prematurity - Genetic abnormalities - Age of infant (younger infants vs older infants) - Sex of infant (Male vs Female)

2.6 Ethical approvals

Ethical approval for the systematic review (Aim 1) was not required since it did not involve human subjects. Ethical approval for Aim 2 was obtained previously during the conduct of ZPRIME. For Aims 3 and 4, for which data were collected prospectively, we sought ethical oversight at the Boston University Medical Center IRB and at the University of Zambia in Lusaka. The Boston University Medical Center IRB through an exempt determination approved the mixed methods study on November 2020 (IRB Number: H-40803, Approval date; 11/24/2020). The University of Zambia Biomedical Research Ethics Committee (UNZABREC) approved the study in April 2021 through a full determination (Ref. No. 1509-2021). Further approval was obtained from the Medical Superintendents of study hospitals. Documentation of ethical approvals are provided in Appendix C. Ethical approval for ZPRIME was also provided by the institutional review board of the University of Zambia (UNZABREC) and Boston University.

2.7 Dissemination of findings

Results from this study will be disseminated in written format to the Zambia Ministry of Health (MOH), the Zambia National Public Health Institute, the National Health Research Authority (NHRA), study sites, and other relevant Zambian authorities. Research findings will also be presented at local and international conferences and prepared for publication in peer review journals. Per guidelines set forth by the NHRA, a copy of all publications will be submitted to UNZABREC.

CHAPTER 3: SYSTEMATIC REVIEW OF THE BURDEN AND RISK FACTORS OF SUDDEN INFANT DEATH SYNDROME (SIDS) AND OTHER SLEEP-RELATED INFANT DEATHS IN AFRICA

3.1 Chapter overview

This chapter presents a summary of results of the systematic review which aimed to estimate the prevalence of SIDS, and its risk factors in Africa. The rationale for this review is presented in the introduction while the methods section details the database search, article selection process, risk of bias assessment and final syntheses plans. Results are organized around the two main research aims: burden of SIDS and prevalence of the known risk factors. A final discussion section compares findings of this review to previous scholarly work in the literature including policy implications of these findings.

3.2 Introduction

In wealthier countries, sudden infant death syndrome (SIDS), a subset of sudden unexpected infant death (SUID), is recognized as a leading preventable cause of infant mortality. According to the U.S. Centers for Disease Control and Prevention (CDC), SIDS was the leading cause of post-neonatal mortality and the fourth leading cause of infant mortality in the United States in 2017.[2] SIDS is “the sudden and unexpected death of an infant under 12 months of age that remains unexplained after a review of the clinical history, complete autopsy and death scene investigation, with the onset of the fatal episode occurring during sleep”.[7,14] Nearly 90 percent of SIDS cases occur between birth and six months of age with a peak incidence around two to four months.[52,78] And while the pathobiology of SIDS may involve genetic or developmental factors, a key event in many SIDS cases is some form of respiratory stress, culminating in accidental suffocation. This

is a critical point to note since the interventions that have successfully reduced SIDS deaths in the U.S. and similar settings have largely focused on changes in infant sleeping conditions, most notably having infants sleep on their backs.

In sub-Saharan Africa, the contribution of SIDS to infant mortality has not been well understood. Very few studies have tried to estimate the incidence or prevalence of SIDS in Africa[11], and even fewer have studied the risk factors of SIDS. [10] Given the paucity of published studies on SIDS/SUID in Africa, this cause of child mortality has not been viewed as a high priority and has largely been ignored. And yet there is no reason to believe that SIDS is not a problem in African populations as it has been wherever else SIDS has been studied. Prior systematic reviews have used data from studies performed in high-income countries.[50] To the best of our knowledge, no systematic review has focused on SIDS/SUID in Africa.

3.3 Study objectives

To fill this knowledge gap, we conducted a systematic review of SIDS/SUID studies conducted in Africa. Our review focused on two main questions:

1. What is the prevalence of known and hypothesized risk factors of SIDS/SUID in Africa?
2. What is the burden of SIDS and/or SUID deaths in Africa?

3.4 Methods

3.4.1 Database and hand searching

PubMed, Embase, Web of Science, Cochrane, and Google Scholar were searched with search terms developed in collaboration with a librarian. The PubMed search was

developed first using the following search terms: ("Sudden Infant Death"[Mesh] OR "Sudden Infant Death Syndrome" OR "SIDS" OR "Sudden Infant Death" OR "Sudden Unexpected Infant Death" OR "Cot Death" OR "Cot Deaths" OR "Crib Death" OR "Crib Deaths" OR "Accidental Suffocation" OR "Unintentional Suffocation" OR "Strangulation in Bed" OR "ASSB")) and an African search filter previously developed by Pienaar et al.[79] (see **Supplemental Table 3** for full PubMed search filter)

All articles up to December 26, 2020 (the date on which the search was executed) were included. There was no prior date restriction on the search. All returned articles were then imported into Covidence (Covidence.org, Melbourne, Australia, <https://www.covidence.org>), a systematic review software, for screening and data extraction. Duplicate articles were removed using the de-duplication feature in Covidence. Duplicate articles that were missed in this initial phase were removed during full-text review manually by the review authors.

3.4.2 Selection process

Two review authors (DrPH candidate and a Research Assistant) independently screened titles and abstracts to identify any relevant articles. Articles that passed this initial review were included in a full-text review. The full texts of included studies were then screened. Articles that met the inclusion criteria were included in the review. Disagreements were resolved through discussion between reviewers until consensus was reached.

3.4.3 Inclusion/exclusion criteria:

Articles were included for review if they met the following inclusion criteria:

- Original research articles, case reports, and case series were included. Editorials, letters to the editor, opinions, and review articles were excluded.
- Articles were restricted geographically to Africa (including North Africa and sub-Saharan Africa).
- Non-English language articles were included if an English translation was available or if it could be translated into English using google translate.
- Articles that specifically mentioned or reported data on Sudden Unexpected Infant Death (SUID) or Sudden Infant Death Syndrome (SIDS) (known or hypothesized risk factors or burden of disease) were included. Articles that reported on a population that included infants but were not necessarily limited to infants were included if they reported on the prevalence of SUID/SIDS in the cohort of infants.

3.4.4 Data collection and analysis

We independently extracted the following data using customized data extraction forms in Covidence: author and institutional affiliation, source of funding and conflict of interest, year of publication, study design, study aim, country of the population studied, sample size including total number of infants studied, number and proportion of infants who died of SIDS and/or SUID and reported prevalence of any risk factors.

We independently assessed risk of bias for each included study using the Newcastle Ottawa scale for observational studies[80] or a modification[81–84]. Case control and cohort studies were assessed on three main domains of selection, comparability, and ascertainment of exposure and outcome. For case reports/case series studies we excluded items on comparability and adjustment since these studies were non-comparable.[81–83]

We assessed cross-sectional/prevalence studies on representativeness of the sample and size, comparability between respondents in different outcome groups, and appropriateness and completeness of the statistical test/analysis.[84] We did not receive nor require ethics approval for this study, as it does not involve human and animal subjects.

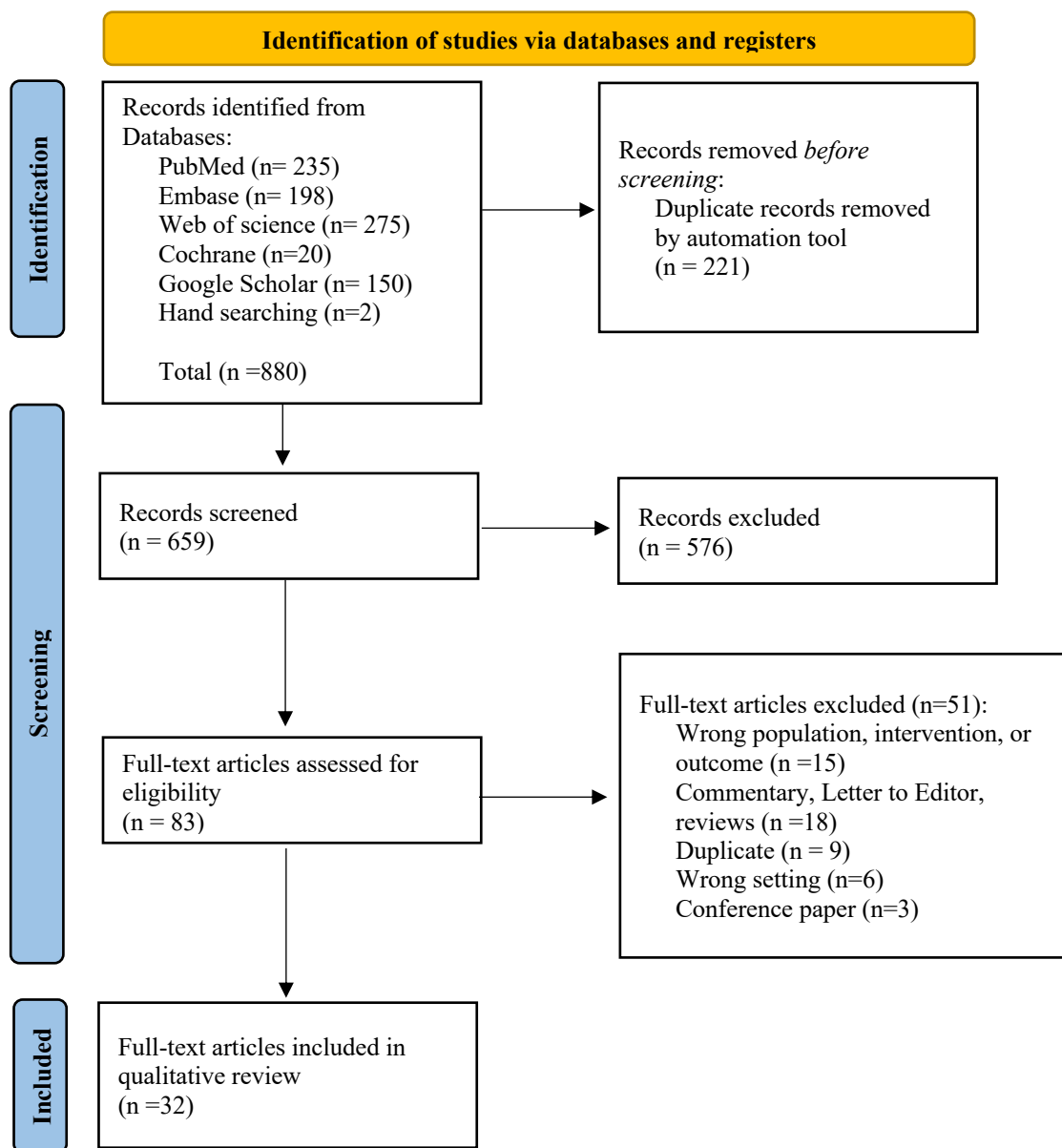
3.5 Results

3.5.1 Study characteristics

Our search yielded 880 articles. 221 were identified as duplicates and were removed by the de-duplication feature in Covidence. The title and abstracts of 659 articles were then reviewed and 576 were judged to be irrelevant. For example, 67 studies were identified with the acronym SIDS which also refers to Small Island Developing States, these were deemed irrelevant.

The full text of 83 articles was reviewed and 51 were excluded. These were: commentaries, editorials, and reviews (n=18); studies that reported on the wrong population, exposure, or outcomes (n=15); conference abstracts/papers (n=3); wrong study setting or non-African studies (n=6); and duplicate articles (n=9) which were missed using the de-duplication feature in Covidence. Thirty-two full-text articles were included in the final qualitative review/synthesis (25 original studies and 7 case reports/case series). This process is summarized in the PRISMA flow diagram as **Figure 3**.

Figure 3: PRISMA Flow Diagram of Search Strategy



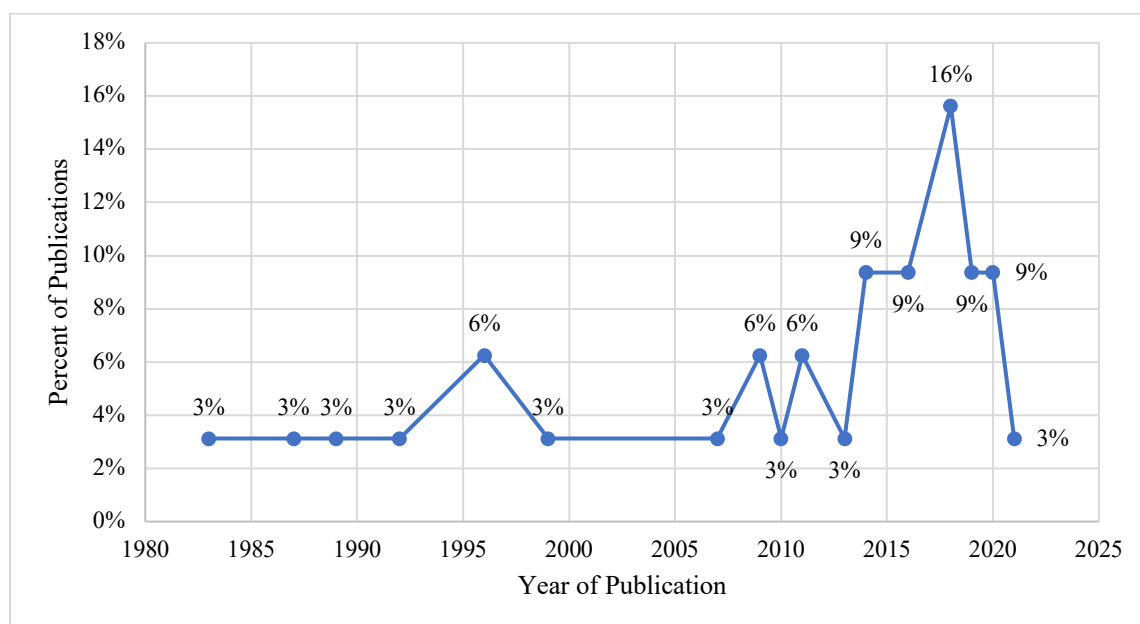
From: Page MJ, McKenzie JE, Bossuyt PM, Boutron I, Hoffmann TC, Mulrow CD, et al. The PRISMA 2020 statement: an updated guideline for reporting systematic reviews. *BMJ* 2021;372:n71. doi: 10.1136/bmj.n71

For more information, visit: <http://www.prisma-statement.org/>

3.5.2 Year of publication

The included studies were published from 1983 to 2021 (we received the pre-print version of the 2021 article from the study authors in December 2020) with most conducted in the last decade. Sixty-nine percent were published between 2010 and 2021, with majority in 2018 (n=5, 16%) (**Figure 4**). Overall, this supports our initial concerns that SIDS in Africa has historically been a very low priority for the global health community, except for a recent set of publications.

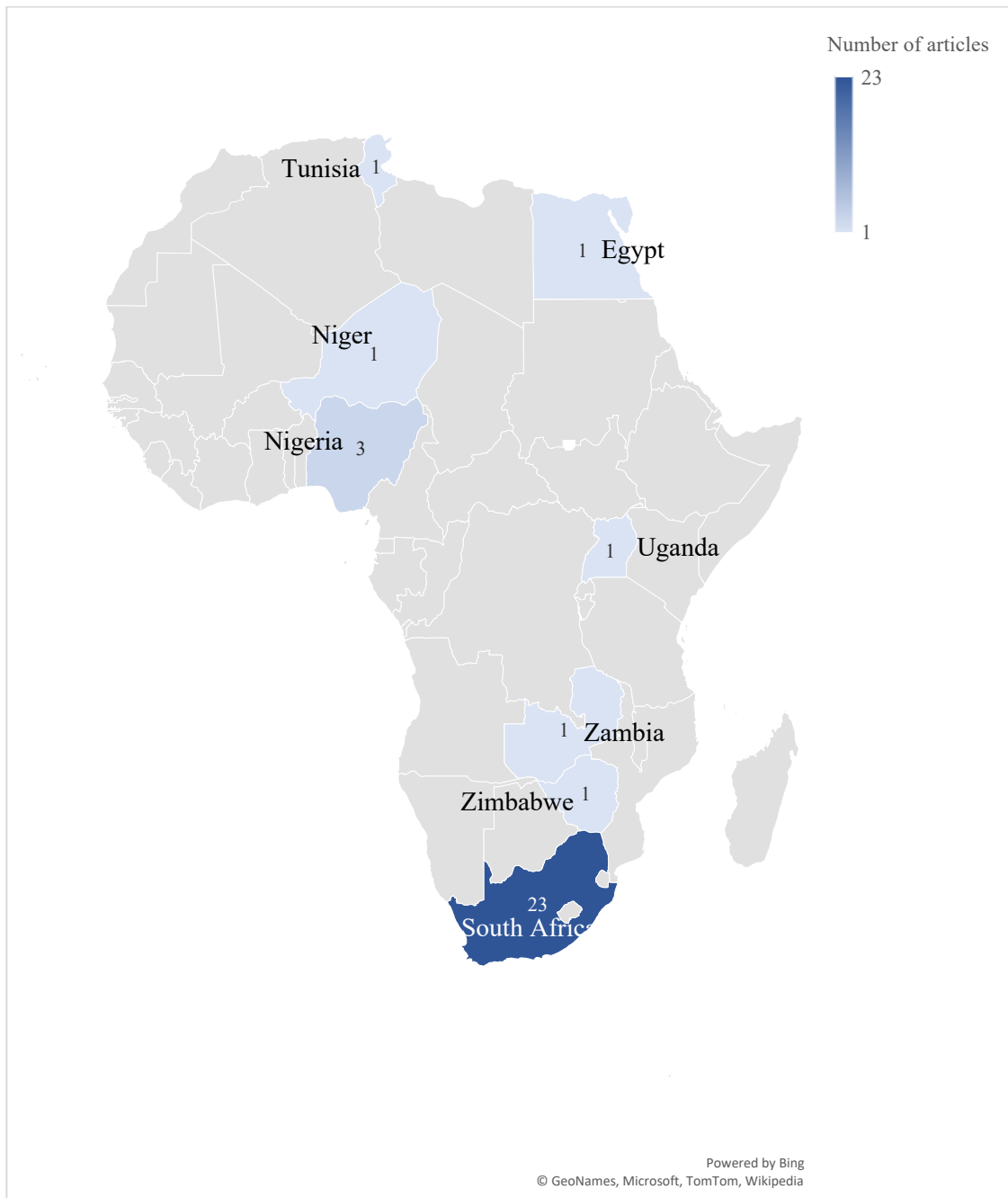
Figure 4: Distribution of included studies by year of publication



3.5.3 Geographic distribution of included studies:

Geographically, the articles were skewed to southern Africa (n=25, 78%) with few from west Africa (n=4, 13%), north Africa (6%), and east Africa (3%). The majority and nearly all of those from southern Africa were published in South Africa (n=23, 72%) (**Figure 5**).

Figure 5: Distribution of included studies across the African Continent



Three studies were published from Nigeria (9%) with one each (3%) from Egypt, Niger, Tunisia, Uganda, Zambia, and Zimbabwe as shown above in **Figure 5**.

3.5.4 Quality scores:

The 25 original articles were assessed for bias on a 9-point scale and classified as high (8–9), medium (5–7), or low quality (0–4). By study design, four case-control studies and three prospective cohort studies were included in this review. We rated all the case-control studies as medium quality (**Supplemental Table 4**), rated one cohort study as high quality and the remaining two as medium quality (**Supplemental Table 5**). Eighteen studies were described as cross-sectional or retrospective/prospective audits. We rated the majority (67%, n=12) of these studies as medium quality (**Supplemental Table 6**).

The 7 case reports/case series were assessed for bias on a 5-point scale and rated similarly as high (5), medium (4), or low quality (0–3). Most of the case reports/case series were also rated as medium quality (57%, n=4) (**Supplemental Table 7**). Overall, 4 high-quality studies were included in this review.

3.5.5 SIDS awareness

Awareness of SIDS was low in the general population. Three studies provided data on SIDS awareness, reporting a SIDS awareness rate of between 12.2% to 44.3%.^[85–87] Two of these studies were of low quality and one of medium quality. The medium quality study reported that 49 (12.2%) of respondents claimed to have heard of SIDS but only 5 (1.2%) had good knowledge of SIDS in a survey of 401 mothers of infants in Enugu, Nigeria.^[85] (**Table 4**).

3.5.6 Risk factors for SIDS

1. Risk factors intrinsic to the infant:

The peak age of SUID/SIDS varied across studies. Two medium quality South African studies found the peak age of SUID/SIDS deaths to be 1–2 months[88,89] while another reported a peak age of 2–4 months.[90] Slightly more male than female infants died of SUID/SIDS.[88–90] Three medium quality studies, two from South Africa and the other from Uganda explored prematurity as a risk factor of SIDS. The South African studies reported that 27% to 40.6% of SUID cases were preterm. [88,91] The Ugandan study found that suspected SIDS was the second leading cause of death in a cohort of preterm infants, accounting for nearly 25% of all deaths in that cohort.[92]

2. Risk factors intrinsic to the mother:

Six studies provided prevalence estimates on maternal/parental smoking and alcohol use. One medium-quality study reported a 10.2% prevalence of exposure to tobacco smoke in Nigeria among mothers at a well-baby clinic.[85] Among SUID cases, exposure to tobacco smoke was reported at a rate of 29% to 53.1% in South Africa.[88,89,91,93,94] Maternal use of alcohol was reported at a rate of 18% to 37.1% among SUID cases in South Africa. [88,89,91,93,94] One high-quality study in South Africa specifically focused on estimating the risk of SIDS in a cohort of infants due to prenatal exposure to alcohol and tobacco smoke. The study found that the adjusted relative risk for SIDS was 2.6 times higher for those who were exposed to alcohol compared to those who were not, and 3.8 times higher for those who were exposed to smoking compared to those who were not.[95]

The study cohort included mothers and infants from South Africa and the U.S.[95] It is not clear what the actual risk is in the African cohort.

3. Infant sleep practices:

Nine of the included studies reported on infant sleep practices in Nigeria, Egypt and South Africa, either as the main outcome of the study or as secondary outcomes.[8,85–88,91,93,94,96] Four articles reported on infant sleeping practices among mothers of infants at well-baby clinics while the remainder of these articles reported on infant sleep practices among SUID cases admitted to medico-legal laboratories in South Africa. The prone sleeping position was preferred by 26.7% to 63.8% of mothers of infants at well-baby clinics.[8,85,86,96] The lateral sleep position was preferred by 20.6% to 51.8% of mothers. [8,85,86,96] The practice of the recommended supine position for infants is less common. A minority (2.7% to 21.5%) of mothers placed their babies in the supine position during sleep. [8,85,86,96]

Among SUID cases, a majority of infants were reported to have been placed in the side position prior to death. The proportion of SUID cases placed to sleep in the side position was reported as 53% to 64% compared to 10% to 12% in the supine or back position.[93,94] 23.6% to 37% of SUID cases were placed in the prone position.[91,93,94] Bed-sharing is also very common. Bed-sharing was reported at a rate of 60% to 91.8% among mothers of infants at well-baby clinics. [8,85,86,96] Among SUID cases, the rate is nearly 95%.[88] Bed-sharing is an important risk factor in suffocation deaths due to being accidentally rolled on by a sleeping adult.

The risk of re-breathing expired gases is increased in the prone or side sleeping position

leading to hypoxia or hypercapnia.[53] However, one included study using post-mortem biomarkers of hypoxia did not find any significant differences between hypoxanthine and urate concentrations in vitreous humor samples of SIDS victims and infants who died of other causes.[97] The results of that study did not support the view that pre-mortem hypoxia is a common feature in SIDS when compared with other causes of death.[97] However, the validity of this forensic tool in the evaluation of SIDS has recently been called into question.[98] **Table 4** summarizes the main findings of studies focused on infant and maternal risk factors.

Table 4: Characteristics and findings of studies focused on infant sleep practices and other maternal risk factors

Study, Year	Country	Study Design	Sample size and population studied	Prone Position	Side Position	Supine Position	Bedsharing	Other Relevant Findings
Potgieter, 1992[96]	South Africa	Cross-sectional study	416 mothers with infants aged 6 days to 6 months	63.8%	33.5%	2.7%	60.0% (94.0% black, 71.0% colored, 4.0% white)	
Ibeziako, 2009[8]	Nigeria	Cross-sectional study	480 mothers with infants aged 1 to 52 weeks	26.7%	51.8%	21.5%	66.9%	
Okpere, 2014[86]	Nigeria	Cross-sectional study	282 mothers of infants aged less than 1 year who presented to well-baby clinics	44.3%	20.6%	18.1%	63.7% with mother (33.5% with both parents; 2.8% with other child)	SIDS awareness, 35.1%, (81.2% were unaware of recommended sleep position for infants).
Burger, 2014[91]	South Africa	Postmortem retrospective case audit	82 Deceased infants admitted as SUID cases	24.0%			65.0%	Parental Smoking, 29.0%, Prematurity, 27.0%, Parental alcohol use, 24.0%
LaGrange, 2014[89]**	South Africa	Postmortem prospective descriptive study	148 deceased infants presenting as SUID cases at Tygerberg Medico-Legal Mortuary	30.5% (32/105)			69.5% (73/105)	Peak age of SUID, 1-2 months Male vs Female (60.1% vs 39.9%) Wrapped in thick heavy blankets, 51.4% (54/105) Parental smoking, 39.0% (41/105) Parental alcohol use, 37.1% (39/105)

Study, Year	Country	Study Design	Sample size and population studied	Prone Position	Side Position	Supine Position	Bedsharing	Other Relevant Findings
Elsobkey*, 2018[87]	Egypt	Quasi-experimental study	70 mothers of preterm neonates with gestational age between 32 and 37 weeks, and weighing > 1500 grams			22.9%		SIDS awareness, 44.3% (Classified as average to good knowledge of SIDS) Firm sleep surface, 40.0% Avoid smoke exposure, 22.9%
Ikenna, 2019[85]	Nigeria	Cross-sectional study	401 mothers of infants aged less than 1 year	29.4%	45.9%	11.7%	91.8%	SIDS awareness, 12.2%, Tobacco smoke exposure, 10.2% Incidence of SUID, 7.7% (Described as mothers who witnessed sudden infant death)
Heathfield, 2020[88]	South Africa	Postmortem retrospective case audit	1199 deceased infants admitted as SUID cases to Salt River Mortuary				94.7%	Peak age of SUID, 1–2 months, Male vs Female (51.7% vs 48.3%), Prematurity, 40.6%, Previous history of SUID, 12.8% Tobacco smoke exposure, 53.1%, Maternal alcohol use, 19.8%

Study, Year	Country	Study Design	Sample size and population studied	Prone Position	Side Position	Supine Position	Bedsharing	Other Relevant Findings
Saayman, 2018[93]**	South Africa	Postmortem descriptive study	168 deceased infants presenting as SUID cases at Tygerberg Medico-Legal Mortuary	23.6% (33/140)	64.3% (90/140)	12.1% (17/140)	96.0% (144/150)	Prenatal alcohol, 18.0% (29/161), Tobacco smoke exposure: Prenatal, 31.0% (50/161), Postnatal, 11.0% (15/136)
Matshazi, 2018[94]**	South Africa	Postmortem descriptive study	183 deceased infants aged less than 1 year admitted as SUID cases to Tygerberg Medico-Legal Mortuary	37.0% (37/101)	53.0% (54/101)	10.0%	95.0% (96/101)	Tobacco smoke exposure, 31.0%, Prenatal alcohol use, 20.0%

* This was a pre/post study. Prevalence estimates are baseline results

** Thesis/Dissertation study

4. Infectious risk factors:

Since symptoms of infectious diseases can be subtle in infants and hence not recognized ante-mortem, much attention has focused on the post-mortem identification of infectious pathogens. Six studies explored the role of infectious agents in the pathogenesis of presumed SIDS in Africa. One medium-quality study highlighted the likely role of tuberculosis in SIDS-like deaths and found evidence of primary pulmonary tuberculosis on autopsy in a 4.5-month-old male infant whose history and death scene investigation fit the profile of a SIDS death.[99] The remaining five studies explored the role of viruses in SIDS deaths. These medium-quality studies used PCR testing to detect viral pathogens in a cohort of SUID/SIDS infants. The commonest viruses detected were HRV, RSV, HCoV, and CMV.[89,91,93,94] Viruses were detected in nearly half of the SIDS cases using PCR in South Africa.[89] Another medium quality study detected Coxsackie B virus in nearly 23% of presumed SIDS cases in Tunisia.[100] (**Table 5**)

Table 5: Characteristics and findings of studies that assessed the role of infections in SIDS/SUID deaths

Study, Year	Country	Study Design	Sample size and population studied	Significant Factor	Relevant Findings
Dempers, 2011[99]	South Africa	Case report study	1 deceased male infant aged 4.5 months who died suddenly and unexpectedly at a day care	Primary TB	Postmortem findings were consistent with Progressive primary pulmonary TB
LaGrange, 2014[89]**	South Africa	Postmortem prospective descriptive study	148 deceased infants presenting as SUID cases at Tygerberg Medico-Legal Mortuary	Respiratory viruses in SUID cases (HRV, RSV, HCoV, Human enterovirus, HMPV, Influenza A&B)	PCR positive HRV in 68 (46.0%), RSV A&B in 16 (10.8%), HCoV in 12 (8.1%), Human enterovirus in 6 (4.1%), HMPV in 5 (3.4%), PIV3 in 4 (2.7%) and Influenza A&B in 4 (2.7%) (PCR positive viruses in 50.0% of SIDS cases, 74.5% in deaths classified as infection and 37.5% in deaths classified as Other) SIDS diagnosed in 33.7% (34/101)
Burger, 2014[91]	South Africa	Postmortem retrospective case audit	82 Deceased infants admitted as SUID cases	Adenovirus, CMV and RSV	PCR positive Adenovirus in 2 (2%), and cytomegalovirus in 29 (35%). RSV detected in 4 (5%) cases using IHC
Gaaloul, 2016[100]	Tunisia	Case-control study	56 deceased infants aged 2 to 11 months (39 SIDS cases and 17 unnatural home death controls)	Coxsackie B virus	PCR positive Coxsackie B virus in 9 SIDS cases (23.0%) (Enterovirus detected by IHC and PCR in 6 SIDS cases (15.3%) with myocarditis and 3 (7.7%) with peri myocarditis)
Saayman, 2018[93]**	South Africa	Postmortem descriptive study (cross-sectional)	168 deceased infants presenting as SUID cases at Tygerberg Medico-Legal Mortuary	EV and B19	PCR positive EV and B19 in 49 cases (29%) SIDS diagnosed in 40% (48/121)

Study, Year	Country	Study Design	Sample size and population studied	Significant Factor	Relevant Findings
Matshazi, 2018[94]**	South Africa	Postmortem descriptive study (cross-sectional)	183 deceased infants aged less than 1 year admitted as SUID cases to Tygerberg Medico-Legal Mortuary	Respiratory viruses in SUID cases	PCR positive Human Rhinovirus A/B/C in 65 (35.5%), Adenovirus in 18 (12.6%), Parainfluenza 3 in 10 (6.0%), Enterovirus in 9 (4.9%) and RSV B in 7 (3.8%) cases SIDS diagnosed in 48.3% (57/118)

HCoV=Human Coronavirus; HRV=Human RhinoVirus; EV=Enterovirus;
 CMV=Cytomegalovirus; RSV=Respiratory Syncytial Virus; B19=Parvovirus B19;
 HMPV=Human Metapneumovirus; PIV3=Parainfluenza virus type 3;
 IHC=Immunohistochemistry; PCR=Polymerase Chain Reaction

**Thesis/Dissertation study

5. Genetic risk factors:

Multiple SIDS deaths in one family may suggest a genetic link in the etiology of SIDS. Five studies, all from South Africa, explored the role of genetic risk factors in SIDS/SUID cases. The earliest study is a case report in 1983 which found genetic factors to be the likely cause of death in one case of three sudden infant deaths in the same family.[101] Recently, one medium quality study found that 12.8% of mothers of SUID cases had a previous history of SUID.[88] (**Table 4**) Pathogenic/probably pathogenic genetic variants were detected in two of these studies. One medium quality study detected pathogenic/probably pathogenic genetic variants in 20.8% of the SUID cases studied.[102] The SCN5A variant which is associated with the long QT syndrome was detected in 6.25% of cases.[102] Another case report detected a pathogenic variant in the SCN10A gene, a gene associated with Brugada syndrome, in a three-month-old male infant who had died of SUID.[103] Other genes and anatomic abnormalities identified in these African studies included

GALT:c.404c>G, a gene associated with galactosemia,[104] and left ventricular hypertrabeculation (an anatomic defect that can lead to fatal arrhythmias).[105] (**Table 6**) These studies confirm the need for more detailed investigations to fully identify the cause of death in SIDS/SUID cases. They also highlight that these lesser-known risk factors of SIDS are likely present in Africa.

Table 6: Characteristics and findings of studies that assessed the role of genetics in SIDS/SUID deaths

Study, Year	Country	Study Design	Sample size and population studied	Significant Factor	Relevant Findings
Van Ieperen, 1983[101]	South Africa	Case report study	3 male siblings aged 6, 3, and 7 weeks who died suddenly and unexpectedly at home during sleep	Genetic etiology: Sibling history	Postmortem findings showed possible genetic abnormality in second case and rapid hypoxia probably caused by smothering in third case. First case was ruled as a natural death since no postmortem was performed
Ker, 2010[105]	South Africa	Case report study	1 deceased male infant aged 3 months who presented with SIDS	Genetic etiology: Cardiac disorders – Left ventricular hyper trabeculation	Postmortem findings concluded that death was due to fatal arrhythmia from left ventricular Hyper trabeculation (Postmortem revealed numerous apical trabeculations of left ventricle)
vanDeventer, 2018[102]	South Africa	Retro-spective case audit (genetic study)	48 FFPE tissue samples from SUID cases, 10 control FFPE samples from deceased infants with known cause of death and 9 blood samples from healthy volunteers	Genetic etiology: SCN5A	Pathogenic/probably pathogenic genetic variants detected in 10 cases (20.8%) SCN5A variants associated with LQTS was detected in 6.2% of cases (3/48)

Study, Year	Country	Study Design	Sample size and population studied	Significant Factor	Relevant Findings
Heathfield, 2019[103]	South Africa	Case report study	1 deceased male infant* aged 2 months admitted as SUID	Genetic etiology: SCN10A	Rare putatively pathogenic variant was found in SCN10A gene (Infant was homozygous for this rare variant) [SCN10A is linked to Brugada syndrome]
Heathfield, 2020[104]	South Africa	Case report study	1 deceased female infant* aged 3 months	Genetic etiology: GALT: c.404C>G	Genetic testing found that infant was homozygous for GALT: c.404C>G (Estimated prevalence: 1 infant out of 102 black African SUID cases)

FFPE=Formalin Fixed, Paraffin-embedded (FFPE); SCN5A= Sodium Voltage-Gated Channel Alpha Subunit 5; SCN10A=Sodium Voltage-Gated Channel Alpha Subunit 10; LQTS=Long QT Syndrome; GALT= Galactose-1-Phosphate Uridylyl transferase.

* Infant was of African ancestry

3.5.7 Burden of SIDS/SUID:

Eleven studies explored the burden of SIDS/SUID in Africa. These studies provided very wide-ranging rates of SIDS in Africa, from an implausibly low rate of 0.2 per 1,000 live births as reported from a study in Zimbabwe[106] to a high of 3.89 per 1,000 live births in South Africa.[107] The Zimbabwean study estimated a SIDS prevalence rate of 0.2 per 1,000 live births in the general population. However, we rated their statistical analyses to have a high risk of bias since the denominator for the population at risk was not the same from which the infants with apparent SIDS were sampled. In addition, one study from Niger reported a SIDS prevalence rate of 2.5 per 1,000 live births in healthy infants and 40 per 1,000 live births in infants with sickle cell disease.[108] We also rated this study as low quality since there was a high risk of bias in the statistical analysis.

The South African studies provide relatively stronger estimates of the SIDS prevalence rate in the general population. The earliest estimate of SIDS prevalence in South Africa was in 1989 when one medium-quality study reported a SIDS prevalence rate of 3.01 per 1,000 live births.[107] Recently, one high-quality prospective cohort study reported an unadjusted risk of SIDS in a cohort of infants in Cape Town as 3.7 per 1,000 live births.[95] Among deceased infants, SIDS accounted for between 2.5% to 21% of infant deaths in South Africa.[90,109–111] However, very few studies outside of South Africa provided estimates on the proportion of infant deaths due to SIDS. One medium quality study from Zambia estimated that 11.3% of infant deaths were due to suspected SIDS.[64] Collectively these studies suggest that SIDS probably accounts for a larger share of infant deaths in Africa than has generally been appreciated (**Table 7**).

