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Exploring Drivers of Infant Deaths in Rural Rwanda Through Verbal Social Autopsy

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Abstract

BACKGROUND Rwanda has been a leader in the global effort to reduce infant mortality, particularly in regions of sub-Saharan Africa. Although rates have dropped, deaths still occur.

OBJECTIVE To explore the care pathways and barriers taken by infant caregivers before the death of their infant through a verbal social autopsy study in 2 districts in eastern Rwanda.

METHODS We adapted the World Health Organization verbal socialautopsy tools to reflect local context and priorities. Caregivers of infants in the 2 districts were interviewed using the adapted quantitative survey and semistructured interview guide. Interviews were recorded and thematic analysis employed on a subsample (n = 133) to extract the content relevant to understanding the drivers of infant death and inform results of the quantitative data until saturation was reached (66). Results were interpreted through a driver diagram framework to explore caregiver-reported challenges in knowledge and experiences with care access and delivery.

FINDINGS Most study participants (82%) reported accessing the formal health system at some point before the infant's death. The primary caregiver-reported drivers for infant death included challenges in accessing care in a timely manner, concerns about the technical quality of care received, and poor responsiveness of the system and providers. The 2 most commonly discussed drivers were gaps in communication between providers and patients and challenges obtaining and using the community-based health insurance. The framework of the driver diagram was modified to identify the factors where change was needed to further reduce mortality.

CONCLUSION This study provides important information on the experiential quality of care received by infants and their caregivers within the current health care space in rural Rwanda. By listening to the individual stories of so many caregivers regarding the gaps and challenges they faced, appropriate action may be taken to bolster the existing health care system.

KEY WORDS barriers to care, infant mortality, mixed methods, Rwanda, verbal social autopsy.

INTRODUCTION

Over the past 2 decades infant mortality globally has decreased by more than 50%.[1] Rwanda has experienced large declines in these deaths through a commitment to strengthening the health care system and addressing barriers to access.[2] These interventions have included expansion of community-based health insurance (CBHI, *mutuelles de santé*, or *mutuelles*), implementation of a community health

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worker (CHW) program capable of providing community-based integrated management of childhood illness, near universal coverage of childhood vaccinations, and a strengthened system of facility-based care.[3,4]

The mortality rate in infants—children between the ages of 1 month and 1 year—worldwide has declined from 22.46 per 1000 live births in 2000 to 12.16 per 1000 live births in 2015, but this still represents more than 1.5 million deaths globally (28.8% of under-5 deaths globally).[5] In Rwanda, rates of infant death in 2015 were 20.3 per 1000 live births, highlighting an area where progress has been made but more work is needed. Over the last 5 years, the leading causes of death in this age group in Rwanda have changed somewhat, with HIV/AIDS no longer in the top 5 causes. However, other causes of preventable mortality, including respiratory infections and diarrheal disease, remained among the top 5 killers of infants in 2015.[6]

Verbal social autopsies (VSA) have been used to identify causes of death and potential contributions of socioeconomic barriers to mortality in children in a number of low- and middle-income countries.[7,8] Performed using structured interview tools, this work has been invaluable in understanding where gaps in the care system have contributed to deaths in children younger than 5 to drive policy changes and health systems strengthening.[8-10] For example, in Niger, use of these data with effective feedback led to evidence-based decision-making and program improvement.[8]

Although VSA results are important to inform areas for improvement, expanding the analysis to include caregivers' narrative histories about care pathways and decisions made can deepen understanding of how and why these deaths occurred. For example, Njuki et al[11] combined quantitative and qualitative analysis to better understand causes of mortality among women with HIV/AIDS in Kenya. The social component of the VSA survey was recorded, transcribed, and coded using grounded theory, which rested in a deeper understanding of the barriers to the women's ability to effectively seek care through the formal health system. This use of an expanded analysis has potential value in increasing the caregivers' voices in the care-seeking experience. This incorporation of user experiences into how quality is measured is important to achieving integrated people-centered health care, a goal established by the World Health Organization as critical to ensuring effective primary care and the quality Universal Health Coverage needed to achieve health-related Sustainable Development Goals.[12]

We describe the results of a mixed methods analysis of a VSA study of deaths in infants conducted in 2 rural districts in Rwanda to better understand the care pathways taken by caregivers before the deaths of their children. We applied a quality improvement lens using a driver diagram to extract themes from the caregiver-reported experiences to identify gaps in knowledge, care access, and delivery. These results and lessons learned from the expansion of the traditional VSA analyses offer important lessons for countries such as Rwanda committed to increasing universal quality health care to further improve survival of infants and children.

METHODS

Setting. This study was conducted in 2 rural districts in eastern Rwanda, Kirehe district and the southern part of Kayonza district, as a part of a health systems strengthening initiative by the Rwanda Ministry of Health (MOH) and Partners in Health, a Boston-based nongovernmental organization, and its Rwanda-based sister organization, *Inshuti mu Buzima.* The work was funded by the Doris Duke Charitable Foundation African Health Initiative. The districts serve a population of 534,000 in the Eastern Province, which has among the highest under-5 mortality rates in Rwanda (86 per 1,000 live births).[13] Overall, antenatal care (ANC) attendance is extremely high (98.9% attended an ANC checkup once) with most women (88.8%) having a facility-based delivery.[13]

Data Collection. A VSA study of under-5 deaths in the study area was conducted between March 2013 and February 2014. The instrument used was based on the 2012 World Health Organization (WHO) verbal autopsy instrument,[14] with additional questions added from the Rwanda MOH's Death Audit Tool and the 2010 Rwanda Demographic and Health Survey to cover additional identified priorities and potential challenges to preventing under-5 mortality. The methodology applies a quantitative survey and semistructured interviews to extract information on demographics, care pathways, and details of the illness associated with the death. The tools were translated into the local language, Kinyarwanda, and back-translated into English to ensure appropriate terms and content. Soon after the VSA started, data collectors recognized the richness of the qualitative data and so the Institutional Review Board agreement was amended to allow for consent for recording and transcription of the interviews.