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Infant Mortality Data: Missing Pieces to Prevention in Lesotho

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MPH 863

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August 7, 2024
Abstract

Lower-middle-income countries (LMICs) like Lesotho lack complete and quality infant mortality data. Without infant mortality data, it can be challenging to develop public health education, programming, and policies to address preventative infant deaths in specific populations (Rao et al., 2004). A literature review identified strategies to improve infant mortality data in LMICs. Through a community engagement model and digital storytelling, community members can gain awareness, begin an ongoing conversation about local public health issues, and participate in an improved data collection system. Infant mortality is often used as an indicator of health for a population; improved infant mortality data can help create a better plan to address the population's health issues for infants and the broader population.

Introduction

Lesotho is a high-altitude, landlocked country in South Africa (World Food Program USA, 2024). The beautiful country has a lush mountain landscape and Africa's only ski resort. Most of the country is rural, utilizes local agriculture, and has a rich herding culture (2024).

The Lesotho culture has a beautiful history of rituals and practices that continue to be practiced and maintained for all life stages (Kammeyer, Heinrich, 2010). When a child is born in Lesotho, various rituals ensure the infant is protected and given a prosperous life (2020). While the woman is pregnant, there is a ritual of prayers in which the pregnant woman wears animal fur and clay on her face (2020). After the child is born, to ensure the mother and child are protected, no one other than the elderly and young are allowed to enter the space of the mother and infant to avoid bringing evil into their space (2020). A reed is placed on the door to remind others not to
enter the home. Additionally, two reeds are placed on the roof to protect the mother and infant from evil. Infants are also always wrapped in a wool blanket while sleeping and used to strap the child to the mother while doing chores or walking (2020).

Unfortunately, like most cultures, misinformation and unsafe practices can make their way into the community and cause harm. In Lesotho, misinformation and unsafe practices endanger infant health. For instance, there has been misinformation around breastfeeding, and some women have been encouraged by family members to delay breastfeeding until the umbilical cord falls off, instead giving the infant water, porridge, or solid foods (United States Agency for International Development, 2008). This practice is developmentally inappropriate and can lead to malnutrition (2008). Still, it can also be deadly since many families in Lesotho lack access to clean, piped drinking water. Access to clean piped drinking water can double an individual’s likelihood of survival (Lekgatho & Khata, 2019).

In another example, Lesotho infants are often wrapped in wool blankets. It is unclear the impact of infants being wrapped in wool blankets in Lesotho, and the death rates related to Sudden Infant Death Syndrome (SIDS) are unknown (Osei-Poku et al., 2021). Safe sleep recommendations by the American Academy of Pediatrics state that it is unsafe to use blankets. At the same time, it is safer if the infant is swaddled in a blanket; if not swaddled or past the appropriate development to be swaddled, the blanket can become a sleeping hazard and potentially cause strangulation or suffocation (Moon et al., 2022). Using a wool blanket is also not part of the safe sleep recommendations due to the risk of the infant overheating (2022).

Beyond misinformation or lack of appropriate preventative information, infants continue to face other preventative health threats in Lesotho, such as infectious diseases like HIV/AIDS, infectious respiratory illnesses leading to pneumonia, and diarrheal illnesses (Lekgatho & Khata,
While there are high infant mortality rates in Lesotho, it is unclear which diseases and risk factors infants are dying from and at what levels. Lesotho’s death registry only registers death and is not always the cause of death.

Death is too common of an occurrence for someone living in Lesotho, which has some of the highest mortality rates. It is estimated that infants are dying at a rate of 73 per 1,000 live births, which is almost double the infant mortality rate of the country that surrounds it, South Africa (UNICEF, 2023). Lesotho has seen a steady decline in infant mortality rates every year but is far from achieving its Sustainability Development Goal of reducing preventable infant and child deaths. By 2030, it hopes to reduce its neonatal mortality to 12 per 1,000 live births and under-five deaths to 25 per 1,000 (SDG, 2017).