Table 7: Characteristics and findings of studies on the burden of SIDS

Study, Year	Country	Study Design	Sample size and population studied	Significant Factor	Relevant Findings
Vix, 1987[108]	Niger	Cross-sectional study	400 mothers of infants at well-baby clinics	SIDS	SIDS prevalence per 1000 live births: 2.5 in healthy infants 40 in sickle cell infants
Molteno, 1989[107]	South Africa	Case-control study	299 children aged 1 month to 5 years (199 cases and 100 healthy controls)	SIDS, Other causes of early childhood death: deaths determined at birth and deaths from accidents and acquired disease	SIDS incidence per 1000 live births: 3.89 overall, 3.05 if obvious cause of death is removed at autopsy (White 1.05 and colored 3.41)
Wolf, 1996[106]	Zimbabwe	Postmortem prospective descriptive study	180 deceased infants aged 1 month to 1 year who died at home	SIDS	SIDS incidence per 1000 live births: 0.20 (95% CI: 0.004 – 0.4)

Study, Year	Country	Study Design	Sample size and population studied	Significant Factor	Relevant Findings
					[4 cases out of 18,889 live births]
Kahn, 1999[112]	South Africa	Cross-sectional study (Demographic and health surveillance)	216 children under 5 years	SIDS	2 SIDS deaths (Number of infants aged <1 year is unclear)
Moyo, 2007[113]	South Africa	Prospective cohort study	11,677 children enrolled in a Tuberculosis vaccine field trial	SUID	SUID prevalence per 1000 live births: 1.03 per 1000 SUID prevalence among deceased infants 8.2% (12/146)
duToit-Prinsloo, 2011[90]	South Africa	Retrospective case audit	813 deceased infants younger than 1 year of age that were admitted to the medico-legal mortuaries of Pretoria and Tygerberg	SIDS	SIDS prevalence among deceased infants 21.0% (171/813)
duToit-Prinsloo, 2013[109]	South Africa	Retrospective case audit	2583 deceased infants younger than 1 year of age that were admitted to 5 academic medico-legal centers across 4 provinces in South Africa	SUID	SIDS prevalence among deceased infants 8.7% (224/2583)
Reid, 2016[110]	South Africa	Retrospective case audit	700 deceased children aged less than 5 years in the Metro West geographical area of the Western Cape Province in South Africa	Under-5 Mortality	SIDS prevalence among deceased infants 2.5% (14/564)
Dempers, 2016[111]	South Africa	Case Series	18 deceased infants admitted as SUID cases	SIDS	SIDS prevalence among deceased infants 38% (7/18) based on 1990 NICHD schema

Study, Year	Country	Study Design	Sample size and population studied	Significant Factor	Relevant Findings
Abdallah, 2018[92]	Uganda	Prospective cohort study	164 preterm infants with birth weight less than or equal to 1500g	Cause of mortality in Preterm infants	Suspected cot death 4.9% (8/164) (SIDS prevalence among deceased infants 25.0% (8/32))
Elliott, 2020[95]	South Africa	Prospective cohort study	10,088 pregnant women in two residential areas within Cape Town South Africa and five areas in the United States. 6240 infants from the South African Site	SIDS	SIDS incidence per 1000 live births: 3.70 per 1000 live births (unadjusted) Adjusted relative risk of SIDS: Alcohol 2.59 (95%CI:1.14–5.90, p=0.024) Smoking 3.84 (95%CI:1.42–10.42, p=0.008) (Continuous/quit late vs None/quit early)
Lapidot, 2021[64]	Zambia	Postmortem prospective descriptive study	230 deceased infants aged 4 days to 6 months	SUID	SUID prevalence among deceased infants 11.3% (26/230)

3.5.8 Diagnostic challenges

Ultimately, SIDS is a diagnosis of exclusion and can only be diagnosed when other causes of death have been ruled out following death scene and detailed post-mortem investigations. Most countries in Africa lack the resources to conduct a proper SIDS investigation. Even South Africa, which is sort of a pioneer in SIDS investigations, lags other well-developed economies. One medium-quality study from South Africa reported on the inadequacy of death scene investigation in SUID cases in South Africa. They noted

that only 59.2% of SUID cases had a complete death scene investigation.[114] Moreover, distinguishing between SIDS and suffocation deaths due to an unsafe sleep environment can be challenging. This challenge is emphasized when one considers that infants who may have a genetic predisposition to SIDS may only experience SIDS in the setting of an additional proximal factor, such as sleep position, bedding composition, or swaddling practices. Study authors in another medium quality study incorporated asphyxia in a new classification schema for SUID cases. They found that this classification schema performed well in assigning the cause of death compared to the standard classification schema.[115]

Table 8: Characteristics and findings of studies on SIDS diagnostic challenges in Africa

Study, Year	Country	Study Design	Sample size and population studied	Significant Factor	Relevant Findings
Belonje, 1996[97]	South Africa	Case-control study	84 infants aged less than 1 year (50 SIDS cases and 34 controls who died of other causes)	Hypoxanthine and Urate as biomarkers of SIDS	No difference in hypoxanthine concentration between SIDS victims and other causes of death (p-value of difference in mean concentration of Hypoxanthine at 1, 2, 3, 4 and 5 postmortem interval days is 0.862, 0.014, 0.331, 0.424 and 0.508 respectively)
Randall, 2009[115]	South Africa	Case series study	10 deceased infants, median age 2 months admitted as SUID cases	Classification Schema	SIDS was diagnosed in 6 infants using standard classification schema compared to 2 infants using new classification schema
Bennett, 2019[114]	South Africa	Retrospective case audit	454 deceased infants admitted as SUID cases	Death scene investigation practices	Proportion of SUID cases with death scene investigation 59.2% Proportion of infant deaths due to SUID 6.6% (454/6922)

3.6 Discussion

Our main conclusions are that, with the singular exception of studies from South Africa, there is a paucity of information about the risk factors for or burden of SIDS in Africa. And yet there is no reason to believe that SIDS would not be a major cause of infant mortality in Africa as it has proven to be wherever else SIDS has been studied. In support of this argument, our review found a high burden of SIDS/SUID and high rates of known risk factors of SIDS in Africa. The rates of the prone and side sleeping positions in this review are much higher than the rates reported from other countries such as the US and the UK. In the UK, the prone sleeping position has remained relatively stable at a rate of 23% to 24% in recent years.[116] In the US, 7.8% of mothers reported placing their infants to sleep in the prone position in a study of 3297 mothers.[117] Additionally, the CDC reported that 21.9% of mothers placed their infants to sleep in a non-supine position in 2015.[118] In Brazil, findings from the 2015 Pelotas Birth Cohort study estimated that less than 2% of mothers placed their infants in the prone sleeping position.[119] The American Academy of Pediatrics (AAP) recommends that infants be placed in the supine position to sleep. The AAP further recommends that infants do not share the same sleep surface with their caregivers.[52] It is worrying that very few infants are placed in the recommended supine/back position to sleep in this review. The reported rates of 2.7% to 21.5% are much lower than the rates reported elsewhere (77% in the US).[117] Moreover, the rates of bed-sharing of 60% to 91.8% in this review are also much higher than the rates reported from the US and Australia. In the US, it is estimated that 20.7% to 24.4% of mothers reported bed-sharing with their infants.[118,120] In Australia, a study by Cunningham et al.

revealed a 44.7% bed-sharing rate among 2745 mothers in Victoria.[121] Since bed-sharing and prone or side sleeping appear to be highly prevalent in the African studies in our review, there appears to be a significant unexplored opportunity to reduce infant mortality in these settings.

Previous studies have established prematurity as a risk factor of SIDS.[122–124] Findings from this review suggest a high risk of SIDS for preterm infants in Africa. Almost half of the SUID cases in South Africa were preterm. Moreover, SIDS was the leading cause of death among a cohort of preterm infants in Uganda. These findings are consistent with results from developed countries. Malloy in 2013 showed that despite the decline in SIDS rates among term infants, the risk of SIDS among the preterm remained high.[124] We also found high rates of maternal smoking and alcohol use among mothers of infants with SUID in South Africa. For instance, almost half of the SUID cases in South Africa were exposed to tobacco smoke either through the mother or another person in the household, and more than a quarter of these mothers reported using alcohol.[88] The reported rates of tobacco smoke exposure to infants in this review are also higher than the rates reported elsewhere. Using linked birth and infant death data from 2007 to 2011, one large study in the US reported that 8.9% of mothers smoked during pregnancy[40] compared to the 10.2% found in this review.[85]

Infectious agents and genetic factors have been suggested as likely causes in the pathogenesis of SIDS. There is evidence to suggest that viral agents play a role in the pathogenesis of SIDS either directly or indirectly through interactions with bacteria.[125] Previous studies have suggested that 80% of SIDS cases report a mild upper respiratory

tract infection in the days prior to death.[125,126] Respiratory viruses were detected in nearly half of the SIDS/SUID cases in this review, lending credence to the possible role of respiratory viruses in the pathogenesis of SIDS. In addition, genetic testing detected pathogenic/probably pathogenic genetic variants in nearly 21% of SUID cases in one included study and a pathogenic variant of the SCN5A gene in 6.25% of SIDS cases in another included study in this review. Our findings are consistent with prior research by Weese-Mayer et al. who estimated that between 5% to 10% of SIDS cases had novel mutations in the SCN5A gene leading to the long QT syndrome.[127] Given the low rates of genetic testing in Africa, these causes of infant mortality are likely going undetected. Whether this represents another opportunity to reduce infant mortality in Africa is very unclear, however. Prospective screening has failed to be effective in high-income settings, making it hard to argue for operationalizing this ineffective strategy in a low-resource setting.

Findings from this review also indicate that Africa likely has some of the highest rates of SIDS in the world. Relying on methodological quality, the most recent estimate from South Africa indicates a SIDS rate of 3.7 per 1,000 live births.[95] This rate is significantly higher than current estimates from the UK (0.3 per 1,000 live births)[116], US (0.3 per 1,000)[128], Australia (SUID rate 0.5 per 1,000), Germany (0.53 SUID rate per 1,000) and Japan (0.6 SUID rate per 1,000).[13] Given the high rates of prone/lateral sleeping position and bed-sharing in this review, more studies conducted outside of South Africa may find the SIDS burden across Africa is actually even higher.

Strengths and limitations:

The main strength of this review is that this is the first systematic review on SIDS in Africa. To our knowledge, no other review has been conducted on SIDS/SUID using studies from Africa. Our study is not without limitations. The majority of the included studies were conducted in South Africa which may affect the generalizability of our findings to the entire continent. However, most of the South African studies were conducted on predominantly Black or bi-racial populations and thus results can be extrapolated to other similar populations on the continent.

3.7 Conclusion

National campaigns to promote a safe sleep environment are lacking in Africa. The “back to sleep” campaign in the UK for instance led to a 40% decline in the SIDS rate in the first year alone.[116] Similar declines were noted in the U.S. following the implementation of safe sleep campaigns.[129] These campaigns target some of the major risk factors of SIDS, such as prone sleeping and bed-sharing[116], and would be worthwhile in Africa to tackle the high infant mortality rates. However, the paucity of high-quality studies outside of South Africa limits our ability to make recommendations for such campaigns. Future research should focus on prospectively estimating the prevalence of SIDS in countries other than South Africa.

CHAPTER 4: ESTIMATING THE BURDEN OF SIDS/SUID IN ZAMBIA

4.1 Chapter overview

This chapter presents results of the analysis of verbal autopsy data from ZPRIME (Zambia Pertussis/RSV infant Mortality Estimation project). The aim of this analysis was to estimate the proportion of decedents aged 4 days to 6 months who died of SUID (Sudden unexpected infant death). SUID infants were defined as infants who were previously well with no admissions in the week prior to death and who were found dead in bed.

4.2 Introduction

Child mortality rates in sub-Saharan Africa are particularly high. In 2019, more than half of the global under-5 mortalities occurred in sub-Saharan Africa.[130] Nearly 1 child in 13 dies before reaching the age of 5 in sub-Saharan Africa.[130] The risk of dying before the age of 5 is almost 20 times higher in sub-Saharan Africa compared to countries in other WHO regions.[130] Sadly, most of these deaths are preventable.

Zambia like other countries in Africa is similarly burdened by high rates of child mortality. In 2018, the under-5 mortality rate in Zambia was estimated to be 61 per 1000 live births, nearly 2 times the global under-5 mortality rate.[65] 69% of the country's child mortality occurred in children under 1 year of age.[65] The infant mortality rate was almost four times the global infant mortality rate (42 vs 11 per 1000 live births).[65] While infectious diseases such as pneumonia, and malaria are recognized as leading causes of child mortality in Zambia, the contribution of sleep related conditions such as sudden unexpected infant death (SUID) to child mortality is less well documented.

SUID includes sudden infant death syndrome (SIDS) and accidental suffocation and

strangulation in bed (ASSB). SIDS is a leading cause of infant mortality in high income countries including the United States (U.S.) and is defined as the sudden unexpected death of an infant less than 1 year of age which cause of death remains unexplained even after an autopsy and death scene investigation, and which event occurred after a sleep episode.[14] The absence of data on the burden of SUIDS in Zambia does not mean it does not contribute to infant mortality.

Most of our knowledge on SIDS in Africa comes from South Africa. Mortality due to SIDS in South Africa is particularly high compared to high-income countries such as the U.S, Australia and the U.K, with estimated rates of between 3.05 to 3.70 per 1000 live births.[95,107] South Africa is an outlier on the continent with relatively better socio-economic conditions compared to other countries in sub-Saharan Africa including Zambia. The risk factors of SIDS include young maternal age, being black, poor maternal education and poor socio-economic status, risk factors which are prevalent in Zambia. Interventions to prevent SIDS are low cost, however without any estimates on the burden of disease in Zambia, a recommendation cannot be made for the implementation of such interventions. Zambia has made tremendous progress in reducing its infant mortality rates from 107 in 1992 to 42 in 2018.[65] To sustain this progress, the contribution of less well documented causes of infant mortality such as SUIDs need to be investigated.

4.3 Study objective

The objective of this study was to estimate the burden of SUIDs in a representative sub-Saharan African country such as Zambia using free text narratives from a modified verbal autopsy tool. To guide this study, our research question was:

1. What proportion of decedent infants died suddenly and unexpectedly during sleep in Lusaka, Zambia?

4.4 Methods

This section describes the study setting, study population, data collection procedures and statistical analysis plans.

4.4.1 Study setting

Data collection for this study occurred in Lusaka, the capital city of Zambia. Lusaka has a predominantly urban population (84%) of 1.7 million.[66] It is surrounded by unofficial peri-urban compounds/towns where most of the city's poor reside bringing the total population of Lusaka to approximately 2.4 million individuals, or roughly 1/8th of the total population of Zambia itself.[66] A dozen primary health facilities provide health care to the population with the University Teaching Hospital (UTH) serving as the main referral facility.[64] UTH is the largest hospital in Zambia with 1655 beds and serves as the main training institution for doctors, nurses and other clinical officers.[67,68]

Data was collected as part of the Zambian Pertussis/RSV Infant Mortality Estimation (ZPRIME) project. The ZPRIME project, a Bill and Melinda Gates sponsored project, was a post-mortem prevalence study designed to identify the proportion of deaths aged 4 days to less than 6 months that were attributable to *Bordetella pertussis* and Respiratory Syncytial Virus (RSV) in Lusaka, Zambia.[66] ZPRIME enrolled deceased subjects aged 4 days to less than 6 months who died in UTH or in the community and presented at the UTH morgue.[66] Ethical approval for ZPRIME was provided by the institutional review board of the University of Zambia (UNZA) and Boston University.

4.4.2 Study population

For this present study, we focus on infant deaths that occurred in the community. Verbal autopsies (VA) were conducted with families and/or caregivers of 809 decedents aged 4 days to 6 months who presented at the University Teaching Hospital Morgue (UTH) as BIDs (Brought in dead).

An infant was eligible for a verbal autopsy if the infant had died

- before arrival at a health facility or
- during receipt of outpatient care at a health facility[64] or
- during referral to a higher level of care without admission at a health facility[64]

4.4.3 Data collection

Data collectors trained in grief counselling conducted verbal autopsies with families of eligible infants using an abbreviated verbal autopsy tool with close ended questions about the symptoms immediately preceding the infant's death. An open response narrative question encouraged respondents to describe in as much detail as possible, the circumstances leading to the infant's death. The open response field was prompted by the question "Now, using your own words, please describe the events leading up to your child's death. Please take as much time as you need and be as detailed as you can." [64] The VA tool modified for use in this study was the IHME-modified version of the verbal autopsy tool created and validated by the Population Health Medical Research Council (PHMRC).[66]

Data collectors were notified if an eligible BID decedent presented at the UTH Morgue. Informed consent was sought from respondents and those who gave consent were

interviewed. In addition to the VA tool, demographic information such as maternal and paternal education, occupation, and household census was collected. We also collected data on the closest clinic where the infant usually received care as a proxy for residential location. In total, 809 verbal autopsies (VAs) were conducted between August 2017 and August 2020 as part of ZPRIME.

4.4.4 Coding and statistical analysis

To estimate the proportion of infants who died suddenly and unexpectedly, we focused our analysis on the open response narrative in the VA tool. We did this in two steps. Firstly, we qualitatively coded the free text narratives in excel and classified the responses into symptomatic and asymptomatic (suspected SUIDs) deaths based on reports of danger signs of ill health within the week immediately preceding death. Any narrative with reports of fever, difficulty breathing, cough, hospital admissions or other symptoms within the week immediately preceding death were classified as symptomatic deaths and assigned a score of 0. Any narrative that described an infant who was otherwise healthy with no antecedent illness prior to death or reported to have no symptoms or hospital admissions in the week prior to death and reported to be found dead in bed after a sleep episode, were classified as asymptomatic deaths or suspected SUID and assigned a score of 1.

We further classified the asymptomatic deaths into unexplained (possible SIDS) and explained deaths (possible suffocation/smothering (ASSB)). A SUID death was explained if the narrative suggested suffocation or smothering as the likely cause of death based on:

- finding of blood or vomitus/milk from the nose/mouth after bed sharing with parents with or without a compressed abdomen

- descriptions of mothers or fathers rolling on the baby after a night of drinking or
- finding of baby in a prone position with a cloth in the mouth or muffled by blankets

In the second step, the coded data was then uploaded into SAS and quantitatively analyzed. We calculated frequencies and percentages for dichotomous and categorical data and estimated mean and standard deviation for continuous data. We used logistic regression for univariate and multivariate analysis to test statistical differences between symptomatic and asymptomatic deaths on key infant, maternal and other demographic risk factors of SUIDs. All statistical analysis were conducted at a 0.05 significance level. We calculated odds ratios (OR), and 95% confidence intervals (95% CI) to show statistical differences in univariate and multivariate analysis. Included are sample narratives for SUID cases to show our coding decisions.

4.5 Results

Results of the analysis of verbal autopsy data are presented below in this section. Sample narratives are included in this section to show coding decisions during analysis.

4.5.1 Population characteristics

There were slightly more females than males in the sample (44% vs 43.8%). Most of the SUIDs occurred in infants younger than 2 months old with a mean age of 2.3 months (std= 1.7 months). Majority had normal birth weight⁶ (mean=2,629 kg, std=643 kg) and lived in households with siblings (79.4%, 642/809). The mothers of these infants were mostly unemployed (78.4%, 634/809) and seldom had education beyond secondary school. Only 2.9% (24/809) of mothers reported completing post-secondary school. Educational

⁶ 83% of infants were missing birthweight

attainment for fathers was also low. 6.1% (49/809) of fathers had some or completed post-secondary school. However, majority of the fathers were reported to be self-employed or salaried employees (79.4%, 642/809). Almost all the infants lived with their mother at the time of death (99.4%). Nearly a quarter of infants did not live with both parents with fathers present in 77.1% (624/809) of households. Household sizes tended to be larger with mean of 5.6 persons and standard deviation 2.4 persons. Majority of these households had greater than 4 children in the household (34.2%, 277/809). Demographic characteristics of BIDs are presented in **Table 9**.

Table 9: Population characteristics of BID deaths

Characteristic	<i>N=809</i>
<i>Infant Characteristics</i>	
Age at death in months, mean (std.)	2.3 (1.7)
Birth weight in grams, mean (std.)	2,629 (643)
Birth weight in grams, n (%)	
<1500	10 (1.2%)
1500 – <2500	36 (4.5%)
>=2500	92 (11.4%)
Unknown	671 (82.9%)
Sex, n (%)	
Male	354 (43.8%)
Female	356 (44.0%)
Unknown	99 (12.2%)
<i>Maternal Characteristics</i>	
Mother's Education, n (%)	
None	33 (4.1%)
Some primary/Completed primary	285 (35.2%)
Some secondary/Completed secondary	444 (54.9%)
Some postsecondary/Completed postsecondary	24 (2.9%)
Unknown	23 (2.8%)
Mother's Occupation, n (%)	
Salaried or Self-employed	163 (20.2%)
Unemployed	634 (78.4%)

Characteristic	N=809
Unknown	12 (1.5%)
<i>Paternal Characteristics</i>	
Father's education, n (%)	
None	15 (1.9%)
Some primary/Completed primary	149 (18.4%)
Some secondary/Completed secondary	463 (57.2%)
Some postsecondary/Completed postsecondary	49 (6.1%)
Unknown	133 (16.4%)
Father's Occupation, n (%)	
Salaried/Self-employed	642 (79.4%)
Unemployed	110 (13.6%)
Unknown	57 (7.1%)
<i>Domestic composition</i>	
Household size, mean	5.6 (2.4)
Number of children in household, n (%)	
1	163 (20.2%)
2	202 (24.9%)
3	163 (20.2%)
≥4	277 (34.2%)
Father lives in home, n (%)	624 (77.1%)
Mother lives in home, n (%)	804 (99.4%)
Both parents live together, n (%)	623 (77.0%)
Has siblings, n (%)	642 (79.4%)

4.5.2 Cause of death

Most of the BID infants, 92.6% (749/809), presented with symptoms prior to death with about 7.4% (60/809) presenting with no symptoms or obvious cause of death. We defined these infants as having died from suspected SUIDs. 27% (16/60) of these SUID infants had narratives that were suggestive of accidental suffocation or strangulation in bed (ASSB). We could not explain the cause of death in 73% (44/60) of these SUID infants. 38.2% (309/809) of the BIDs presented with respiratory symptoms and 54.4% (440/809) presented with non-respiratory or other symptoms. The proportions of each cause of death

identified in the narratives are shown in **Table 10**.

Table 10: Narratives assigned to cause of death

Cause of death, n (%)	<i>N=809</i>
Asymptomatic deaths (suspected SUID ^a)	60 (7.4%)
Unexplained (possible SIDS ^b)	44 (5.4%)
Explained (possible suffocation/smothering (ASSB ^c))	16 (2.0%)
Symptomatic deaths	749 (92.6%)
Respiratory causes	309 (38.2%)
Non-respiratory or other causes	440 (54.4%)

^a SUID= Sudden Unexpected Infant Death.

^b SIDS= Sudden Infant Death Syndrome.

^c ASSB= Accidental Suffocation and Strangulation in Bed

Tables 11, and 12 contain verbatim list of representative narratives for possible SIDS and ASSB to show the coding decisions made in distinguishing between these two causes of SUIDS. See **Appendix A** for full list of narratives.

Table 11: Representative narratives documenting asymptomatic deaths (suspected SIDS)

	Narrative	Age at Death, m
1	Informant Father: The infant was born at Bauleni clinic. The baby cried after birth. The baby was fine yesterday nothing appeared to be wrong even as we went to sleep. In the early hours of this morning when we wake up to check on the baby, we discovered yellow fluids coming out from the nose. The baby was NOT breathing and was already dead. We then brought the body to UTH BID section for death certification.	0.26
2	Informant the grandfather, according to the parents of the baby this baby was not ill, the day before it happened the baby was very active and feeding well. The baby slept after feeding, the next time the mother went to check on the baby it was not breathing they called me and narrated what happened we went to the police, and we were asked to do a postmortem to ascertain the cause of death, but this is just a baby let it rest in peace.	0.33
3	According to the grandmother yesterday the baby was fine, active, and feeding well. Just in the night the mother woke up to feed the baby afterwards it slept, next time the mother went to check on the baby, she observed some blood and froth coming out of the nostrils and the mouth tried to shake the baby it was already dead. That is how we went to the police.	2.60
4	We were at the funeral gathering for one of our relatives where we had to spend nights. The child has been well all along at the funeral and didn't show any signs of illness, Fever or cough, and the child was breast feeding very well. I last breast fed the baby at about 05:00 early this morning and after breast feeding the baby, I put him on the mat to sleep while I continued with food preparations for the people at the funeral gathering. After about one hour, I decided to check on the baby where I had left him sleeping and found the baby dead. There was no sign of injury at all.	2.73
5	The child was well yesterday even at bedtime. We went to bed together since we use the same bed me (father), the mother and the child. Without any noticed illness, we noticed the child dead on the bed at about passed midnight. There was no sign of injury noticed either. It was just sudden death Without any illness.	4.7
6	The aunt stated that, "the mother left the baby sleeping in bed. Healthy baby. She went to attend to some household errands. When she went to the bedroom, she observed the baby was not breathing. Took the baby to the clinic where the baby was confirmed to be dead.	5.91

Table 12: Representative narratives documenting suspected ASSB (Accidental suffocation and Strangulation in Bed)

Obs.	Narrative	Age at Death, m
1	<p>.....The baby was very well all along. Yesterday Thursday..., around 15:00 hours, the mother breastfed the baby there after the baby slept and she put her on the bed. The mother went to continue with her household errands. After 1 hour, she went to check on the baby only to note that the baby was lying in prone position muffled by the blanket. She turned the baby in supine position. She suddenly noticed that thick mucus mixed with blood were coming from the Nostrils. The baby was not breathing. She summoned the husband who tried to arouse the baby but to no avail. The couple rushed the baby to the Clinic, unfortunately could not make it. The Doctor informed the couple that the baby was brought in already dead.</p>	1.02
2	<p>The child was not known to be sick, was well, breast feeding well. We went to bed in the evening with the child well. We use the same bed the three of us (mother, father, and baby). When we woke up at night to check on the baby and have the baby breast fed by the mother, we noticed the child bleeding from the nose and mouth. We don't know for how long the child had been bleeding. She was born at 8 months of pregnancy and did not cry soon after birth. The child died at home before we could start off to the clinic.</p>	1.25
3	<p>Baby was fine the past days and also before we went to bed. At night she cried but thought it was normal cry. Around 04 in the morning noticed baby had cloth in the mouth and we went to report to the Police.</p>	5.19
4	<p>What I (grandmother) can say is that the child was not sick as such, it was the mother who was drunk who forgot that she was with a baby on the same bed and rolled over the baby. Yesterday, in celebration of Christmas, the mother decided to go for a drink with friends, but I (grandmother) got the baby from her. But when she came back from drinking, she got the baby in order to breast feed him. Then she went to her home since it was late in the evenings. Knowing that she was drunk last evening and that she has a baby, I decided to check on her in the morning. I found her crying with the baby on the bed. The child was dead with vomitus and blood from the mouth and nose. The abdomen looked compressed. And from that I knew that she rolled over the baby at night.</p>	5.72

4.5.3 Population characteristics of asymptomatic and symptomatic cases

More than half, 51.7% (31/60) of the suspected SUID cases were female with a mean age of 2.1 months (*std*=1.6 months). Majority lived in households with a sibling, 80% (48/60). Educational attainment of SUID mothers was seldom beyond secondary school. Only 1.7% (1/60) was reported to have completed post-secondary school. Most of these mothers were also unemployed, 86.7% (52/60), lived in larger households with mean household size of 6.1 persons with more than 4 children in the household (40%, 24/60). All the suspected SUID cases lived with their mother in the household at the time of death with fathers present in 78.3% (47/60) of these households. Nearly 22% (13/60) of mothers were single mothers.

Symptomatic cases were likely to be aged 2.3 months (*std*=1.7 months), male (44.6%, 334/749), and with normal birthweight (mean=2,646 grams, *std*=642 grams). Mothers of symptomatic cases were also likely to have had some or completed secondary education (55.3%, 414/809), and unemployed 77.7% (582/749). Household sizes of symptomatic cases tended to be smaller (mean=5.6, *std*=2.3), and almost always included the mother (99%, 744/749) or father (77%, 577/809). Demographic characteristics of asymptomatic and symptomatic cases are shown in **Table 13**.

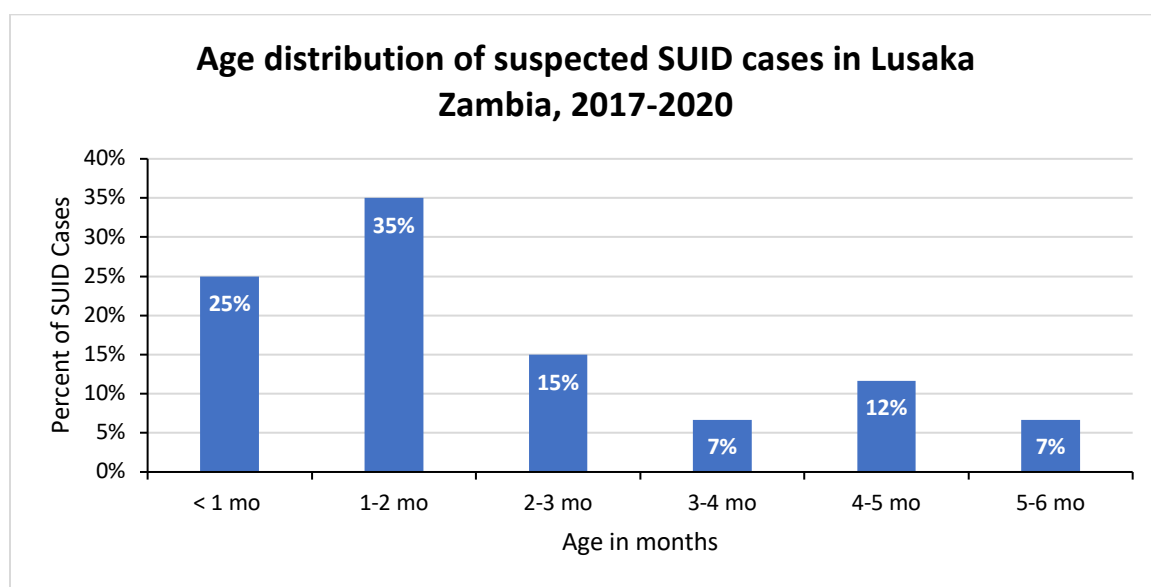
Table 13: Population characteristics of asymptomatic and symptomatic BIDs

Characteristic	<i>Asymptomatic or Suspected SUID</i> N=60	<i>Symptomatic</i> N=749
<i>Infant Characteristics</i>		
Age at death in months, mean (sd.)	2.1 (1.6)	2.3 (1.7)
Birth weight in grams, mean (sd.)	2,461 (647)	2,646 (642)
Birth weight in grams, n (%)		
<1500	1 (1.7%)	9 (1.2%)
1500 – <2500	5 (8.3%)	31 (4.1%)
>=2500	7 (11.7%)	85 (11.3%)
Unknown	47 (78.3%)	624 (83.3%)
Sex, n (%)		
Male	20 (33.3%)	334 (44.6%)
Female	31 (51.7%)	325 (43.4%)
Unknown	9 (15.0%)	99 (12.0%)
Has siblings, n (%)	48 (80.0%)	594 (79.3%)
<i>Maternal Characteristics</i>		
Education, n (%)		
None	1 (1.7%)	32 (4.3%)
Some or completed primary	24 (40.0%)	261 (34.9%)
Some or completed secondary	30 (50.0%)	414 (55.3%)
Some or completed postsecondary	1 (1.7%)	23 (3.1%)
Unknown	4 (6.7%)	19 (2.5%)
Occupation, n (%)		
Salaried or Self-employed	6 (10.0%)	157 (21.0%)
Unemployed	52 (86.7%)	582 (77.7%)
Unknown	2 (3.3%)	10 (1.3%)
<i>Domestic composition</i>		
Household size, mean (sd.)	6.1 (3.4)	5.6 (2.3)
Number of children in household		
1	11 (18.3%)	152 (20.3%)
2	13 (21.7%)	189 (25.2%)
3	11 (18.3%)	152 (20.3%)
≥ 4	24 (40%)	253 (33.8%)
Father lives in home, n (%)	47 (78.3%)	577 (77.0%)
Mother lives in home, n (%)	60 (100.0%)	744 (99.3%)
Both parents live together, n (%)	47 (78.3%)	576 (76.9%)
Single mothers, n (%)	13 (21.7%)	166 (22.2%)

4.5.4 Peak age of SUID cases

Although the mean age of suspected SUID cases was 2.1 months, deaths were concentrated in infants younger than 2 months with a peak age of 1–2 months as shown in figure 1. A quarter, 25% (15/60) of SUID deaths occurred in infants within the first month of life (4 days to less than 1 month).

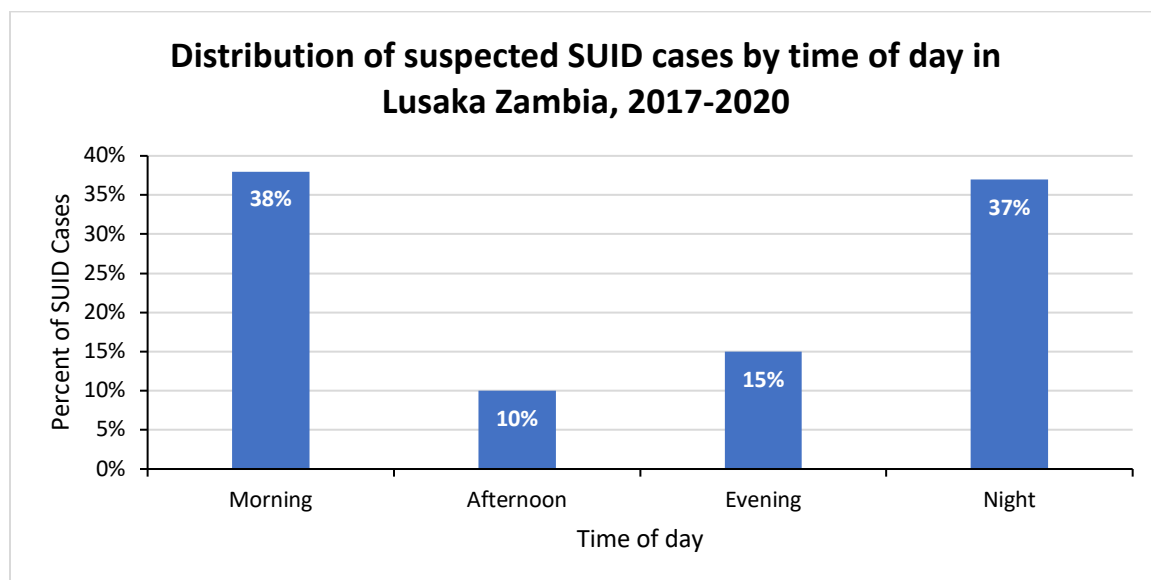
Figure 6: Age distribution of suspected SUID cases



4.5.5 Time of SUID

All the suspected SUID cases occurred during sleep with peak incidence in the night, 37% (22/60), and early morning, 38% (23/60), similar to what has been reported previously in prior studies. Very few occurred in the evening, 15% (9/60) with even fewer in the afternoon, 10% (6/60) as shown in **Figure 7**.

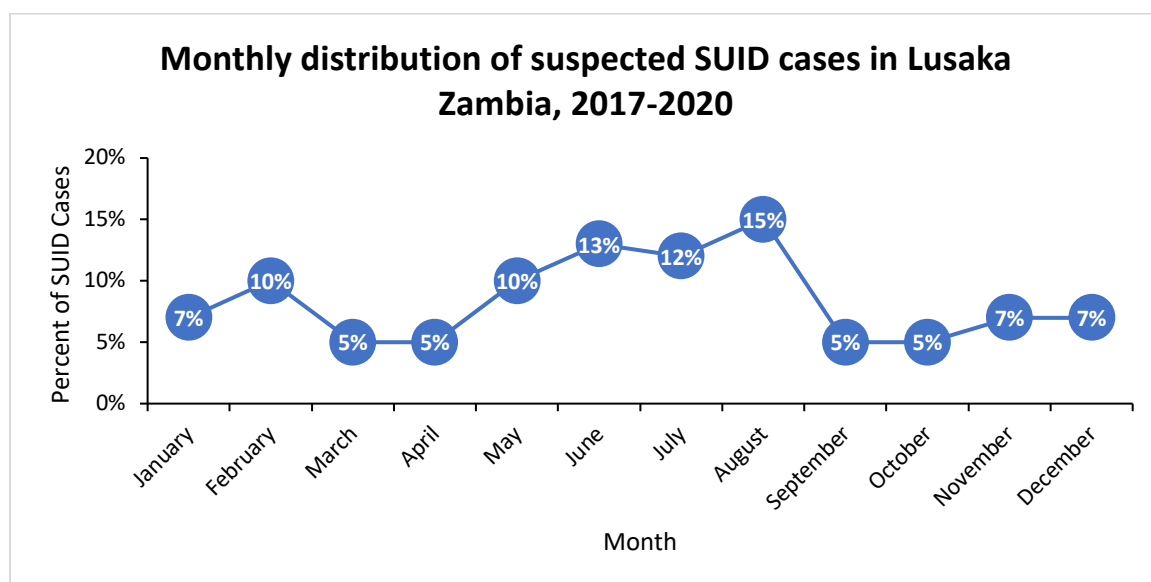
Figure 7: Distribution of suspected SUID cases by time of day



4.5.6 Month and season of SUID

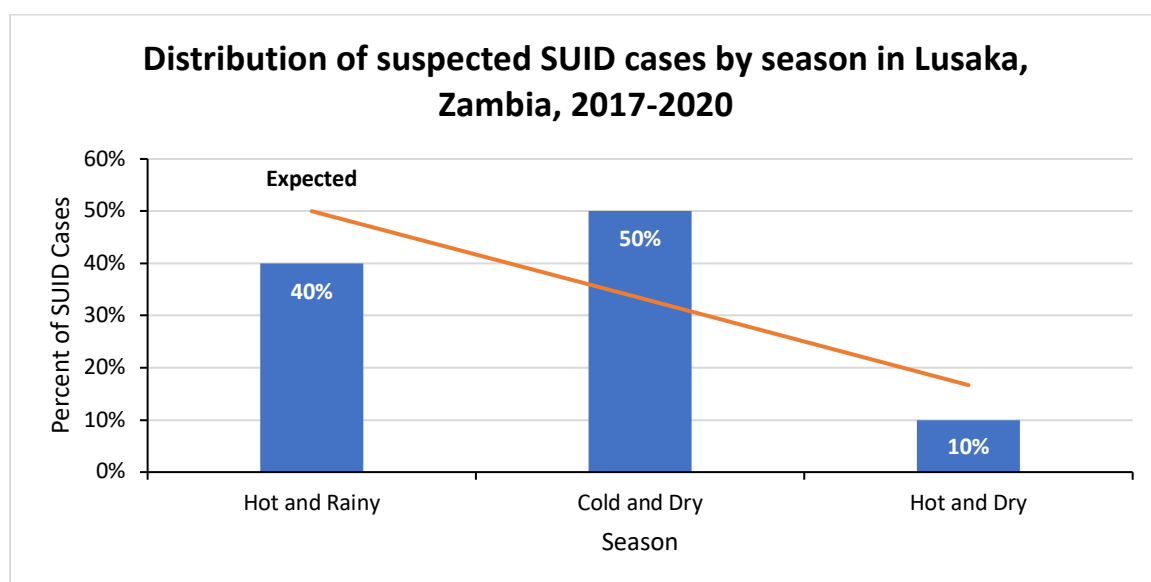
Majority of the suspected SUID cases occurred in the cold months of May, June, July, and August with peak incidence in August, 15% (9/60). (**Figure 8**)

Figure 8: Distribution of suspected SUID cases by month



By season, this corresponds to the cold and dry seasons of Lusaka. Half of the suspected SUID deaths occurred in the cold and dry season with almost 40% (24/60) occurring during the rainy season. Fewer deaths occurred in the hot and dry season of September and October as shown in **Figure 9** below.

