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

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.

Figure 1. Initial driver framework for infant survival. Abbreviation: **CHW, community health worker.**
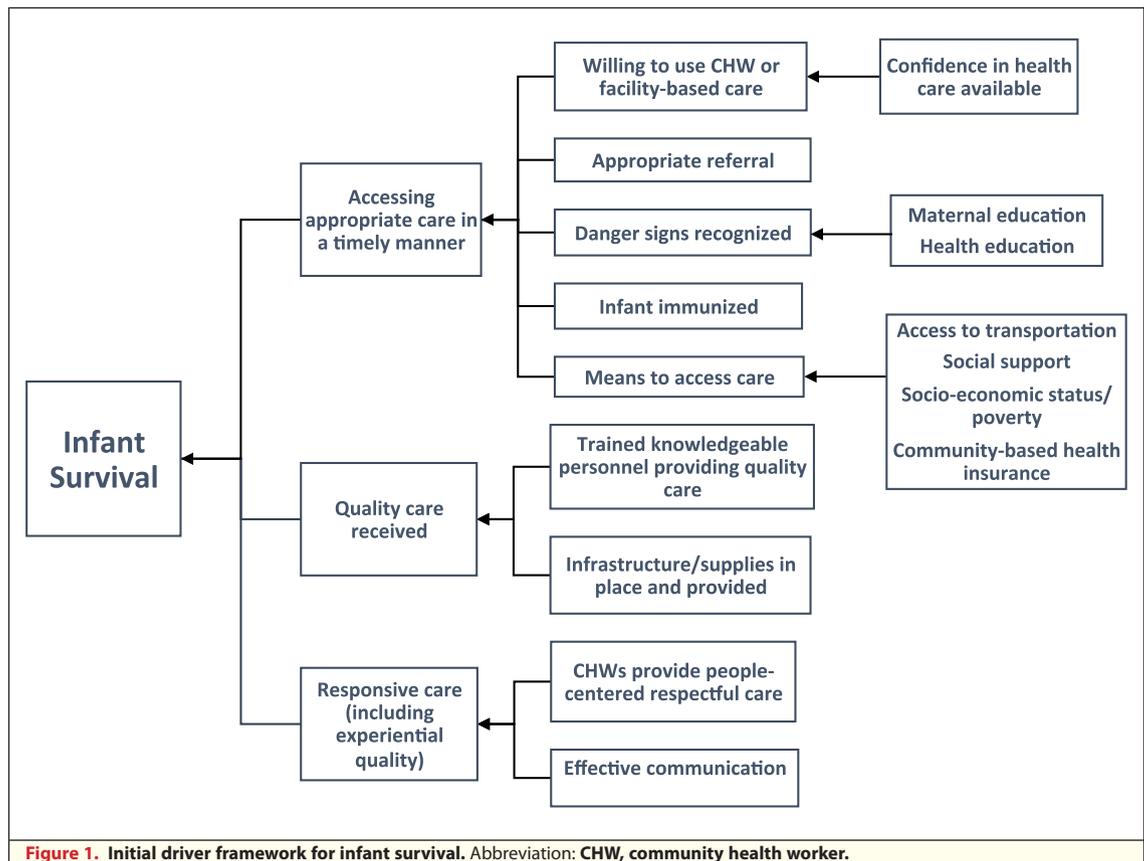
Families and caregivers of children younger than 5 who died between March 2013 and February 2014 while residing in the 2 districts were eligible for inclusion. Under-5 deaths were identified through the triangulation of existing MOH reporting systems, community level data collection through the Monitoring of Vital Events Using Information Technology program, and CHW household registry books. In total 182 infant deaths were identified and included in the VSA, of which 133 (73%) had recordings completed (63% in Kirehe, 37% in Southern Kayonza).

Trained data collectors traveled to villages within both districts, accompanied by a CHW, to meet participants at their homes and conduct interviews. The data collectors used tablets to record the information with the families and caregivers of the deceased children. The interviews were conducted in Kinyarwanda. Audio files of interviews were selectively transcribed to include information provided by participants, expanding on the closed-ended questions of the VSA survey. All transcripts were translated into English from Kinyarwanda by an external translator. Members of the research team who spoke both

English and Kinyarwanda reviewed the translations to ensure accuracy. In areas of uncertainty, the other members of the research team were consulted to ensure the appropriate translation was agreed on before the transcripts were analyzed.