Improving sanitation and access to clean piped water have been interventions that have helped to reduce infant mortality (Lekgatho & Khata, 2019). Educational campaigns have also been conducted to promote breastfeeding for at least six months and provide counseling to mothers who are HIV-positive on how to make breastfeeding safe and prevent transmission (United States Agency for International Development, 2008).

One such intervention relates to data collection. Through the Lesotho Demographic and Health Survey (Ministry of Health & ICF International, 2016), Lesotho surveys the health of Lesotho individuals every ten years. While this is helpful in better understanding the demographics and health of Lesotho citizens, the reliability of the data can be questionable. For infant death survey questions, the survey relies on the recall of the mother to supply an accurate account of how the infant died and whether the mother is still alive to report it herself. This data helps understand risk factors such as maternal education and income, whether infant deaths occur in rural or urban settings, and which district (2016).
No accurate mortality data exists in Lesotho. Like most low-middle income countries (LMIC), due to low and incomplete death registrations, causes of death can be complex to precisely determine as deaths do not always occur in a healthcare facility where a physician can identify a cause of death on the death certificate (Jha, 2014). Even if there is a cause of death on the death certificate that a physician issues, it does not necessarily mean that the information will be transmitted onto the death registry.

In Lesotho, individuals must register their death with the Ministry of Home Affairs if they have a death certificate. Still, only 54.8% of death registrations are complete (Lesotho Centre of Excellence, n.d.). Like many LMICs, Lesotho’s registration process is not congruent with international standards in death reporting. Lesotho needs to incorporate into its death certificate reporting protocols the use of the World Health Organization’s (WHO) International form of medical certificate of cause of death as its reference to be consistent with death certificate reporting worldwide (World Health Organization, 2021). The WHO international form includes following the International Classification of Disease guidelines when reporting the cause of death. Lesotho’s medical systems do not use ICD codes and would require medical staff training on using these codes (2021). Additionally, for deaths that occur in the community, utilizing a standard tool like the WHO Verbal Autopsy report could be integrated into the community health village system to ensure consistency of mortality data (Rao et al., 2004).

The infant death reporting system in Lesotho lacks consistency and a unified system and does not meet international death reporting standards. This paper will address these issues and propose solutions for collecting data on the causes of infant death through a literature review and the community engagement model (Health Communication Capacity Collaborative, 2014). The process for identifying how an infant died and reporting it involves everyone in the community
at all the different levels: community members, village leaders, village health workers, nurses, doctors, and the Ministry of Health; therefore, this approach is appropriate to ensure a successful infant death reporting system.

Methods

Research Strategy

I conducted a literature review to explore the existing research and interventions relating to infant mortality data in LMICs, particularly nations like Lesotho. This review will inform strategies to improve infant mortality data collection to inform preventative strategies to reduce preventable mortality.

Target Population

Infants (<1 year old) of Lower Middle Income Countries with high infant mortality and lacking infant mortality data.

Keywords

Search keywords included ICD 10 or 11 infant mortality codes, SIDS rates, Death Certificate data, Cause of Death (COD) data, death registry, medical death certificate data, and their connection to LMIC and Lesotho.

Databases

Multiple databases were utilized including Google Scholar, PubMed and Journal of Global Health. Results were limited to publications in English from years 2004 to 2024.

Exclusion and Inclusion Criteria:
I limited my review to papers written in English between 2004 and 2024 that explored infant mortality data and reporting in LMICs. My initial search resulted in 10 papers. Of these, 4 met my inclusion criteria and were included in my review.

Results

Systems and lack of Collecting Infant Mortality Data in Lesotho

Most LMICs like Lesotho lack death data due to incomplete death registration and lack of death scene investigations (Lesotho Centre of Excellence, n.d.) (Osei-Poku et al., 2021), do not use the ICD codes for tracking and reporting (Rao et al., 2004), and many deaths do not occur in the hospital, leading to no death registration or no hospital involvement to determine the cause of death (COD) (Lekgatho & Khata, 2019). To better understand population health and COD for vulnerable populations like infants, Lesotho, and many other LMICs, Demographic and Health Surveys are conducted in collaboration with the worldwide Demographic and Health Surveys Program (Ministry of Health & ICF International, 2016).