Figure 9: Seasonal distribution of suspected SUID cases

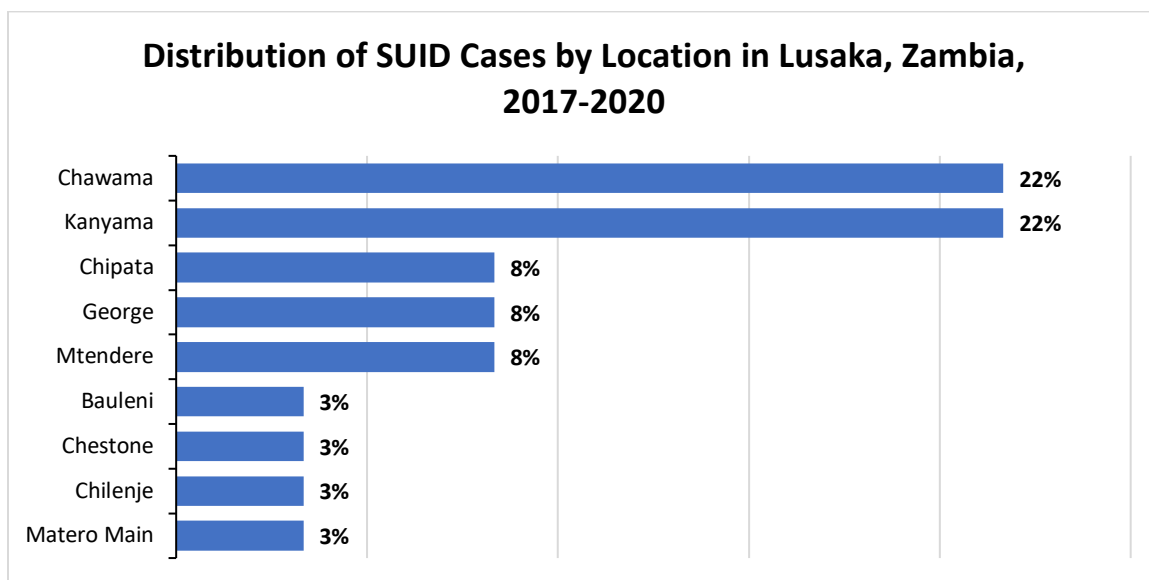


Hot and Rainy: Nov, Dec, Jan, Feb, Mar, Apr; Cold and Dry: May, Jun, Jul, Aug; Hot and Dry: Sept, Oct

4.5.7 Residence of SUID cases

The largest proportion of SUID cases were reported from Chawama (22%, 13/60) and Kanyama (22%, 13/60), followed by Chipata, George, and Mtendere with 5 cases each. These are densely populated informal peri-urban settlements surrounding Lusaka and are considered as low-income areas. Moreover, these are townships with high rates of infant mortality.

Figure 10: Distribution of SUID cases by location



NB: 1 case each was reported from 11 locations, not shown. See appendix for full list of locations

4.5.8 Univariate and multivariate analysis of factors associated with SUID

In univariate analysis, age of death in months and time of death were found to be statistically associated with an asymptomatic presentation. Compared to infants aged less than 1 month, infants aged between 1 to 2 months had 2.6 times increased odds of suspected SUIDs, and this risk was statistically significant (OR: 2.6, 95% CI: 1.31–5.27). The odds of SUID occurring in the night was also 2.64 times higher compared to the afternoon (OR: 2.64 95% CI: 1.04–6.63). There was an increased odds of SUIDs for female infants, mothers with low education or no employment, larger families with four or more children, weekday, and the cold/dry season. However, these were not statistically significant with 95% CI which contained the null value as shown in **Table 14**. In multivariate analysis, infants aged between 1–2 months had 2.93 increased odds of suspected SUIDs compared to infants in the first month of life (OR: 2.93, 95% CI: 1.36, 6.33). Unemployed mothers

also had 2.49 increased odds of suspected SUID compared to salaried or self-employed mothers (OR: 2.49, 95% CI:1.02, 6.08)

Table 14: Univariate and multivariate odds ratios (95% Confidence Interval) of factors associated with SUIDs

Characteristic	Univariate OR (95% CI)	Multivariate OR (95% CI)
Infant Characteristics		
Age in months		
<1	1.00	1.00
1–2	2.63 (1.31, 5.27)	2.93 (1.36, 6.33)
2–3	1.23 (0.52, 2.89)	1.29 (0.52, 3.21)
3–4	0.68 (0.22, 2.11)	0.82 (0.25, 2.67)
4–5	1.45 (0.57, 3.69)	1.76 (0.66, 4.70)
5–6	0.85 (0.28, 2.64)	0.66 (0.18, 2.46)
Sex/Gender		
Male	1.00	1.00
Female	1.59 (0.89, 2.85)	1.51 (0.80, 2.83)
Unknown	1.67 (0.74, 3.79)	2.03 (0.81, 5.08)
Has siblings		
No	1.00	1.00
Yes	1.12 (0.57, 2.22)	1.00 (0.45, 2.19)
Maternal Characteristics		
Education		
Secondary/Postsecondary	1.00	1.00
Primary/Never attended school	1.20 (0.70, 2.08)	1.02 (0.57, 1.82)
Occupation		
Employed	1.00	1.00
Unemployed	2.34 (0.99, 5.54)	2.49 (1.02, 6.08)
Domestic composition		
Number of children		
1–3	1.00	1.00
≥4	1.34 (0.78, 2.30)	1.62 (0.86, 3.07)
Father lives in household		
No	1.00	1.00
Yes	1.07 (0.56, 2.02)	1.33 (0.65, 2.71)
Time of day, and Season		
Time of day		
Afternoon	1.00	1.00
Night	2.64 (1.04, 6.63)	2.70 (0.97, 7.51)
Morning	1.92 (0.77, 4.83)	2.06 (0.75, 5.68)
Evening	2.03 (0.70, 5.87)	2.65 (0.84, 8.37)
Season		
Hot and Rainy	1.00	1.00

Characteristic	<i>Univariate OR (95% CI)</i>	<i>Multivariate OR (95% CI)</i>
Cold and Dry	1.60 (0.91, 2.79)	1.67 (0.90, 3.12)
Hot and Dry	0.91 (0.36, 2.29)	1.08 (0.41, 2.83)

4.6 Discussion

Our main finding from this analysis is that sudden unexpected infant death accounts for 7.4% of all BIDS in Lusaka Zambia. Unexplained (possible SIDS) infant deaths accounted for 5.4% of all BIDS in this sample. Our findings are similar to estimates from South Africa, where SIDS/SUID deaths accounted for between 6.2% to 8.7% of all infant deaths in medico legal laboratories.[109,113] These findings suggests that SIDS/SUIDS are an important cause of infant death in Zambia, however it is going unreported.

Our analysis revealed three surprising findings. Firstly, the peak age of SUID in our analysis was 1–2 months. Age at death was the only factor which was significant in multivariate analysis with infants aged 1–2 months at significantly higher odds of SUID compared to infants in the first year of life. Our findings are different from estimates in the U.S and other high-income countries where the peak age of SUID has been reported as 2–4 months.[131] However, our findings are similar to findings by Heathfield et al in South Africa where they reported a peak age of 1–2 months in SUID cases.[88] In addition, we found a quarter of our SUID cases occurred in the first month of life. The triple risk model suggest that SIDS occurs in a vulnerable infant, at a critical period of development in the presence of an exogenous stressor.[29] More than half of the SUID cases occurred in families residing in the densely populated peri-urban townships surrounding Lusaka. We hypothesize that these infants are exposed to exogenous stressors at a much earlier age such as infections compared to infants in high income countries. Moreover, Heathfield et al

hypothesized that infants in overcrowded settlements experience a faster decline in maternal IgG, than infants in high income countries, making them vulnerable to sudden death at an earlier age.[88]

Secondly, more than half of our SUID cases were female (51.7% vs 33.3%). This finding is different from what has been reported elsewhere. Most studies report higher rates of SUIDS in males than females.[33] Although not statistically significant, we found females to be at increased odds of SUID compared to males. However, this finding should be interpreted with caution since 15% of our cases were missing a gender assignment. We also found the same socio-economic risk factors that have been reported previously including higher SUID cases among unemployed mothers, mothers with lower educational attainment, larger families with more than four children, during the cold season, and in the early morning hours when infants are sleeping.[62,132,133] Confirming the presence of some of the risk factors of SIDS in these communities.

Policy implications:

This is the first study to report on the prevalence of SUIDs in Zambia. Our findings suggest SUID could be accounting for a significant proportion of infant deaths, but this cause of infant mortality is going unrecognized. The risk factors of SUIDs are modifiable with simple interventions. We have shown that there is a large enough burden of disease to inform the implementation of specific interventions or programs targeted at reducing sudden infant deaths. A sudden infant death can be stressful to the family especially young mothers. Some of the narratives were heart breaking. A common theme in these narratives was a need to understand what caused the death of their child. The response to SIDS/SUID

has been one of blame and sometimes mothers have been criminalized on suspicion that they intentionally caused the death of their child. We want to shed a light on this important cause of infant mortality and make a case for the implementation of targeted campaigns and programs in Zambia.

Limitations:

Our study is not without limitations. A key limitation of this study is that we relied on VA narratives to assign a cause of death. We did not conduct a death scene investigation or formal autopsy. However, the VA tool we used has been validated and has been shown to be accurate in assigning cause of death. The free text narratives provided enough detail to determine the circumstances surrounding the infant's death. We combined the VA narratives with other symptoms reported in the VA tool to assign a cause of death. Another limitation is that we did not collect any information on other key risk factors of SIDS such as maternal smoking or alcohol use and infant sleep practices.

4.7 Conclusion

This study provides preliminary estimates of the burden of SUID in Lusaka, Zambia and shows that there is a sufficient burden of SUID in Zambia to encourage additional research. Future studies should systematically and prospectively characterize SUID deaths with a complete diagnostic autopsy (or a culturally acceptable autopsy), death scene investigation and review of the clinical history. Such research should be geared towards providing accurate estimates of the true burden of SUID to inform public health policy.

CHAPTER 5: QUANTITATIVE ASSESSMENT OF THE RISK FACTORS OF SIDS IN ZAMBIA

5.1 Chapter overview

This chapter presents results of the quantitative study which aimed to determine the prevalence of the risk factors of SIDS in Zambia. Evidence in support of this study is presented in the introduction. Next, a methods section describes the data collection procedures and statistical analysis conducted. The results section presents key findings of this analysis. Prevalence ratios are reported as measures of association. The chapter concludes with a discussion and synthesis of the main findings.

5.2 Introduction

The most significant risk factors of SIDS (sudden infant death syndrome) are related to the infant's sleeping environment and position. Previous research in high income countries suggest a more than 2 fold increased risk of SIDS with prone sleeping and bed-sharing.[134,135] Public health campaigns which targeted the prone sleeping position such as the "back to sleep" campaign in the U.S. and other countries accounted for the more than 50% decline in SIDS related infant mortalities in the last decade.[136] More significantly, these declines in the SIDS rate were also associated with marked declines in post neonatal mortality in these countries.[21] Based on this, the American Academy of Pediatrics recommends that infants should be placed to sleep on the back and on a separate sleep surface ideally in the same room as the mother. [52]

It is informative that the risk factors for SIDS and other sleep-related infant deaths such as accidental suffocation or strangulation in bed (ASSB) are very similar since it is difficult to distinguish between them.[3] Other risk factors commonly associated with an increased

risk of SIDS include little or no prenatal care, maternal age less than 20 years, prematurity or low birth weight, and maternal smoking.[4,5] There is also a strong association of SIDS with low socioeconomic status, low maternal education, single marital status and being black, risk factors that have been described as “native” to African countries.[6,8]

In Africa and other low to middle income countries, data on an infant’s sleep environment or sleeping position is lacking, except for a few studies from Nigeria [8,85,86] and South Africa.[88,96] In Zambia specifically, at present, little is known regarding the prevalence of these risk factors. To fill this knowledge gap and inform public health policy in Zambia, we conducted cross-sectional surveys with mothers of infants aged less than 1 year in Lusaka, to explore the risk factors of SIDS and other sleep related infant deaths. To our knowledge, this was the first study to assess the risk factors of SIDS in Zambia. For purposes of this dissertation, we will use the term SUID (sudden unexpected infant deaths) to describe SIDS and other sleep related infant deaths.

5.3 Study objective

The primary objective of this study was to determine the prevalence of modifiable risk factors of SIDS and other sleep related infant deaths in Lusaka, Zambia. Our secondary objective was to determine if there are any significant differences in prevalence of these risk factors between peri-urban townships with different socio-economic profiles in Lusaka, Zambia.

5.4 Methods

This section outlines the data collection procedures with details on study sites, sampling and recruitment strategies, sample size considerations and statistical analysis.

5.4.1 Study design and timeline

This was a cross-sectional survey of mothers at two study sites in Lusaka, Zambia. Surveys were administered over 4 weeks between April and May 2021.

5.4.2 Study location/sites

Data collection occurred at postnatal clinics across two study sites in Lusaka, the capital city of Zambia. The two sites were Chilenje and Chawama first level Hospitals in Lusaka. Both are public hospitals managed by the Government of the Republic of Zambia (GRZ).[69] These sites were selected for several reasons. First, both sites are in large urban communities in Lusaka with a high burden of infant mortality. Second, Chilenje general attends to a wealthier and more advantaged population in Lusaka, whereas the Chawama township is one of the most densely populated and economically stressed parts of the city, with very high rates of poverty. Third, and for the same reason, both are sites where Boston University has invested time and resources to develop relationships with local staff that facilitate working in these communities.

Both hospitals offer in-patient and out-patient services with maternal and child health departments that offer daily antenatal, labor and delivery, postnatal, family planning and child health services.[137] Chilenje hospital is a 46-bed hospital which offers care to a reported catchment area of 95,007 in 2012.[69] Chawama is a 30 bed hospital which similarly offers services to a catchment population of 128,858 in 2012.[69] Participants were recruited from within the catchment area of each hospital.

5.4.3 Recruitment and sampling

Surveys targeted mother-baby pairs at each study site. Through a non-probability convenience sampling method, designated nurses at each study site identified mothers who met the inclusion criteria for participation in the study. Eligible participants were aged 18 to 49 years, nursing an infant aged under 1 year of age, resident within the catchment area of each study hospital and able to give either verbal or written consent for participation in the study.

Participants who opted to participate in the study (which was nearly all the mothers we approached) were referred to study data collectors at each study site to complete study enrollment procedures. At enrollment, study staff verbally outlined the consent process and discussed with each participant the purpose of the study, all procedures, the risks, and benefits, as well as the voluntary nature of participation. Questions and concerns were encouraged. Written informed consent was obtained from all participants. Study staff assisted illiterate mothers by verbally reading through the consent form to obtain permission. Consent forms were provided in both English and Nyanja, the local language.

5.4.4 Data collection

A pretested 64-item questionnaire was administered to each study participant at the clinic on mobile devices through an online survey software, Qualtrics (<https://www.qualtrics.com>). The questionnaire was adapted from the U.S Center for Disease Control and Prevention's sudden unexpected infant death investigation reporting form (SUIDIRF)[138], and the 2018 demographic and health survey of Zambia.[65] These are publicly available validated data collection instruments. Additional questions were

developed by the study team in consultation with a member of the study team, a pediatrician based in Lusaka, Zambia.

Questionnaires were administered on the same day respondents gave consent to reduce non-response. The questionnaire had 8 main sections that collected information on previous family history of sudden infant death, prenatal care attendance, breastfeeding practices, alcohol, or cigarette use during pregnancy, recreational drug use during pregnancy, infant sleeping practices and knowledge and awareness of SIDS.

5.4.5 Variables

Our primary focus was to understand sleeping practices (bed sharing and infant sleep position), since these are understood to be the most important risk factors for SIDS or smothering deaths. Bed sharing was our primary outcome and was defined as routinely sharing a bed with the mother, father, or other relatives (sibling, aunt, grand parent, etc.). Infant sleeping position was classified as on the “tummy/stomach” as prone, “on the back” as supine and “on the side” as lateral. Information on the routine sleeping place for the infant was also noted. Demographic information on maternal age, highest educational attainment, occupation, parity, marital status and the child's sex, age and presence of birth defects were obtained. Survey responses were checked daily for completeness.

5.4.6 Sample size determination

Sample size requirements for this survey were driven by our primary outcome of interest, bed-sharing. A literature search did not yield local prevalence rates of bed-sharing in Zambia. However, a qualitative report by the American Institute of Research (AIR) and UNICEF in 2018 [139] revealed that majority of mothers indicated they sleep with the baby

in the same bed until the babies are at least 2 years old. In addition, a study in South-Eastern Nigeria reported a 67% prevalence rate of infant bed-sharing with adults.[8] Thus, we assumed a 50% prevalence rate of bed-sharing in Zambia and estimated our sample size using the formula: $Z^2 P (1-P)/d^2$ where Z is the statistic corresponding to the level of confidence (Z=1.96 for 95% Confidence Interval), P is the expected prevalence of the outcome and d is the level of precision. Using a 95% confidence level, and 5% level of precision, the required sample size was 384 mother-baby dyads. To account for a 20% non-consent rate, we estimated that we would need to enroll up to 480 participants (240 from each study site).

5.4.7 Statistical analysis

All statistical analyses were conducted in SAS 9.4. Frequencies/proportions, means and standard deviations were calculated as appropriate. Differences in proportions of categorical variables were tested for statistical significance using chi-square test. Log-binomial regression was used to determine demographic factors that are predictive of bed-sharing and the prone sleeping position. We report prevalence ratios (PR) and 95% confidence intervals (95% CI) as our measures of effect. All statistical analysis were conducted at a 0.05 significance level.

5.5 Results

This section summarizes main findings from this study. Characteristics of the study population are presented including key findings on the main risk factors of SIDS.

5.5.1 Population characteristics

We had much higher consent rates than expected, so ultimately, we enrolled 478 mothers with young children. Four mothers withdrew from the study after initially agreeing to participate. We did not collect any data on these mothers. **Table 15** summarizes the demographic features of mothers and their infants, stratified by residence in Chawama or Chilenje compounds. Mothers were on average aged 28 years (*std*=6.1 years). Most were married or cohabiting and had 1–2 children. Roughly half were unemployed or had completed secondary school. There were several notable differences between survey respondents at Chawama compared to Chilenje. Survey respondents at Chawama were slightly younger and were far less likely to have attended post-secondary school (9.6% vs 52.9%). There were more single/divorced/widowed mothers at Chilenje compared to Chawama (26.1% vs 12.9%). In addition, more than half of the mothers in Chilenje were formally employed (57.1%) compared to only a little over a third of mothers in Chawama (37.5%). At a high level, we hypothesize that these differences are likely explained by or are manifestations of the substantial economic gradient that distinguishes the very poor Chawama compound from the far more affluent Chilenje compound.

Table 15: Population characteristics of survey respondents

Characteristic	Total N=478	Study Site	
		Chawama N=240	Chilenje N=238
Maternal Characteristics			
<i>Age, mean (std.)</i>	28.0 (6.1)	26.7 (5.5)	29.4 (6.5)
<i>Age in years, n (%)</i>			
<20	31 (6.5%)	16 (6.7%)	15 (6.3%)
20–29	272 (56.9%)	160 (66.7%)	112 (47.1%)
30–39	153 (32.0%)	59 (24.6%)	94 (39.5%)
>=40	22 (4.6%)	5 (2.1%)	17 (7.1%)
<i>Marital status, n (%)</i>			
Single/Divorced/Widowed	93 (19.5%)	31 (12.9%)	62 (26.1%)
Married/Co-habiting	385 (80.5%)	209 (87.1%)	176 (73.9%)
<i>*Highest Education, n (%)</i>			
Never attended school	6 (1.3%)	5 (2.1%)	1 (0.4%)
Primary	82 (17.2%)	64 (26.7%)	18 (7.6%)
Secondary	240 (50.2%)	148 (61.7%)	92 (38.7%)
Postsecondary	149 (31.2%)	23 (9.6%)	126 (52.9%)
<i>*Occupation, n (%)</i>			
Salaried employee/Self employed	226 (47.3%)	90 (37.5%)	136 (57.1%)
Unemployed	251 (52.5%)	149 (62.1%)	102 (42.9%)
<i>Parity</i>			
1–2	287 (60.0%)	144 (60.0%)	143 (60.1%)
>=3	191 (40.0%)	96 (40.0%)	95 (39.9%)
Infant Characteristics			
<i>Age in months, n (%)</i>			
<2mo	93 (19.5%)	65 (27.1%)	28 (11.8%)
2–4mo	159 (33.3%)	97 (40.4%)	62 (26.1%)
5–7mo	98 (20.5%)	32 (13.3%)	66 (27.7%)
8–10mo	78 (16.3%)	29 (12.1%)	49 (20.6%)
11mo	50 (10.5%)	17 (7.1%)	33 (13.9%)
<i>Gender/Sex, n (%)</i>			
Male	249 (52.1%)	125 (52.1%)	124 (52.1%)
Female	229 (47.9%)	115 (47.9%)	114 (47.9%)

*Maternal education and occupation were unknown for one participant

5.5.2 Awareness of SIDS

A large proportion, 67.6% (323/478) of survey respondents reported that they knew someone or had heard about someone losing an infant suddenly and unexpectedly during sleep, indicating a high level of awareness of sudden unexpected infant deaths. A

significantly larger proportion of respondents indicated that they were familiar with SIDS in Chawama compared to respondents in Chilenje (72.9% vs 62.2%) (PR: 1.16, 95% CI: 1.03, 1.32).

5.5.3 Risk factors intrinsic to the infant

Overall, 7.3% (24/331) of respondents reported previously losing an apparently healthy infant suddenly and unexpectedly during sleep (SUID). The reported rate of suspected SUID appeared higher among twins. 12% (3/25) of mothers with twins reported losing one twin suddenly and unexpectedly during sleep. Birth defects were not common in this population. Only 1.3% (6/478) of mothers reported a history of apparent birth defect in their infant. We assessed prematurity by asking mothers to estimate if the infant was born early compared to their expected delivery date. 19% (91/478) of mothers reported giving birth to the infant early. Related to this, only 9.8% (47/478) of infants were reported to have been born with a birth weight less than 2500g (low birth weight). The risk of a previous history of SUID was not significantly different between mothers who reported giving birth to the infant early or with low birthweight compared to those who did not; (PR: 0.66, 95% CI: 0.20, 2.14) and (PR: 1.74, 95% CI: 0.63, 4.80) respectively.

Participants in Chawama were more likely to report higher rates of these intrinsic risk factors compared to participants in Chilenje. Whereas 8.5% (17/176) of mothers at Chawama reported a previous history of SUID, only 5.8% (9/155) of mothers at Chilenje reported such losses (PR: 1.47, 95% CI: 0.66, 3.26). In addition, while slightly more infants were low birthweight in Chawama than Chilenje (10.8% vs 8.8%), far more infants were reported as premature (born “early”) at Chawama compared to Chilenje (24.2% vs 13.9%)

(PR:1.74, 95% CI: 1.18, 2.57). (Table 16)

Table 16: Prevalence of risk factors intrinsic to the infant

Characteristic	Total		Study Site		
	n/N	Prevalence % (95% CI)	Chawama n/N	Chilenje n/N	PR (95% CI)
Previous history of SUID [^]	24/331	7.3 (4.7, 10.6)	15/176	9/155	1.47(0.66, 3.26)
Twin birth	25/478	5.2 (3.4, 7.7)	13/240	12/238	1.07(0.50, 2.30)
Previous SUID in twins	3/25	12.0 (2.6, 31.2)	2/13	1/12	1.85(0.19, 17.84)
Birth defects	6/478	1.3 (0.5, 2.7)	4/240	2/238	1.98(0.37, 10.68)
Birth weight					
<2500g	47/478	9.8 (7.4, 12.9)	26/240	21/238	1.24(0.72, 2.14)
≥2500	429/478	89.7 (84.1, 90.2)	212/240	217/238	0.98(0.92, 1.04)
Time of delivery					
Early	91/478	19.0 (15.6, 22.9)	58/240	33/238	1.74(1.18, 2.57)
On time or late	387/478	80.9 (77.2, 84.4)	182/240	205/238	0.88(0.81, 0.96)

[^] This was asked of only mothers with more than 1 previous live birth (parity > 1)

5.5.4 Infant sleep practices

There is broad consensus in the literature that co-sleeping with parents and having infants sleep in positions other than on their backs are the most important, proximate, and modifiable risk factors for SIDS. Therefore, our primary interest was understanding the prevalence of these risk factors among the Zambian mothers.

1. Usual sleeping place and bed-sharing/co-sleeping:

Co-sleeping with an infant either on the same bed or in the same room was widely practiced. Nearly all infants were reported to share a sleep surface with an adult or other person, 89.5% (428/478). Conversely, very few infants slept alone in a crib, 5.6% (27/478). There was no difference in the prevalence of bedsharing between participants in Chawama and Chilenje (PR, 0.99, 95% CI: 0.93, 1.05) (Table 17). When asked how often they share

a bed with the baby, most participants, 47% (224/478) reported “always” sleeping with the infant. Bedsharing was also more common at night compared to the daytime (**Supplemental Figure 1**).

2. Sleep position and sleep surface:

Table 4 summarizes infant sleep positions and bedding types across the two cohorts. Overall, putting infants to sleep in the lateral position was clearly preferred over having infants sleep supine or prone. 73.0% (349/478) of participants reported placing their infant to sleep in the lateral position compared to 6.7% (32/478) in the recommended supine position. When asked about the best position to place an infant to sleep and the best place for a baby to sleep, majority indicated that sleeping in the same bed with the mother (60.5%, 289/478) and being placed in the lateral position (70.1%, 335/478) was best. Education on supine positioning from health care/medical personnel was lacking. Only about 24.1% (115/478) of mothers indicated that they had ever been advised by medical personnel to put the infant to sleep on the back. However, most respondents 65.5% (313/478) indicated a willingness to change their sleep practices if educated about safe infant sleep practices.

By study site, significantly more mothers at Chawama (80.0%, 192/240) placed their baby to sleep in the lateral position compared to 66.0% (157/238) at Chilenje (PR: 1.21, 95% CI: 1.09, 1.36)). Interestingly, the prone and supine positions were less frequently used by mothers at Chawama compared to mothers at Chilenje; (PR: 0.66, 95% CI: 0.46, 0.96) and (PR: 0.39, 95% CI: 0.18, 0.82) respectively. The type of mattress babies slept on was also reported to be mostly used (68.6%, 328/478) and soft (41.6%, 199/478) posing a

risk of suffocation or rebreathing of expired gases to the infant.

Table 17: Prevalence of risk factors related to infant sleep practices

Characteristics	Total		Study Site		
	n/N	Prevalence % (95% CI)	Chawama n/N	Chilenje n/N	PR (95% CI)
<i>Infant's usual sleeping place</i>					
Parents bed	445/478	93.1 (90.4, 95.2)	229/240	216/238	1.05 (1.00, 1.10)
Crib or Bassinet	27/478	5.6 (3.8, 8.1)	7/240	20/238	0.35 (0.15, 0.81)
Sofa or Floor	6/478	1.2 (0.5, 2.7)	4/240	2/238	1.98 (0.37, 10.73)
<i>Infant sleeps alone in a separate room</i>	19/478	4.0 (2.4, 6.1)	8/240	11/238	0.72 (0.29, 1.76)
<i>Bedsharing with infant</i>	428/478	89.5 (86.4, 92.1)	214/240	214/238	0.99 (0.93, 1.05)
<i>Usual Position placed to sleep</i>					
Lateral	349/478	73.0 (68.8, 76.9)	192/240	157/238	1.21 (1.09, 1.36)
Supine	32/478	6.7 (4.6, 9.3)	9/240	23/238	0.39 (0.18, 0.82)
Prone	95/478	19.9 (16.4, 23.7)	38/240	57/238	0.66 (0.46, 0.96)
<i>Type of Mattress</i>					
New	143/478	29.9 (25.8, 34.2)	55/240	88/238	0.62 (0.47, 0.83)
Used	328/478	68.6 (64.3, 72.8)	181/240	147/238	1.23 (1.09, 1.38)
<i>Sleep surface</i>					
Soft	199/478	41.6 (37.2, 46.2)	108/240	91/238	1.18 (0.95, 1.46)
Medium	127/478	26.6 (22.7, 30.8)	69/240	58/238	1.18 (0.87, 1.59)
Firm/Hard	118/478	24.7 (20.9, 28.8)	52/240	66/238	0.78 (0.57, 1.07)
<i>Best position to place baby to sleep</i>					
Lateral	335/478	70.1 (65.8, 74.2)	180/240	155/238	1.15 (1.02, 1.30)
Supine	38/478	7.9 (5.7, 10.7)	11/240	27/238	0.40 (0.21, 0.80)
Prone	98/478	20.5 (17.0, 24.4)	45/240	53/238	0.84 (0.59, 1.20)
<i>Best place for baby to sleep</i>					
In bed with mother	289/478	60.5 (55.9, 64.9)	145/240	144/238	1.00 (0.86, 1.15)
Same room with mother	97/478	20.3 (16.8, 24.2)	38/240	59/238	0.64 (0.44, 0.92)
Alone in a crib	82/478	17.2 (13.9, 20.8)	53/240	29/238	1.81 (1.20, 2.75)
In separate room	6/478	1.3 (0.5, 2.7)	2/240	4/238	0.50 (0.09, 2.68)
<i>Advise by medical personnel to lay baby on back</i>	115/478	24.1 (20.3, 28.2)	59/240	56 (238)	1.04 (0.76, 1.44)
<i>Willingness to change infant sleep practices</i>	313/478	65.5 (61.0, 69.7)	151/240	162/238	0.92 (0.81, 1.05)

Multivariate analysis of factors predictive of bedsharing and prone sleeping:

In multivariate analysis, none of the maternal or infant demographic factors were significantly associated with bedsharing. However, infant age was significantly associated with prone sleeping. Older infants aged between 2 to 10 months had a significantly increased risk of prone sleeping compared to infants aged under 2 months old. For instance, infants aged 2–4 months had a 2.33 increased risk of prone sleeping compared to infants aged less than 2 months (PR: 2.33, 95% CI: 1.16, 4.71) (Table 18)

Table 18: Multivariate analysis of factors predictive of bedsharing and prone sleeping

Characteristic	Bedsharing PR (95% CI)	Prone sleeping PR (95% CI)
<i>Maternal age in years, n, %</i>		
20–29	1.00	1.00
<20	1.06(0.93, 1.21)	1.47 (0.75, 2.88)
30–39	1.02 (0.92, 1.12)	0.89 (0.57, 1.39)
>=40	0.97 (0.80, 1.17)	1.02 (0.44, 2.37)
<i>Marital status, n (%)</i>		
Married/Co-habiting	1.00	1.00
Single/Divorced/Widowed	0.92 (0.83, 1.03)	1.16 (0.74, 1.81)
<i>Maternal Education, n (%)</i>		
Never attended school/Primary	0.99 (0.88, 1.13)	1.02 (0.54, 1.91)
Secondary	0.97 (0.86, 1.10)	1.04 (0.66, 1.62)
Postsecondary	1.00	1.00
<i>Maternal Occupation, n (%)</i>		
Salaried or Self employed	1.00	1.00
Unemployed	1.02 (0.93, 1.11)	0.95 (0.63, 1.43)
<i>Infants age in months, n (%)</i>		
0–1mo	1.00	1.00
2–4mo	0.96 (0.87, 1.07)	*2.33 (1.16, 4.71)
5–7mo	0.96 (0.84, 1.09)	*2.25 (1.08, 4.68)
8–10mo	1.05 (0.93, 1.19)	*2.44 (1.16, 5.13)
11–12mo	0.99 (0.85, 1.15)	1.63 (0.66, 4.03)
<i>Infant's gender/Sex, n (%)</i>		
Female	1.00	1.00
Male	1.03 (0.95, 1.12)	0.97 (0.67, 1.40)
<i>Study Site</i>		
Chilenje	1.00	1.00
Chawama	0.99 (0.88, 1.12)	0.75 (0.48, 1.17)

*Significant at alpha<0.05

5.5.5 Other exposures during and after pregnancy

Prior epidemiologic studies suggest a strong association of SIDS with maternal substance use including alcohol, cigarette smoking and recreational drugs such as marijuana. We assessed these risk factors by asking mothers to indicate if they used any of these substances during their most recent pregnancy.

1. Alcohol and cigarette use:

12.1% (58/478) of survey respondents reported drinking alcohol in their most recent pregnancy. Smoking of cigarettes during pregnancy was however not a common practice in this population. Only 0.8% (4/478) of mothers reported smoking cigarette in their most recent pregnancy. Use of other tobacco products in pregnancy was also very low (1.0%, 5/478). However, exposure to secondhand smoke from another adult or family member in the household appears to be the most significant substance related risk factor. 18.6% (89/478) and 17.6% (84/478) of survey respondents reported exposure to cigarette smoke during their most recent pregnancy and exposure of the infant to cigarette smoke in the months after birth respectively.

When stratified by study site, mothers at Chawama were less likely to report alcohol use in their most recent pregnancy compared to mothers at Chilenje (PR: 0.61, 95% CI: 0.37, 0.99). There was however no difference in exposure to secondhand smoke by study site as shown in **Table 19** below.

Table 19: Prevalence of prenatal and postnatal exposure to alcohol, tobacco, and solid fuels

Characteristic	Total		Study Site		
	n/N	Prevalence % (95% CI)	Chawama n/N	Chilenje n/N	PR (95% CI)
<i>Prenatal alcohol use</i>	58/478	12.1 (9.3, 15.4)	22/240	36/238	0.61 (0.37, 0.99)
<i>Prenatal smoking</i>	4/478	0.8 (0.2, 2.1)	1/240	3/238	0.33 (0.03, 3.14)
<i>Secondhand smoke exposure</i>					
Prenatal	89/478	18.6 (15.2, 22.4)	51/240	38/238	1.31 (0.90, 1.92)
Postnatal	84/478	17.6 (14.3, 21.3)	45/240	39/238	1.14 (0.78, 1.69)
<i>Prenatal OTP* (nsunko)</i>	5/478	1.0 (0.3, 2.4)	2/240	3/238	0.65 (0.11, 3.90)
<i>Primary place for cooking</i>					
In the house	300/478	62.8 (58.3, 67.1)	122/240	178/238	0.68 (0.59, 0.78)
In a separate building or outdoors	177/478	37.0 (32.7, 41.5)	118/240	59/238	1.98 (1.53, 2.55)
<i>Primary cooking fuel</i>					
Firewood or Charcoal	295/478	61.7 (57.2, 66.1)	201/240	94/238	2.12 (1.79, 2.51)
Electricity	169/478	35.4 (31.2, 39.8)	37/240	132/238	0.28 (0.20, 0.38)
Gas	14/478	2.9 (1.6, 4.9)	2/240	12/238	0.17 (0.04, 0.73)

2. Ambient/Indoor air pollution:

Although the evidence is not strong, indoor pollution from household cooking has been suggested as a risk factor for SIDS.[140] More than half of the survey respondents reported cooking with inefficient solid fuels such as firewood and charcoal (61.7%, 295/478) with most cooking in the house (62.8%, 300/478). More than a third of mothers reported cooking with electricity while less than 3% used gas for cooking. (**Table 19**).

Indoor exposure to solid fuels appears to be more common in Chawama than Chilenje. A significantly higher proportion of mothers at Chawama (83.8%, 201/240) reported using charcoal/firewood for cooking compared to 39.5% (94/238) at Chilenje (PR: 2.12, 95% CI: 1.79, 2.51). (**Table 19**) Nearly three quarters (68.9%, 84/122) of those who reported

cooking indoors in Chawama used charcoal/firewood compared to 20.8% (37/178) in Chilenje. (**Table 20**) Moreover, when asked how often the infant is exposed to smoke from cooking with charcoal, mothers at Chawama were more likely to report daily exposures compared to mothers at Chilenje (PR: 4.31, 95% CI: 2.06, 9.06). (Not shown in table, see **Supplemental Figure 4** for chart)

Table 20: Primary place for cooking and type of fuel at Chawama and Chilenje

Primary cooking fuel	Study Site			
	Chawama		Chilenje	
	Primary place for cooking		Primary place for cooking	
	In the house N=122	In a separate building or outdoors N=118	In the house N=178	In a separate building or outdoors N=59
Firewood or Charcoal, n (%)	84 (68.9%)	117 (99.2%)	37 (20.8%)	57 (96.6%)
Electricity, n (%)	37 (30.3%)	.	129 (72.5%)	2 (3.4%)
Gas, n (%)	1 (0.8%)	1 (0.8%)	12 (6.7%)	.

3. Marijuana use and history of parental mental illness:

To assess the use of drugs/other substances during pregnancy, we asked respondents to indicate if they ever used marijuana at any time during their most recent pregnancy. No mother reported any use of marijuana. We note that recreational/medicinal use of marijuana is illegal in Zambia, and this could have influenced their willingness to respond openly. In addition, given the stigma associated with mental health in these communities, very few mothers (5.4%, 26/478) reported a history of mental illness, and even fewer reported that the father of the infant had a history of mental illness (0.6%, 3/478). (**Supplemental Figure 3**)

5.5.6 Protective Factors

Adequate prenatal/antenatal care attendance and breastfeeding are associated with a reduced risk of SIDS. In addition to assessing the risk factors of SIDS, we explored how these protective factors could be utilized in a SIDS prevention program.