Analysis. Descriptive statistics were used to depict the demographics, care-seeking patterns, and potential barriers to care (insurance, distance from facility). Cause-of-death analyses were done using the InterVA-4 tool.[15]

An initial driver diagram was developed based on targeted review of existing literature and feedback from subject matter experts. The primary drivers included access to appropriate care in a timely manner, quality of care received, and responsive care. Secondary drivers included having the means to access care, ability to recognize danger signs, technical quality of care, availability of needed supplies, and health care providers (Fig. 1). The driver diagram was then used as the analytical framework to create the initial codebook and to help identify and group the factors identified by respondents connected with the infant deaths in this study, focusing on the gaps in the health care system and service delivery. Based on the results
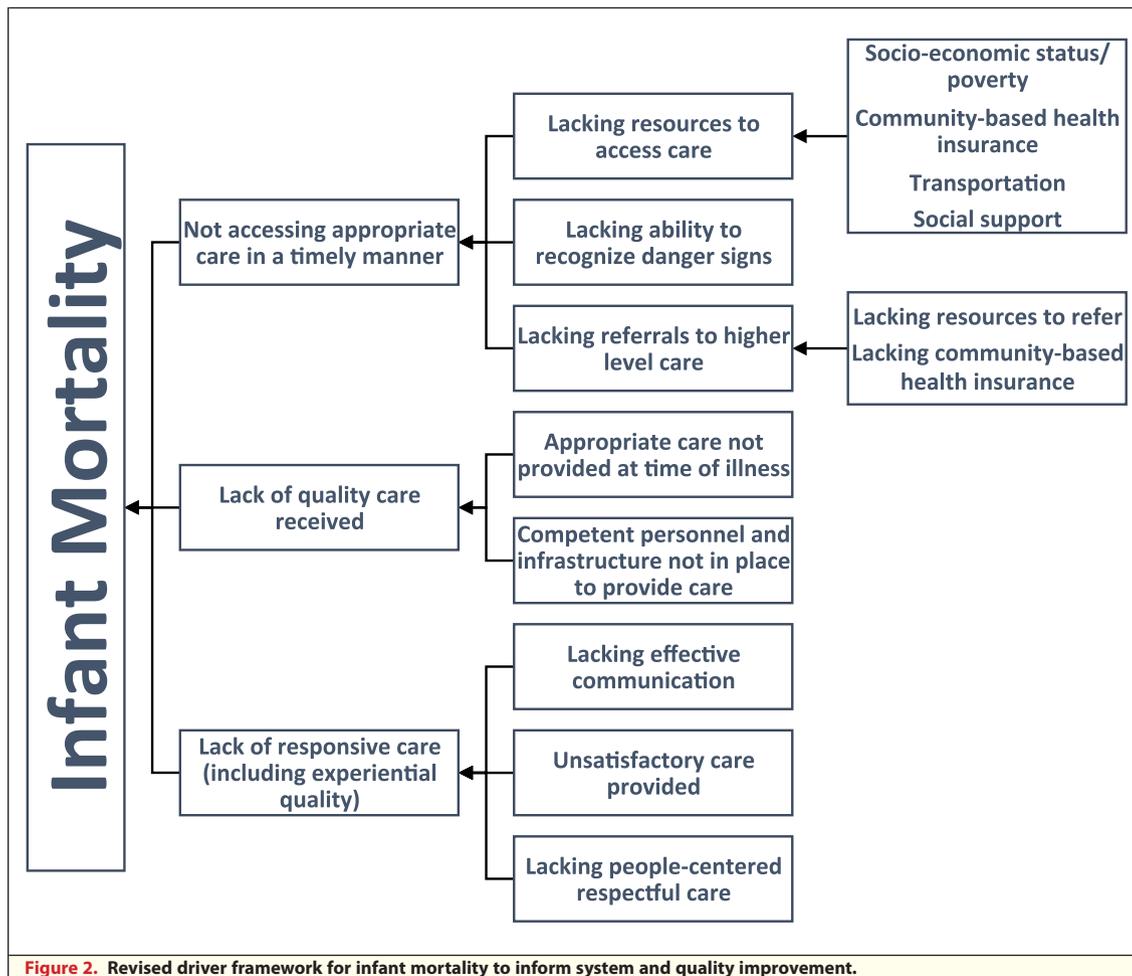
Figure 2. Revised driver framework for infant mortality to inform system and quality improvement.

of the analysis, further modifications were made to the initial diagram during the iterative reviews. Finally, this was converted to a driver diagram of infant mortality to serve as a tool to drive improvement of identified gaps in the districts (Fig. 2).