In LMICs, complete and quality mortality data reported to the Ministry of Home Affairs is an issue (Committing to Child Survival: A Promise Renewed, 2015); in Lesotho, for example, only 54.8% of registered deaths are considered complete (Lesotho Centre of Excellence, n.d.). If a death occurs in a home, there is not a death scene investigation, which limits information on infant deaths occurring from Sudden Infant Death Syndrome (SIDS) which is unknown in Lesotho and known preventative risk factors are not addressed or given awareness to the public (Osei-Poku et al., 2021).

After a death, the family is responsible for registering the death, but there are only civil registry locations in urban areas, not rural ones, which is a barrier for a country that is mostly
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rural (World Health Organization, 2021). After the family registers the death of the individual, a burial permit is given, and they can proceed with the burial of the deceased (Lesotho Centre of Excellence, n.d.). A cause of death (COD) is only issued if death occurred in a hospital, or a physician evaluated the deceased (n.d.). The COD is included on the death certificate, which is given to the family to bring to register the death with the Ministry of Health (n.d.). If a death occurs in the community, the village chief gives verbal or written authorization to bury the body and where they can bury them (n.d.). The person who witnessed the death can also register the death with the Ministry of Health. Reasons why someone would need to register the death would be to obtain the official death certificate to claim the death for insurance, inheritance, or assistance for orphaned children (n.d.). This process incentivizes death registration for adults who die in urban areas but not for the death of an infant, especially in rural Lesotho.

ICD codes are the international gold standard for tracking disease and death (Leisher et al., 2016). Unfortunately, many LMICs do not use ICD codes, lacking a standardized process for categorizing a cause of death to compare across their country or with other countries (Paoin et al., 2018). Given that many deaths occur outside a healthcare facility, this wouldn’t necessarily be used for all deaths in a country like Lesotho but would standardize the causes of deaths that do occur in a healthcare facility. Additionally for death data in the hospital, many LMIC’s collect minimal death data on the death certificates (Jha, 2014). For Lesotho, they currently are only collecting age, date of death, sex, marital status, and district of residence (“Vital Statistics Dashboard,” 2021). Additional recommended data would include more information about residence like name of village or city, cause of death, comorbidities, education level (of parents if child), economic status (of parents or caregivers if child), and location of death (home or medical facility name) (Jha, 2014).
For deaths that occur in the community in LMIC’s, the World Health Organizations (WHO) verbal autopsy report template is a tool that is used in rural, low resource countries (Rao et al., 2004). The report is translated to the primary language and utilized by community health workers to collect standardized death data in the community (2004). Lesotho does not use the WHO verbal autopsy report in the community (2004).

The Lesotho Demographic and Health Survey (LDHS) is released every 10 years and is a resource for looking at infant mortality (Ministry of Health & ICF International, 2016). While the LDHS is a resource in the right direction, there are many flaws to the survey that impact data quality (Ministry of Health & ICF International, 2016). For infant death survey questions, the survey relies on the recall of the mother to supply an accurate account of how the infant died and whether the mother is still alive to report it herself (Ministry of Health & ICF International, 2016). Due to the data being released every 10 years, the relevance of the data for current issues is also questionable. While a flawed survey, an important component of this data is that it contributes to understanding the impact of social determinants of health on infant mortality by collecting information on maternal education and income, whether infant deaths occur in rural or urban settings, and which district (Ministry of Health & ICF International, 2016). Infant deaths in Lesotho are largely impacted by social determinants of health (Lekgatho & Khata, 2019). Infant deaths were high among rural mothers versus urban, higher deaths with low income, higher deaths with less maternal education, and an increased threat of life if living in an area with unimproved water sources and sanitation (2019). The centennial Lesotho Demographic and Health Survey (LDHS) for 2023-24 was conducted and released as of June 2024 (Ministry of Health & ICF International, 2024). Unfortunately, the survey released limited details on infant and child mortality compared to the 2014 LDHS (Ministry of Health & ICF International, 2016).
and may release a final report with more details but as of now, only mortality numbers have been
released. The recent survey showed a decrease in infant mortality but an increase in child
mortalities, deaths from age one to five (Ministry of Health & ICF International, 2024). The
2014 LDHS identified the districts with the highest and lowest neonatal mortalities, Quthing had
the lowest, 23 deaths per 1,000, while Mafeteng had the highest of 50 deaths per 1,000 live
births.