1. Adequacy of antenatal care:

Attendance at antenatal care was nearly universal in this population (99.8%, 477/478). Early initiation of antenatal care offers the most protection against SIDS.[141] Most participants started antenatal care in the 2nd trimester of pregnancy (52.9%, 253/478) with most completing 5–6 visits (36.6%, 175/478). Overall, majority of survey respondents completed between 3–6 antenatal care visits. We note that antenatal care is one of the strongest services within Zambia's publicly funded health delivery system.

However, there were important differences in antenatal care between the two study sites. Fewer mothers in Chawama reported starting antenatal care in the 1st trimester compared to those in Chilenje (PR: 0.72, 95% CI: 0.57, 0.92). Mothers at Chawama were also less likely to complete more than 7 visits compared to mothers at Chilenje (PR,0.25, 95% CI: 0.15, 0.41).

Table 21: Adequacy of antenatal care attendance and breastfeeding among survey respondents

Characteristic	Total		Study Site		
	n/N	Prevalence % (95% CI)	Chawama n/N	Chilenje n/N	PR (95% CI)
<i>Attended antenatal care</i>	477/478	99.8 (98.8, 100.0)	240/240	237/238	1.00 (1.00, 1.01)
<i>Start of antenatal care</i>					
1st Trim.	173/478	36.2 (31.9, 40.7)	73/240	100/238	0.72 (0.57, 0.92)
2nd Trim.	253/478	52.9 (48.3, 57.5)	140/240	113/238	1.23 (1.04, 1.46)
3rd Trim.	46/478	9.6 (7.1, 12.6)	24/240	22/238	1.08 (0.62, 1.88)
<i>Antenatal care visits</i>					
1–2	38/478	7.9 (5.7, 10.8)	21/240	17/238	1.23 (0.66, 2.26)
3–4	172/478	36.0 (31.7, 40.5)	111/240	61/238	1.80 (1.40, 2.33)
5–6	175/478	36.6 (32.3, 41.1)	86/240	89/238	0.96 (0.76, 1.21)
>7	85/478	17.8 (14.5, 21.5)	17/240	68/238	0.25 (0.15, 0.41)
<i>General infant feed</i>					
Breastmilk only	271/478	56.7 (52.1, 61.2)	172/240	99/238	1.72 (1.45, 2.04)
Breastmilk/ Comp. ^/ Formula	191/478	40.0 (35.5, 44.5)	65/240	126/238	0.51 (0.40, 0.65)
Not BF*	16/478	3.3 (1.9, 5.4)	3/240	13/238	0.23 (0.07, 0.79)
<i>Exclusive breastfeeding ^^</i>					
< 3mo	29/205	14.1 (9.7, 19.7)	5/67	24/138	0.43 (0.17, 1.08)
3–4mo	45/205	22.0 (16.5, 28.3)	18/67	27/138	1.37 (0.82, 2.31)
5–6mo	120/205	58.5 (51.5, 65.4)	37/67	83/138	0.92 (0.71, 1.19)
7+ mo	11/205	5.4 (2.7, 9.4)	7/67	4/138	3.60 (1.09, 11.9)

* Breastfeeding

^ Complementary feeding

^^ This was limited to infants on complementary feeding

2. Breastfeeding:

Survey respondents reported high levels of breastfeeding, only 3.3% (16/478) were not currently breastfeeding. 56.7% (271/478) were currently exclusively breastfeeding at the time of the survey while 40% (191/478) had introduced complementary feeds in addition to breast milk. Among those who had introduced complementary feed, majority (58.5%, 120/205) exclusively breastfed for the required 5–6 months. Moreover, 91.4% (85/93) of the under 2-month-old and 82.4% (131/159) of the 2–4-month-olds were being exclusively breastfed at the time of the survey (**Table 22**).

Table 22: Breastfeeding rates by age of infant

What do you generally feed your baby	Infants age in months				
	<2mo N=93	2–4mo N=159	5–7mo N=98	8–10mo N=78	11mo N=50
Breastmilk only, n (%)	85 (91.4%)	131 (82.4%)	31 (31.6%)	15 (19.2%)	9 (18.0%)
Breastmilk/ Complementary/ Formula, n (%)	8 (8.6%)	25 (15.7%)	62 (63.3%)	59 (75.6%)	37 (74.0%)
Not Breastfeeding, n (%)	.	3 (1.9%)	5 (5.1%)	4 (5.1%)	4 (8.0%)

Breastfeeding also appeared to be related to infant sleep position. 77.5% (210/271) of infants on breastmilk only and 68.1% (130/191) of those on breastmilk and complementary or formula feed were placed to sleep in the lateral position compared to 56.3% (9/16) of those who were not currently being breastfed. Prone sleeping was also more common among infants who were not currently being breastfed (37.5%, 6/16) compared to infants on breastmilk only (18.1%, 49/271) or on breastmilk with complementary feed (20.9%, 40/191). (Data not shown)

5.6 Discussion

Responses in our survey suggest sleep related infant deaths are not alien to Zambian community. 7.3% of mothers in this study reported a previous history of SUID and 67.6% indicated they were familiar with SIDS/SUID. Unsafe sleep practices were also quite prevalent. Bedsharing was widely practiced, with most mothers indicating that they preferred to share the same sleep surface with the infant. Moreover, contrary to recommendations from the American Academy of Pediatrics, few infants were placed to sleep in the recommended supine position, mothers instead preferred the lateral position. In addition, nearly 2 in 10 mothers placed their infant in the prone position to sleep, falling

short of the post “back to sleep” target of less than 10%.[142] Significantly, infants aged 2–4 months had an increased risk of being placed prone to sleep. This increases their risk of SIDS since this is the peak age of SIDS. Further, majority of infants in this study were placed to sleep on a soft mattress despite evidence to suggest a strong association between sleeping on a soft surface and an increased risk of SIDS.[49]

Our findings on these unsafe sleep practices are consistent with that of prior studies. For instance, the bedsharing rate in our study is not very different from what has been found in the few studies conducted elsewhere in Africa [85,96] but significantly higher than the rates reported from high income countries such as the U.S.[118] A key point to note is that these unsafe sleep practices cut across different communities in Lusaka since we found no significant differences in these sleep practices between our two study sites. Given that Zambia is a low resource country, this finding is not surprising since the socio-economic gradient is not clearly defined between communities. Responses in this study also suggest that mothers are generally willing to change their sleep practices, unfortunately education from healthcare workers about safe sleep practices are lacking. A little under a third of mothers reported being told by medical personnel to place their infant to sleep on the back.

Prenatal exposure to substances did not appear to be highly prevalent in our study. We found an overall prenatal alcohol use rate of 12.1% and a prenatal smoking rate of 0.8%, which are much lower than rates reported from South Africa.[88,91] Related to this, secondhand smoke exposure was reported at slightly higher rates in this study. Almost 18–19% of respondents reported prenatal or postnatal exposure to secondhand smoke. This

rate was higher than rates reported in Nigeria [85] but lower than rates reported in South Africa. [88,91] Public health campaigns in Zambia should thus focus on reducing prenatal and postnatal secondhand smoke exposure with emphasis on smoking cessation.

Prenatal care attendance and breastfeeding are important protective factors against SIDS. Prenatal care attendance was very high in this study. Almost all respondents (99.0%) had attended prenatal care, most completing the required 4–6 visits. This is a strength of Zambia’s public health care delivery system and could be leveraged in any SIDS prevention program. Additionally, majority of survey respondents indicated that they had breastfed exclusively for at least 5–6 months. Breastfeeding was also age appropriate with almost all infants aged between 1 and 4 months on exclusive breast milk. Several epidemiologic studies indicate that infants who were exclusively breastfed have a reduced risk of SIDS [143], however any breastfeeding is protective.[144] The breastfeeding rates also appear to be related to a preference for placing infants in the lateral position to sleep. Public health campaigns to address SIDS in Zambia should explore interventions that will enable mothers to breastfeed the infant while practicing safer sleep positions.

Strengths and limitations:

To our knowledge, this is the first study to assess the risk factors of SIDS in Zambia. We present here preliminary prevalence estimates on the main risk factors of SIDS in Zambia. However, this study is not without limitations. Given our study design and study location, findings in this study may not be generalizable to the entire population of Zambia. Our study was set in peri-urban townships in Lusaka which may not be representative of rural communities in Zambia. Our findings are thus generalizable to other similar peri-

urban or urban communities in Zambia and other African countries. Responses in this study were self-reported which could bias our estimates. For instance, our finding of a prematurity rate of 19% is higher than rates reported previously by Pusdekar et al (12.4%) [145] and Blencowe et al (13%) [146] for Zambia. Mothers could have misreported whether the infant was born “early”, “on time” or “late”. Recall bias was minimized by asking specifically about respondents most recent pregnancy and sleep practices for their youngest child (Child for whom they were in the clinic on the day of the survey). We were also unable to assess some of the genetic and infectious risk factors associated with SIDS.

5.7 Conclusion

Prior research has shown that infant sleep position and bedsharing are the two most important predictors of SIDS. This study provides preliminary estimates of the burden of these risk factors in Zambia. The rates of the side sleeping position and bedsharing in this survey are sufficiently large enough to require intervention with safe sleep campaigns. The evidence for such campaigns cannot be overemphasized. Existing partnerships between the Ministry of Health of Zambia and its international development partners should be relied on to develop context specific safe sleep campaigns to address these unsafe sleep practices. However, our study provides a snapshot of these risk factors. It is not clear how these sleep practices are associated with a risk of SIDS in Zambia. There is a need for additional research to fully investigate these risk factors within Zambia communities. Future research could systematically or prospectively collect information on these risk factors and determine which of these are most associated with an increased risk of SIDS/SUID in Zambia.

CHAPTER 6: QUALITATIVE ASSESSMENT OF THE RISK FACTORS OF SIDS IN ZAMBIA

6.1 Chapter Overview

This chapter presents results of the qualitative study which aimed to explore the views and perceptions of mothers and other caregivers of infants about the risk factors of SIDS. The chapter is divided into two main sections, each devoted to a specific data collection method (Focus Group Discussion (FGD) or Interviews). A common discussion which synthesizes key findings from both data collection methods is presented at the end.

6.2 Introduction

In Africa, prior research studies on the risk factors of SIDS have generally been few. Despite this paucity of information, studies in Africa on the risk factors of SIDS report relatively higher rates of bedsharing and prone sleeping. For instance, Ibeziako et al reported a high incidence of prone sleeping position and bed-sharing in a cohort of infants in South Eastern Nigeria.[8] Moreover, among sudden unexpected death in infancy (SUID) cases in South Africa, the bedsharing rate was nearly 95%. In our survey exploring the risk factors of SIDS among mothers of infants in Zambia, we similarly found high rates of these risk factors. Most respondents (89.5%) in our survey preferred to share a bed with the infant and place the infant prone (19.9%) or in the lateral position (73.0%).

However, there is very little information on the beliefs and perceptions of mothers about SIDS in general and the risk factors associated with SIDS in Africa. To the best of our knowledge, no study in Africa or Zambia has explored the beliefs and perceptions of mothers and other caregivers about SIDS and its associated risk factors. To better understand parental decisions about the risk factors of SIDS, we conducted the first

qualitative study of mothers and other caregivers of infants in Zambia. We conducted focus groups with mothers and other caregivers of infants aged under 1 year to explore their beliefs and perceptions about sudden infant death and the risk factors associated with these deaths. We further conducted in-depth interviews with mothers who previously lost an infant through apparent SIDS to describe the practice of SIDS risk behaviors in these mothers.

Section 1. Focus Group Discussion (FGDs)

This section provides detailed study methods for the focus group discussions (FGDs). Key themes that emerged from the focus group discussions are also presented in this section.

6.3 Objective

The objective of this study was to explore the beliefs and perceptions of mothers and other care givers of infants regarding the risk factors of SIDS and other sleep-related infant deaths in Lusaka, Zambia.

6.4 Methods

This section provides a detailed overview of study methods for the Focus group discussions. The sampling and recruitment strategies, data collection and analysis plans for the FGDs are presented including an overview of consent procedures for study participants.

6.4.1 Sampling and recruitment

FGDs targeted mothers and other caregivers to assess their views and perceptions about the risk factors of SIDS and/or SUID. Eligible participants were aged 18–49 years, caring for an infant aged less than 1 year, resident within the catchment area of each study site,

and able to give informed consent. Designated nurses at each study site purposively identified and recruited participants for FGDs. Participants were recruited after having finished their appointment for the day or waiting for lab results and had a break before transitioning to their next service. Women who opted to participate in the study were screened for inclusion in the study, provided written informed consent, and completed a pre-FGD demographic questionnaire. Demographic questionnaires were free from personal identifiers except for age and study site location. Data collectors assisted illiterate participants by verbally reading through the consent form to obtain permission and the questionnaire to capture relevant information. Consent forms were provided in both English and Nyanja.

6.4.2 Data collection

Focus groups were conducted in private rooms at each study site on the same day participants gave consent for participation. Two data collectors of Zambian origin moderated these focus group discussions in Nyanja, participants preferred language. One data collector facilitated the focus groups while the other took notes and asked additional questions where further clarification was needed. FGDs ran for roughly 60–90 minutes in length, including the consent and questionnaire process. All FGDs were audio-recorded, transcribed, and translated into English. FGDs centered on participants' views and perceptions of sudden infant death, use of antenatal care services, use of alcohol or cigarettes while pregnant and infant sleep practices which included bed-sharing, and their preferred sleep position for infants.

6.4.3 Analysis

FGDs were analyzed using inductive thematic content analysis. The study PI (DrPH candidate) and the facilitator of FGDs (who has experience transcribing and coding qualitative data) independently reviewed a subset of transcripts and generated initial codes and a code book. They then reached consensus on major themes through discussion. Disagreements were discussed until consensus was reached. The DrPH candidate then coded transcripts in Nvivo 12, a qualitative analysis software (QSR International, Melbourne, Australia, www.qsrinternational.com/nvivo-qualitative-data-analysis-software/about/nvivo) based on these themes, iteratively revising them during the coding process.

6.5 Results

Demographic features of FGD respondents including key themes that arose from the FGD sessions are presented below. Themes are organized around five main focus areas: maternal awareness and knowledge of SIDS, maternal perspectives of infant sleep practices, maternal perspectives on prenatal alcohol and tobacco exposures and maternal perspectives on breastfeeding.

6.5.1 Participant characteristics

Between April 2021 and May 2021, we conducted 6 focus group discussions with mothers of infants at the Chawama and Chilenje first-level hospitals in Lusaka, Zambia. A total of 35 women (all were mothers of infants) participated in these sessions. Participants had a mean age of 27.9 years ($std=6.3$ years). Most were aged between 20 to 29 years

(60.0%, n=21), and married or staying with a partner (80.0%, n=28). Educational attainment was rarely beyond secondary school (17.1% postsecondary school).

There were on average 6 participants at each session (range, 5–7). Infants of participants had a mean age of 6.4 months (*std*=3.5 months). Other demographic features of FGD participants are shown in **Table 23**.

Table 23: Population Characteristics of FGD participants

Characteristic	Total N=35	Study site	
		Chawama N=17	Chilenje N=18
Maternal Characteristics			
<i>Maternal age, mean (std.)</i>	27.9 (6.3)	27.8 (6.9)	28.1 (5.9)
<i>Age in years, n, %</i>			
<20	1 (2.9%)	1 (5.9%)	.
20–29	21 (60.0%)	10 (58.8%)	11 (61.1%)
30–39	11 (31.4%)	5 (29.4%)	6 (33.3%)
>=40	2 (5.7%)	1 (5.9%)	1 (5.6%)
<i>Marital status, n (%)</i>			
Single/Divorced/Widowed	5 (14.3%)	1 (5.9%)	4 (22.2%)
Married/Co-habiting	28 (80.0%)	16 (94.1%)	12 (66.7%)
Missing/Unknown	2 (5.7%)	.	2 (11.1%)
<i>Education, n (%)</i>			
Primary	2 (5.7%)	.	2 (11.1%)
Secondary	27 (77.1%)	16 (94.1%)	11 (61.1%)
Postsecondary	6 (17.1%)	1 (5.9%)	5 (27.8%)
Infant Characteristics			
<i>Infant age, mean, std.</i>	6.4 (3.5)	5.2 (3.2)	7.6 (3.4)
<i>Infants age in months, n (%)</i>			
0–1mo	2 (5.7%)	2 (11.8%)	.
2–4mo	13 (37.1%)	8 (47.1%)	5 (27.8%)
5–7mo	6 (17.1%)	3 (17.6%)	3 (16.7%)
8–10mo	8 (22.9%)	3 (17.6%)	5 (27.8%)
11–12mo	6 (17.1%)	1 (5.9%)	5 (27.8%)
<i>Infants Gender/Sex, n (%)</i>			
Male	14 (40.0%)	8 (47.1%)	6 (33.3%)
Female	19 (54.3%)	9 (52.9%)	10 (55.6%)
Missing/Unknown	2 (5.7%)	.	2 (11.1%)

6.5.2 Maternal awareness and knowledge of SID

Three main themes emerged on maternal awareness and knowledge of SIDS: Stories of SIDS-like deaths were common in the community; mothers frequently cited accidental smothering as the main cause of SIDS-like deaths; and most believed being vigilant could prevent these SIDS-like deaths. These themes are discussed below.

Stories of sleep-related sudden infant losses are common in the community:

FGD participants were generally aware of SIDS. Although none of the participants had experienced a previous sudden infant loss, they had heard stories, involving neighbors or other women in the community who had lost an infant during sleep. Their descriptions involved an infant who was placed to sleep and was found dead later in bed.

“I heard of it, both parents were medical personnel. They are saying they put the baby to bed at night, by the time they checked on the baby in the early hours of the day they just found the baby dead” (P2, Chawama 2)

I heard my neighbor had a 3-month-old baby, they woke up in the morning, the baby was okay, after breastfeeding, the baby slept. The mother went to wash outside then when she went back inside just found the baby was dead, she didn't know how the baby died, only found the baby was not breathing (P3, Chilenje 2)

SIDS-like deaths were thought to be due to accidental smothering by an adult:

When asked what caused these deaths, mothers often cited suffocation as the main cause of death. Three main themes emerged on suffocation: from an adult (often drunk) accidentally smothering or overlaying an infant,

“I heard they slept on the baby you know those who drink beer they have a baby they sleep on the baby; they can't even hear the baby crying, they wake up in the morning they find the child is dead” (P1, Chawama-1)

“My neighbor was celebrating new year, they had a party, when they came back, she bathed the baby, then put the baby to bed. They slept the baby was silent, she thought that is how the baby sleeps not crying, only to realize in the morning the

baby was dead..... they went to drink so I think she slept on the baby” (P2, Chawama 3)

suffocation on soft bedding such as blankets,

“I just heard of the baby who died in the bus. They had taken the baby for BCG, they covered the baby with blankets, so it seems that was too much for the baby that it caused suffocation when the mother got home to uncover the baby only to find the baby was dead, so I think it was due to blankets that the baby suffocated” (P6, Chilenje-3)

and suffocation resulting from how the infant was placed to sleep (positional suffocation).

“I just heard, there was a friend we went to the same school she said that my sister had put the baby to sleep while facing down so then the baby was not breathing fine that is how in the morning the baby was found dead” (P2, Chilenje-2)

That said, other participants were uncertain about what caused these deaths, indicating that they did not know or were not told what had caused the infant’s death since in most instances, the infant was well.

“.. My sister-in-law had put the child to bed there after they just found the child dead

*I: what do you think caused the death of the child
I don’t know” (P1, Chawama-2)*

“.. I have heard and seen, where I used to stay, we had a neighbor who had a child. The child was big about 5, 6 months so then was even playing with her in the afternoon and then she even put her to sleep in the afternoon around 16:00 then the mother just shouted that the baby is not breathing

*I: so, you didn’t know what caused the death
no, we were not told about what caused the death because the child was not sick”.
(P4, Chilenje-1)*

Child abandonment, a sick infant dying suddenly, an infant falling from the bed and accidental aspiration of milk were discussed by one to two participants as minor themes related to the cause of SIDS-like deaths. Child abandonment here refers to the practice of leaving an infant in a public latrine.

Participants believe being vigilant can prevent SIDS-like deaths:

Most mothers were concerned about their infant dying suddenly. Several expressed that being vigilant was the best strategy to prevent such deaths. Most suggested frequently checking on the baby when they are sleeping, waking up at night to check on the infant and rarely leaving the infant to sleep alone (unobserved sleep) as some strategies to reduce SIDS-like deaths.

“.. Like how I keep my child from the time I started hearing these [programs], when the child is asleep am not supposed to leave the child alone. If am washing outside I will spread for the baby even outside so that I will be seeing the baby, whatsoever that might happen am near so that I can help them not to have a problem” (P1, Chawama-1)

“.. when sleeping, I don't have to fall into deep sleep I should be checking on the baby. Even breastfeeding, like how I feed my child, I don't do it while sleeping, I wake up and sit or when I wake up I have to see that the baby is safe. After doing house chores I can't stay for an hour or 30 minutes short I go and see how the child is and when [he/she] sleeps for too long I put my child on my back when I feel tired, I take the baby back to the bed”. (P6, Chawama-3)

“..if the baby is sleeping we need to be checking on them, when the baby baths they sleep for a long time but you should be checking on the baby, so when you want to wake them up and start throwing them up just by taking off the socks the baby wakes up then you notice they are okay” (P3, Chilenje-3)

6.5.3 Maternal perspectives on sleep practices

Several themes emerged on maternal perspectives on infant sleep practices. We centered our findings on seven main themes related to infant sleep position, bedsharing, sources of information on infant sleep practices, being alert to prevent smothering, perceived comfort with using a soft sleep surface, bundling of infants to prevent hypothermia and use of pillows or toys.

Mothers perceive the side or prone sleeping positions to be safer for the infant:

Most participants preferred the side and prone sleeping positions for their infants. Several indicated that these positions were safer since they prevented the infant from accidentally aspirating their vomitus. These positions, especially the side position, also allowed infants to breathe well, sleep well and sleep longer. The supine position was seldom recommended since this was deemed to be the most dangerous position for the infant to sleep in.

*“The reason why we place them on the sides is that even when they vomit, things will drop on the sides, **but when facing up, the vomit might go into the nose, they fail to breath** that is when you now find the child dead” (P4, Chawama-2)*

*“I think putting the baby on the sides at night is better **because even breathing is easier**. Even during the day, you can still put him on his tummy because you are there to check what is happening to the baby, perhaps the baby turns you can easily turn the baby. At night, it’s easier to put the baby on his sides” (P5, Chilenje-3)*

One mother indicated that she preferred the prone position since it was more stable and allowed the infant to sleep well.

*“I put them facing down that is **when they sleep well** not facing the sides **you find they turn on their own**..... they think as though they are on the back because on the back, they sleep a lot so if you keep them that way, **they take a long sleep**” (P2, Chawama-1)*

However, a few mothers recognized the dangers of the prone sleeping position indicating that it could lead to suffocation.

*“I have heard where a baby suddenly dies the baby died from suffocation, **she was put on the tummy**, so the baby died I don’t know if she died of suffocation or choking but what I know it’s not good for the baby to sleep on the tummy.” (P4, Chilenje-3)*

Family members and healthcare workers are sources of information on sleep position:

Several participants indicated that their main sources of information on sleep position were their mother and other family members including aunties, sister-in-law, and grandmothers. A surprising finding was that health care workers were also cited as sources of information on these unsafe sleep practices. Most indicated that they receive advice from healthcare workers such as nurses at postnatal clinics to place the infant to sleep on the side.

“At the clinic when you come for first injection for BCG, they say that the best position is for the sides” (P4, Chawama-3)

“Me I was taught here at the hospital before and after having this baby because is the first.” (P3, Chilenje-1)

“I was told by mum when the baby was born that the baby should be sleeping like this and you should be doing this and that” (P4, Chilenje-1)

“Being my first born I get advice from experienced people mothers, aunties and even at the clinic” (P7, Chilenje-2)

“My grandma, mother in-law and my mum they have more experience than we do because they raised us so anything they say must be important yes” (P6, Chilenje-3)

Bed-sharing or co-sleeping is convenient for breastfeeding:

Most mothers in this study prefer to sleep on the same bed (bedsharing) and in the same room (room sharing) with infants. The major themes related to bedsharing, or room sharing included: it is easy to monitor the child when in the same room or on the same bed, and it is convenient for breastfeeding without interrupting their sleep. Several believed that it is comfortable and easier to feed the baby in the same room and on the same bed without having to get up and move to another room to feed the infant.

“It’s comfortable like that, I can easily breast feed him at night” (P2, Chilenje-2)

“For safety and also at night I breast feed, so to avoid the baby from waking up to disturb my sleep..... when he wakes up and needs breast milk, he makes a sign so if I delay, he will disturb so it’s better I breast feed him then I continue with my sleep” (P2, Chawama-2)

“We sleep with the baby on the same bed because am more comfortable when he is with me than with anyone, more probably they won’t give much attention as I do, and feeding is easier. You feed without even moving around the room, it disturbs the baby so it’s easier when the baby is next to you” (P5, Chilenje-3)

Most were also concerned that if the baby sleeps in another room, they might not be able to keep an eye on him/her and could miss any important cues.

“I also sleep with my child at night. When they sleep alone you won’t know what will happen, its better you sleep with them to monitor them” (P2, Chilenje-1)

“As for me I can’t manage what the Europeans do, the baby is left in the other room then you sleep elsewhere, maybe that side the blanket covers the baby, I can’t accept, I want to sleep with the baby closely” (P2, Chawama-1)

“I sleep with the baby in the same room I think it’s easier to check on the baby and know what is happening around the baby” (P1, Chilenje-3)

The threat of someone stealing the baby was also an important reason why these mothers sleep in the same room with the infant.

“for the safety..... even putting the baby in the sitting room I can’t, when the thieves come they find my child in the sitting room” (P4, Chawama-2)

Bedsharing is also thought to enhance bonding between the mother and the infant.

“We share the same bed with the baby, and it is important I think, somehow it helps in bonding before the child is 2 years. You build that closeness of always being safe when your mom is around so for me, I think it is very important for the child to sleep with you” (P5, Chilenje-3)

An equally important theme, although minor was mothers' inability to afford a separate room or bed for the infant due to their socioeconomic circumstance.

"..... But what makes us to sleep with them, we don't have money to get another bed but when they grow you can let them sleep alone" (P1, Chawama-3)

"Some the baby sleeps alone in the baby cot but if you don't have better, you sleep with the baby together" (P1, Chilenje-2)

Being alert was suggested as a mechanism to prevent smothering:

Most were concerned that the infant could be smothered by an adult when in the same bed. To prevent this, participants indicated they have devised several mechanisms to keep the infant safe when sleeping with them in bed. These include being very conscious and alert to the presence of the infant in bed, sleeping very close to the infant when in bed with a father who drinks alcohol, and being very careful not to sleep on the infant.

"... the baby sleeps on my side because the father can be turning without noticing that there is a child that is why they say they slept on the child" (P3, Chawama-1)

".... The mind is alert, we know that there is the baby here [in same bed]. When the father is on this side, you know that the baby is in the middle, so when turning, you are careful. The mind is always alert" (P7, Chilenje-2)

"I sleep very close to my baby because the father drinks alcohol even when he turns, I just pull my child near" (P3, Chilenje-2)

Mothers perceive a soft sleep surface to be ideal for the infant:

When asked how they prefer the sleep surface of the infant to be, most indicated that they prefer a soft sleep surface. The main reason for this preference is that a soft sleep surface is more comfortable and appropriate for babies whose bodies are still soft. Most would even spread blankets on the bed or floor to provide a softer sleep surface for the infant.

“They need to sleep where its soft because the body is soft, they are still babies” (P1, Chawama-1)

“.. They need to sleep where it is soft because even big people can’t sleep where it is hard, our bodies pain, what more for the baby or you find that you put them where it is hard even the bed leaves a mark on the baby (laughs) you find you carry the baby, she is crying because the body is aching” (P4, Chawama-2)

“It should be a soft surface not something hard because the baby is not yet how do I say it okay, something soft comfortable for the baby” (P1, Chilenje-3)

One, however, felt a soft mattress or sleep surface may not be appropriate for the baby

“I think it shouldn’t be too soft if it’s too soft even for an adult it tends like swallow you so it should be in between hard and soft even you when you sleep you are comfortable it should be moderate” (P5, Chilenje-3)

Bundling of babies is guided by concerns about hypothermia:

Several participants reported bundling their babies with at least two blankets during sleep. In cold weather especially, mothers preferred to bundle their infant with blankets to keep the baby warm, often in accordance with prior advice from health providers at the clinic. Concerns about hypothermia leading to cough, pneumonia, or even death also guided their decisions about bundling. However, some were aware that bundling inappropriately could lead to suffocation by the infant and indicated that they usually take steps to prevent the blanket from accidentally suffocating the infant.

“.. its good because like in the month we are in its cold so it’s good to cover them, but the care is with you, like I said, you cover them halfway to avoid accidents like you asked earlier on just like at the clinic they say when going we go with blankets just because when they feel cold, they may die” (P1, Chawama-1)

“.. we need to be using blankets on the child because the child needs to be where it is warm so that they don’t get a cough or pneumonia” (P5, Chawama-1)

“... yes, you put a baby blanket then you add yours on top maybe the baby blanket is not enough, so you add yours to avoid the baby from freezing” (P5, Chilenje-1)

Pillows and toys are seldom used in the infant's sleep environment:

Most mothers recognize the dangers associated with keeping pillows and other toys in the baby's sleeping area.

"We don't use pillows, they are babies we just put a blanket, we spread it becomes level" (P1, Chawama-1)

"I don't give him a pillow not even his big sister, they are not advisable until they are 3, no toys, no anything just bed sheets with blankets" (P2, Chawama-2)

"I don't use a pillow for the baby, so I just fold a small blanket which is not that thick because a pillow is too big" (P1, Chilenje-1)

6.5.4 Maternal perspectives on prenatal alcohol consumption and smoking

Maternal use of alcohol and smoking during pregnancy were generally low. However, three main themes emerged on exposure to substances. These include, pregnancy-related cravings, use of other tobacco products and avoidance of exposure to indoor solid fuels.

Pregnancy-related cravings prompt prenatal alcohol use:

Prenatal alcohol use is generally low among the mothers in the focus group. However, participants expressed that they know several women in the community who drunk alcohol while pregnant.

"there are many [women], but there is one who used to drink throughout, even to the time of giving birth, she didn't know she was in labor" (P2, Chawama-2)

The few participants who drunk alcohol during pregnancy indicated that their use of alcohol and that of others was due to severe pregnancy-related craving for alcohol.

"... on my side I drank alcohol on this child because I had that lust, the thirst for beer, I used to tell the father that please buy me that beer which they call score, I used to take that one, I drink I go to bed. On my side I drank, I can't say I didn't, I did" (P4, Chawama-1)

“I used to feel like taking fresh beers like chibukku, I used to drink” (P3, Chilenje-2)

“I have a cousin who was pregnant last year, so she used to crave for alcohol, and she used to take those up to 8 months. When she went for antenatal, she discovered that the baby had died in the womb, so I don’t know if it was beer which caused it or it was just a natural cause” (P4, Chilenje-3)

Moreover, some perceived alcohol to have some beneficial effects on the unborn child. A few mothers reported using a local brew (Chibukku) with the mistaken belief that it will make their babies fat and beautiful at birth.

“... women drink beer so that the baby maybe born healthy and fat, with light color..... They drink Chibuku so that the baby will be born fat” (P5, Chawama-3)

“I know someone who was even telling me saying, now that you are pregnant you want to have a fair baby you be taking Lusaka beer mix with sour milk so I think I will say that’s what I was told but I never take, I would just joke” (P1, Chilenje-3)

In addition to this, others cited family members who took alcohol while pregnant but ended up delivering healthy babies.

“my cousin when she was pregnant she would go out and when she goes out, she used to come after 2 days just drinking, not lagers but even strong alcohols like whisky and when you tell them, she would say I had a friend who used to drink more than what am doing but the baby is healthy but we thank God the baby was born healthy or maybe we don’t know, there are somethings we don’t know but she had a safe delivery despite that she put the baby in danger by going out drinking” (P5, Chilenje-3)

Despite these reasons, most mothers recognized that prenatal alcohol use can be detrimental to the child and not advisable for pregnant women to drink alcohol, citing brain damage and stillbirth as likely harms of prenatal consumption of alcohol.

“but what made me to know that beer has an effect when I went to give birth I was found with a problem. That beer I used to drink had become water in the stomach,

so when giving birth the [baby] just was [drowning] in the water, so I saw that beer is very dangerous, so I even advise my fellow women that beer is dangerous. A lot of children die at birth, others have complications so beer you can drink but after giving birth, not when you are pregnant that's my contribution" (P1, Chawama-1)

"I have seen people drinking when pregnant, but it is not good because it causes brain damage to the baby, even to the mother they say alcohol damages the liver so when you become pregnant you are vulnerable to such diseases. I personally I can't drink when am pregnant actually I don't drink alcohol so I wouldn't advise a pregnant woman" (P4, Chilenje-1)

Prenatal smoking is low but other tobacco products are used:

Prenatal smoking was generally low in the population of women in the FGDs. Interestingly, while several reported never smoking during pregnancy, some indicated that they knew women in the community who used other tobacco products while pregnant. A local other tobacco product (nsunko) was often cited. Women were reported to use "nsunko" to "feel good" and as a sexual stimulant.

"There are many they smoke nsunko (other tobacco), they put underneath the tongue you find they are walking it's just there, now I ask them, now smoking nsunko (Sniffing tobacco) how do you feel, they say, they feel good" (P2, Chawama-1)

"we see them they smoke; they smoke nsunko they say it warms the body not know how warm they want it to be they smoke they put in the bra if you want to know women very well come at funerals they smoke it doesn't keep them sober it even makes them feel dizzy it's not I don't know it treats them it makes them to be disrespectful" (P6, Chawama-3)

"Some say it warms the body for women others say they make you feel high and good that is what they say" (P1, Chilenje-3)

Participants were generally aware of the harms of tobacco and hence nearly all indicated that they do not smoke. Some of these harms included possible neonatal nicotine addiction, stillbirth and even SIDS/SUID.

“it can kill the child because they fail to breathe. That heat and smoke which goes inside affects the child, some are born with cough, [when] they are even sick when you get medicine from the clinic they can’t help because the baby is addicted to smoke, so when you smoke in their presence that is when they feel better because they are addicted with that smoke” (P1, Chawama-1)

“some people they smoke tobacco and the child is born dead, it gives problems to the doctors they go for antenatal the child is just okay then during birth they die at birth and blame the doctors that they killed my child forgetting what they were doing and when you tell them that tobacco is harmful they say no it keeps the body warm so we don’t know if God created us different others its warm, others its cold” (P4, Chawama-1)

“There are others who smoke even when pregnant, so you find that they give birth, in the chest for adults they become destroyed what more the unborn baby, so you give birth then the baby dies in sleep” (P3, Chilenje-3)

Mothers recommend avoiding indoor smoke exposure:

Avoiding indoor smoke exposures was a minor but important theme in these discussions. At least one participant emphasized the need to avoid indoor smoke exposure from cooking as a way of preventing sudden infant death.

“...just avoiding certain things for instance, you want to use a brazier with smoke avoid taking it in the house to prevent suffocation of the baby. You don’t have to wait until it happens to you then you start saying so it really happens, just have to take precaution” (P3, Chawama-2)

6.5.5 Maternal perspectives on breastfeeding

Breastfeeding was viewed positively by participants. One main theme emerged which was centered on the benefits of breastfeeding as discussed below

Perceived benefits of breast milk encourage exclusive breastfeeding:

Breastfeeding is protective against SIDS. Refreshingly, most mothers reported breastfeeding exclusively for as long as 7 months. Breast milk is perceived to be good for the infant since it contains vitamins and helps the infant to grow well or prevent diseases.

While most practiced exclusive breastfeeding for its perceived benefits for the infant, others were just following rules given to them at the clinic.

“The reason I breast feed my baby I want them to grow well....” (P5, Chawama-2)

“All my children I breast feed them up to 6 months and after 6 months I introduce porridge, but I don't stop breast feeding until 1 year 8... breast milk has a very good vitamin even when the child is unwell, they refuse to eat I give them milk they feed they will be satisfied they will even feel better even me I eat I become satisfied so that breast milk will be plenty for my child” (P6, Chawama-3)

“..... because they advised us that the child should breast feed from 1 to 6 months, so we need to follow the rules” (P5, Chawama-3)

“..... so that they grow well, the children through breast milk is where they find the nutrients” (P1, Chilenje-1)

“Even the diseases, babies don't just fall sick easily because of breast feeding they even have a nice skin and even the weight, there are many” (P2, Chilenje-1)

That said, a few mothers introduced complementary food as early as 4 months because they felt the breastmilk was not enough for the child.

“I started early to give the child food when [he/she] was 4 months because the baby was often crying, I thought that the baby is not satisfied so I introduced porridge” (P1, Chilenje-1)

“I started giving my baby porridge at 5 months because the baby was crying, I never knew maybe it was hunger” (P3, Chilenje-1)

“She used to cry a lot, so they told me maybe it is because the milk is not enough, so we started to give her porridge to stop the crying” (P1, Chilenje-2)

Section 2. In-depth Interviews

This section outlines the study methods, and results of the in-depth interviews with mothers whose infants died of apparent SIDS. Key themes that emerged from these interviews are summarized in the results section.

6.6 Objective

The objective of this study was to assess the practice of SIDS risk behaviors in mothers who lost an infant through apparent SIDS. We specifically focused on the sleep environment at the time of the infant's death and other risk behaviors during the infant's pregnancy.

6.7 Methods

This section presents a detailed review of the sampling and recruitment strategy including data collection and analysis plans for the in-depth interviews.