Initial coding validation was completed on a small sample of interviews by comparing the codes from 2 team members with adjustments after discussion with the coding team for areas where differences were found. Thematic analysis was undertaken to extract the relevant content to better understanding the drivers of infant survival in relation to access and use of care services and circumstances around causes of death. Primary coding was completed on a sample of randomly selected interviews until theoretical saturation was met (n = 66). Double coding of an initial set by a second team member after discussion of key findings further ensured agreement. Analyses were done using Dedoose Version 7.0.23 (SocioCultural Research Consultants, Los Angeles, CA).

RESULTS

Characteristics of Infant Deaths. The demographic characteristics and care-seeking behaviors were similar between the group with recorded interviews and the subsample of 66 included in this analysis (Tables 1 and 2). The mean age at death was 160 days (standard deviation 12.8), and 47% of the infants were female. Most of the respondents (95.5%) were 1 or both of the infant's parents. Just more than half of participants (56.1%) reported having all family members covered by the national CBHI, whereas 27.3% reported having no insurance coverage. About three-quarters of the infants (77.3%) had infectious diseases such as acute respiratory infections, malaria, or diarrhea identified as the most likely cause of death. Despite high proportions of care seeking, the majority of infants (56.1%) were reported to have died at home. Of these, 42% of respondents reported the infant's death as being sudden.

Table 1. Demographics and Most Likely Cause of Death for Infants Included in Qualitative Analysis for the Verbal Autopsy Study

	Recorded Interviews (N = 133)	Recorded and Coded Interviews (N = 66)
Mean age (d) of infant at time of death (SD)	166.5 (8.9)	160 (12.8)
Female	65 (48.9%)	31 (47.0%)
Mean age of mother (SD)	31.0 (0.6)	31.3 (7.3)
≥4 ANC visits for pregnancy with infant	37 (27.8%)	21 (31.8%)
Complicated delivery with infant	34 (25.6%)	11 (16.7%)
Respondent is parent	127 (95.5%)	63 (95.5%)
Household with >4 individuals	59 (44.4%)	31 (47.0%)
Family insurance coverage		
All	85 (63.9%)	35 (53.0%)
Partial	21 (15.8%)	11 (16.7%)
None	27 (20.3%)	17 (25.8%)
>2-h travel time to health facility	48 (36.1%)	24 (36.4%)
Reported care quality at nearest health facility good/very good	98 (73.7%)	52 (78.8%)
Site of death		
Home	75 (56.4%)	37 (56.1%)
Health facility	13 (9.8%)	7 (10.6%)
Hospital	22 (16.5%)	9 (13.6%)
Other	23 (17.3%)	13 (19.7%)
Most likely cause of death[*]		
Infectious (overall)	102 (76.7%)	50 (75.8%)
Respiratory	59 (44.4%)	31 (47.0%)
Malaria	16 (12.0%)	8 (12.1%)
Diarrhea	14 (10.5%)	4 (6.0%)
HIV/AIDS	7 (5.3%)	3 (4.5%)
Other	6 (4.5%)	4 (6.0%)
Trauma	4 (3.0%)	1 (1.5%)
Other[†]	21 (15.8%)	9 (13.6%)
Indeterminate	6 (4.5%)	5 (7.6%)
Respondent described death as sudden	88 (66.2%)	42 (63.6%)

ANC, antenatal care; SD, standard deviation.
[*] From InterVA-4 analysis.
[†] Includes included congenital malformations, acute abdomen, and severe malnutrition.

More than one-third of respondents (37.9%) reported travel time of 2 hours or longer to the nearest health facility. Although mothers reported having attended on average 2.9 ANC visits during their pregnancy for the infant who died, only 31.8% attended the recommended 4 visits. When asked where care was sought for their child during the illness that ended in death, more than half of caregivers reported medical pluralism, having visited multiple providers (Table 2). Most study participants (81.8%) reported accessing the formal health system (CHW, health center, or district hospital) at some point before the infant's death, and these were often the first sites of reported care. Informal sources were also used, with traditional healers (22.7% of all caregivers) the most commonly reported.

Gaps in Primary Survival Drivers. Gaps in all 3 of the primary drivers for survival were identified: not ac-

cessing appropriate care in a timely manner; perceived lack of technical quality care received; and lack of responsive care, including experiential quality and communication (Table 3).