In high middle-income countries, child death review (CDR) teams or systems are utilized
to understand how and why children are dying by reviewing individual death cases and broader
population death data (Ornstein et al., 2013). The CDR is able to promote preventative efforts in
public health programming, public awareness, health and safety education, and change or create
new policies and legislation to prevent deaths (2013).

**Understanding the Community Engagement Model with Improving Infant Mortality Data**

The Community Engagement Model has five key components that will promote an
effective strategy for improving infant mortality data collection in the community (Glanz et al.,
2015, pp. 283–287). First is community capacity; the community needs to be active participants
in identifying high infant mortality as a problem in their community and have the capacity to be
problem solvers and collaborators to address the issue (Glanz et al., 2015, 283-284). Second is
empowerment; everyone has a role to play in collecting quality infant mortality data, and
everyone in the community needs to know their power in their role in the community to make
change through collaboration (Glanz et al., 2015, pp.284-285). Third is critical consciousness;
engaging everyone at all infant mortality data collection levels will require reflective participants
to see ways to improve the system and maintain effective strategies for obtaining infant mortality
data (Glanz et al., 2015, pp.284-285). Fourth is participation and relevance; everyone should feel
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like they have equal importance and involvement in achieving the goal of obtaining quality infant mortality data (Glanz et al., 2015, pp.286-287). Lastly, health equity ensures that all the communities of Lesotho have an equal opportunity to have quality and accurate data to reflect the disparities and infant health needs in their community, such as equal opportunity for urban and rural areas (Glanz et al., 2015, p. 287).

Recommendations

To improve infant mortality data throughout the country of Lesotho, stakeholders might consider piloting an infant mortality improvement plan in the district with the highest infant mortality rates. While there is no specific protocol for developing a infant mortality data improvement plan, the plan would integrate recommended interventions from the literature review and public health program strategies. Interventions would include a needs assessment, digital storytelling, and building an infant mortality review board which would implement additional evidence based strategies. Once the district is identified, I would recommend first conducting a needs assessment relating to infant mortality to assess the districts' current data and their baseline, their strengths, and weaknesses. Individuals that will be conducting the needs assessment will be representatives from the Lesotho Ministry of Health, district hospital leaders, and local village chiefs. This assessment would allow the team to begin to engage the community and illicit stakeholders that would like to be involved to take leadership and identify funders to support an improvement plan (Bani, 2008). As part of this needs assessment, I recommend having open community meetings to engage community awareness and interest by reviewing the available data, such as the 2014 LDHS data and the 2024 LDHS data, once the final report is released. To ensure the data review process is accessible to all individuals at different education
levels and backgrounds, digital storytelling will be used to tell the story of the data in Lesotho, collect data during the needs assessment, share the process for the improvement plan, and share outcome results (Fiddian-Green et al., 2023). For low-resource areas, non-profit organizations can help facilitate in-person digital storytelling workshops to teach the local professionals how to conduct them and support them with implementing the project (2023). Digital storytelling is ideal for global health and low-resource countries as it can empower the local community to learn the skills to tell their story digitally. It also supports an approach that is not rooted in colonization but rather in traditional knowledge-sharing practices (2023). "For historically marginalized and stigmatized populations, the use of stories and storytelling can shift the focal point from the (possibly previously objectified) storyteller to the final story in ways that can support productive problem solving" (pp.17, Fiddian-Green et al., 2023).

The needs assessment will include digital storytelling as a communication tool, data collection, showcasing current data, a SWOT analysis of the district chosen, and key informant interviews of community members, village chiefs, infant health advocates, health professionals, non-profit leaders, private organizations, and public or government professionals in infant health (Bani, 2008).