6.7.1 Sampling and Recruitment

In-depth interviews (IDIs) targeted women in the community who had lost an infant suddenly and unexpectedly during sleep. Respondents for IDIs were identified with a screener question on the survey that asked, "Did any of your children die suddenly and unexpectedly in infancy?" Mothers who answered "Yes" to this question were asked to describe the circumstances surrounding this infant death. Mothers whose initial description fit a sleep-related sudden unexpected infant death, were invited to complete the in-depth interview. Keywords used in screening mothers for inclusion in the IDI included: a child who was previously well, with no admissions in the week prior to death and found dead after a sleep episode. Due to the time commitment for the IDI, some women opted out of the IDI and subsequently referred us to other women in the community who had experienced sudden infant death. We followed up with these women and scheduled an interview at a time of their convenience. Written informed consent was sought from these women before completing the interview.

6.7.2 Data collection

A data collector of Zambian origin conducted 8 interviews with eligible participants. Interviews were conducted in Nyanja, participants preferred language. 7 were in-person and the last one was by phone. Interviews were audiotaped, transcribed, and translated into English. We used open-ended questions to probe further about the infant's sleeping environment at the time of death including the position the infant was last laid to sleep, any co-sleeping with an adult at the time of death, and whether there were any blankets, articles of clothing, and toys in the immediate vicinity of the infant at the time of death.

6.7.3 Analysis

We analyzed each interview transcript on a rolling basis to identify emerging themes. Nvivo 12, a qualitative analysis software (QSR International, Melbourne, Australia, www.qsrinternational.com/nvivo-qualitative-data-analysis-software/about/nvivo) was used to organize, sort and code interview transcripts.

6.8 Results

A brief overview of demographic features of participants are presented in this section. Key risk factors present at the time of the infant's death are presented subsequently.

6.8.1 Respondent characteristics

IDI respondents were aged between 28 and 42 years, most were married, had completed secondary school and were self-employed.

6.8.2 Risk factors intrinsic to infant

Most of the infants died aged between 1 to 2 months. One infant was reported to have died at 6 months of age. The youngest was 1 week old. There was an equal number of male

and female infants. One infant was a twin. Two mothers reported a previous history of sudden infant death.

“Just this one died I wake up I just found is dead even the other one that is how it happened” (P1, Chawama)

“I don’t know what is happening to me, you see my first born died in that same way then I had another child, that child also died the same way that is why am happy that maybe I sit so that I learn what causes that” (P3, Chawama)

6.8.3 Circumstance of infant’s death

Nearly all the mothers described situations that fit a sudden unexpected infant death. Most indicated that the child was previously well, had no hospital admissions in the week prior to death and was found dead in bed after sleeping.

“He was feeling well, we slept together at night, we were just okay I just slept a short time I just found the baby was cold..... no they didn’t admit her, this one they never admitted her” (Chawama-1)

“The child was just okay until somewhere around 03 that is when the baby died” (Chawama-2)

“Was not sick, not even having high fever, nothing” (Chawama-3)

“The baby was just okay even when the father left for work the baby was alive, we were together on the bed” (Chilenje-2)

“We slept well at night with the child and woke up together. The baby was fine after the uncle left for work, me I was around, I went to do the house chores I left the baby sleeping but when I went back inside, I found the baby was not breathing, he was cold, so what really killed the child I don’t know” (P4, Chilenje)

Moreover, most reported finding blood in the mouth or nose on finding the infant dead suggesting smothering or overlay as a likely cause of death

“I found him with blood in the nose” (Chawama-2)

“I just woke up only to find there was blood, went to the clinic, we were told that the child is already dead... from the nose” (Chilenje-2)

However, most did not know what might have caused the death of the infant. Some thought it was due to suffocation on blankets, or an act of God, while one blamed it on witchcraft

“I equally don’t know because at the hospital they are saying they don’t know what happened so am equally confused I don’t know” (Chilenje-3)

“then the day was just okay she slept around 16 after sleeping we started working at home then it reached 18 the baby was sleeping when I went to check I found the child was not breathing I just found whitish things on the mouth so that I how we got the child rushed to the hospital we were told that the baby was long dead the baby didn’t cry, not even the body temperatures rising the child was just okay, it was hard to know what happened to the child until now we are still confused just finding the baby dead” (Chileenje-5)

“I can’t tell because there were a lot of blankets maybe when she turned because this side there was a blanket and also where we slept, we had a blanket so the other blanket was this side maybe the air was less because I was confused so she had faced this side near the wall there was a blanket I had put the blanket on the side because it was cold” (Chawama-1)

“What I think of is just that it was the neighbors who bewitched my child because she was never sick nothing happened, we tried to go to see witch finders but the father of the baby said no because we are Christians we just put everything in God hand but me I suspect my child was bewitched” (Chilenje-5)

6.8.4 Infant sleep environment at time of death

Bedsharing/co-sleeping:

Almost all the participants reported bedsharing or co-sleeping with the infant at the time of death. One indicated that a drunk father was in bed with them. The average number of people on the bed including the infant was 3 (the mother, father, and infant).

“Then when her father came from drinking alcohol he just came and slept so she had to wake up, then I woke up and breast fed her. I saw she dosed off, so I placed her to bed then I slept” (Chawama-1)

*“I: where was the child sleeping when he died
R: we used to sleep on the same bed” (Chawama-3)*

*“I: so, you used to sleep on the same bed with the baby
R: yes, on the same bed me, father and the baby” (Chilenje-3)
“I: where was the baby sleeping at the time of death
R: on our bed where we used to sleep, I used to sleep with her” (Chilenje-5)*

Sleep position:

Nearly all the mothers reported placing the infant to sleep on the side. No infant was placed supine or prone and most were found in the supine position.

*“I: when you took the child to bed how did you place the baby in bed
R: when I took her to bed, I placed her for the sides” (Chawama-1)*

*“I: when you took the baby to sleep in which position did you put the baby to sleep
R: for the sides like this because the baby was young, they choke when they are like this” (Chilenje-3)*

*“I: when you found the child dead, in what position did you find the baby sleeping
R: she had turned she looked up” (Chawama-1)*

*“I: when the baby died was found in which position
R: was facing up” (Chawama-3)*

*“I: when you found the baby dead you found her sleeping in which position
R: facing up” (Chilenje-5)*

Sleep surface:

Several participants reported that the infant slept on an old mattress which often was soft. A few indicated that the mattress was medium to hard.

*“I: in which form was the mattress
R: it was soft” (Chawama-2)*

I: we talk a bit about the mattress, was it new or old
R: it was an old one
I: so was it soft or hard
R: soft” (Chilenje-2)

One participant reported sleeping on the floor with a mat and blankets at the time the infant died

“at that time when the baby died I had no mattress we were just using a traditional Mat (mpasa) with other blankets” (Chawama-1)

No other items such as pillows, toys, or washed clothing were found on the bed at the time of the infant’s death

“There was nothing like you put a baby doll maybe plastic, pillow or other clothes
R: no, I didn’t” (Chawama-1)

I: so, we move forward a bit, so on the bed we talk about pillows and dolls how many where there on the bed the teddy bears
R: no the pillows where on the other side
I: okay you never gave her teddy bears with pillows
R: no the pillows where on the other side” (Chilenje-1)

Bundling at time of death:

Most of the infants were bundled with at least 5 items of clothing at the time of death. Nearly all the mothers indicated the infant was wearing a vest, shirt, jersey, trouser, nappies and stockings.

“I: if you were to count the clothes, she wore on the upper part of the body they were how many
R: they were six a vest, shirt, Jersey, trouser, nappies and stockings”

“I: what did the baby wear that night maybe you can count them or mention them
R: legs had stockings, a hut on the head with jersey, and nappies with a shirt inside” (Chawama-2)

I: so when you put him to bed you said it was in June so what was the baby was wearing

R: nappies, with a romper with a trouser and a hat” (Chilenje-2)

I: what type of outfit was the baby wearing at a time the baby was found dead

R: romper, jersey, vest, socks, with a head sock

I: how many were they all together

R: about 7” (Chilenje-5)

In addition to the above, the babies were often bundled with two blankets: a baby blanket, and an adult blanket or receiver.

I: okay so how many blankets did you cover the child with?

R: I just used a baby receiver with her blanket and the one I had protected the cold wall with

I: you used 2 blankets

R: yes” (Chawama-1)

I: when you put the baby to bed the blankets?

R: normal just because the baby you can't put a lot of blankets and you can't leave them in the cold, so I used a baby blanket with another that's all” (Chilenje-1)

Temperature of room at the time of death:

Most of the mothers reported that the room was of normal temperature (neither hot nor cold) at the time of the infant's death. A few (2 each) indicated that the room was cold or hot.

I: where you left the child how was the temperature in the room

R: it was just normal in the room..... everything was just normal we were surprised just die like that cause after scanning everything was just okay” (Chilenje-3)

6.8.5 Parental alcohol and tobacco use

None of the participants smoked nor drank on the pregnancy of the infant who died.

I: now when you had this baby did you drink alcohol or smoke tobacco

R: no I don't drink” (Chawama-2)

*I: you never took alcohol or even smoking perhaps marijuana
R: I neither drink nor smoke” (Chilenje-5)*

*I: how about when you were pregnant or I ask you like this do you smoke
R: my brother I have already told you I don't smoke I don't smoke not even a simple thing” (Chilenje-4)*

However, a few fathers were reported to drink alcohol or smoke and thus predisposing the infant to smothering or secondhand tobacco smoke exposure.

*I: is there anything that you used something like beer, tobacco, weed when you were pregnant or when the child was born
R: I have never used such unless the father is the one who smokes, that time he used to drink beer” (Chawama-1)*

*I: at home is there anyone who smokes
R: my husband drinks
I: how about smoking
R: no only that one for putting in the mouth Ashish, kubbe” (Chilenje-2)*

6.8.6 Adequacy of antenatal care

Most of the participants attended prenatal care, indicating that they completed a minimum of three or more visits (range, 3–7 visits)

*“Ooh maybe you can tell me the number of times you went for antenatal maybe 5, 6 or so, how many times did you go to the clinic
R: going to the clinic on this child I went 5 times” (Chawama-1)*

*I: if you can recall how many times did you go for antenatal
R: I went on 4,5,6,7,8 and on 9 I went twice” (Chilenje-1)*

*I: how many times did you go to the clinic
R: 3 times. When I went, they told me you should come for review and the last one was for giving birth” (Chilenje-3)*

6.9 Discussion

Several women in focus group discussions indicated that they had neighbors or had heard stories of infants who were otherwise well and died during sleep. Most found a link between these deaths and suffocation. Others were simply uncertain of the cause of such deaths and believed these deaths could be due to witchcraft or an act of God. Interview recipients were especially devastated by the loss of their infant since they could not explain the cause of death, and healthcare workers seldom provided an explanation for why these infants died.

Our study participants generally believed that they could prevent some of these SIDS-like deaths by being more vigilant and keeping an eye on the child. In almost all instances, mothers shared the same room with the infant, believing that this afforded them the best opportunity to monitor the child and protect them from suffocation, and other harms. Unfortunately, this belief also led to several of the study participants putting their infants at risk of SIDS by sharing the same bed with the infant. Almost all infants in interviews shared a bed with an adult during sleep. Our findings are consistent with that of prior qualitative studies among African American women in the U.S. which found that mothers believed bedsharing offered them the best opportunity to keep their infant safe.[147,148]

Most mothers in our study believe that the infant would aspirate or vomit when placed to sleep in the supine position. Moreover, they believe the side/lateral position makes it easy for the infant to breathe and sleep well. They found the supine position to be very risky for the infant and preferred the side or prone position. Almost all infants in interviews were placed to sleep in the side position prior to death. To further worsen this, education

from healthcare workers about safe sleep practices was lacking. In fact, healthcare workers were cited as sources of information for these unsafe sleep practices. Participants are thus forced to rely on their mothers and other family members for advice on the best position to place the infant to sleep.

Several mothers in this study indicated that a soft sleep surface was ideal for the infant to sleep on since it makes them sleep comfortably. This finding is consistent with findings from prior qualitative research among black parents in the U.S.[149] Majority of infants in the survey were placed to sleep on a soft mattress. Previous research has found a strong association between sleeping on a soft surface and an increased risk of SIDS.[49] Although pillows and toys were seldom used, and motivated by a desire to keep the infant warm, most mothers would bundle the infant with blankets and/or clothing during sleep, further placing the infant at increased risk of soft bedding suffocation.[49] Nearly all the infants in interviews were bundled with at least 5 items of clothing and 2 blankets prior to death. There may be socio-economic reasons for this, at least one participant indicated that they “don’t have better”. It may be difficult to tackle these socio-economic reasons without a system wide collaboration between the government and its development partners. Public health campaigns should also target practices related to infant bundling and the use of blankets during sleep.

Responses in the focus groups and interviews indicated that mothers were generally aware of the harms of tobacco and alcohol to the mother and unborn child. None of the mothers of SIDS infants drank alcohol nor smoked while pregnant. However, in focus group discussions, respondents indicated that they knew several women in the community

who either drank alcohol or smoked or used other tobacco products while pregnant. Pregnancy-related cravings [150] and the desire to give birth to fat, beautiful children motivated the use of alcohol during pregnancy. Nsunko (local other tobacco product) was desired as a sexual stimulant and generally to make women feel good. The link between nicotine in tobacco and SIDS has long been established.[40,151] Nicotine is thought to affect the arousal response in neonates.[152] There is no way of predicting how much nicotine is in these products and the effect of prenatal use of these products on an infant's SIDS risk. More research is needed to determine the effect of these local tobacco products on SIDS.

Prenatal care attendance and breastfeeding are important protective factors against SIDS. Infants who were exclusively breastfed have a reduced risk of SIDS. [143,144] Respondents in the focus group discussions were generally aware of the benefits of breast milk to the infant and indicated that they had exclusively breastfed their infants for at least 3–6 months. In addition, the high bedsharing rates could be explained by the high breastfeeding rates since most mothers found bedsharing to be convenient for breastfeeding. Strategies that make co-sleeping and breastfeeding safer may be worthwhile in these *Zambian* communities.

Strengths and limitations:

The main strength of this study is that this is the first qualitative study on the risk factors of SIDS in *Zambia*. By using this study design, we have been able to provide some context to the unsafe sleep practices we found in our survey and provide an explanation for why mothers performed these risk behaviors. Additionally, our study triangulated very well.

Our findings on infant sleep practices were complementary across surveys, FGDs and in-depth interviews. Thus, we were able to use different data collection streams to arrive at very similar conclusions.

However, this study is not without limitations. Self-selection bias and recall bias are key limitations of the in-depth interviews. We minimized recall bias by recruiting women who had lost an infant to a SIDS-like death in the two years preceding the study. Responses in this study were also self-reports, we could not confirm these reported infant losses objectively with medical records or autopsy. In addition, our sample in the interviews was small (8 participants) which can affect generalizability of our findings. This calls for additional research. Interviewer or translation bias is also likely. We however, minimized this by going into this research with no preconceived ideas of what to find. We allowed themes to emerge inductively during the study.

6.10 Conclusion

Our findings have important implications for public health. Safe sleep campaigns have been shown to be effective in other countries. However, implementing such campaigns in Zambia will require a deeper understanding of the beliefs and perceptions of mothers and care givers about an infant's sleep environment, data which this study provides. Interventions to address SIDS in Zambia should be designed to address maternal/parental concerns about the supine position. In addition, interventions that will make it safe for mothers to breastfeed while co-sleeping with the infant could be explored and prioritized for implementation. Ultimately, deciding on these interventions will require immense stakeholder engagement on which interventions will be feasible, and culturally acceptable

to Zambian mothers and other family members.

CHAPTER 7: POLICY/PROGRAMMATIC RECOMMENDATIONS TO ADDRESS SIDS/SUID IN ZAMBIA

7.1 Chapter Overview

This chapter is the concluding chapter for this dissertation. It is drafted as a white paper for the Ministry of Health (MOH-Zambia) and provides a summary of key findings from this study. Suggestions for policy and programmatic considerations to ensure optimal uptake of recommendations for safe sleep are made.

7.2 Executive summary

Sudden infant death syndrome (SIDS) is consistently mentioned as one of the leading causes of infant mortality in high income countries.[13] It is part of a larger group of sudden unexplained infant deaths (SUID) including accidental suffocation or strangulation in bed (ASSB). SIDS is defined as the death of an infant less than 1 year of age, which event occurred during sleep, and which remains unexplained even after a thorough death scene investigation and autopsy.[7,14] The key feature of these deaths is that they are unobserved, occurring when the infant is sleeping. The majority of infants who die of SIDS were also healthy prior to the event and had no identifiable condition or acute illness at the time of death.

However, several modifiable risk factors have been identified from prior research. These include side and prone sleeping position, bed sharing, use of soft bedding, and prenatal exposure to cigarette smoke.[153] Sleeping in the prone or side position and bed sharing are the most important risk factors of SIDS. Much of the progress in reducing post neonatal mortalities in high income countries including the U.S. have been due to implementation of safe sleep campaigns that target these risk factors of SIDS.[52,153]

Despite this, SIDS is rarely mentioned as a cause of infant mortality in Africa including Zambia.

To better understand the role of SIDS on infant mortality in Zambia, we conducted a research study with two main goals: 1) to estimate the burden/prevalence of SIDS among decedent infants aged 4 days to 6 months in Lusaka, and 2) to explore the views of mothers and other caregivers of infants regarding the risk factors of SIDS/SUID in peri-urban townships in Lusaka. Findings from our study indicate that SIDS may be occurring silently within peri-urban townships in Lusaka with widely prevalent unsafe sleep practices. Based on our findings, we propose additional research to fully investigate and characterize SIDS/SUID, and to raise awareness of SIDS/SUID among key stakeholders in Zambia.

Our proposed strategies are outlined below:

- **S1:** Collaborate with researchers to further explore the determinants and burden of SIDS/SUID in Zambia
- **S2:** Raise awareness and build consensus with key stakeholders about SIDS/SUID in Zambia

7.3 SIDS in Africa and Zambia

Sudden infant death syndrome (SIDS) is defined as the “the sudden and unexpected death of an infant under 12 months of age that remains unexplained after a review of the clinical history, complete autopsy and death scene investigation, with onset of the fatal episode occurring during sleep”. [7,14] Global estimates of the SIDS mortality rate are difficult to ascertain. Most statistics on SIDS are reported from high income countries with little to none from developing countries. [21,22] Data from these high-income countries

suggest that SIDS is a leading preventable cause of infant mortality.[19,20] In the U.S. and U.K. for instance, SIDS is consistently mentioned in the top tier of causes of infant mortality. [19,20]

In Zambia and most African countries, little is known about the prevalence of SIDS. SIDS is rarely included in infant mortality statistics in most African countries.[10] Most of the focus of research in Africa has been centered on infectious diseases such as HIV, malaria, pneumonia, malnutrition and diarrheal disease. For instance, according to the global fund to fight AIDS, Tuberculosis and Malaria, roughly \$2.7 billion dollars was invested in malaria control and prevention efforts globally in 2018 with nearly three quarters spent in Africa.[154,155] It is not known how much has been spent on SIDS research in Africa but given the paucity of research publications, it is likely to be small. Moreover, without national protocols for death scene investigation and with generally low autopsy rates, accurately assigning SIDS deaths is challenging in most African countries. [10,11] As a result, many infant deaths are incorrectly attributed to infections and other causes of infant mortality, making it difficult to estimate the true burden of SIDS.[156]

The lack of data on the SIDS prevalence in Africa prompted a systematic review of publications on SIDS in Africa. The review confirmed the paucity of research on SIDS across the African continent. It centered on 32 articles conducted over the last 38 years from eight African countries. Majority of the studies were from South Africa (72%, 23/32) with three from Nigeria and one each from Egypt, Tunisia, Niger, Uganda, Zambia, and Zimbabwe. The systematic review revealed that the prevalence of SIDS in Africa may be higher compared to wealthier countries. For instance, the SIDS mortality rate was found to

be high in South Africa, with reported prevalence/incidence rates of between 3.01 and 3.7 per 1000 live births compared to 0.3 per 1000 live births in the U.S.[95,107]

Further, to provide preliminary estimates of the SIDS prevalence in Zambia, we analyzed verbal autopsy data collected as part of the Zambia Pertussis/RSV Infant Mortality Estimation Study (ZPRIME). Between August 2017 and August 2020, verbal autopsies were conducted with 809 families of decedent infants at the University Teaching Hospital (UTH) morgue who presented as brought in dead (BIDs). Out of these 809 decedent infants, approximately 7.4% died suddenly and unexpectedly with 5.4% presumably dying of SIDS. The peak age of these deaths was 1–2 months and were more common during the colder months of June, July, and August. Most of these deaths occurred in the densely populated and economically disadvantaged townships of Chawama and Kanyama. Our conclusion from these analyses is that SIDS may be an important cause of infant mortality in Zambia, but it is going unrecognized or unreported.

7.4 Patterns of risk of SIDS in Africa and Zambia

SIDS is widely believed to be multifactorial in origin as no single cause has been found. Rather, SIDS is thought to occur due to the convergence of three factors: (1) a vulnerable infant, (2) a critical period of development, and (3) the presence of exogenous acute stressors.[29] Vulnerability is explained by non-modifiable intrinsic factors in the infant including, gender, age, prenatal exposure to cigarette smoke or alcohol and certain rare genetic polymorphisms. Exogenous stressors are often present at the time of the infant's death and include the position in which the infant was placed to sleep, bedsharing, sleeping on a soft sleep surface, bundling and postnatal exposure to cigarette smoke.

Within these factors, research clearly indicates that the most important of all is sleeping in the prone or side position and bedsharing.[22] The importance of sleep factors is underscored by the significant reduction in SIDS deaths following the successful implementation of advocacy campaigns to change sleeping positions and to find alternatives to co-sleeping. In fact, it seems likely that without these final, proximal factors, most SIDS deaths could be avoided even in the setting of infants who would otherwise be considered high risk or vulnerable. Based on this, the American Academy of Pediatrics (AAP) in 2016 made the following recommendations for reducing the risk of SIDS/SUID: Supine sleep position at all times, room sharing without bedsharing, avoidance of soft bedding and overheating, use of a firm sleep surface, avoidance of exposure to smoke, alcohol and illicit drugs, breastfeeding, routine immunization and use of a pacifier.[3]

Our systematic review confirmed that the sleep-related risk factors of SIDS were highly prevalent in countries⁷ where these risk factors were assessed with rates of bedsharing and prone sleeping ranging between 60.0% to 91.8% for bedsharing and 26.7% to 63.8% for prone sleeping.[8,85,86,96] Only a handful of studies outside of South Africa assessed these risk factors with none from Zambia. To provide estimates on these risk factors in Zambia, we conducted a series of quantitative and qualitative investigations among groups of young Zambian mothers. From the 19th of April to the 7th of May 2021, surveys, focus group discussions and interviews were conducted with mothers and other caregivers of infants at postnatal clinics at Chawama and Chilenje first level hospitals in Lusaka.

⁷ 4 studies from Nigeria and South Africa assessed the risk factors of SIDS

Findings from these studies suggest that the main risk factors of SIDS, prone/lateral sleeping and bedsharing are highly prevalent in these peri-urban townships in Lusaka.

Nearly all mothers (89.5%) shared a sleep surface with an infant and most preferred to lay the infant to sleep in the lateral (73.0%) or prone position (19.9%). The supine position was rarely used (6.7%). Interestingly, the supine position was disfavored by most mothers believing this poses an aspiration risk to the infant, when in fact the opposite is clearly true. Bedsharing was deemed to be more convenient for the mother since it allows them to keep an eye on the infant and breastfeed. Most also indicated that being vigilant could prevent SIDS. Healthcare workers rarely provided advice on safe sleep practices and when they did, only nearly a quarter (24.1%) of mothers indicated that they had received advice from a health care worker to place the infant to sleep in the supine position. In focus group discussions, health care workers were frequently cited as sources of information promoting these unsafe sleep practices.

Direct prenatal exposure to tobacco was low. Less than 1% of mothers reported cigarette smoking in their most recent pregnancy. On the other hand, prenatal and postnatal exposure to secondhand smoke emerged as important risk factors with reported rates of 18% and 19% respectively. Prenatal use of alcohol was also low. 12% of mothers reported prenatal use of alcohol. There were important differences in these exposures between our two study sites suggesting socio-economic differences in these exposures. Maternal use of alcohol in pregnancy was much higher in Chilenje (15.1%) where mothers reported slightly higher levels of education compared to Chawama (9.2%). On the other hand, prenatal and postnatal exposure to secondhand smoke were reported at higher rates in the poorer, less

educated township of Chawama compared to Chilenje (21.3% vs. 16.0%, and 18.8% vs. 16.4%, respectively for prenatal and postnatal exposure to cigarette smoke).

However, the unsafe sleep practices we found were not different between Chawama and Chilenje suggesting strong societal and cultural influences on these sleep practices. Despite this, there were socio-economic reasons that impacted a mother's ability to afford a separate sleep surface for the infant such as cribs or bassinets.

7.5 Current National Programs for SIDS prevention in Zambia

Although Zambia has implemented several child-survival programs or interventions, there is currently no formal SIDS prevention program. National programs for child survival have focused mainly on infectious and vaccine preventable causes of infant mortality. Some of these interventions include a strengthened expanded program on immunization (EPI), inclusion of newborn care in pre-service curriculum for nurses, and integrated management of childhood disease (IMCI).[157] While these interventions have contributed to steady improvements in child survival, infant mortality rates have stagnated⁸ over the last few years requiring the need to prioritize other causes of infant mortality such as SIDS in national programs.

7.6 Interventions to address SIDS

Several strategies have been implemented in high income countries to address SIDS with varying degrees of success. Most have been focused on using education to change behavior, often targeting health care workers, parents/mothers, and the public with

⁸ The infant mortality rate declined by 7% from 45 to 42 per 1000 live births from 2013 to 2018, compared to 36% from 70 to 45 per 1000 live births between 2007 and 2013[65]

messaging on safe sleep recommendations.[158,159] These educational approaches include public health campaigns, health care worker training programs, parental education programs, targeted educational programs for high-risk families and/or parenting or peer support programs which aim to improve awareness and knowledge of SIDS among infant caregivers and health care providers. [158,159]

Other interventions have focused on providing a safer sleep environment for the infant through the distribution of devices such as baby boxes, infant sleeping bags, locally made safe sleeping aids such as the Wahakura (which is a shallow woven wicker bassinet that can be placed on the bed next to the mother) or Pepi-Pod (Supplemental Figure 7) and cribs or bassinets.[159] These devices create a physical barrier around the baby but still allows co-sleeping with the parent and ready access to the baby for nighttime breastfeeding and nursing. Indeed infant mortality rates in Finland declined markedly in the late 1930's after the distribution of baby boxes by the government to all expectant mothers.[159,160] Recently, pilot baby box distribution schemes have been implemented in the U.S, and UK.[161–163] However, the evidence base for baby box distribution schemes in reducing SIDS is not conclusive, requiring further research on the value of such an intervention.[159,164,165] In New Zealand, the use of a Wahakura or Pepi-Pod⁹ by mothers was also associated with high adherence to safe sleep practices and declines in infant mortality.[158,159] The Wahakura were culturally accepted by Maori women

⁹ The Pepi-Pod is made from the bottom section of a plastic clothes container and is fitted with a simple mattress, a sheet, or blanket and safer sleep instructions. This emerged as a cheaper alternative to the Wahakura and was introduced as a temporary sleep aid during the Christchurch earthquakes in New Zealand[166]

among whom bedsharing with the infant is culturally preferred and widely practiced.[167] Due to the high cost of manufacture of Wahakura, this intervention was not sustainable.[159]

However, the most effective interventions to date have been the various “back to sleep” educational campaigns which have been described as “one of the great public health success stories of the 20th century”. [159] The National Institute of Child Health and Human Development’s (NICHD) “Back to Sleep” campaign in 1994 in the United States (U.S.) for example led to a more than 50% decline in mortality from SIDS.[52,129,168] (Supplemental Figures 5 & 6) The declines in SIDS rates were associated with declines in overall post-neonatal mortality.[21,169] Despite evidence in support of the impact of public health campaigns to address SIDS, in Zambia and most African countries, such campaigns or programs have not been implemented. A recommendation for implementation of such interventions cannot be made without a more accurate picture of the burden of SIDS and its associated risk factors in these countries.

7.7 Proposed strategies to address SIDS

Several years of well-designed epidemiologic studies combined with robust medicolegal death investigations, autopsy and accurate data collection were used to fully characterize SIDS in wealthier countries. Currently, accurate statistics on the prevalence or incidence of SIDS in Zambia do not exist. Our research provides preliminary evidence that SIDS/SUID may be occurring silently within Zambian communities with widely prevalent unsafe infant sleep practices. However, additional research is still needed to fully characterize the burden of SIDS and its risk factors in Zambia. Based on this, we propose

that the Ministry of Health considers establishing a research portfolio on SIDS/SUID to further investigate this important cause of infant mortality in Zambia. Our proposal hinges on two strategies outlined below in **Table 24**.

Table 24: Strategies and corresponding objectives to address SIDS in Zambia

	Strategy	Objective of strategy
S1	Collaborate with researchers to further explore the determinants and burden of SIDS/SUID in Zambia	Provide a baseline for SIDS prevalence to establish the scale of the problem and provide a comparison against which to infer the impact of SIDS reduction campaigns. Expand evidence base to inform decision making at the national level
S2	Raise awareness and build consensus among key stakeholders about SIDS, and the need for SIDS reduction strategies.	Build awareness of SIDS with key stakeholders and agree on optimal interventions that would be feasible, acceptable, and effective in Zambia to reduce` SIDS. Create messaging strategies that will maximize uptake and acceptance of interventions by families and health care workers

7.7.1 Collaborate with researchers to further explore SIDS in Zambia:

Based on the San Diego definition of SIDS, three criteria need to be met to make an accurate and complete diagnosis of SIDS: 1) review of the clinical history, 2) conduct of complete autopsy and 3) completion of a death scene investigation.[14] Our study relied on verbal autopsy data to make a diagnosis of SIDS without a standard autopsy and death scene investigation. In addition, we were only able to explore the risk factors of SIDS in peri-urban townships in Lusaka, Zambia which limits generalizability of our findings to the rest of the country. Moreover, most of the interventions for SIDS were implemented in wealthier countries. The feasibility and acceptability of such interventions in poorly resourced low-income countries have not been studied.

Further research is also needed to understand key barriers to adoption of safe sleep practices. Given the strong societal and cultural influences on sleep practices, a deeper understanding of the barriers to adoption of safe sleep practices is required. There is also the need for systematic collection of information on the risk factors of SIDS. Further, Zambia also lacks any standardized SIDS/SUID investigation protocol making the diagnosis of SIDS difficult or nearly impossible. Zambia currently has an acute shortage of forensic pathologists to conduct investigations of sudden infant death. Mucheleng'anga et al reported that there were only 4 pathologists based in Lusaka who conduct forensic autopsies.[170] Of these, only one is a trained forensic pathologist. Other parts of the country are served by general medical officers with no formal training in medicolegal death investigation procedures. Investigating sudden infant death is currently not a priority. There is a need to develop context specific SIDS investigation protocols in Zambia to facilitate collection of accurate data on the burden of SIDS.

Based on this, there are still outstanding gaps in the research that need to be addressed including:

- Examining the underlying political and societal context that promote SIDS risk behaviors in Zambia
- Exploring the range of options/interventions that would be feasible, acceptable, and effective to make co-sleeping and breastfeeding safer in Zambia
- Exploring the behavioral or cultural barriers to getting infants to sleep on the back
- Examining the challenges of making a diagnosis of SIDS in the context of a low to middle income country

- Exploring the feasibility of developing and implementing context specific SIDS investigation protocols in the context of a low to middle income country

Well-designed research studies for SIDS can be resource intensive. Competing for funding within the budget will be challenging given the resource constraints of the country. Based on this, we propose collaborations with external research groups to further explore the contribution of SIDS to infant mortality in Zambia as the first step in any public health program for SIDS. Most of the research in South Africa on SIDS were conducted through a collaboration of local researchers and an international collaborative research group, the Prenatal Alcohol in SIDS and Stillbirth (PASS) Network.[11] Several studies came out of this collaboration leading to the development of SIDS/SUID investigation protocols and a strong research focus on SIDS in South Africa. For example, Dempers et al conducted a study to test the potential for the institution of a standardized autopsy and infant death scene investigation protocol for SIDS in Cape Town.[11,111] The standardized autopsy included detailed external examinations, histology, bacteriology, viral cultures, HIV testing, and toxicology screening. [11,111] The death scene investigation protocol was based on the CDC's SUIDIRF form.[171] The study showed that it is feasible to establish SIDS/SUID death investigation protocols in areas with significant infrastructure challenges.[111] The study also led to the implementation of a locally relevant SUID questionnaire which is used when interviewing families of deceased infants.

A few research organizations including Boston University's Department of Global Health have started exploring work in this space in Zambia and would be essential collaborators to investigate some of these questions. Additionally, getting the World Health

Organization (WHO) and large funders such as the United States Agency for International Development (USAID), the UK's Department for International Development (DFID) now Foreign, Commonwealth & Development Office (FCDO), German Technical Cooperation (GTZ) and the Bill & Melinda Gates Foundation to provide logistic and technical support for SIDS research and prevention will be important. Suggestions should be made for additional modifications to the demographic and health surveys (DHS) and the multiple indicator cluster surveys (MICS) to systematically collect information on the risk factors of SIDS. The Ministry should also support calls for the Institute for Health Metrics and Evaluation (IHME) to include SIDS in its annual modeling reports. The first step, however, will be getting these organizations to recognize that SIDS is a problem worth addressing in Zambia which can only be done through more robust research studies.

7.7.2 Raise awareness and build Consensus among stakeholders about SIDS

Raising awareness of SIDS and other sleep related infant deaths among key stakeholders in Zambia may be an important initial step in addressing SIDS in Zambia. Our study suggest that the risk factors of SIDS were highly prevalent within peri-urban communities in Lusaka. In addition, SIDS/SUID was an important cause of death among decedent infants in Lusaka. An extensive stakeholder engagement process is advised at this initial stage. A rolling program of consultation with leaders of physician groups, midwives, nurses, local community leaders, leadership of international development partners (UNICEF, WHO and USAID), and other non-governmental organizations (NGOs), will serve to create awareness about SIDS and obtain the perspectives of these stakeholders about SIDS and its related risk factors. Stakeholders may be engaged in a series of regular

meetings, workshops, conferences, and other informal gatherings in the community. For instance, the Pediatric Association of Zambia's annual general meeting could serve as an opportunity to engage pediatricians and other doctors about SIDS. The purpose of these sessions would be information-sharing across groups as well as strategy development for potential interventions. To be successful, a consultative approach could be adopted. In addition, concerns or comments from stakeholders should be considered and addressed.

Early and authentic stakeholder engagement has the potential to lead to consensus-building about the need for SIDS reduction strategies and the optimal way of implementing these within Zambia's unique cultural context. For example, mothers in our study preferred to sleep in the same bed with the infant since this was convenient for them to breastfeed the infant. Several interventions have been tried in other countries to make breastfeeding and co-sleeping safer for the infant. Such interventions have included a baby box in Finland or Wahakura in New Zealand. However, such interventions may not be feasible or acceptable in Zambia. There may be a need to build consensus with key stakeholders to agree on interventions that would be feasible, acceptable, and effective in Zambia to reduce SIDS. Further, recognizing that knowing what to do is distinct from how to do it, there may also be a need to create messaging strategies that will maximize uptake and acceptance of these interventions by Zambian families and by the health care workers who will be delivering these messages. Developing a learning community of stakeholders in parallel with enhanced research on SIDS will better allow for a nimble and responsive system of care as more is learned.

7.8 Exemplar public health campaigns for future consideration

Public health campaigns have been shown to be effective in high income countries in addressing SIDS. As Zambia continues to explore the scope and impact of SIDS through research and stakeholder feedback, a future public health campaign may be considered to educate health care workers, mothers, and the public about SIDS/SUID as a precursor to desired behavior change. **Table 25** outlines three strategies that may be effective in such a public health campaign. These should be considered as long-term strategies that might be prioritized for implementation after research has created a more accurate picture of SIDS in Zambia and with extensive stakeholder input. These could also be implemented together with other policy or programmatic interventions that may be deemed feasible and acceptable by key stakeholders in Zambia.

Table 25: Long-term strategies and corresponding objectives to address SIDS in Zambia

	Strategy	Objective of strategy
S1	Train health care workers on SIDS and safe sleep recommendations	Improve knowledge base of providers and equip them with skills to communicate the benefits of safe sleep practices clearly and effectively as outlined by the AAP
S2	Educate parents on SIDS and safe sleep recommendations	Improve parental awareness and knowledge of SIDS and safe sleep recommendations
S3	Educate and sensitize the public on SIDS and safe sleep practices	Scale up education on SIDS to a wider audience through public campaigns and provide mothers and other individuals in the community with information to make informed decisions about infant safe sleep practices

7.8.1 Health care worker training on SIDS and safe sleep recommendations

Nurses, doctors, and other healthcare workers are crucial to preventing SIDS. Mothers rely on health care workers for education on how to take care of their infants. Mothers in our study cited health care workers as sources of information on infant sleeping position and bedsharing. Research has also found that mothers are more likely to practice infant safe sleep at home if they see such behaviors modeled by health care providers in the hospital.[172–174]

The Ministry could consider developing educational programs for nursing staff at antenatal, postnatal, and labor and delivery units. With an 84% skilled birth rate and a nearly 93% antenatal care attendance rate, [65] engaging nursing staff in these units will be most impactful. These could be as short as 30-minute educational sessions about SIDS and safe sleep recommendations that also highlight the importance of modeling recommended safe sleep behaviors such as placing all newborns in the unit to sleep in the supine position.[158] These educational programs could also be incorporated into existing continuous professional development (CPD) programs where healthcare workers will be required to demonstrate proficiency in safe sleep practices before recertification to practice. Informal education strategies such as the use of posters, and crib cards placed in the ward may also serve as reminders for health care workers and reinforce their knowledge. A long-term goal would be to integrate training on SIDS and safe sleep recommendations into the existing curriculum for nursing schools, medical schools, and other health care professional training institutions. To the best of our knowledge, SIDS is currently not included in the curriculum of health care professionals. It is thus not surprising that health care workers

provided contradictory messages on safe infant sleep practices to mothers.