1. *Not accessing appropriate care in a timely manner.*

Despite the high percent of individuals who sought care through the formal sector, timely access to appropriate care (initially or in follow-up) was one of the main challenges discussed by caregivers throughout their interviews. Participants reported 2 main secondary drivers that either hampered or facilitated their ability to access appropriate timely care for their infant: resources (means) to access care and knowledge (ability) to recognize danger signs.

Table 2. Reported Access to Care and Barriers Among Infants Included in the Verbal Autopsy Study Based on Quantitative Interview Component

	Recorded Interviews (N = 133)	Recorded and Coded Interviews (N = 66)
First source of care		
Formal system		
Health center	51 (38.3%)	25 (37.9%)
Community health worker	43 (32.3%)	22 (33.3%)
District hospital	4 (3.0%)	0 (0%)
Informal system		
Traditional healer	8 (6.0%)	5 (7.6%)
Other (includes pharmacies)	4 (3.0%)	3 (4.5%)
Any care provided by		
Health center	93 (69.9%)	44 (66.7%)
Community health worker	56 (42.1%)	27 (40.9%)
Hospital	36 (27.1%)	15 (22.7%)
Traditional healer	29 (21.8%)	15 (22.7%)
Other source	8 (6.0%)	6 (9.1%)
Care from ≥ 2 sources	74 (55.6%)	35 (53.0%)
No care from formal system	26 (19.6%)	12 (18.2%)
Any issue with care received (n = 86)		
Admissions issue	16 (18.6%)	7 (10.6%)
Treatment issue	11 (12.8%)	7 (10.6%)
Diagnosis issue	10 (11.6%)	5 (7.6%)
If self-identified delay to care (at time of death), reported cause		
Did not recognize danger of illness	6 (13.6%)	3 (4.6%)
Died too quickly	16 (36.4%)	10 (15.2%)
Financial barrier	9 (20.5%)	4 (6.1%)
Other	24 (54.6%)	12 (18.2%)
Don't know	1 (2.3%)	1 (1.5%)
Barriers to care		
Get money	78 (58.6%)	42 (63.6%)
Get permission	5 (3.7%)	2 (3.0%)
Distance	49 (36.8%)	24 (36.4%)
Not go alone	29 (21.8%)	14 (21.2%)
No barrier	39 (29.3%)	18 (27.3%)

1.1 Resources to access care.

Challenges to having adequate resources to access care predominantly included socioeconomic factors such as lack of financial or other resources needed to reach the facility. A main financial factor identified was the overall resources of the family to absorb out-of-pocket expenses. Respondents worried about potential out-of-pocket expenses, which delayed or prevented them from seeking care from the health system. Not having CBHI was reported as a barrier both in deciding when to seek care from a health care facility and in receiving care when respondents reached the facility. One participant described how lack of financial resources and insurance, as well as fear of out-of-pocket expenses, contributed to the decision not to seek care at the health facility.

"*If I had had* mutuelles*, I would have taken the baby to the health facility for health professionals to perform tests to identify the cause of the baby's death. I didn't take the baby to the health facility. Nor did I have it tested such that I didn't know the cause of its death. We were so poor we couldn't afford to pay for medical bills. As a result, the baby died.*" — KACA110030WI

Several participants also reported that even after going to the health facility, care was denied for the infant because they lacked CBHI.

"*I took the infant back to the health facility. When I arrived, they asked me if the infant was enrolled in the community-based health insurance scheme. I replied, 'As you can see, the infant was born early. I am currently trying to find money*

Table 3. Key Themes and Subthemes Found Within the Data

Key Themes	Subthemes
Household factors	Use of home-based or alternative remedies
	Tendency to use traditional healers
	Poor perceived quality of care at health facility
Maternal factors	Poor maternal health
	Complicated delivery
Vulnerable infant	Born sick or underweight
	Chronic illness
	Sudden onset of illness
	Insufficient breastfeeding
Lack of recognition of danger signs in infant leading to delay in timely accessing (or re-accessing) care	Acuteness of illness/seriousness not recognized by caregiver
	Lack of knowledge of infant health/health care
	Sudden illness/death
	Poor communication during first encounter
Means to access care not available	Low socioeconomic status/poverty
	Lack of transportation
	Lack of community-based health insurance (CBHI)
	Fear of being turned away (for not having CBHI)
Perceived technical quality care not received at health facility	Appropriate care not given at health facility at time of illness
	Infrastructure or medical supplies unavailable
	Referral services unavailable or delayed
Care given not responsive to patient/caregiver needs/expectations (poor experiential quality)	Perceived poor quality of care at time of illness and dissatisfaction
	Poor communication
	Reported disrespect/abuse by health care personnel

to pay for his/her enrollment in the community–based health insurance scheme. Why could you not let me seek treatment for the infant using my enrollment card?' However, they refused to attend to the infant and hence neglected me." —KICA108090PK