Recruitment for an Infant Mortality Review Board will occur after the needs assessment and critical stakeholders and leaders are identified. The infant mortality review board will be asked to review data of the needs assessment and death data every year to identify trends and opportunities for prevention (Ornstein et al., 2013). The board can do an annual review of gaps in data and issues with infant death data collection in the hospital and community and make recommendations to hospitals, public health, community health workers, and policymakers on strategies to prevent infant death (2013). The board will also utilize digital storytelling to
promote public awareness and education on the importance of infant death data. After establishing the board, they will develop a data improvement plan for the various settings. For the hospital settings, based on the literature review, recommendations would include integrating ICD codes for infant deaths in the hospital setting (Leisher et al., 2016) and optimizing the current death certificate data, adding more information about residence like name of village or city, cause of death, comorbidities, education level (of parents if child), economic status (of parents or caregivers if child), and location of death (home or medical facility name) (Jha, 2014). For the community setting, recommendations would be to integrate verbal autopsy reports for village health workers and village chiefs to use for infant deaths (Rao et al., 2004). The board could also assist hospitals and community health entities in implementing these recommendations, identify funding sources, and be a resource to solve any challenges. Throughout this process, the board could also develop an improvement plan based on piloting this project with a district to have a process for other districts to refer to and replicate in their district and study its effectiveness.

**Implications and Discussion**

Through the needs assessment, digital storytelling, the development of an infant mortality review board, and the promotion of a data improvement plan, Lesotho stands to gain a deeper awareness of the health and safety factors contributing to infant death. This heightened awareness will spark important conversations on how to leverage community health, hospitals, and legislation to reduce preventable infant deaths.

Some limitations to the hospital and community recommendations will be limited by financial and human resources needed to implement the data improvement plan.
recommendations (Jha, 2014). Obtaining financial assistance from stakeholders, grants, and the Lesotho government could alleviate this burden. To address the human resource issues, depending on the needs assessment and each organization’s human resource capacity, current staff could be trained to assist with the data improvement plan by implementing ICD coding for infant deaths and verbal autopsy reports, but additional staff may be needed to ensure the improvement plan is successful.

Adding more data fields on the death certificate could be done unofficially and just collected at the hospital for local purposes in the pilot phase with the first district. If this is shown to be essential data to support infant mortality prevention, the Infant Mortality Review Board leaders could promote this to the Ministry of Health and Home Affairs to implement nationwide. Piloting this data improvement process with one district will give a blueprint for implementing this process across the country and could change practice for all death data, not just infant death data.

**Conclusion**

Through improving infant death data collection, Lesotho will not only have a better idea of what targeted interventions should occur to prevent deaths but also have an improved awareness of community health. The current death data system only collects minimal data that is not standardized from urban and hospital settings. By integrating the verbal autopsy report and adding more details to the death certificate to show district and village details, the death data will have more rural representation and help guide public health programming and education more tailored to rural needs. Integrating ICD codes in the hospital setting with infant deaths will be a good starting point to understand the resources needed to integrate ICD codes for all hospital deaths and have a more standardized process. Utilizing a non-profit to conduct digital
storytelling will create community awareness, acknowledge many families' struggles to stay healthy, and empower them to share their stories and be a part of the change. While many of these interventions will take time, money, and human resources, their impact on reducing preventable infant deaths and the country's overall health is worth the process.
References


*Committing to child Survival: a promise renewed.* (2015, September 1).

UNICEF. https://www.unicef.org/reports/committing-child-survival-promise-renewed


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UNITED STATES AGENCY FOR INTERNATIONAL DEVELOPMENT. Success Story:


World Food Program USA. (2024, January 9). Lesotho - World Food Program USA.