A key barrier to implementing this campaign is resistance to these safe sleep recommendations from health care workers themselves. Given the strong societal and cultural influences on infant sleep practices, it is likely that health care workers may have similar concerns as parents about the supine position and thus, they may lack confidence when advising parents about safe sleep practices. To be successful, educational programs for health care workers should explicitly address these concerns which may be facilitated by early stakeholder engagement. Ultimately these educational programs should be geared towards creating a culture of infant sleep safety with a consistent standard of care expected of all health care workers.[158]

7.8.2 Parental/maternal education on SIDS and safe sleep practices

Nurses at labor and delivery units are ideally placed to provide initial education on SIDS and safe sleep recommendations to mothers. Several mothers in our FGD had concerns about the supine position for infants (risk of aspiration, infant comfort and choking). Most also felt that being vigilant could prevent their infants from suffering a sudden death. Using the health belief model, an individual's perception of risk directly impacts their adherence to behavior change.[175] Thus, mothers who do not perceive their infant to be at risk of SIDS may not see the need to adhere to safe sleep recommendations.

Parental education should address parental concerns about the supine position and emphasize that parental vigilance may not be enough to prevent SIDS without adherence to recommended sleep practices. Short easy to understand sessions could be held with parents especially new mothers before they are discharged home. Indeed, in a study in the

U.S., 15-minute educational sessions were held with low income mothers to address parental concerns about the supine position and perceived benefits¹⁰ of bedsharing.[176] The study found that 6 months after the intervention, mothers in the intervention group were more likely to place their infants on the back (75% vs 45%, $p<0.0001$) and less likely to share a bed with the infant during sleep (16% vs 44.2%, $p<0.0001$) compared to the control group.[176] This type of strategy could be augmented to incorporate local feedback that simultaneously address breastfeeding strategies with safe sleep practices in a culturally relevant and feasible way.

To ensure most mothers are reached with this intervention, safe sleep messages should be included in routine antenatal and postnatal care educational sessions with mothers at the antenatal and postnatal care clinic.

7.8.3 Public education and sensitization on SIDS and safe sleep practices

To ensure large scale changes in SIDS risk behaviors, a national campaign on SIDS and safe sleep might be needed. The rationale for this campaign is to provide communities and the public with objective information to assist them in making informed decisions on infant sleep practices. Safe sleep campaigns need not be expensive and can be as simple as posters at clinics, lorry parks, churches, markets, and other public spaces. Simple messages such as “ABC- Alone, Back, or Crib” explained as infants sleeping alone on the back and in a crib, can be used to raise awareness and educate the public about safe sleep recommendations.

¹⁰ Mothers perceived bedsharing to be the best way to maintain vigilance over the infant while sleeping.[176] Mothers in our FGDs expressed similar sentiments about bedsharing

The Ministry of health could consider collaborating with media houses and other international partners to roll out a media campaign with specific messages that target the modifiable risk factors of SIDS/SUID; prone sleeping, bedsharing, bundling and parental smoking. Prior research has shown that media such as television, radio and newspapers can be used effectively to reduce SIDS.[159,177] The success of these campaigns will hinge on the development of a deliberate communication plan with specific messaging on context-specific SIDS risk behaviors. These messages should be easy to understand and implement. In fact the back to sleep campaigns were successful due to the clarity and simplicity of the message to lay infants to sleep on the “back”. [159]

Further, to ensure acceptability of these campaigns influential people both nationally and locally in the community may be recruited as potential contributors and champions for these campaigns. In the U.S. for instance, involvement of champions such as Tipper Gore (wife of then vice president of the U.S. Al Gore) helped raise public awareness of the back to sleep campaigns.[159] Women in the community who have experienced SIDS should also be recruited to serve as champions. Involving local women in the community will reinforce the message that no infant is immune to SIDS. Funding for these campaigns could be sourced from international development partners such as the Gate’s foundation. Indeed the Gate’s foundation provided funding for a SIDS prevention program in the state of Washington, Indiana and Washington DC.[158]

7.9 Conclusion

Our research shows that SIDS does exist in peri-urban communities in Lusaka, Zambia with widely prevalent unsafe sleep practices. Given the lack of accurate statistics on SIDS

in Zambia, there is a need for additional research to create a more accurate picture of SIDS in Zambia. Additionally, consensus building with key stakeholders in Zambia may be required to raise awareness about the need for SIDS reduction programs and agree on optimal interventions that will be feasible and acceptable to address SIDS. A public health campaign may be prioritized as a long-term strategy to educate parents, health care workers and the public on SIDS and safe sleep recommendations. Healthcare worker education might especially be needed in a country with most mothers with educational attainment rarely beyond secondary school. By improving the knowledge and skills of healthcare workers, communication between mothers and health care workers about safe sleep recommendations will be more effective. Moreover, mothers will be more likely to practice safe infant sleep if they see such behaviors modelled by health care workers. This strategy combined with public campaigns to scale up awareness of SIDS to the public will be most impactful in a low resource setting such as Zambia. These evidence-based strategies should be considered when evaluating strategies to address SIDS in Zambia.

However, the above strategies should not be implemented in a vacuum. A deliberate strategic plan could be developed that will include consulting, involving, and collaborating with communities directly about these educational programs. These additional steps will serve to obtain feedback from communities, address public concerns and ensure buy-in of key opinion and community leaders.

APPENDIX A: SUPPLEMENTAL TABLES

Supplemental Table 1: San Diego definitional subcategories of SIDS

SIDS Subcategory	Features
Category IA SIDS (Classic features with complete investigation)	<p>Meets requirements of general definition with all the following:</p> <ul style="list-style-type: none"> - <i>Clinical</i>: Older than 21 days and under 9 months with normal clinical history including term pregnancy (≥ 37 weeks gestational age); normal growth and development; no similar deaths in siblings, close genetic relatives (uncles, aunts, and first-degree cousins), or other infants in the custody of the same caregiver - <i>Circumstances</i>: Investigation of the various scenes where incidents leading to death may have occurred, and determination that they do not provide an explanation for death found in a safe sleeping environment with no evidence of accidental death. - <i>Autopsy</i>: Absence of potentially lethal pathological findings; minor respiratory system inflammatory infiltrates are acceptable; intrathoracic petechial hemorrhages are a supportive but not an obligatory or diagnostic finding; no evidence of unexplained trauma, abuse, neglect, or unintentional injury; no evidence of substantial thymic stress effect (i.e., thymic weight less than 15 g, and/or moderate to severe cortical lymphocyte depletion). Occasional “starry sky” macrophages or minor cortical depletion are acceptable; toxicology, microbiology, radiology studies, vitreous chemistry and metabolic screening studies are negative
Category IB SIDS (Classic features with incomplete investigation)	<p>An infant death that meets the requirements of the general definition and also meets all of the above criteria for Category IA except that: investigation of the various scenes where incidents leading to death may have occurred was not performed, and/or one or more of the following analyses was not performed: toxicology, microbiology, radiology, vitreous chemistry, and metabolic screening.</p>
Category II SIDS	<p>An infant death that meets Category I criteria except for one or more of the following:</p> <ul style="list-style-type: none"> - <i>Clinical</i>: Age range — outside Category IA or IB, i.e., 0 to 21 days or 270 to 365 days; similar deaths of siblings, close relatives, or other infants in the custody of the same caregiver that are not considered suspicious for infanticide

SIDS Subcategory	Features
	<p>or for recognized genetic disorders; neonatal and perinatal conditions (e.g., those resulting from preterm birth) that have resolved by the time of death.</p> <ul style="list-style-type: none"> - <i>Circumstances of death</i>: Mechanical asphyxia or suffocation by overlaying not determined with certainty. - <i>Autopsy</i>: Abnormal growth and development not thought to have contributed to death; marked inflammatory changes or abnormalities not sufficient to be unequivocal causes of death.
USID (Unclassified sudden infant deaths)	This includes deaths that do not meet the criteria for Category I or II SIDS, but where alternative diagnoses of natural or unnatural conditions were equivocal (including cases where autopsies have not been performed)
<p>Source: Krous HF, Beckwith JB, Byard RW, et al. Sudden Infant Death Syndrome and Unclassified Sudden Infant Deaths: A Definitional and Diagnostic Approach. <i>Pediatrics</i>. 2004;114(1):234–238. doi:10.1542/peds.114.1.234 [15]</p>	

Supplemental Table 2: Phases of thematic analysis and means of establishing trustworthiness

Phase of thematic analysis	Means of establishing trustworthiness
Phase 1: Familiarize with data	Upon completion of transcription, the PI reviewed a subset of FGD and interview transcripts and documented initial thoughts about potential codes or themes.
Phase 2: Generate initial codes	The PI and RA independently read two FGDs and interviews and generated initial codes. Codes were generated inductively, allowing the data to guide our coding decisions. The initial codes were then discussed at two debriefing sessions to develop a coding framework. A code manual with definitions were generated in this phase. Disagreements were resolved through discussion.
Phase 3: Search for themes	Following agreement on initial codes, themes were generated by sorting and collating all potentially relevant data extracts. Themes were generated inductively from the data; thus data was coded without trying to fit it to any pre-existing coding frame. The analysis was data driven. Initial codes formed major themes, while new codes formed sub themes where appropriate. Codes that did not fit any main theme were kept in a miscellaneous group. Detailed notes were kept about the development of concepts and themes. NVivo 12, a qualitative analysis software (QSR International, Melbourne, Australia, www.qsrinternational.com/nvivo-qualitative-data-analysis-software/about/nvivo) was used to sort and analyze data.
Phase 4: Review themes	Coded data extracts for each theme were then reviewed by the PI to ensure they formed a coherent pattern. Individual themes were validated to determine whether the themes accurately reflect the meaning evident in the raw data. Inadequacies in initial codes and themes were revised to make them more accurate. All themes and sub themes were vetted during biweekly meetings between the PI and the RA. Themes or subthemes that did not have enough data to support them were discarded. In addition, some themes were collapsed into others.
Phase 5: Define and name themes	For each theme, a detailed analysis was written to identify the narrative that each theme tells. Team meetings were held to discuss each theme. Themes were finalized after the research team had read though all available data, coding scrutinized by other members of the research team and consensus reached about the credibility of the findings.
Phase 6: Produce report	A final report of findings was written after finalizing themes. The consolidated criteria for reporting qualitative research (COREQ) reporting guidelines were used in writing the final report. Relevant quotes were included in the narrative. Quotes were accompanied by participant numbers and site. Additional tables were used to present themes, and subthemes, related codes, and their definitions to show the coding decisions made during analysis.

Supplemental Table 3: SIDS/SUID in Africa Search Filter

Database	Search Filter
PubMed	(("Sudden Infant Death"[Mesh] OR "Sudden Infant Death Syndrome" OR "SIDS" OR "Sudden Infant Death" OR "Sudden Unexpected Infant Death" OR "Cot Death" OR "Cot Deaths" OR "Crib Death" OR "Crib Deaths" OR "Accidental Suffocation" OR "Unintentional Suffocation" OR "Strangulation in Bed" OR "ASSB")) AND ((“Africa”[MeSH] OR Africa*[tw] OR Algeria[tw] OR Angola[tw] OR Benin[tw] OR Botswana[tw] OR “Burkina Faso”[tw] OR Burundi[tw] OR Cameroon[tw] OR “Canary Islands”[tw] OR “Cape Verde”[tw] OR “Central African Republic”[tw] OR Chad[tw] OR Comoros[tw] OR Congo[tw] OR “Democratic Republic of Congo”[tw] OR Djibouti[tw] OR Egypt[tw] OR “Equatorial Guinea”[tw] OR Eritrea[tw] OR Ethiopia[tw] OR Gabon[tw] OR Gambia[tw] OR Ghana[tw] OR Guinea[tw] OR “Guinea Bissau”[tw] OR “Ivory Coast”[tw] OR “Cote d’Ivoire”[tw] OR Jamahiriya[tw] OR Kenya[tw] OR Lesotho[tw] OR Liberia[tw] OR Libya[tw] OR Libia[tw] OR Madagascar[tw] OR Malawi[tw] OR Mali[tw] OR Mauritania[tw] OR Mauritius[tw] OR Morocco[tw] OR Mozambique[tw] OR Mocambique[tw] OR Namibia[tw] OR Niger[tw] OR Nigeria[tw] OR Principe[tw] OR Reunion[tw] OR Rwanda[tw] OR “Sao Tome”[tw] OR Senegal[tw] OR Seychelles[tw] OR “Sierra Leone”[tw] OR Somalia[tw] OR “South Africa”[tw] OR “St Helena”[tw] OR Sudan[tw] OR Swaziland[tw] OR Tanzania[tw] OR Togo[tw] OR Tunisia[tw] OR Uganda[tw] OR “Western Sahara”[tw] OR Zaire[tw] OR Zambia[tw] OR Zimbabwe[tw] OR “Central Africa”[tw] OR “Central African”[tw] OR “West Africa”[tw] OR “West African”[tw] OR “Western Africa”[tw] OR “Western African”[tw] OR “East Africa”[tw] OR “EastAfrican”[tw] OR “Eastern Africa”[tw] OR “Eastern African”[tw] OR “North Africa”[tw] OR “North African”[tw] OR “Northern Africa”[tw] OR “Northern African”[tw] OR “South African”[tw] OR “Southern Africa”[tw] OR “Southern African”[tw] OR “sub Saharan Africa”[tw] OR “sub Saharan African”[tw] OR “subSaharan Africa”[tw] OR “subSaharan African”[tw]) NOT (“guinea pig”[tw] OR “guinea pigs”[tw] OR “aspergillus niger”[tw]))
The PubMed search filter was developed first and adapted to the other databases with minor modification	

Supplemental Table 4: Methodological quality scores for Case Control

Study, Year	Country	C1	C2	C3	C4	C5	C6	C7	C8	Quality Score
Molteno, 1989	South Africa	1	1	1	1	0	1	1	1	7
Belonje, 1996	South Africa	1	0	1	0	0	1	1	1	5
Gaaloul, 2016	Tunisia	1	0	1	1	0	1	1	0	5
vanDeventer, 2018	South Africa	1	1	1	1	0	1	1	1	7
<p>Criteria: C1: Case Definition: C2: Representativeness of cases C3: Selection of controls C4: Definition of controls C5: Comparability of cases and controls C6: Ascertainment of exposure C7: Ascertainment of cases and controls C8: Non-response rate</p> <p>Scoring: A maximum of 2 points was assigned to comparability, all others were assigned a score of 1 if the criterion was satisfied; 0–4 was considered low quality; 5–7 was considered medium quality; and 8–9 was considered high quality.</p>										

Supplemental Table 5: Methodological quality scores for Cohort Studies

Study, Year	Country	C1	C2	C3	C4	C5	C6	C7	C8	Quality Score
Moyo, 2007	South Africa	1	0	1	1	0	1	1	1	6
Abdallah, 2018	Uganda	1	0	1	1	0	0	1	1	5
Elliott, 2020	South Africa	0	1	1	1	2	1	1	1	8

Criteria:
C1: Representativeness of cohort
C2: Selection of non-exposed cohort
C3: Ascertainment of exposure
C4: Demonstration that outcome was not present at start of study
C5: Comparability of cohorts
C6: Ascertainment of outcome
C7: Was follow-up long enough for outcomes to occur
C8: Adequacy of follow-up of cohorts

Scoring: A maximum of 2 points was assigned to comparability, all others were assigned a score of 1 if the criterion was satisfied; 0–4 was considered low quality; 5–7 was considered medium quality; and 8–9 was considered high quality.

Supplemental Table 6: Methodological quality scores for cross-sectional/retrospective audits

Study, Year	Country	C1	C2	C3	C4	C5	C6	C7	Quality Score
Vix, 1987	Niger	1	1	1	1	0	0	0	4
Potgieter, 1992	South Africa	1	0	0	1	0	1	1	4
Wolf, 1996	Zimbabwe	1	1	1	1	0	1	0	5
Kahn, 1999	South Africa	1	1	1	1	0	2	0	6
Ibeziako, 2009	Nigeria	1	1	1	1	2	2	1	9
duToit-Prinsloo, 2011	South Africa	1	1	1	0	0	1	0	4
duToit-Prinsloo, 2013	South Africa	1	1	1	1	0	2	0	6
Okpere, 2014	Nigeria	1	0	0	1	0	1	1	4
LaGrange, 2014	South Africa	1	1	1	1	0	1	1	6
Burger, 2014	South Africa	1	1	1	1	0	1	1	6
Reid, 2016	South Africa	1	1	1	1	0	2	1	7
Saayman, 2018	South Africa	1	0	0	1	1	1	1	5
Matshazi, 2018	South Africa	1	1	0	1	1	1	1	6
Elsobkey, 2018	Egypt	0	0	0	1	0	1	1	3
Ikenna, 2019	Nigeria	1	0	1	1	0	1	1	5
Bennett, 2019	South Africa	1	1	1	1	0	1	1	6
Heathfield, 2020	South Africa	1	1	1	1	0	2	1	7
Lapidot, 2021	Zambia	1	1	1	1	0	1	1	6

Criteria:
C1: Representativeness of sample
C2: Sample size
C3: Non-respondents
C4: Ascertainment of exposure
C5: Comparability
C6: Assessment of outcome
C7: Statistical test

Scoring: A maximum of 2 points was allocated to comparability and assessment of outcome, all others were assigned 1 point if the criterion was met; 0–4 points was considered low quality; 5–7 points was considered medium quality; and 8–9 was considered high quality

Supplemental Table 7: Methodological quality scores for Case reports/Case series studies

Study, Year	Country	C1	C2	C3	C4	C5	Quality Score
Van Ieperen, 1983	South Africa	1	0	0	1	1	3
Randall, 2009	South Africa	0	1	1	1	1	4
Ker, 2010	South Africa	1	1	1	1	1	5
Dempers, 2011	South Africa	0	1	1	1	1	4
Dempers, 2016	South Africa	0	1	1	1	1	4
Heathfield, 2019	South Africa	1	1	1	0	1	4
Heathfield, 2020	South Africa	1	1	1	1	1	5
<p>Criteria: C1: Representativeness of case(s) C2: Diagnosis has been correctly made C3: Alternative diagnosis has been indicated C4: All important data have been cited C5: Outcome has been correctly ascertained</p> <p>Scoring: Each criterion was assigned a score of 1; 0–3 was considered low quality; 4 was considered medium quality and 5 was considered high quality</p>							

Supplemental Table 8: Full narratives documenting possible sudden infant death syndrome (SIDS)

Obs.	Narrative	Age at death, m
1	Informant the grandmother. Am not very sure what really happened because this baby has been fine, now this morning when I asked the mother to give me the baby so I can give it a bath, I just noticed the baby was not responding the neck was floppy when I asked the mother, she had no idea then I told her that the baby was dead. Up to now I don't know what happened.	0.13
2	The aunt stated that " the baby was ok all along until yesterday afternoon when the mother went to check on the baby, whom she left sleeping in bed, only to find the baby not breathing but warm. We took the baby to Chawama police where we got a police report then proceeded to UTH morgue were the doctor certified dead at 16:00 hrs on 03-05-18." The baby was born out of wedlock hence information given by grandfather and aunt is not much.	0.13
3	The father to the deceased stated that, " the baby was our first born. She was born at Levy Mwanawasa Teaching Hospital via SVD and normal delivery. We are really devastated with the loss of our baby. The baby woke up around 03:00 hours of 26-06-18 crying. The mother breastfed her then she slept. I woke up around 05:00hours to switch off security lights. When I went back to the bedroom, the mother woke up to check on the baby only to note that the baby was lying stiff not breathing. We took the baby to Mtendere Clinic where we were advised to go to the Police. We took the body to Kalikiliki Police where we obtained a Police report then proceeded to the UTH morgue."	0.16
4	The aunt stated that the mother reported the infant crying in the night. In the morning around 08:00, the infant breastfed well and was fine. The next time the mother went to check on the baby felt the body extremely cold and had collapsed. They rushed to Mtendere clinic, and the baby was pronounced dead.	0.2
5	The respondent to the deceased is the grandmother her narrative over the deceased was that the baby died suddenly due to too much crying since birth. No other illness was noticed before the baby died. The mother took the infant to the clinic today for BCG & OPV0 vaccinations which she did not receive soon after birth. It is not clear whether the infant was given these vaccines today. They took the body to George Police Post to get a death report and after getting the report they were referred to UTH BID section. They are going for burial soon after this process.	0.2

Obs.	Narrative	Age at death, m
6	This was a term baby with birth weight of about 2kg. The birth went well, and mum and baby were discharged after a day in hospital. On the material day, all seemed well and both mother and baby retired to bed. Around three in the morning the grandfathered the baby crying and woke up and asked the mother to breastfeed. After feeding the baby they all went back to sleep. It was around six in the morning when the mother woke up that she noticed that the was not ok. She alerted her father who upon being alerted noticed that the baby was not breathing. He alerted the neighbor who later escorted them to the police and later to UTH.	0.23
7	Informant Father: The infant was born at Bauleni CLINIC. The baby cried after birth. The baby was fine yesterday nothing appeared to be wrong even as we went to sleep. In the early hours of this morning when we wake up to check on the baby, we discovered yellow fluids coming out from the nose. The baby was NOT breathing and was already dead. We then brought the body to UTH BID section for death certification.	0.26
8	Informant the grandfather, according to the parents of the baby this baby was not ill the day before it happened the baby was very active and feeding well the baby slept after feeding the next time the mother went to check on the baby it was not breathing they called me and narrated what happened we went to the police and we were asked to do a postmortem to ascertain the cause of death but this is just a baby let it rest in peace.	0.33
9	The child was well in the evening but at night, the child started crying a lot and refusing to breast. The baby cried up to midnight then he slept. We thought the child slept because he was tired of crying, so we put him on the bed to rest. Later, towards the morning, when the mother checked on the baby, she found the baby dead on the bed.	0.39
10	The child had no history of illness but died at home at night from what I think was extreme coldness as the parents and the child slept in an incomplete house without part of the roof. The child has been calm all night and there was no sign of being unwell and nothing suspicious was noticed.	0.59
11	The grandmother stated that the baby was well when they all went to sleep. When the mother woke up around 03:00 to breastfeed, she noticed the baby was not breathing and was dead. The body was taken to police station for certification of death. Baby died in sleep.	0.66
12	The grandmother stated that, " the baby was born premature. All these days, the baby has been well until this morning when the mother went to prepare some milk to feed the baby. When she went to wake up the baby	0.72

Obs.	Narrative	Age at death, m
	to feed, she discovered the baby Was floppy, sluggish. Tried to arouse the baby but failed, that was when she called me for help. When i arrived at home, decided to take the baby to the clinic, unfortunately, on the way, the baby died."	
13	We never so anything wrong with the child yesterday the whole day and at bedtime, the child was well. The child was found dead on the bed when the parents woke up in the morning. We just took the body to the clinic for confirmation of the death, for which the cause we don't know.	0.82
14	Informant: Grandmother. The baby was born - second twin, at Chawama L 1 Hospital. She was delivered via SVD premature. The delivery was normal and uneventful. She weighed 900 grams. She was the third born of the 3 siblings. The other two are alive and health. The baby was very well all along. This morning of Monday 10/06/2016 around 04:00 hours, the mother woke up and breastfed the babies and there after the babies slept. The mother woke up around 06:00 hours to check on the babies only to find the second male twin stiff, not breathing, froth coming from the mouth. The body was still warm. The couple summoned the grandmother together rushed the baby to Chawama L1 Hospital. On arrival at the Hospital, the Doctors examined the baby and later informed them that the baby was dead. "We went to obtain a Police report at Chawama Police Post then proceeded here to the UTH morgue."	1.02
15	The mother to the deceased stated that " the baby was born as a premature in UTH on 18-04-18. Was discharged from UTH on 18-05-18. All along, since discharge, the baby was fine and breastfeeding well. This morning around 04:00 hours - 24-05-18, my usual waking up time to attend to my baby, I observed that the baby was lying stiff - was not breathing. We took the baby to UTH Police who issued us a police report then took the body to the morgue. Police report issued 24-05-18 at 08:40 hours. Cause of death said to be Fever."	1.18
16	Informant: Aunt. " The baby was well all along. Evening of Saturday 22-09 - 18, mother bathed and fed porridge to the baby. Thereafter, the baby slept and was put to bed. The mother went to attend to some other household errands; by the time she went to check on the baby, she found the baby not breathing and some porridge coming out through the mouth and nostrils. We took the baby to Chawama Police for Police report. Time of death was recorded 19:00 hours. We then proceeded to UTH morgue. "	1.25
17	The child has been well yesterday morning but later started crying a lot. Since the child is being fed on milk as she is not breast feeding from the mother, (Reason not given), the mother gave the child milk to drink, and the child drunk the milk well. After taking the milk, the child stopped	1.25

Obs.	Narrative	Age at death, m
	crying and fell asleep. Later, after minutes, the mother went to check on the baby and found the baby dead on the bed.	
18	The father stated that," the baby was delivered on 07-09-17 at Chawama level 1 Hospital. Normal delivery, bwt 3700 kgs. Received BCG and OPV On 08-09-17. Two weeks ago, developed difficulty breathing, bleeding from the mouth, chest in drawing, nasal flaring and baby was irritable. Was diagnosed as pneumonia and treated with Cefotaxine. The baby was thereafter, well and playing until Thursday 19-10-17 around 18:00hrs, when the mother left the baby sleeping in bed and went to have a bath. After bathing, the mother went back to the bedroom only to find the baby stiff, bleeding from the mouth and on the side of the mouth. We took the baby to Chawama hospital and were told the baby was already dead. This is the second baby to die in similar manner. We wish the study you are doing will reveal the causes of death to our babies."	1.38
19	Informant: Father The father said that twin babies have been fine and growing well since birth. Yesterday the twins were taken for vaccinations of opv1, dpt1, pcv1 and Rota1. It is common that babies cry after vaccinations at the clinic. We went to bed and slept. When we wake up around 04:00 hours to check on the babies, we were shocked find out that baby Israel was not breathing had died already and was stiff. We brought the body to UTH BID section for death certification and storage before burial. The other twin is fine.	1.55
20	This morning, father said baby started crying and the mother was breastfeeding her then he left for work. But even the previous day, baby was okay, but father said he got a call that baby had died at home, and they were waiting for him. He narrated to say those at home mentioned to him that the mother left baby sleeping and she was washing outside. But when her sister came wanted to see baby and got her but was surprised to see no movements from the baby and that's how they called the father.	1.58
21	Baby was ok, early morning I went for family planning with her and afterwards, I breastfeed her then put her on my back. When we reached I put her to sleep. Now she slept for a long time and when we check on her, she was cold. Then we went to report.	1.61
22	Father says the couple found the baby died in the morning.	1.61
23	Informant: Father A female baby was born at Kanyama 1 st Level Hospital on 15/05/2019, delivered via SVD, cried, and sucked well. Shx: 2nd born. First born is alive and healthy. Pmhx: Non. Medication: Non given. Onset of the Illness: The baby was well all along. They all retired to bed in the evening uneventful. Around 03:00 hours of today Friday	1.68

Obs.	Narrative	Age at death, m
	05/07/2019, the mother woke up to breastfeed the baby only to notice thick mucus plus white stuff coming from the Nostrils. The baby was not breathing. The couple shook the baby but there was no response. They rushed the baby to the Clinic where she was certified dead, hence took the body to the police for report.	
24	Grandmother says the baby was taken for routine under 5 vaccinations last week with no problems. Around 0300hrs today she heard the baby cry and asked the mother to breast feed. Mother reported that the baby breast fed well, and both later fell asleep. Upon waking up this morning that is when they discovered that baby was not breathing.	1.77
25	Informant the grandmother. The baby was just fine active and feeding very well. So yesterday after breastfeeding the baby was sleeping when the mother checked on the baby she noticed some fluid running from the nostrils when she tried to lift the baby blood started coming out and the baby was not responding, we rushed to Chawama clinic the Doctor examined the baby we were told the baby is already dead.	1.81
26	The grandmother stated that " whilst the mother was sleeping in bed, she woke up in the night to check on the baby who was sleeping by her side., only to find the baby stiff, warm and not breathing. Shook the baby but there was no response. We were summoned to see the baby after ascertaining the baby was not breathing, we took the baby to George police where we got a police report then took the baby to UTH morgue, said to be dead 03-05-18 at 23:00 hrs.	2.2
27	The grandmother stated that" the baby walk up this morning very well, breast fed and thereafter slept. The mother went outside the house to attend to some domestic errands. When the mother went back in the house, she found the baby stiff not breathing, called the grandmother together took the baby to Chawama level 1 hospital were the doctor informed them that the baby was dead, and it was at 11:45 hours. We then brought the baby to UTH morgue."	2.33
28	According to the grandmother yesterday the baby was fine, active, and feeding well. Just in the night the mother woke up to feed the baby afterwards it slept, next time the mother went to check on the baby, she observed some blood and froth coming out of the nostrils and the mouth tried to shake the baby it was already dead. That is how we went to the police.	2.6
29	We were at the funeral gathering for one of our relatives where we had to spend nights. The child has been well all along at the funeral and didn't show any signs of illness, Fever or cough, and the child was breast	2.73

Obs.	Narrative	Age at death, m
	feeding very well. I last breast fed the baby at about 05:00 early this morning and after breast feeding the baby, I put him on the mat to sleep while I continued with food preparations for the people at the funeral gathering. After about one hour, I decided to check on the baby where I had left him sleeping and found the baby dead. There was no sign of injury at all.	
30	Sudden death	2.86
31	The child had a cough last week and was taken to the clinic and got treatment. Baby apparently looked well. The grandmother found baby not to be responsive when she tried to wake her up this morning.	2.89
32	Mother put the baby to bed after breast feeding then went to check on the baby and fun found the baby died with milk coming from the nose.	2.96
33	Informant: Grandfather " The baby was born at Palabana Clinic on 27-05-2018; normal delivery via SVD. Cried and sucked well. The baby was born from a family of 2 siblings and now remaining one alive aged 4 years old. He was receiving vaccinations at Palabana Clinic. The baby was very healthy all along. Sunday 26-08-18 around midday, the mother put the baby in bed as she was sleeping. At around 14:00 hours when she went to check on the baby with a view of breastfeeding him, she found the baby not breathing hence they took the dead baby to Palabana Police for Police report then brought the body here at Uth Morgue."	2.99
34	No problems were noted. Aunt was only notified by her niece in the early hours of today that baby was not responsive.	3.19
35	As a family we are all just confused, the baby was just okey she had no problem that we can point at and say this was a problem we would lie. She was surfed in the chair while the mother was busy cleaning up. The next time she went to check on the baby she found baby motionless, she screamed asking what is going on the elderly neighbor came in only to confirm the baby was dead. Right now, she is so confused, but as a family we would like a postmortem to be done so that we know what has killed this baby. (encouraged to go ahead with the postmortem).	3.51
36	Informant: Mother The baby was fine all along. Yesterday he slept around 10 hours and when she went to check on him, she found white stuff coming out from the nose and mouth. They rushed him to the clinic where he was pronounced dead. The clinic staff requested us to bring the baby UTH for certification of death.	3.71

Obs.	Narrative	Age at death, m
37	The grandmother stated that" the baby was well all along until this morning 22-02-2018 around 04:00hrs when the mother was checking on the baby, only to find the baby not breathing. Took the baby to Mumbwa road police stations where we were advised to bring the body to UTH morgue as the baby was dead."	3.78
38	There is no history of ill health reported by the father. He said on the morning of the tragedy he left the family well and went for work. He was later called from work by the neighbor who said the baby was not ok. It was when he got home that his wife told him that the baby had been sleeping and she was outside doing some house chores. It was the neighbor who alerted her to say they were hearing the baby crying in the house. When she went o check on the baby, she found that the baby was limp and not responding to stimuli. They then called her husband who was at work. When he arrived, they took the baby to Mandeville clinic where they were informed that the baby had died, and they should go to the police. He wants a postmortem done to understand what really happened.	4.07
39	The grandmother reports being alerted to the incident on the fateful day. Upon arrival she found the baby had already died. She denies any knowledge of ill health in the baby. The mother also claimed that the baby was well with no cause for concern. She only reported that the baby cried excessively in the night prior to death otherwise she did not notice any changes in baby's behavior.	4.14
40	Uncle reports having visited the family home where the child resides earlier in the day. He found the child well with no obvious complaints from the mother and grandmother. He only received a report in the early evenings that his child had died.	4.3
41	The father stated that a month ago, the baby was admitted at UTH ICU for organophosphorus poisoning. The baby recovered and was later discharged from the hospital. The mother and her baby went to stay with grandmother out of town just for change of the environment because they had lost the first-born daughter from the same poisoning. On 25th November 2018, the baby had fully recovered and this day they were planning to come back home in town. The baby was fed porridge that morning and then slept after eating. The mother started preparing for the journey back to town. When the mother went to check on the baby who was sleeping, she discovered the baby was NOT breathing. They brought the body to UTH police station BID and was certified dead.	4.63

Obs.	Narrative	Age at death, m
42	The child was well yesterday even at bedtime. We went to bed together since we use the same bed me (father), the mother and the child. Without any noticed illness, we noticed the child dead on the bed at about passed midnight. There was no sign of injury noticed either. It was just sudden death Without any illness.	4.7
43	The auntie to the deceased stated that, " the baby was born at Chawama Clinic at term. Cried and sucked the breast well. The baby was receiving vaccinations at Chawama Clinic. The baby woke up well today Friday 10 -08-18 and was playing. The mother went outside the house to wash some clothes. The father remained with the baby inside the house attending to the porridge which was left on the brazier by the wife. When the porridge was ready, the father went outside the house to call his wife so that she could save the porridge to feed the baby, when they got inside the house, they found the baby lying on the floor frothing and breathing was slow. As they were planning to take the baby to the Clinic, she suddenly stopped breathing around 09:30 hours They took the baby to UTH Police where they obtained a Police report then brought the body here to the morgue."	5.06
44	The aunt stated that, " the mother left the baby sleeping in bed. Healthy baby. She went to attend to some household errands. When she went to the bedroom, she observed the baby was not breathing. Took the baby to the clinic where the baby was confirmed to be dead.	5.91

Supplemental Table 9: Full narratives documenting possible accidental suffocation and strangulation in Bed

Obs.	Narrative	Age at Death, m
1	<p>Informant: Grandmother The baby was well all along. The Mother and the baby went to sleep last night uneventful. This Morning of Wednesday 30-10-2019, around 05:00hours, the mother woke up to check on the baby, only to note that the baby was not breathing. The body was still warm. The grandmother was called as they live in the same household. She checked on the baby and witnessed that the baby was not breathing, had blood clots in the nostrils. She removed the clots then suddenly the blood started flowing from the Nostrils. The Mother and Grandmother sent for the father of the baby as at the time of the mother's advanced stage of pregnancy, she had gone to live with her parents up until she delivered. The Couple accompanied by the grandmother, took the body to Plain View Police Station for report then proceeded here to the UTH Morgue. Bhx. Born at Kanyama West Clinic via SVD. She cried and sucked well. The baby weighed 1900g. The mother's RVD Status when she was pregnant was NR. Body Exposure revealed mucous and blood clots clogged on the nasal floor.</p>	0.92
2	<p>The grandmother says the baby was found died in the morning with blood coming from nose and mouth. The twins were ok with no sign of illness.</p>	0.95
3	<p>Informant: Uncle Bhx: The baby was born on 03/06/2019 at Cheston Clinic. She was delivered via svd at term. Shx: 3rd born of the 3 siblings. The other 2 siblings are alive and healthy. Pmhx: Noncontributory Medication: Non given Onset of the illness: The baby was very well all along. Yesterday Thursday 04/07/2019, around 15:00 hours, the mother breastfed the baby there after the baby slept and she put her on the bed. The mother went to continue with her household errands. After 1 hour, she went to check on the baby only to note that the baby was lying in prone position muffled by the blanket. She turned the baby in supine position. She suddenly noticed that thick mucus mixed with blood were coming from the Nostrils. The baby was not breathing. She summoned the husband who tried to arouse the baby but to no avail. The couple rushed the baby to the Clinic, unfortunately could not make it. The Doctor informed the couple that the baby was brought in already dead.</p>	1.02
4	<p>Baby didn't get sick, I wanted to turn her then I felt the baby cold with blood coming from the mouth and nose. Immediately i called my neighbors and we waited until it was morning then we went to the police station then after being issued with police report we came here to the hospital. The baby was just okey the previous day, she was sucking well, no fever.</p>	1.18
5	<p>The child was not known to be sick, was well, breast feeding well. We went to bed in the evening with the child well. We use the same bed the three of us (mother, father and baby). When we woke up at night to check on the baby</p>	1.25