Despite the relative proximity to health care facilities for many families, transportation to a health facility, complicated by distance and cost, was also reported as a challenge to accessing health facility–based care faced by many.

"Our major challenge is the long distance we have to travel as the health facility is a far from our village to such an extent that a person may die without reaching the health facility." —KICA411070AU

1.2. Ability to recognize danger signs.
The development of acute illnesses not recognized as potentially serious also resulted in delays in timely care seeking. One participant described surprise at the death of their child after what seemed like a mild illness at the time.

"Frankly speaking, the infant's illness started off as a mild illness and I thought there was no reason to take the infant to the health facility especially because the infant only had a cough… It came as a surprise to me because the infant died of a sudden illness." — KACA113050WI

2. *Poor perceived technical quality of care received.*

Many of the participants described the challenges of receiving what they perceived as quality care from the health care system. Issues identified by participants included not receiving care they felt reflected the severity of the infant's illness and not having trained and competent personnel, infrastructure, and supplies in place and used in the care delivery.

2.1 Perceived inadequate intensity of care.
Some caregivers reported a lack of confidence in the appropriateness of care at health facilities during the time of the child's illness, both on initial and return visits, which they felt contributed to the poor outcomes.

"I think the baby died because they didn't perform medical consultations on the baby. Since they never performed medical consultations, we never knew the cause of the baby's death… I had mutuelles but they decided to give me three tablets. They didn't know the illness the baby had… When a patient arrives, they only give them tablets." —KACA126020WI

Another caregiver described the absence of testing and how the treatment choices were not effective.

"The medical treatment was not helpful. I went to the health facility thinking they would perform some tests to see if the illness was pneumonia as the infant would wheeze…They did not perform any test on the infant; the medications did not help and the infant's condition kept worsening."
—KACA205080PB

2.2. Lack of perceived competent, motivated, and responsive personnel and infrastructure in place.

Having trained, competent, responsive, and motivated health care providers and the infrastructure in place are critical to ensuring quality care. Participants noted concerns with their health care providers and the gaps in infrastructure at the health facilities. This theme overlapped with the perceptions of poor quality care and the variability in quality even within a facility. One participant mentioned that the type of care they received depended on the health care provider they had.

"At the health facility, it depends on the health professional you meet there. One health professional may give you good care, check the child's illness and perform all the tests. Sometimes, you may come across a health professional who does not care for you. Frankly, the health professional I came across did no care for me at all!" —KACA205080PB

Availability of supplies was a challenge reported both in facilities and for CHW-delivered care.

"As we took the infant to the CHWs for them to give us tablets, they told [us] that no tablets were available. After that, we planned to take the infant to the health facility the following morning. However, the infant died late in the night." —KICA522050AU

3. Lack of people-centered responsive care and experiential quality.

Responsive people-centered care including experiential quality is important to ensure that caregivers understand the needed care, play an active role in care, and generate trust in the system for this illness and future illnesses. These include communication, respect, accessibility, and care that reflects the patient's and family's needs and meets their expectations.[16] Interviews with the caregivers identified gaps in secondary drivers critical for receiving people-centered care. These gaps included health care providers not delivering respectful people-centered respectful care, not receiving care that met expectations, and ineffective communication during the encounter.

3.1. Disrespectful care.

One participant mentioned disrespect shown by the health care professional when the mother went to breastfeed the infant, resulting in a sense of not being welcome and care not being provided.

"There is a health professional who is disrespectful. The infant was severely sick and was crying. While the health professional was prescribing the meds, I went aside to breastfeed the infant. At that time, the professional called me and did not find me around. When I came back, he/she told me, "Go home, I will not give you any drugs."" — KICA222050PK

3.2. Low satisfaction with care provided.

Although care not meeting expectations is associated with lower satisfaction, the correlation is not always strong, highlighting the need to explore both of these important measures of quality. Several caregivers described dissatisfaction with the services provided at their local health facility, which they associated with the death of their child.