https://www.wfpusa.org/countries/lesotho/

Appendix

**Table 1: Defining Terms and Keywords**

<table>
<thead>
<tr>
<th>Term</th>
<th>Definition</th>
</tr>
</thead>
<tbody>
<tr>
<td>SIDS</td>
<td>Sudden Infant Death Syndrome: death of an infant that cannot be explained by a thorough death investigation and “is inclusive of deaths with combinations of extrinsic factors and/or intrinsic vulnerabilities or abnormalities that do not reach a diagnostic threshold for a specific cause of death” (Moon et al., 2022).</td>
</tr>
<tr>
<td>Infant Mortality</td>
<td>Infant that died between 1 day and 1 year of age (Eunice Kennedy Shriver National Institute of Child Health and Human Development, n.d.).</td>
</tr>
<tr>
<td>Neonatal Mortality</td>
<td>Death classification used when an infant dies before 28 days (Eunice Kennedy Shriver National Institute of Child Health and Human Development, n.d.).</td>
</tr>
<tr>
<td>ICD codes</td>
<td>International Classification of Disease: coding system for classifying disease and death (International Classification of Diseases (ICD), 2023)</td>
</tr>
<tr>
<td>LMIC</td>
<td>Lower- and Middle-Income Country: World Bank classification of countries based on income per person (Prydz &amp; Wadhwa, 2019) rather than “developing country”.</td>
</tr>
<tr>
<td>COD</td>
<td>Cause of Death</td>
</tr>
</tbody>
</table>
Table 2: Literature Review of challenges and solutions to improved infant mortality data in LMICs

<table>
<thead>
<tr>
<th>Article</th>
<th>Factors</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Committing to Child Survival: A Promise Renewed, 2015</td>
<td>Poverty, rural household, lack of education, limited access to health</td>
<td>The “A Promise Renewed” 2015 UNICEF progress report of assessing progress with reducing preventable deaths of women and children identified that 9 out of 10 deaths under five still occur in low- and -middle income countries. On average globally, children are likely to die before the age of five if they; live in poverty (1.9 times), rural households (1.7 times), or lack education (2.8 times). The rural disadvantages are found to be related to access to health facilities and “basic health interventions”. Globally, all countries could improve “high-quality disaggregated data” to detect and reduce disparities in child mortality. Infectious diseases remain a large portion of preventable deaths for children under five, leading causes are pneumonia and diarrhea.</td>
</tr>
<tr>
<td></td>
<td>facilities and basic health interventions, infectious diseases, and a</td>
<td></td>
</tr>
<tr>
<td></td>
<td>lack of quality data to identify and reduce deaths.</td>
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</tbody>
</table>
| Improving death registration and statistics (Rao et al., 2004)         | Cause of death data impacts the ability to do population health,        | Mortality data supports population health planning, programming, and policies. Summary of the top factors that will contribute improving death registration:  
- Well-functioning death registration system.  
- Collaborative and consistent structure for those involved in death registration, from hospitals to rural leaders.  
- Use ICD coding, improve administrative capacity, while increasing funding to support the change.  
- Implement quality control activities to assess usability of data for health policy and monitoring.  
- Engaged political will to enhance death data and public awareness of its’ importance and process.  
- Utilizing a standard verbal autopsy report for rural areas. |
|                                                                        | implementing policies, planning, and enable preventative health programs. |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                     |
|                                                                        | Identified factors that would improve death data.                      |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                     |
| Factors Associated with Infant Mortality In Lesotho                   | Socio-economic and demographic factors impact infant mortality and must be understood to prevent and reduce infant mortality. | Cross sectional analysis of the 2014 Lesotho Demographic and Household Survey (LDHS). Results showed that about 9% of infants died by age 1 and 51.3% died by the first month. Infant deaths were high among rural mothers versus urban, higher with educated mothers, higher deaths with low income, and an increased threat of life if living in an area with unimproved water sources and sanitation. |
A systematic review of the burden and risk factors of sudden infant death syndrome (SIDS) in Africa (Osei-Poku et al., 2021) | Sudden Infant Death Impact on African LMIC’s | The findings of the systematic review showed that the African countries they reviewed did not have a complete infant death scene investigation and could not be classified as SIDS but found that there were many unsafe infant sleep practices and where SIDS has been studied shows a large burden of SIDS on infant mortality. There was also a lack of awareness of SIDS in the African countries reviewed and SIDS was not a priority. This review is more specific to South Africa and is difficult to generalize the findings for other African countries and more studies should be done to support promoting safe sleep campaigns.

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**Figure 1: Process of digital storytelling** (Fiddian-Green et al., 2023)