Obs.	Narrative	Age at Death, m
	and have the baby breast fed by the mother, we noticed the child bleeding from the nose and mouth. We dont know for how long the child had been bleeding. She was born at 8 months of pregnancy and did not cry soon after birth. The child died at home before we could start off to the clinic.	
6	The family came from Mumbwa visiting relatives here in Lusaka. The father says he cannot recall any incident of illness in the child. He is just shocked that when he woke up in the night to go to the bathroom, he discovered that the child was bleeding from the nose . Upon close inspection he realised that the child was not breathing.	1.28
7	The child has been doing well since birth. The only problem the child presented soon after birth was crying a lot and only calmed after given a breast. Last evening the child had some shot lived body hotness which disappeared without medication. Later in the night, the child had some difficulties in breathing but again recovered and slept calmly. Early this morning, we found the child lying still on the bed dead. She had some blood coming out of her mouth and nose. The right side of the chest had the skin looking reddish. The child was on drug syrup she was given at birth at the hospital to prevent the child getting HIV from the mother.	1.35
8	Following baby death, she was okey when i reached home and i did play with her but she was crying and mother breastfeed her. Then early hours as mother was checking on her realised baby has died with blood like mucus coming from the nose then we went straight to the police to report.	1.38
9	The child was born at 8 months of pregnancy and so was admitted to UTH - D11 (neonatal ICU) for three weeks. After discharge, we kept the child home for 2 weeks and the child was very well and breast feeding well. Last night, we went to bed as usual, the child breast fed well at bedtime and once at midnight. Without any apparent illness, the child was found dead in the morning on the bed where he was sleeping. We could not understand the cause of the death. The only thing we noticed was that the child had vomitus in the mouth which were still oozing from the mouth.	1.41
10	Verbal Autopsy. Informant: Mother P/c. . Bleeding from the Mouth and Nostrils x few hours Onset of the Illness: The baby was well all along. Yesterday Tuesday 18/02/2020, the mother took the baby in the morning to Kanyama Level 1 Hospital for vaccinations there after went back home uneventfully. The baby was well all day. In the evening the mother went to sleep along with the baby uneventfully. The Mother woke up around 04:00 hours of today Wednesday 19-02-2020 to breastfeed the baby and thereafter she put the baby to sleep. Around 08:00 hours today, she woke up to check on the baby, only to find the baby was bleeding from the Nostrils and Mouth. He was not breathing but the body was still warm, hence she rushed the baby	1.61

Obs.	Narrative	Age at Death, m
	to Kanyama Level 1 Hospital accompanied by her neighbor as her husband was away to the Farm. Upon arrival at the Hospital, the baby was rushed in the emergency room where the medical staff attended to him and later confirmed that, he was brought dead. Bhx: Born at Kanyama Level 1 Hospital at term via cesarean section due to Breech presentation. The baby cried and sucked well following delivery. The baby was the 5th born of 5 offspring. The remaining 4 live children are said to be all health. Exposure of the Body: Revealed very healthy baby with dried blood clots on the floors of the Mouth and Nostrils.	
11	Informant the grandmother. We are also confused because this baby from yesterday it was just fine and very active. The mother said she had only fed the baby once in the night but then this morning when the mother woke up, she noticed that the baby was not breathing quickly went to tell the neighbor who also came and confirmed that the baby was not breathing she also noticed fluid like milk coming out of the baby's nostrils. Went to report to the village headman who suspected foul play and asked the police to arrest the mother to the deceased so right now she is in the police custody. The father travelled to month we don't know what to tell him because this was his firstborn.	1.68
12	Informant: Father. The baby was born at Chawama 1st Level Hospital in multiple twin pregnancy at preterm (8 months). She was born via Svd uneventful as the 1st twin. She was the 4th born of the 5 siblings. All the other 4 remaining siblings are alive and health. The babies were fine by the evening. They were breastfed and put to sleep by their mother. Around 19:00 hours of Monday 10/06/2019, the mother woke up to change the babies' nappies. She noted that the 1st twin was not breathing but the body was warm. The baby was bleeding from the Nostrils and the eyes were swollen. The couple rushed the baby to Chawama 1st Level Hospital, as they arrived at the Hospital the Doctor's examined the baby and informed them that the baby was dead.	2.33
13	Verbal Autopsy. Informant: Aunt Pc : . Bleeding from the eyes. Frothing from the mouth and nostrils * Duration not known. The baby was very fine and healthy all along. THE Mother went to bed to sleep along with the baby in the evening of Thursday 06-02-20 Uneventfully. Early hours of the Morning of today Friday 07-02-20, around 01:00 hours; the Mother woke up to check on the baby and noted that, the baby was not breathing. She was bleeding from the eyes and froth was coming out from the Mouth and Nostrils. Upon noting that the baby was not breathing, the baby was rushed to the University Teaching Hospital- Casualty department where the Doctors after examining the baby, informed the parents that the baby was already dead. Bhx: Born at Sikanze Police Hospital at term via Svd. Cried and sucked well. Only Child According to the parents, the baby's Vaccination record was	4.04

Obs.	Narrative	Age at Death, m
	up to date. Exposure of the body; Revealed some dried blood Stain on the lower left eyelid on a very healthy female baby.	
14	The Aunt to the deceased stated that " The baby was well all along. Single young mother (divorced) with 3 siblings living in a family cottage. The surviving 2 siblings are all in good health. The baby woke up around 21:00 hours in the night of Tuesday 31-07-18 crying. The mother woke up, cuddled and breastfed the baby until he slept. The mother woke up early hours of Wednesday 01-08-18 to prepare porridge for the baby. She did not check on the baby as she took it for granted that the baby was sleeping well. After having prepared the porridge, she went back to the bedroom to wake up the baby so that could feed him. She uncovered the baby off the blankets and suddenly noted that the baby was lying stiff and not breathing, milk was flowing from the mouth and nostrils and was cold to touch. The mother summoned other family members who accompanied her to Makeni police Post where they obtained a Police report around 04:00 hours then proceeded to the Uth Morgue."	4.27
15	Baby was fine the past days and also before we went to bed. At night she cried but thought it was normal cry. Around 04 in the morning noticed baby had cloth in the mouth and we went to report to the Police.	5.19
16	What I (grandmother) can say is that the child was not sick as such, it was the mother who was drunk who forgot that she was with a baby on the same bed and rolled over the baby. Yesterday, in celebration of Christmas, the mother decided to go for a drink with friends, but I (grandmother) got the baby from her. But when she came back from drinking, she got the baby in order to breast feed him. Then she went to her home since it was late in the evenings. Knowing that she was drunk last evening and that she has a baby, I decided to check on her in the morning. I found her crying with the baby on the bed. The child was dead with vomitus and blood from the mouth and nose. The abdomen looked compressed. And from that I new that she rolled over the baby at night.	5.72

Supplemental Table 10: Representative narratives documenting symptomatic deaths due to respiratory causes

Obs.	Narrative	Age at Death, m
1	Last month the baby developed cough and the baby was taken to the clinic and received amoxicillin antibiotic for 5 days and the baby got better, was sucking well. On the 15 th of Oct. Baby developed a flu with a cough that was in the morning it got worse in the evening same day then we rushed the baby to the clinic upon arrival we were told that the baby must have died on the way because there was no sign of life, and we were told to go to the police.	2.66
2	According to the grandmother the baby has not been well for some time it only lived well in the first month of life thereafter it got sick it had pneumonia and they were admitted in UTH for 8 days and they were discharged but still the baby remained unwell, but they didn't go back to UTH for review instead we went to the private hospital where the baby was put on injections for 10 days. (Can't remember the name of the drug). Still the baby did not recover completely it was just on and off with fever diarrhea and the cough continued until yesterday in the night the baby cried a lot and in the morning the mother tried to feed the baby it refused and then she put the baby at the back, the next thing the mother saw was the baby's neck became floppy that's how she called for help rushed to the clinic only to be told that the baby is dead and we were told that the baby had no blood.	3.71
3	When the baby was born it suffered flu which was treated there and then. Since then, the baby has been fine active and feeding well until yesterday when the baby developed flu and coughing but it was not that bad. We slept and this morning my wife tried to wake up the baby, but it was not responding she called me when I went and checked on the baby only to discover the baby was not breathing. Rushed to the clinic they just confirmed it and we were told to go to the police.	1.02
4	The baby has been suffering from chest pains and coughing for 2 weeks now. Earlier we took the baby to 173 anyama clinic and was admitted for 2 days then we were discharged stayed home for few days just yesterday the baby started breathing fast again and the coughing worsened today we decided to take the baby to the clinic just upon arrival we were told the baby is dead.	3.06
5	Informant the grandfather. The child was with mother in Lusaka west, she told us that the baby started coughing 6 days ago it was taken to the clinic where they were given a prescription to buy the medicine. But then 2 days ago the cough got worse the baby was even failing to breastfeed that was when they rushed to our place so that we could help with the money to buy medicine, as we were planning to go to the clinic the baby died, and we went to the police.	1.64

Supplemental Table 11: Representative narratives documenting asymptomatic deaths due to other causes

Obs.	Narrative	Age at Death, m
1	The baby was just ok except for some fever which was not serious after midnight we only observed some white stuff coming through the nose and the baby was not breathing took her to the clinic only to be told the child was dead go to the police.	0.36
2	The baby has been fitting since birth because it was a difficult delivery the baby did not cry; this has been on and off, but we used to manage at home. Yesterday the baby developed fever so this morning we took the baby to the clinic, and we were referred to UTH it was on the way that we discovered the baby was not breathing when we reached the hospital we were told to go to the police and report a death.	2.53
3	Informant the grandfather. This is a twin, and they were born prematurely but they were just okey until 3 days ago when we noticed the baby was having a problem when swallowing feeds so it could only take very little feeds at a time but then today it was not able to swallow anything by the time, we were preparing to go to the clinic the baby died that is how we went to the police.	1.87
4	Informant the grandmother. On Friday the baby developed a high temperature we took the baby to the clinic, we were given Panadol syrup, Seprin syrup and Piriton which we started giving the baby but then on Monday around 04:00hrs the condition got worse the baby started convulsing the whole body rushed the baby to Kanyama clinic and we were referred to UTH on the way the breathing changed when we arrived just when the doctor was examining the child it stopped breathing and we were told the baby has died we need to go to the police.	5.98
5	Informant the auntie, yesterday the was just fine until around 01:00hrs when the baby developed some fever and started crying, refusing to breastfeed we rushed the baby to Chilenje clinic, before we started off the baby's breathing changed it started gasping, upon arrival at the clinic we were told the baby is already dead that is when we went to the police.	0.49
6	The baby was born prematurely but it was very active and feeding very well but after 4 days the baby developed a high temperature took the baby to the hospital and was admitted, it only stayed 3 days in hospital, and it was discharged. But then yesterday the baby after breastfeeding was put to sleep the next time the mother went to check on the baby it was dead. In hospital the baby was treated for presumed sepsis in syndromic baby and was given Cefalexin and Cloxacillin information got from the discharge slip.	0.33

Supplemental Table 12: Closest Clinic to SUID household (Household Location)

Closest Clinic to Household (Location)	N (%)
Chawama	13 (22.0)
Kanyama	13 (22.0)
Chipata	5 (8.0)
George	5 (8.0)
Mtendere	5 (8.0)
Bauleni	2 (3.0)
Chestone	2 (3.0)
Chilenje	2 (3.0)
Matero Main	2 (3.0)
Chianama	1 (2.0)
Kalingalinga	1 (2.0)
Kamwala	1 (2.0)
Mandevu	1 (2.0)
Matero Reference	1 (2.0)
Garden Clinic	1 (2.0)
Kanyama West Clinic	1 (2.0)
Kazimva clinic - Lusaka west	1 (2.0)
Nampundwe Clinic	1 (2.0)
Palabana	1 (2.0)
St John's Medical Center	1 (2.0)

Supplemental Table 13: Major themes and codes from FGD sessions

Major theme	Sub-theme	Codes
Awareness and Knowledge of SIDS	Awareness	- <i>Heard about SIDS-like deaths in the community</i>
	Presumed cause of SIDS-like deaths	- <i>Suffocation from overlay or soft-bedding or sleep position</i> - <i>Uncertainty about cause</i> - <i>Baby-dumping</i> - <i>Sick Child</i> - <i>Fall from bed</i> - <i>Milk aspiration</i>
	Mechanisms to prevent SIDS	- <i>Vigilance or monitoring of child</i>
Sleep position	Reason for sleep position	- <i>Prevent aspiration/vomiting</i> - <i>Easy for infant to breathe well</i> - <i>Infant sleeps well</i> - <i>Chosen position is stable</i>
	Information sources	- <i>Family and friends</i> - <i>Healthcare providers</i>
Co-sleeping/ bedsharing and room sharing	Reasons for co-sleeping or room sharing	- <i>Easy to monitor child</i> - <i>Convenient for breastfeeding</i> - <i>Can't afford separate bed or room for child</i> - <i>Helps in maternal/infant bonding</i>
	Concern about smothering/mechanism to prevent smothering	- <i>Conscious of sleeping child and</i> - <i>Sleep carefully</i> - <i>Protect from sleeping father</i>
Parental alcohol use	Aware of harms of alcohol on infant	- <i>Confuse unborn child</i> - <i>Brain damage</i>
	Reasons for alcohol intake	- <i>Pregnancy related cravings</i> - <i>Perception that child will be fat and beautiful</i> - <i>Underestimate harms of alcohol</i>
	Other women drink	- <i>Know other women in community who drank while pregnant</i>

Major theme	Sub-theme	Codes
Breastfeeding	Duration of EBF	- <i>Months of exclusive breastfeeding</i>
	Reason for breastfeeding	- <i>Infant grows well on breast milk</i> - <i>Prevent diseases</i>
	Reason for starting complementary food early	- <i>Breastmilk is inadequate for child</i>
Sleep surface	Blankets and other covering	- <i>Spread blanket for baby to sleep</i> - <i>Pillows seldom used</i>
	Type of mattress	- <i>Preference for soft mattress</i>
Parental smoking	Aware of harms of tobacco	- <i>Destroys lungs or chest</i> - <i>Can cause cancer</i> - <i>Likely cause SIDS</i> - <i>Stillbirth</i> - <i>Brain damage</i>
	Other tobacco	- <i>Feel good</i> - <i>Warms body (Sexual stimulant)</i> - <i>Tightens vagina</i> - <i>Cause cancer</i>
	Other women smoke	- <i>Know other women in community who smoke</i>
Bundling with blankets	Reason for bundling	- <i>Keep infant warm</i>

Supplemental Table 14: Maternal awareness and knowledge of SIDS (perspectives on SIDS)

Theme	Sub-themes with illustrative quotes
<p>Awareness and Knowledge of SIDS</p>	<p>Aware - heard stories of SIDS-like deaths in the community</p> <ul style="list-style-type: none"> - “My sister in-law had put the child to bed there after they just found the child dead” (P1, Chawama 2) - “According to what I read it was due to suffocation they slept at night so to my thought I think the mother was breast feeding then she fell asleep then the breast covered the nose of the baby causing suffocation that is what I thought” (P1, Chilenje-3) - “I just heard around but have never seen. I just heard maybe that the person had a baby then the baby just died while sleeping, I just heard but I don’t know anyone. Some people said maybe it is time, you can’t really specify, maybe the baby was sick because the baby was playing the baby cannot be poisoned maybe it was God”. (P4, Chilenje-2) <p>Presumed cause of SIDS-like deaths</p> <p><i>Smothering or overlay:</i></p> <ul style="list-style-type: none"> - “We hear them that the baby has died from home, maybe they have slept on the baby, others they say they just found them dead” (P4, Chawama-2) - “I just heard but I have never seen there was a woman……. when they went to sleep the baby was just okay and was 1 week old, I don’t know if she slept on the baby only to wake up to find the baby dead, then she called her parents that come and see what has happened in the bedroom. But I just heard, a friend of mine narrated it to me” (P1, Chilenje-1) <p><i>Soft-bedding suffocation:</i></p> <ul style="list-style-type: none"> - “Sometimes you may cover the baby in blankets they may suffocate, sometimes they have hiccup, or maybe they have not slept well, that may cause death” (P5, Chawama-1) - “there is you find that you cover them [with blankets] then they have rolled over it covers their head, of course it may cause suffocation” (P3, Chawama-2) <p><i>Positional suffocation:</i></p> <ul style="list-style-type: none"> - “I just heard that the child died in sleep maybe was not feeling well they don’t talk or maybe the position they

Theme	Sub-themes with illustrative quotes
	<p><i>slept in” (P5, Chilenje-1)</i></p> <p><i>Uncertain or Unexplained</i></p> <ul style="list-style-type: none"> - <i>“I heard my neighbor had a 3 month old baby, they woke up in the morning the baby was okay after breast feeding the baby slept the mother went to wash out side then when she went back inside just found the baby was dead she didn’t know how the baby died only found the baby was not breathing” (P3, Chilenje-2)</i> - <i>“.....what causes this sometimes is, you find you are busy working outside then you leave the child on the bed, you just go to find she is dead, what has killed him you don’t know” (P3, Chawama-1)</i> <p><i>Baby-dumping:</i></p> <ul style="list-style-type: none"> - <i>“like us where we stay one was pregnant she took medicine gave birth and threw the child in the toilet” (P4, Chawama-1)</i> - <i>“I have never had a child die, but I heard they say a lot that they have found a child is dead because they dump children in toilets others die in the house” (P2, Chawama-2)</i> - <i>“Others they dump children because they don’t love them or even putting in a plastic because they don’t love the baby” (P3, Chilenje-1)</i> <p><i>Sick child:</i></p> <ul style="list-style-type: none"> - <i>“I heard from my neighbor the child it’s like had (inaudible) they took him at the hospital he recovered then they brought him home it seems had another attack in the night in the morning was found dead” (P5, Chawama-1)</i> - <i>“I heard of it the child was sick she slept then when waking up her she thought that is just how the baby is unwell then prepared porridge now to go and carry the baby only to find the baby is dead” (P6, Chawama-3)</i> <p><i>Fall from bed:</i></p> <ul style="list-style-type: none"> - <i>“Sometimes we leave them on the bed while these children we have crawl, they may fall from the bed they die.” (P2, Chawama-1)</i> <p><i>Milk aspiration:</i></p> <ul style="list-style-type: none"> - <i>“What I can say is that babies you can’t know what can happen you find that maybe you as a mother you want to sleep then the baby was breast feeding..... then you sleep that one also causes the milk to go where it is not</i>

Theme	Sub-themes with illustrative quotes
	<p data-bbox="472 362 1241 391"><i>supposed to go then you just find the baby dead” (P2, Chilenje-3)</i></p> <p data-bbox="375 407 730 436"><i>Mechanisms to prevent SIDS</i></p> <ul data-bbox="426 459 1793 756" style="list-style-type: none"> <li data-bbox="426 459 1793 524">- <i>“this is my first born so what I do is when we sleep where the baby is facing that is where I face too (everyone laughs) I don’t know what might happen” (P2, Chilenje-1)</i> <li data-bbox="426 540 1793 605">- <i>“you can’t leave the child for a long time you have to leave the child with someone even when sleeping at least there has to be someone, its either I leave the child with the aunty or the grandmother” (P5, Chawama-3)</i> <li data-bbox="426 621 1793 756">- <i>“I think we should wake up at night, especially the young ones because they wake up in the middle of the night to suck, so if you notice that from the time you slept the baby hasn’t woken up you should worry. With me if I reach 01 without noticing anything I wake up to check the pulse or the heartbeat then I lift him up, if she moves then I know she is okay. I also check for the sleeping position, if she turns then I know she is okay” (P5, Chilenje-3)</i>

Supplemental Table 15: Maternal perspectives on unsafe sleep practices

Themes	Sub-themes with Illustrative Quotes
<p>Sleep position</p>	<p>Reason for side/prone sleep position</p> <p><i>Prevent aspiration:</i></p> <ul style="list-style-type: none"> - <i>“At times after breast feeding when the baby faces up the milk will come out as vomit then it might enter the nose the baby won’t breathe well. At times when they sleep like this [supine], they don’t breathe well so for the sides its better because when they vomit it drops on the sides” (P4, Chawama 3)</i> - <i>“I put my baby to sleep on his sides because I think it’s safe even when the baby sleeps and vomits it’s easier for them to come out than when you put for the back it won’t even come out it will lead to choking” (P5, Chilenje-3)</i> - <i>“Can be for the sides or for the stomach it is the same because when the baby faces upright maybe was from breast feeding the milk might come out through the nose which is not good for the baby so position is also important can either be for the sides or stomach” (P5, Chilenje-1)</i> <p><i>Infant breathes well:</i></p> <ul style="list-style-type: none"> - <i>“it’s safe for me when it comes to rolling rather than making him to sleep with the stomach facing down, he might place the nose and fail to breath” (P2, Chawama-2)</i> - <i>“... so that it is easy for him to breathe” (P4, Chilenje-3)</i> <p><i>Infant Sleeps well:</i></p> <ul style="list-style-type: none"> - <i>“Me the position is that for the sides (baby cries) (inaudible) children differ especially mine when I put him the other, they don’t sleep well but for the sides they sleep well” (P4, Chawama-1)</i> <p>Informational sources</p> <p><i>Family:</i></p> <ul style="list-style-type: none"> - <i>“I: who do you listen to for advice on how to place your baby to sleep P: our parents because we were once babies, so they told us how to keep the baby” (P4, Chawama-2)</i> - <i>“When she was still a baby like when she was born I had my mother and my sister in-law but now as she is growing it’s me and my husband so we have noticed that now she is able to do this and that so I think we are also able to say this is better” (P1, Chilenje-3)</i>

Themes	Sub-themes with Illustrative Quotes
	<p><i>Healthcare workers:</i></p> <ul style="list-style-type: none"> - <i>“I: who do you listen to when they tell you the position for placing the baby to sleep P: just here at the clinic they teach us” (P2, Chawama-3)</i> - <i>“I: who do you listen to on the position of placing the baby to sleep P: the nurses at the hospital when they teach us” (P6, Chawama-3)</i>
<p>Co-sleeping/ bedsharing and room sharing</p>	<p><i>Reasons for co-sleeping or room sharing</i></p> <p><i>Easy to monitor infant:</i></p> <ul style="list-style-type: none"> - <i>“I sleep with my child because I have to sleep with my child, maybe at night the blanket covers the baby, so I have to be checking on the baby, so I have to sleep with the baby even when wants to feed I just carry her and start breast feeding perhaps it becomes cold I cover her” (P5, Chawama-3)</i> - <i>“I share the same bed and it is because it is easier for me to check the breathing, to feed him, to turn him when he is sleeping than him sleeping in another room” (P4, Chilenje-3)</i> - <i>“Maybe the child you put them to bed they are okay then at night the temperature rises so that is what we fear maybe they are sick they drop or maybe the thieves steal your baby or do something to the baby so unless when the child grows, he or she can be able to defend herself” (P5, Chilenje-1)</i> <p><i>Convenient for breastfeeding:</i></p> <ul style="list-style-type: none"> - <i>“If you have a child who is still an infant you have to sleep with them so that when they cry you breast feed them you can’t be managing to wake up you go and breast feed them. When you are sleeping it’s the same as being dead now if the child is near, we easily tell when the baby moves especially when they are 1 month, 10 months you should sleep with them on the same bed” (P1, Chawama-1)</i> <p><i>Can’t afford separate room:</i></p> <ul style="list-style-type: none"> - <i>“I sleep with my child on the same bed, same room here in Lusaka. Our stay is not good unless our friends from high-cost area who sleep some meters apart” (P1, Chawama-1)</i> <p><i>Mechanisms to prevent smothering</i></p> <ul style="list-style-type: none"> - <i>“You just have to be conscious, ensure you see the position that he or she is sleeping. For me, I make sure that I put the baby where she can’t fall and me as a mother am careful I can’t sleep on her” (P, Chawama-1)</i>

Themes	Sub-themes with Illustrative Quotes
	<ul style="list-style-type: none"> - <i>“The mind is alert we know that there is the baby here when the father is this side you know that the baby is on the middle so when turning you are careful the mind is always alert” (P7, Chilenje-2)</i> - <i>“... yes, especially when the baby is growing, they like touching things, making movements, so you just have to be careful, you even put pillows to prevent the baby from falling” (P5, Chilenje-1)</i>
Sleep surface	<p data-bbox="390 526 730 553"><i>Blankets and other covering</i></p> <ul style="list-style-type: none"> - <i>“we just fold a blanket for the child we lay him down and get another blanket we put for them to put the head so that they sleep well” (P4, Chawama-1)</i> - <i>“On the mattress that I lay on I use her blanket because it is a little thick that is what I use to put down” (P1, Chilenje-3)</i> - <i>“As for me even on the bed with a big mattress I get this baby blanket I fold it then I spread where they sleep, same in the village where you don’t have a bed you sleep on the ground, we get a blanket we spread for the baby” (P5, Chawama-1)</i> <p data-bbox="390 824 779 852"><i>Preference for soft sleep surface</i></p> <ul style="list-style-type: none"> - <i>“We need to spread where the baby sleeps so that it can be soft” (P1, Chawama-2)</i> - <i>“It has to be soft so that the baby would sleep comfortably” (P5, Chawama-3)</i> - <i>“It should be soft because you can’t put the baby where it is hard” (P2, Chawama-3)</i>
Bundling with blankets	<p data-bbox="390 1008 806 1036"><i>Reason for bundling with blankets</i></p> <ul style="list-style-type: none"> - <i>“I was saying that the child has his blanket first, you start with their blanket then you put your blanket on top to keep them warm, so we start with their blanket and put ours, then we also join them to keep them warm” (P2, Chawama-1)</i> - <i>“.. yes, we use blankets.....to avoid them from freezing” (P5, Chawama-2)</i> - <i>“I: do you use a blanket I have seen you have a shawl P: yes, to prevent them from feeling cold” (P1, Chawama-2)</i>

Supplemental Table 16: Maternal perspectives on parental alcohol or tobacco smoking and breastfeeding

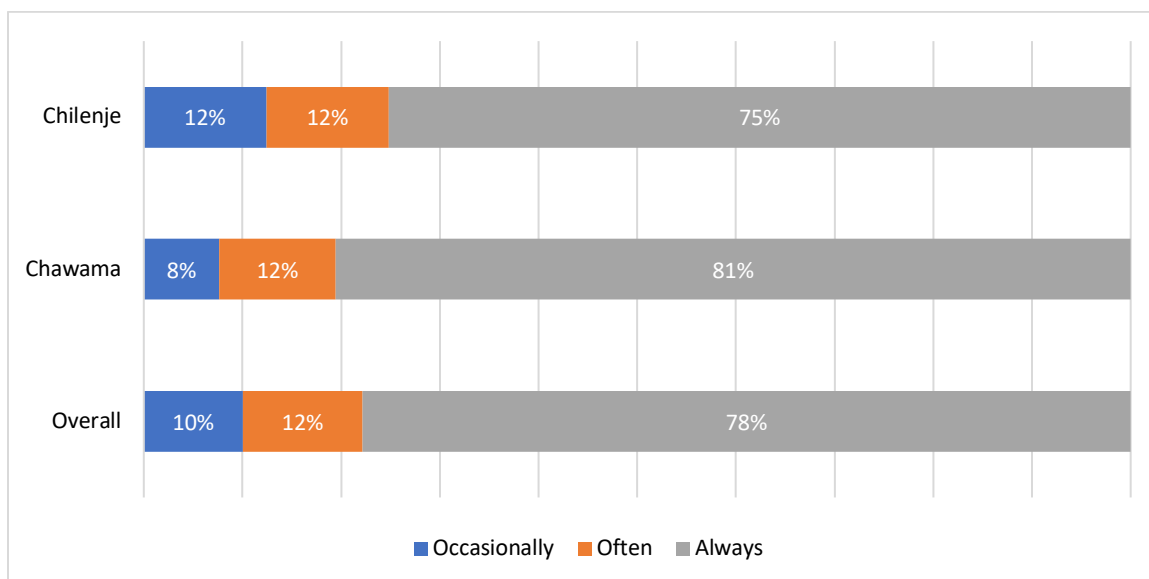
Themes	Sub-themes and illustrative Quotes
<p>Parental alcohol use</p>	<p><i>Reasons for alcohol intake</i></p> <p><i>Pregnancy related craving for alcohol:</i></p> <ul style="list-style-type: none"> - <i>“alcohol I took on my first born child what causes that is the pregnancy takes us differently others when they are pregnant they just want to eat fruits, sour, cold tea others sugar solution, though cold things they don’t allow at the clinic even beer its cold that is why they don’t allow, it gives a problem to the child’s skin others brain so beer they don’t allow now the problem us who are pregnant we have that thirsty so mean how I used to drink I was mixing milk, sugar with chibuku shake shake I put in the jar I used to take a day I cup when I feel thirsty not every day” (P1, Chawama-1)</i> - <i>“Yes, they do depending on the appetite they have, you find sometimes the baby wants them to drink beer. When they drink that is when they feel better..... I think because pregnancy comes in different ways, others they will be craving for this and that....” (P2, Chilenje-1)</i> - <i>“.. yes, even my sister in-law, my co-sister in-law, she was craving but not every day but when she feels like then she drinks” (P3, Chawama-2)</i> <p><i>Desire to have a beautiful child:</i></p> <ul style="list-style-type: none"> - <i>“I saw someone drink who was pregnant. Some they drink shake shake to give birth to a beautiful child..... they are many” (P5, Chawama-1)</i> <p><i>To cope with problems:</i></p> <ul style="list-style-type: none"> - <i>“There are many who drink beer, they even smoke nsunko, because most women think that when they have a problem it will end with beer but by the time it is morning the problem will come back. It is better you remain sober so that you ask someone who can give you an idea if it’s a business you start beer is bad but, on my side, I don’t drink beer” (P1, Chilenje-3)</i> <p><i>Other women drink</i></p> <ul style="list-style-type: none"> - <i>“I saw someone drink who was pregnant” (P5, Chawama-1)</i> - <i>“I don’t drink but I see people drink like the ladies from the bars you find that they drink even when they are pregnant” (P4, Chawama-2)</i>

Themes	Sub-themes and illustrative Quotes
	<ul style="list-style-type: none"> - <i>“They are many who drink even with heavy pregnancy just starting from day one until they give birth they are with beer” (P6, Chilenje-3)</i> - <i>“Yes, I have a neighbor we both were pregnant mine was small but hers was big, but she was drinking beer” (P3, Chawama-3)</i> <p>Aware of harms of alcohol on infant</p> <ul style="list-style-type: none"> - <i>“I don’t drink but I see people drink like the ladies from the bars you find that they drink even when they are pregnant so you find those things are toxic and they affect the baby inside that may cause the baby to die in the womb, so alcohol is dangerous for our unborn babies” (P4, Chawama-2)</i> - <i>“I will just add on what R5 left, when we are pregnant at the clinic, they give us drugs they give us for blood appetite now if there is alcohol the drugs won’t be working so your health and that of the baby will be affected so in the future it will result into a problem” (P1, Chawama-3)</i> - <i>“So, you should not drink during pregnancy it can cause a lot of problems not only that even after the baby is born, we heard it can cause brain damage, there are so many things it can do to the baby” (P5, Chilenje-3)</i> - <i>“I also know the effects of drinking beer while you are pregnant so I was reading something, the most dangerous stage for drinking beer while you are pregnant is from 0 to 3 months, that is when the baby is forming the brain, but you can drink not just excessive” (P4, Chilenje-2)</i>
Parental smoking	<p>Aware of harms of tobacco</p> <ul style="list-style-type: none"> - <i>“Smoking is bad with or without pregnancy its bad because it destroys in the body” (P3, Chawama-1)</i> - <i>“Smoking is bad it destroys the lungs, it causes cancer it just causes a lot of diseases” (P5, Chawama-1)</i> - <i>“Cigarette is harmful to everyone they are times when someone used to smoke while pregnant but gave a normal birth then you also want to try then things don’t go well perhaps your immune system is not that strong it causes the child to die in the womb or after birth” (P6, Chilenje-3)</i> <p>Other tobacco</p> <ul style="list-style-type: none"> - <i>“I had a best friend who used to smoke nsunko putting it in the nose, and mouth but she was pregnant. We advised her that nsunko was not for pregnancy. Even at the clinic when they know, they will give you a form to go to the police because any problem they will blame the doctor, that they didn’t attend to the child while it is the mother who brought that problem a pregnant woman does not need to smoke those things are harmful” (P1, Chawama-1)</i>

Themes	Sub-themes and illustrative Quotes
	<ul style="list-style-type: none"> - <i>“Okay let me help her mostly if you have ever heard that a lady should be warm so there are substances that women take, though others say it is faster than anything else, some puts in the mouth and nose although some put in the vagina that it keeps warm and tightens. I think none of the types is good because if it has the capacity to burn you what more down there what can it do, imagine you are pregnant, you put that stuff down there it will go into your system and then it finds where the baby is so it can be harmful to the baby” (P5, Chilenje-3)</i> <p>Other women smoke</p> <ul style="list-style-type: none"> - <i>“Me I can’t lie I have never smoked but I saw a lot of people who smoke just two days ago I saw one who is 15 years was smoking and drinking beer and the mother used to sale kachasu (Local win) so that boy has swollen legs” (P2, Chawama-1)</i> - <i>“I have never smoked unless my sister she smokes even when pregnant” (P3, Chawama-1)</i>
Breastfeeding	<p>Duration of EBF</p> <ul style="list-style-type: none"> - <i>“I started at 4 months though here they say we start at 6 months, but it depends, maybe the milk is not enough we feed them” (P5, Chilenje-1)</i> - <i>“I breast feed until 6 months” (P5, Chilenje-3)</i> - <i>“I: in which month did you start giving the baby other foods P: at 7 months” (P5, Chilenje-2)</i> <p>Reason for breastfeeding</p> <ul style="list-style-type: none"> - <i>“we do that because we learn that it has nutrients coming from the mother to the baby” (P6, Chilenje-2)</i> - <i>“breast milk is good for the baby it has all the vitamins” (P1, Chilenje-2)</i> - <i>“I want my baby to be healthy, the breast is very important to the child so I have to breast feed up to 6 months that is when I will introduce porridge” (P3, Chilenje-3)</i> <p>Reason for starting complementary food early</p> <ul style="list-style-type: none"> - <i>“I: what made you to start giving them food R4: because the breast was not producing enough milk” (P4, Chawama-1)</i>

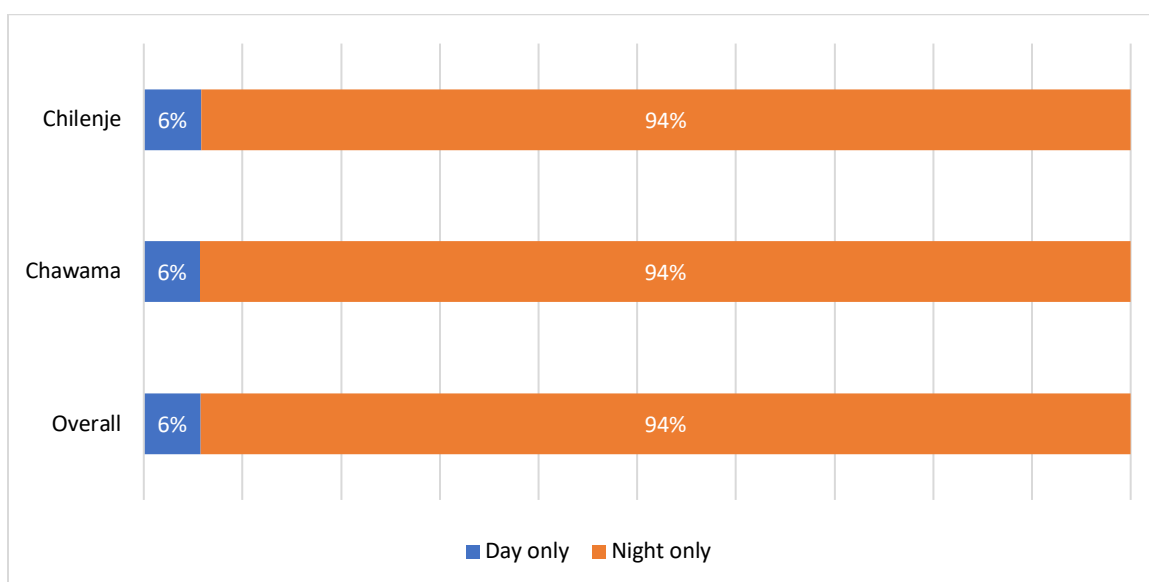
APPENDIX B: FIGURES

Supplemental Figure 1: Frequency of bedsharing, overall and by study site



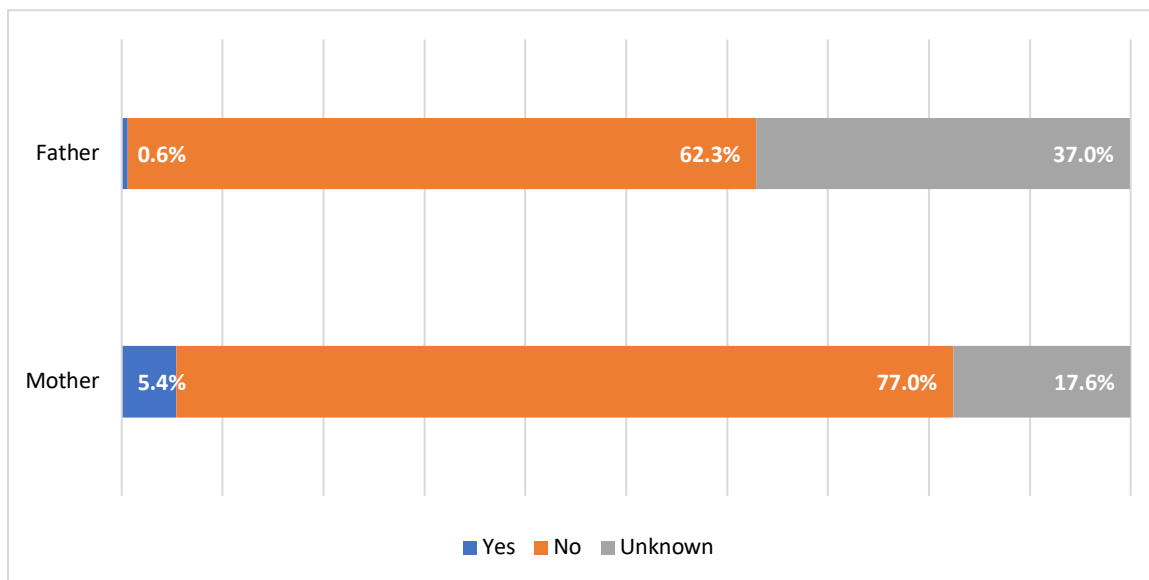
**Data in this figure are restricted to the subset of participants who chose these three options