"…There were delays in getting treatments for my child as soon as necessary. We didn't get treatments quickly." —KICA521080NC

Another participant mentioned that even with CBHI coverage, the services received at the health facility were unsatisfactory.

"Their services aren't quite good. I can't confirm that customer satisfaction is [a] hundred percent especially because even mutuelles *takes a long time."* —KICA118030PK

3.3. Ineffective communication.

Caregivers described gaps in communication. Often no explanation of why certain tests or procedures were being conducted on the infant was given; caregivers described not knowing what was happening during their visits to the health facility, including the potential cause of illness.

"They gave him treatments, but they didn't tell me anything. They just hospitalized us. They gave him a serum, and when it finished, they gave him another one and pills. They didn't tell me the illness they had found." —KACA229050WI

The communication gaps affected knowledge about the potential severity of the illness, contributing to delayed access to appropriate levels of care. One participant described a delay in accessing facility-based care despite a CHW's instructions.

"When I arrived at the CHW's house, the CHW said to me, 'We don't administer medications to infants this age. You need to take your infant to the health facility.' I took the infant home and thought to myself, 'Should the infant's condition keep deteriorating, I will take him/her to the health facility.' At around noon on the following Thursday, the infant's condition deteriorated, I said to myself, 'If I go to [HF100], the infant will die before reaching the health facility.' Following this, I immediately took the infant to the nearest health facility…" —KACA113050WI

Final Driver Diagram. Modifications were made to the initial driver diagram based on the results from the quantitative and qualitative analyses (see Fig. 2). The overall framework was also changed to identify drivers toward mortality to help communication on the results to drive change. Adaptations to the driver diagram included removing secondary drivers not supported by caregiver responses such as lack of infant immunization and lack of willingness to use a CHW or facility-based care. New secondary drivers in the mortality model included timeliness, provision of appropriate care, and unsatisfactory care provided. Tertiary drivers not found in our setting based on the results included maternal education, health education, and confidence in care available; new tertiary drivers included lacking CBHI and inadequate resources for completing referrals.

DISCUSSION

Using a mixed methods approach to expand the understanding of the quantitative results and leverage the rich stories of care seeking, experiential quality, and potential contributors to infant deaths, we identified areas where improvement is needed to continue Rwanda's remarkable progress to reducing under-5 mortality focusing on infant deaths. Caregivers of infants who died described several drivers they perceived as contributing to the death of the infant, in particular those related to not accessing care in a timely manner, the technical quality of care received, and the responsiveness of the system and providers (Table 3). Two of the most commonly discussed secondary drivers of infant death mentioned by caregivers were the gaps or lack of communication between providers and patients, at times leading to repeated efforts to seek care, and the issues surrounding obtaining and using the CBHI. These results explain some of the patterns of care seeking seen in the quantitative data, including some caregivers not accessing formal care, the use of multiple providers, and causes of death reflecting treatable illnesses if care had been timely and effective.

Communication is a critical component to health system responsiveness and to ensuring that the needs of a patient and family are met, that prescribed treatment and instructions are understood, and that follow-up is timely if the child does not improve.[17] Caregivers who described interactions with CHWs and health care providers mentioned gaps in communication around the need for and results of testing and treatment of the infants. As previously reported in studies examining patient and provider interactions, low communication skills and low quality of services are often co-occurring and often related.[18] Enabling caregivers to recognize danger signs would help them to know when to take their child to a health care facility or return after initial treatment, reducing a potentially fatal delay in care as well as increasing individual empowerment as an advocate for their child.[19] It is also important to improve how medical personnel communicate with caregivers on what type of clinical investigations and treatments are necessary for their child, the reasoning behind a particular course of treatment, the diagnosis, and when they need to return, particularly in the setting of poor response. This gap in effective communication by providers was clearly described by caregivers in this study and may have contributed to the high percentage of home deaths discussed later. Ensuring that the patient or caregiver understands the potential causes, courses of action, and when to return for reassessment is crucial in a patient's adherence to a treatment plan and to avoid a delay when the child is not responding to the initial treatment.[18]

The CBHI scheme was designed to ensure that even the most vulnerable and marginalized do not encounter financial barriers to accessing the formal health system and to protect them from catastrophic costs.[3] Although largely successful in establishing broad coverage (90.7% in 2012), Lu et al[3] found that individuals in Rwanda's poorest quartile had the lowest rate of CBHI coverage and the highest rate of catastrophic spending. Policies surrounding CBHI were modified in 2011-2012 to increase enrollment in more rural regions and among the poorest by prorating CBHI fees based on a family's socioeconomic status.[20] However, we found close to one-half of families reported incomplete coverage and in the qualitative results some caregivers reported not having CBHI and not seeking care as a result of fear of being turned away because of an inability to pay. A few caregivers also reported seeking care but encountering delays because of demands for payment. This represents an opportunity for further understanding the challenges of universal coverage and the gaps in knowledge

and functioning of community and health care systems to ensure financial barriers are completely eliminated as a cause of delay in care seeking for children.