Supplemental Figure 2: Nighttime and daytime bedsharing of infant with mother

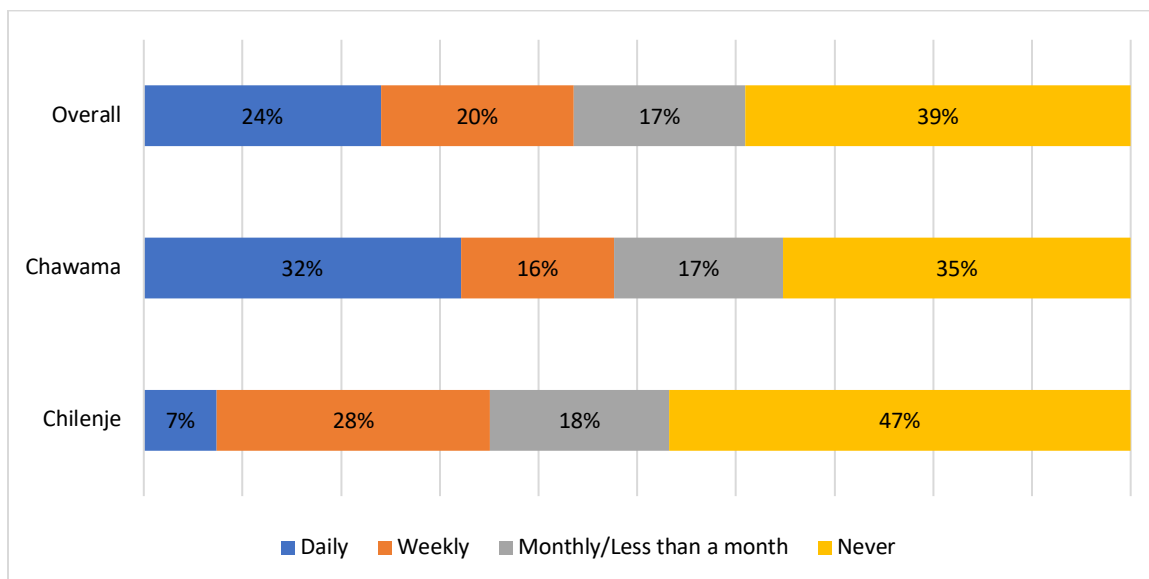


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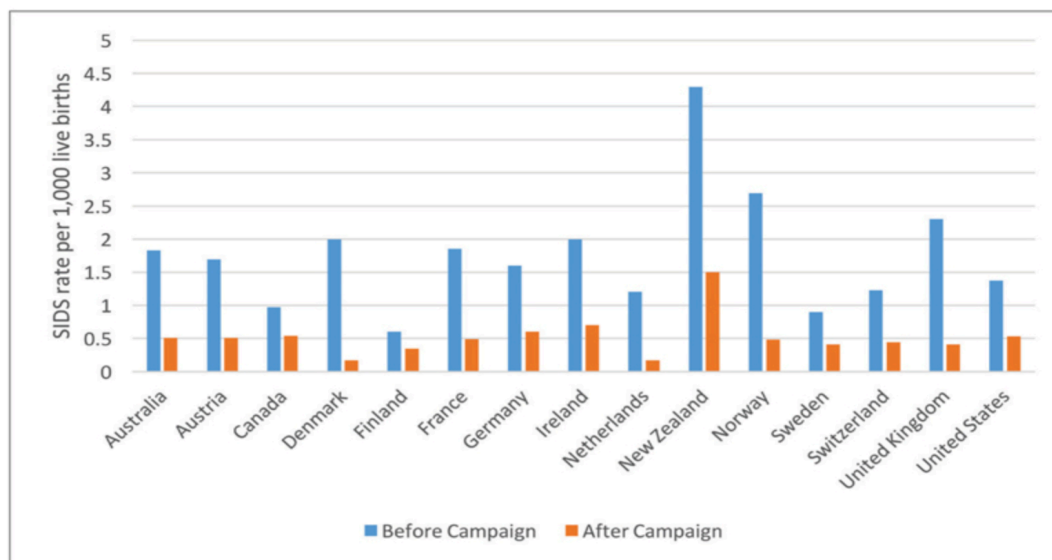
Supplemental Figure 3: Maternal and paternal history of mental illness



Supplemental Figure 4: Frequency of exposure to smoke from charcoal/firewood



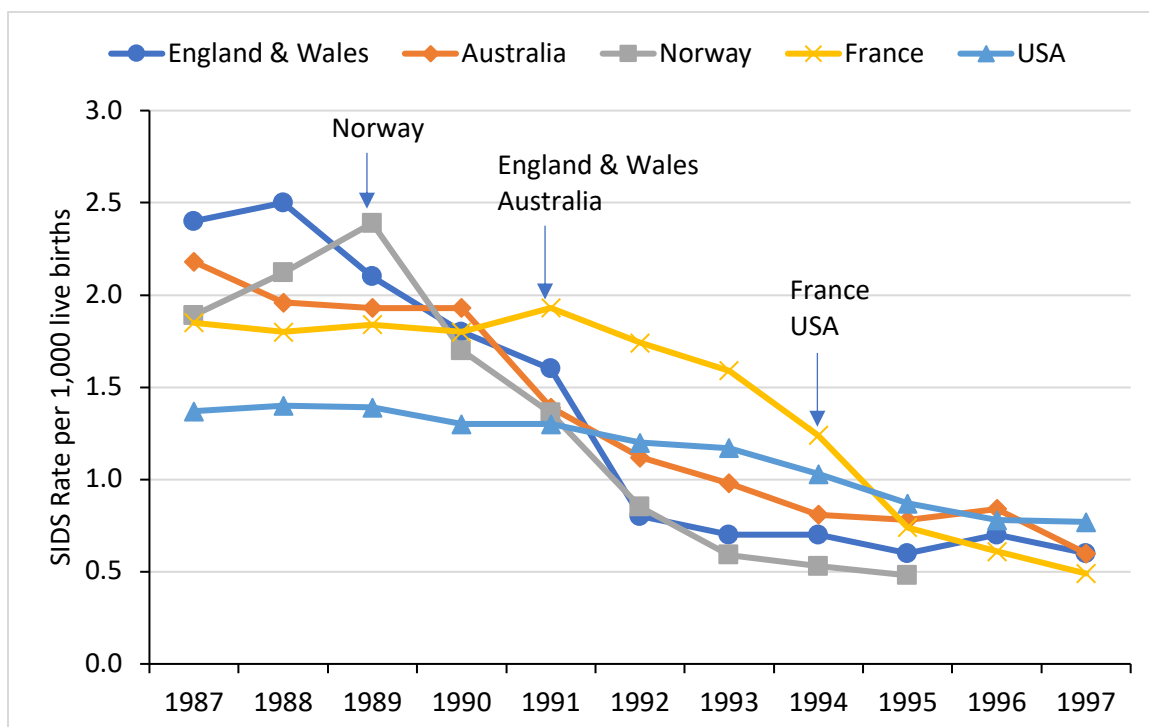
Supplemental Figure 5: SIDS rates in different countries before and after “Back to sleep” campaigns



Source: Sidebotham P, Bates F, Ellis C, Lyus L. Preventive Strategies for Sudden Infant Death Syndrome. In: Duncan JR, Byard RW, eds. *SIDS Sudden Infant and Early Childhood Death: The Past, the Present and the Future*. University of Adelaide Press; 2018. Accessed October 26, 2021.

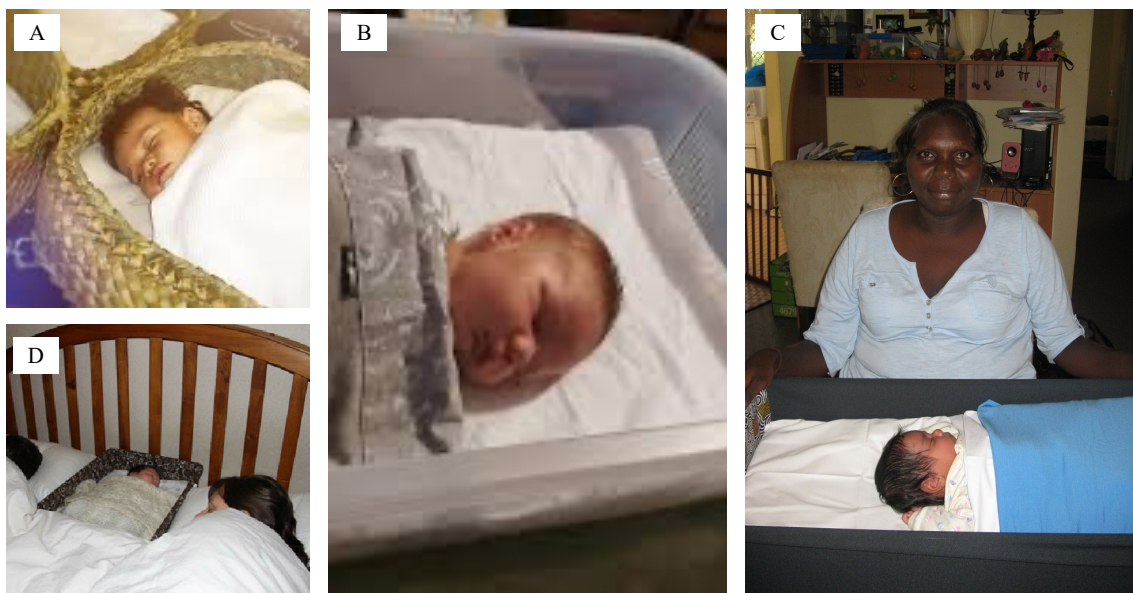
<http://www.ncbi.nlm.nih.gov/books/NBK513383/>[159]

Supplemental Figure 6: Trend chart showing SIDS rates in 5 high income countries before and after “Back to sleep” campaigns



Data for this chart was extracted from: Ponsonby AL, Dwyer T, Cochrane J. Population trends in sudden infant death syndrome. *Semin Perinatol.* 2002;26(4):296–305. doi:10.1053/sper.2002.34774 [168]

Supplemental Figure 7: Barrier methods to protect infants during sleep



Barrier methods to protect infants during sleep. A. The Wahakura; B. The Pepi-Pod; C. A baby box; D. A baby box placed between sleeping parents

APPENDIX C: DATA COLLECTION INSTRUMENTS

Survey Guide¹¹:

Zambia SIDS Risk Factor Survey

Start of Block: Introduction - Mar 21, 2021

Intro We are conducting research on the risk factors of sudden infant death. Very little is known about what causes sudden infant death especially in Zambia. The purpose of this research is to find out how common some of the risk factors of sudden infant death are in Zambia and to learn more about what you think might be causing these deaths.

This survey should only take 11 minutes, and your responses are completely anonymous. The following questions refer to you and your baby (youngest child). We really appreciate your input!

End of Block: Introduction - Mar 21, 2021

Start of Block: Participant and Hospital Identifiers - Mar 21, 2021

Q2 Participant Unique ID\${e://Field/Random%20ID}

Q3 Hospital ID

▼ 1 (1) ... 2 (2)

End of Block: Participant and Hospital Identifiers - Mar 21, 2021

Start of Block: Demographic questions - Mar 21, 2021



¹¹ Survey questions were adapted from CDC's sudden unexpected infant death investigation form, the Zambia demographic and health survey, a publicly available SUID/SIDS survey and additional questions developed by the study team. Demographic questions on this survey were adapted from ZPRIME (Zambia Pertussis and RSV Infant Mortality Estimation study)

Q4 What is your age in years?

Q5 What is the age of your baby in months?

- 0–1 month (1)
- 2–4 months (2)
- 5–7 months (3)
- 8–10 months (4)
- 11–12 months (5)

Q6 What is your baby's sex?

- Male (1)
- Female (2)

Q7 What is your marital status?

- Single (Includes Separated) (1)
 - Co-habiting (2)
 - Married (3)
 - Divorced (4)
 - Widowed (5)
 - Refused to answer (6)
-

Q8 What is your highest level of education?

- Never Attended School (1)
 - Some Primary Education (2)
 - Completed Primary Education (3)
 - Some Secondary Education (4)
 - Completed Secondary Education (5)
 - Some Post-Secondary (6)
 - Completed Post-Secondary (7)
 - Refused to answer (8)
 - Don't know (9)
-

Q9 What is the highest level of education completed by the father of your baby?

- Never Attended School (1)
 - Some Primary Education (2)
 - Completed Primary Education (3)
 - Some Secondary Education (4)
 - Completed Secondary Education (5)
 - Some Post-Secondary (6)
 - Completed Post-Secondary (7)
 - Refused to answer (8)
 - Don't Know (9)
-

Q10 What is your main occupation?

- Self employed (1)
 - Salaried employee (2)
 - Unemployed (3)
 - Unknown (4)
-

Q11 What is the main occupation of the father of your baby?

- Self employed (1)
 - Salaried employee (2)
 - Unemployed (3)
 - Unknown (4)
-

Q12 What is the name of the health facility closest to your home?

▼ Bauleni (1) ... Unknown (27)

End of Block: Demographic questions - Mar 21, 2021

Start of Block: Infant risk factors/Past history of sudden unexpected infant death - Mar 21, 2021

Q13 How many children have you given birth to (only live births)?

- 1 (1)
- 2 (2)
- 3 (3)
- 4 (4)
- 5 or more (5)

Skip To: Q15 If How many children have you given birth to (only live births)? = 1

Q14 Did any of them die suddenly and unexpectedly in infancy (between birth and 1 year)?

- Yes (1)
 - No (2)
 - Refused to answer (3)
 - Don't Know (4)
-

Q15 Are any of your children twins?

- Yes (1)
- No (2)
- Refused to answer (3)
- Don't Know (4)

Skip To: Q17 If Are any of your children twins? = No

Skip To: Q17 If Are any of your children twins? = Refused to answer

Skip To: Q17 If Are any of your children twins? = Don't Know

Q16 If yes, did any of them die suddenly and unexpectedly in infancy?

- Yes (1)
 - No (2)
 - Refused to answer (3)
 - Don't Know (4)
-

Q17 Do any of your children have any birth defects?

- Yes (1)
 - No (2)
 - Refused to answer (3)
 - Don't Know (4)
-

Q18 How much did your baby weigh at birth?

- Less than 1500g (Very low birth weight) (1)
 - 1500 – 2499g (low birth weight) (2)
 - 2500 – 4000g (normal birth weight) (3)
 - More than 4000g (4)
 - Refused to answer (5)
 - Don't Know (6)
-

Q19 Compared to the delivery date, was your baby born on time, early, or late?

- On time (1)
- Early - how many months (2)

- Late - how many months (3)

- Refused to answer (4)
- Don't Know (5)

End of Block: Infant risk factors/Past history of sudden unexpected infant death - Mar 21, 2021

Start of Block: Pregnancy related risk factors - Mar 21, 2021

Q20 Did you attend prenatal/antenatal care during your most recent pregnancy?

- Yes (1)
- No (2)
- Refused to answer (3)

Skip To: Q23 If Did you attend prenatal/antenatal care during your most recent pregnancy? = No

Skip To: Q23 If Did you attend prenatal/antenatal care during your most recent pregnancy? = Refused to answer

Q21 If yes, when did you begin prenatal/antenatal care?

- Within first trimester (0–3 months) (1)
 - Within second trimester (3–6 months) (2)
 - Last trimester (6–9 months) (3)
 - Refused to answer (4)
 - Don't Know (5)
-

Q22 How many prenatal/antenatal care visits did you complete during your most recent pregnancy?

- 1–2 (1)
 - 3–4 (2)
 - 5–6 (3)
 - >7 (4)
 - Refused to answer (5)
 - Don't Know (6)
-

Q23 How many months during your most recent pregnancy were folate/iron supplementation taken?

- 0–3 months (less than 12 weeks during the pregnancy) (1)
- 4–6 months (for almost half of the pregnancy or more) (2)
- 7–9 months (most of the pregnancy) (3)
- Refused to answer (4)
- Don't Know (5)

End of Block: Pregnancy related risk factors - Mar 21, 2021

Start of Block: Prenatal alcohol use - Mar 21, 2021

Q24 Did you drink alcohol regularly during your most recent pregnancy?

- Yes (1)
- No (2)
- Refused to answer (3)
- Don't Know (4)

Skip To: Q28 If Did you drink alcohol regularly during your most recent pregnancy? = No

Skip To: Q28 If Did you drink alcohol regularly during your most recent pregnancy? = Refused to answer

Skip To: Q28 If Did you drink alcohol regularly during your most recent pregnancy? = Don't Know

Q25 If yes, did you drink 4 or more drinks on the same occasion at any time during the pregnancy?

- Yes (1)
 - No (2)
 - Refused to answer (3)
 - Don't Know (4)
-

Q26 Please indicate during which months of the pregnancy that you consumed alcohol. Check all that apply.

- All 9 months (1)
 - During the first trimester (0–3 months) (2)
 - During the second trimester (4–6 months) (3)
 - During the last trimester (7–9 months) (4)
 - Refused to answer (5)
 - Don't Know (6)
-

Q27 If you consumed alcohol on a regular basis while pregnant, how many drinks did you consume per week?

- 1–5 (1)
- 6–12 (2)
- 13–20 (3)
- More than 20 (4)
- Refused to answer (5)
- Don't Know (6)

Display This Question:

If How many children have you given birth to (only live births)? != 1

Q28 Did you drink alcohol regularly in your other pregnancies?

- Yes (1)
- No (2)
- Refused to answer (3)
- Don't Know (4)

End of Block: Prenatal alcohol use - Mar 21, 2021

Start of Block: Prenatal cigarette/tobacco smoking and other indoor smoke exposures - Mar 21, 2021

Q29 Did you smoke cigarettes/tobacco at any time during your most recent pregnancy?

- Yes (1)
- No (2)
- Refused to answer (3)
- Don't Know (4)

Skip To: Q33 If Did you smoke cigarettes/tobacco at any time during your most recent pregnancy? = No

Skip To: Q33 If Did you smoke cigarettes/tobacco at any time during your most recent pregnancy? = Refused to answer

Skip To: Q33 If Did you smoke cigarettes/tobacco at any time during your most recent pregnancy? = Don't Know

Q30 Please indicate the months/trimesters in which you smoked cigarettes/tobacco while pregnant. Check all that apply.

- All 9 months (1)
- During the first trimester (0–3 months) (2)
- During the second trimester (4–6 months) (3)
- During the third trimester (7–9 months) (4)
- None (5)
- Refused to answer (6)
- Don't Know (7)

Q31 How many cigarettes/tobacco did you smoke on an average day when you were pregnant?

- 1–5 (1)
 - 6–10 (2)
 - 11–20 (3)
 - More than 20 (4)
 - Refused to answer (5)
 - Don't Know (6)
-

Q32 Did you smoke cigarettes after your baby was born and during the months you were breastfeeding?

- Yes (1)
 - No (2)
 - Refused to answer (3)
 - Don't Know (4)
-

Q33 Were you exposed to secondhand smoke on a regular basis (at least 4 days per week) during your most recent pregnancy? For example, residing with a family member that smokes.

- Yes (1)
 - No (2)
 - Refused to answer (3)
 - Don't Know (4)
-

Q34 Was your baby or any of your children regularly exposed to secondhand smoke in the home?

- Yes (1)
 - No (2)
 - Refused to answer (3)
 - Don't Know (4)
-

Q35 Did you smoke any other tobacco product (nsunko, hookah or shisha etc.) at any time during your most recent pregnancy?

- Yes (1)
 - No (2)
 - Refused to answer (3)
 - Don't Know (4)
-

Display This Question:

If How many children have you given birth to (only live births)? != 1

Q36 Did you smoke during other pregnancies?

- Yes (1)
- No (2)
- Refused to answer (3)
- Don't Know (4)

Skip To: Q38 If Did you smoke during other pregnancies? = No

Skip To: Q38 If Did you smoke during other pregnancies? = Refused to answer

Skip To: Q38 If Did you smoke during other pregnancies? = Don't Know

Display This Question:

If How many children have you given birth to (only live births)? != 1

Q37 If yes, how many other children did you give birth to (live births) that you smoked while pregnant?

- 1 (1)
- 2 (2)
- 3 (3)
- 4 (4)
- 5 or more (5)
- Refused to answer (6)
- Don't know (7)

Q38 What is the primary place for cooking in your household?

- In the house (1)
 - In a separate building (2)
 - Outdoors (3)
 - Other (4)
 - Refused to answer (5)
 - Don't Know (6)
-

Q39 What is the primary cooking fuel in your household?

- Firewood (1)
- Charcoal (Mbaula) (2)
- Gas (3)
- Electricity (4)
- Refused to answer (5)
- Don't Know (6)

Skip To: End of Block If What is the primary cooking fuel in your household? = Gas

Skip To: End of Block If What is the primary cooking fuel in your household? = Electricity

Skip To: End of Block If What is the primary cooking fuel in your household? = Refused to answer

Skip To: End of Block If What is the primary cooking fuel in your household? = Don't Know

Q40 If firewood or charcoal is your primary cooking fuel, how often is your baby exposed to smoke from cooking?

- Daily (1)
- Weekly (2)
- Monthly (3)
- Less than once a month (4)
- Never (7)
- Refused to answer (5)
- Don't Know (6)

End of Block: Prenatal cigarette/tobacco smoking and other indoor smoke exposures - Mar 21, 2021

Start of Block: Prenatal recreational drug use and history of mental illness - Mar 21, 2021

Q41 Did you smoke marijuana or use other substances at any time during your most recent pregnancy?

- Yes (1)
- No (2)
- Refused to answer (3)
- Don't Know (4)

Skip To: Q43 If Did you smoke marijuana or use other substances at any time during your most recent pregnancy? = No

Skip To: Q43 If Did you smoke marijuana or use other substances at any time during your most recent pregnancy? = Refused to answer

Skip To: Q43 If Did you smoke marijuana or use other substances at any time during your most recent pregnancy? = Don't Know

Q42 If yes, how often did you smoke marijuana or use other substances?

- Daily (1)
 - Weekly (2)
 - Once a month (3)
 - Refused to answer (4)
 - Don't Know (5)
-

Q43 Have you ever been diagnosed with any type of mental illness (depression, bipolar, schizophrenia etc.)?

- Yes, please specify: (1) _____
 - No (2)
 - Refused to answer (3)
 - Don't Know (4)
-

Q44 Has your baby's father ever been diagnosed with any type of mental illness?

- Yes, please specify: (1) _____
- No (2)
- Refused to answer (3)
- Don't Know (4)

End of Block: Prenatal recreational drug use and history of mental illness - Mar 21, 2021

Start of Block: Infant feeding practices - Mar 21, 2021

Q45 What do you generally feed your baby? Check all that apply

- Breast milk (1)
- Formula (2)
- Complementary foods (3)
- Refused to answer (4)
- Don't Know (5)

Skip To: End of Block If What do you generally feed your baby? Check all that apply = Refused to answer

Skip To: End of Block If What do you generally feed your baby? Check all that apply = Don't Know

Display This Question:

If What do you generally feed your baby? Check all that apply = Breast milk

And What do you generally feed your baby? Check all that apply = Formula

Or What do you generally feed your baby? Check all that apply = Breast milk

And What do you generally feed your baby? Check all that apply = Complementary foods

Or What do you generally feed your baby? Check all that apply = Formula

And What do you generally feed your baby? Check all that apply = Complementary foods

Or What do you generally feed your baby? Check all that apply = Formula

Or What do you generally feed your baby? Check all that apply = Complementary foods

Q46 How many months did you exclusively breastfeed your baby?

- 0 months (1)
 - 1–2 months (2)
 - 3–4 months (3)
 - 5–6 months (4)
 - 7 or more (5)
 - Refused to answer (6)
 - Don't Know (7)
-

Display This Question:

If What do you generally feed your baby? Check all that apply = Complementary foods

Q47 If you are not currently exclusively breastfeeding, how old was your baby when you introduced complementary foods?

- 1–2 months (1)
 - 3–4 months (2)
 - 5–6 months (3)
 - 7 or more (4)
 - Refused to answer (5)
 - Don't Know (6)
-

Display This Question:

If What do you generally feed your baby? Check all that apply != Breast milk

Q48 If you are not currently breastfeeding, how old was your baby when you stopped breastfeeding?

- 1–2 months (1)
- 3–4 months (2)
- 5–6 months (3)
- 7 or more (4)
- Refused to answer (5)
- Don't Know (6)

End of Block: Infant feeding practices - Mar 21, 2021

Start of Block: Infant sleep practices - Mar 21, 2021

Q49 Where does your baby usually sleep?

- In parents or another person's bed (1)
 - In a Crib/Bassinet/Playpen (2)
 - In a Couch/Sofa/armchair (3)
 - On the Floor (Mat or cloth on the floor) (4)
 - Other, describe (5) _____
-

Q50 Does your baby sleep alone in a separate room?

- Yes (1)
 - No (2)
 - Refused to answer (3)
 - Don't Know (4)
-

Q51 How often does your baby sleep alone in your bed or a crib, bassinet or playpen?

- Never (1)
 - Occasionally (2)
 - Only during the day (3)
 - Often (4)
 - Always (5)
 - Only at night (6)
-

Q52 Do you or anyone else co-sleep with your baby?

- Yes (1)
- No (2)
- Refused to answer (3)
- Don't Know (4)

Skip To: Q54 If Do you or anyone else co-sleep with your baby? = No

Skip To: Q54 If Do you or anyone else co-sleep with your baby? = Refused to answer

Skip To: Q54 If Do you or anyone else co-sleep with your baby? = Don't Know

Q53 If yes, how often do you or anyone else co-sleep with your baby?

- Occasionally (1)
 - Only during the day (2)
 - Often (3)
 - Always (4)
 - Only at night (5)
-

Display This Question:

If How many children have you given birth to (only live births)? != 1

Q54 Did either you or anyone else co-sleep with any of your other children (when they were babies)?

- Yes (1)
 - No (2)
 - Refused to answer (3)
 - Don't Know (4)
-

Q55 Considering your friends and family, how many parents do you know that co-sleep (occasionally or regularly) with their babies?

- None (1)
 - 1–2 (2)
 - 3–4 (3)
 - 5 or more (4)
 - Refused to answer (5)
 - Don't Know (6)
-

Q56 What position do you usually place your baby to sleep?

- Side (lateral) (1)
 - Back (supine) (2)
 - Tummy/stomach (prone) (3)
 - Refused to answer (4)
 - Don't Know (5)
-

Q57 What position do you find your baby sleeping in the morning?

- Side (lateral) (1)
 - Back (supine) (2)
 - Tummy/stomach (prone) (3)
 - Refused to answer (4)
 - Don't Know (5)
-

Display This Question:

If Where does your baby usually sleep? = In a Crib/Bassinet/Playpen

Q58 If your baby sleeps in a crib, is the mattress an approved mattress for babies to sleep on?

- Yes (1)
 - No (2)
 - Refused to answer (3)
 - Don't Know (4)
-

Display This Question:

If Where does your baby usually sleep? = In parents or another person's bed

Or Where does your baby usually sleep? = In a Crib/Bassinet/Playpen

Q59 Does your baby primarily sleep on a new mattress (never used by another baby) or a used mattress (previously used by other babies and handed down)?

- New (1)
 - Used (2)
 - Refused to answer (3)
 - Don't Know (4)
-

Display This Question:

If Where does your baby usually sleep? = In parents or another person's bed

Q60 If your baby sleeps in a larger type of bed (for older children/adults) is this mattress

- Firm/hard (1)
- Soft (2)
- Medium (3)
- Refused to answer (4)
- Don't Know (5)

End of Block: Infant sleep practices - Mar 21, 2021

Start of Block: Knowledge and awareness of sudden unexpected infant death (SUID) - Mar 21, 2021

Q61 Are you familiar with Sudden Infant death Syndrome or Sudden Unexpected Infant Death (SIDS/SUID)?

- Yes (1)
 - No (2)
 - Refused to answer (3)
 - Don't Know (4)
-

Q62 What do you think is the best position to place your baby to sleep?

- Side (lateral) (1)
 - Back (supine) (2)
 - Tummy/stomach (prone) (3)
 - Refused to answer (4)
 - Don't Know (5)
-

Q63 Have you ever been told by any medical personnel to lay your baby down on his/her back to sleep?

- Yes (1)
 - No (2)
 - Refused to answer (3)
 - Don't Know (4)
-

Q64 What do you think is the best place for your baby to sleep?

- In bed with me (1)
 - Alone in a crib (2)
 - In a separate room (3)
 - In the same room with me (4)
 - Refused to answer (5)
 - Don't Know (6)
-

Q65 Would you be willing to change your current infant sleep practices?

- Yes (1)
- No (2)
- Refused to answer (3)
- Don't know (4)

End of Block: Knowledge and awareness of sudden unexpected infant death (SUID) - Mar 21, 2021

Focus Group Discussion Guide:

1. Have you/has anyone had a baby die suddenly or do you know anyone who has had a baby die suddenly?
What do you think caused your baby or other person's baby to die suddenly?
2. Do you/does any of you worry about your baby dying suddenly or unexpectedly?
Do you think that you can do anything to try to keep your baby from dying suddenly and unexpectedly? If so, what? If not, why not?

3. Did you/did any of you drink alcohol regularly when you were pregnant?
Why or why not? Which trimester and how often did you drink?
Do you think drinking alcohol while pregnant can cause your baby to die suddenly?
4. Did you/did any of you smoke cigarettes regularly when you were pregnant?
Why or why not? Which trimester and how often did you smoke? Did you smoke after delivery and while breastfeeding?
Do you think smoking during pregnancy can cause a baby to die suddenly?
5. Did you/did any of you breastfeed your baby?
Why or why not? If yes how long and why? When was any other food introduced (formula, drinks, solids) and why? What does your baby get now?
Is your baby fed at night? How often and in what way? How long after feeding is your baby placed to sleep?
6. Does your baby bed share (co-sleep) with you or anyone else in the same bed?
Why or why not?
What do you think about babies co-sleeping with you or anyone in the bed or sofa?
Do you worry about accidentally rolling over your baby when you co-sleep with him/her?
7. Do you/does any of you use blankets for your baby when he or she goes to sleep?
Why or why not?
Do you think there is anything dangerous about using blankets for your baby?
Why or why not?
8. What do you think is the best way for your baby's mattress or sleep surface to be?
Soft or hard?
How do you prefer your baby's mattress or sleep surface to be? Hard or soft?
Why?
9. What position is your baby put to sleep in and in what position does your baby wake up in?
Why do you place your baby in this position?
In your opinion what is the best position to place your baby to sleep?
Who do you listen to for advice on how to place your baby to sleep?
10. Does your baby sleep with you in the same room or alone?
Why or why not?
What does your baby sleep with (pillows, toys, laundry items etc.)?

In-Depth Interview Guide¹² :

1. Describe the circumstances surrounding your baby's death?
 Probe mother's opinion on what caused baby to die suddenly looking specifically for terms that describe sudden unexpected infant death e.g., child who was previously well, no admissions in week prior to death, noticed dead after sleep episode?
 Continue interview for mothers whose description fits a sleep related infant death
2. Did you receive prenatal care for the baby's pregnancy?
 Probe where, when and number attended
3. Did you use any substances during the baby's pregnancy?
 Probe any alcohol, tobacco, and marijuana use and any infant exposures to tobacco from other family members
4. What did the baby eat in the 24 hours prior to death?
 Probe about breastmilk, formula, or other food item eaten prior to death
5. Where was the baby sleeping at the time of death?
 Probe for bed-sharing, infant sleeping in a separate room and temperature of the room in which the baby was found dead.
6. What type of mattress was the baby sleeping on when he/she was found dead?
 Probe about whether mattress was new or used and whether firm, soft or medium
7. In what position was the baby last placed to sleep?
 Probe what position baby was found dead, position baby generally sleeps in and if there was any spit up, saliva or blood on the baby's face, clothes, or sheets when the baby was found?
8. What items were on the baby or within a few inches from the baby's face at the time the baby was found dead?
 Probe specifically for type and number of Blanket/s, Stuffed animals, Plastic/other toys, Pillow/s, Laundry/other items of articles of clothing
9. What type of outfit was the baby wearing at the time the baby was found dead?
 Probe for how many layers of clothing or bundling occurring prior to death.

¹² Adapted from CDC's Sudden Unexpected Infant Death Investigation Form (SUIDIF)

APPENDIX D: APPROVAL LETTERS

Supplemental Letter 1: Boston University Review Board

Boston Medical Center • School of Medicine • School of Public Health • Goldman School of Dental Medicine



Institutional Review Board
72 E. Concord St., Robinson 4 – Suite 414
Boston, Massachusetts 02118-2307
Tel: 617-358-5372

Title of Study: Assessing the burden and risk factors of Sudden Infant Death Syndrome (SIDS) and other sleep-related infant deaths in Sub-Saharan Africa: A case study of Zambia

IRB Number: H-40803

RE: Initial Review Submission Form

Review Type: Exempt

Action: Exempt Determination

Date of Action: 11/24/2020

Status Check-In Due Date: 11/23/2023

Funding Source: Student/Resident Research with no External Funding

November 24, 2020

Dear Godwin Osei-Poku,

A qualified member of the Institutional Review Board (IRB) staff has reviewed the above referenced submission and has determined that the study qualifies for an exemption determination under the policies and procedures of the Human Research Protection Program (<http://www.bumc.bu.edu/ohra/hrpp-policies/hrpp-policies-procedures/#10.2.4>) under category (2).

This exemption determination is valid through the expiration date indicated above. You may close the study at any time when research activities are complete. You will be asked to file a brief status report prior to the above expiration date to indicate whether research activities are ongoing to renew this exemption determination.

This determination corresponds with the versions of the application and attachments in the electronic system most recently given an outcome of 'Reviewed' as of the date of this letter.

Protocol Specific Determinations

No PHI collected, accessed, used or distributed under 45 CFR 164.514.

All determinations regarding this project have been made based on the information submitted by the investigator. Any modifications to the research plan that would possibly change this exempt determination must be submitted to the IRB for review and confirmation of continued exempt status prior to initiation of the change.

As principal investigator, you are reminded that you must comply with the responsibilities listed here <http://www.bumc.bu.edu/irb/maintaining-irb-approval/responsibilities-of-the-principal-investigator/> **with the exception of point #13. PLEASE NOTE:** Minor changes to the study that do not

Supplemental Letter 2: University of Zambia Biomedical Research Ethics Committee



UNIVERSITY OF ZAMBIA BIOMEDICAL RESEARCH ETHICS COMMITTEE

Telephone: 260-1-256067
 Telegrams: UNZA, LUSAKA
 Telex: UNZALU ZA 44370
 Fax: +260-1-250753
 Federal Assurance No. FWA00000338

Ridgeway Campus
 P.O. Box 50110
 Lusaka, Zambia
 E-mail: unzarec@unza.zm
 IRB00001131 of IORG0000774

13th April 2021

Your REF. No. 1509-2021

Dr. Goldwin Osei-Poku,
 Boston University School of Public Health,
 Department of Global Health,
 Lusaka.

Dear Dr. Osei-Poku,

RE: SIDS RISK FACTOR STUDY (ZSIRFS) (VERSION 1) (REF. NO. 1509-2021)

The above-mentioned research proposal was presented to the Biomedical Research Ethics Committee on 13th April, 2021. The proposal is approved. The approval is based on the following documents that were submitted for review:

- Study proposal
- Questionnaires
- Participant Consent Form

APPROVAL NUMBER : REF. 1509-2021

This number should be used on all correspondence, consent forms and documents as appropriate.

- APPROVAL DATE : 13th April 2021
- TYPE OF APPROVAL : Standard
- EXPIRATION DATE OF APPROVAL : 12th April 2022

- After this date, this project may only continue upon renewal. For purposes of renewal, a progress report on a standard form obtainable from the UNZABREC Offices should be submitted one month before the expiration date for continuing review.
- SERIOUS ADVERSE EVENT REPORTING:** All SAEs and any other serious challenges/problems having to do with participant welfare, participant safety and study integrity must be reported to UNZABREC within 3 working days using standard forms obtainable from UNZABREC.
- MODIFICATIONS:** Prior UNZABREC approval using standard forms obtainable from the UNZABREC Offices is required before implementing any changes in the Protocol (including changes in the consent documents).
- TERMINATION OF STUDY:** On termination of a study, a report has to be submitted to the UNZABREC using standard forms obtainable from the UNZABREC Offices.
- NHRA:** You are advised to obtain final study clearance and approval to conduct research in Zambia from the National Health Research Authority (NHRA) before commencing the research project.

- QUESTIONS:** Please contact the UNZABREC on Telephone No.256067 or by e-mail on unzarec@unza.zm.
- OTHER:** Please be reminded to send in copies of your research findings/results for our records. You're also required to submit electronic copies of your publications in peer-reviewed journals that may emanate from this study. Use the online portal: unza.rhinno.net for further submissions.

Yours sincerely,

Sody Mweetwa Munsaka, BSc., MSc., PhD
 CHAIRPERSON
 Tel: +260977925304
 E-mail: s.munsaka@unza.zm

Supplemental Letter 3: Ministry of Health, Chilenje General Hospital

Address All correspondence to the
Medical Officer in Charge and not to individuals
Po. Box 50827, Lusaka
Telephone: + 260 954044519



In reply please quote No.....

REPUBLIC OF ZAMBIA
MINISTRY OF HEALTH
Chilenje General Hospital

16th November 2020

Dr Lawrence Mwananyanda
Chief Scientific Officer
Lusaka.

Dear Dr Mwananyanda

**RE: REQUEST FOR AUTHORITY TO CONDUCT A STUDY AT CHILENJE
GENERAL HOSPITAL**

The above subject matters refer.

We are in receipt of your letter requesting for permission to conduct research at Chilenje General Hospital entitled; **“Zambia SIDS Risk factor study.”**
My office is glad to inform you that we have no objection to your request provided that:

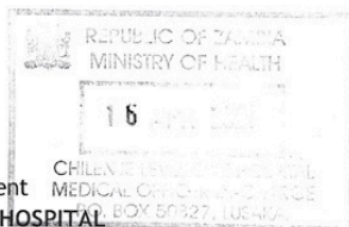
1. The ward in-charges and the nursing officer are fully appraised.
2. You provide us with progress updates.
3. The final study is shared with hospital management.
4. Ensure that there is minimum disruption in health service delivery as you carry out your research study.

I wish you well.

Yours Faithfully

Dr. Allan Musonda
Medical Superintendent

CHILENJE GENERAL HOSPITAL



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