As noted earlier, an important finding was the high proportion of reported deaths occurring at home. This is consistent with earlier findings by the WHO estimating that most newborn deaths in Africa occur at home, often related to home delivery,[21] but we were unable to find similar statistics for infants, who likely have quite different causes of death. This high percentage of deaths outside of facilities was found in our study despite the broad use of the formal health system by caregivers and may relate to communication gaps and financial barriers, which could prevent a timely return for treatment. It will be important to develop a better understanding of both the choices families make with extremely sick children after initial care seeking and how to increase the use of the formal system when children do not respond to initial treatments or worsen after initial response. The themes we heard suggest a need for both supply-side interventions to improve experiences of care and demand-side interventions to increase ability to detect danger signs and navigate access barriers including insurance. Work to better understand the high rates of home deaths in our cohort is underway.

The key findings from this study highlight several areas where further exploration is needed to understand and address caregivers' concerns and reported barriers. Strengthening caregivers' ability to recognize and respond to signs of infant illnesses can help reduce the time to seeking care as well as streamline the referral process when care at the appropriate level is sought. More than half of caregivers did not report seeking care from a CHW for their infant during the life-ending condition, a concern because previous work has found a reduction in risk of childhood death in the setting of effective community-delivered care.[22] The integration of a demand-side intervention of community health education combined with strengthened people-centered care and quality of community-based integrated management of childhood illness services could also increase the impact of CHWs as first contact and ensure timely care seeking.[4] Addressing barriers to the existing CHW system and ensuring the technical and experiential quality of those services is important to increase the potential for children to receive lifesaving interventions.

Our study had a number of limitations. The original VSA study was not designed as a qualitative study;

follow-up questions to explore responses were not standardized but rather based on the data collectors' need to extract elements of histories for the quantitative VSA study. Some areas were thus not investigated as deeply as they would have been with a study designed to focus on qualitative inquiry. Although the data collectors were trained to conduct the interviews using the VSA protocol, there was likely still variation in probing style and the depth of information provided by the participants, which may have resulted in more in-depth responses from some participants than others. Some bias in responses was possible due to the nature of the information being collected, specifically surrounding contributing factors toward a child's death. Even if some of the contributing causes were external to the health systems, caregivers may have assigned responsibility solely to the health system due to the emotional toll of the loss of their infant. They may have also reported lack of satisfaction with the care they received due to assigning responsibility for their infant's death to health system factors when it was due to these external factors. Finally, we were unable to verify the reported care-seeking behaviors and quality and timeliness of care received.

The use of the driver diagram as our framework for understanding barriers to successful care seeking in this study was an innovative approach for a quality improvement tool in a VSA study. Driver diagrams have mainly been used to explore factors needed to achieve a specific overall goal, in the context of a quality improvement initiative, and to show how factors are connected to help explain a change in strategy. The use of the driver diagram allowed us to extract and understand the main drivers of infant mortality in this setting while identifying the secondary determinants, to be targets of initial improvement work. The use of mixed methods also supported the deeper understanding of challenges faced by families in seeking care for critically ill infants and areas where responsiveness of the health system could be strengthened to ensure effective people-centered care in Rwanda, a country that has already achieved remarkable progress in reducing under-5 mortality.[2]

The WHO recently called for a stronger focus on integrated people-centered care as critical for quality Universal Health Coverage to achieve health-related Sustainable Development Goals.[1] The results from our study and the methods employed increase the capture of the voice of caregivers of very young children. This is critical in helping better understand the experiences of care seeking and quality to inform

countries where further strengthening of health systems, community education, and other interventions are needed. This work will help strengthen the primary care system across the levels of care delivery and ensure the access, continuity, coordination, and trust in the first contacts of the health system that are critical to reducing infant mortality and under-5 mortality more broadly.

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