

BMJ Open

BMJ Open is committed to open peer review. As part of this commitment we make the peer review history of every article we publish publicly available.

When an article is published we post the peer reviewers' comments and the authors' responses online. We also post the versions of the paper that were used during peer review. These are the versions that the peer review comments apply to.

The versions of the paper that follow are the versions that were submitted during the peer review process. They are not the versions of record or the final published versions. They should not be cited or distributed as the published version of this manuscript.

BMJ Open is an open access journal and the full, final, typeset and author-corrected version of record of the manuscript is available on our site with no access controls, subscription charges or pay-per-view fees (<http://bmjopen.bmj.com>).

If you have any questions on BMJ Open's open peer review process please email info.bmjopen@bmj.com

BMJ Open

The Four Delays of Child Mortality in Rwanda: A Mixed-Methods Analysis of Verbal Social Autopsies

Journal:	<i>BMJ Open</i>
Manuscript ID	bmjopen-2018-027435
Article Type:	Research
Date Submitted by the Author:	24-Oct-2018
Complete List of Authors:	Roder-DeWan, Sanam; Harvard University T H Chan School of Public Health, Global Health and Population Gupta, Neil; Brigham and Women's Hospital, Global Health Equity; Partners in Health/Inshuti Mu Buzima Kagabo, Daniel; Partners in Health/Inshuti Mu Buzima Habumugisha, Lameck; Partners in Health/Inshuti Mu Buzima Nahimana, Evrard; Partners in Health/Inshuti Mu Buzima Mugeni, Catherine; Maternal Child and Community Health Rwanda Biomédical Center, Rwanda Ministry of Health Bucyana, Tatien; Maternal Child and Community Health Rwanda Biomédical Center, Rwanda Ministry of Health Hirschhorn, Lisa; Ariadne Labs; Northwestern University Feinberg School of Medicine
Keywords:	PAEDIATRICS, Community child health < PAEDIATRICS, Quality in health care < HEALTH SERVICES ADMINISTRATION & MANAGEMENT, QUALITATIVE RESEARCH

SCHOLARONE™
Manuscripts

1
2
3
4
5
6
7
8
9
10
11
12
13
14
15
16
17
18
19
20
21
22
23
24
25
26
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60

The Four Delays of Child Mortality in Rwanda: A Mixed-Methods Analysis of Verbal Social

Autopsies

Authors:

- Sanam Roder-DeWan - Harvard Chan School of Public Health, 677 Huntington Avenue, Boston, MA, USA, roderdewan@mail.harvard.edu (corresponding author)
- Neil Gupta-Division of Global Health Equity, Brigham & Women's Hospital, 75 Francis St. Boston, MA USA, Partners In Health / Inshuti Mu Buzima, Rwinkwavu, Rwanda, ngupta@pih.org
- Daniel M. Kagabo- Partners In Health / Inshuti Mu Buzima, Rwinkwavu, Rwanda, dankagabo@gmail.com
- Lameck Habumugisha- Partners In Health / Inshuti Mu Buzima, Rwinkwavu, Rwanda, habumugisha4@gmail.com
- Evrard Nahimana- Partners In Health / Inshuti Mu Buzima, Rwinkwavu, Rwanda, enahimana@pih.org
- Catherine Mugeni-Maternal Child and Community Health, Rwanda Biomédical Center, Rwanda Ministry of Health, KN 3 Rd, Kigali, Rwanda, cmugeni@gmail.com
- Tatien Bucyana- Maternal Child and Community Health Rwanda Biomédical Center, Rwanda Ministry of Health, KN 3 Rd, Kigali, Rwanda, tbucyana@yahoo.fr
- Lisa R. Hirschhorn- Northwestern University, 633 N. Saint Clair Street, 19th Floor Chicago, IL, USA, lisa.hirschhorn@northwestern.edu

ABSTRACT

Objectives

We sought to elucidate healthcare-seeking patterns and delays in obtaining effective treatment for rural Rwandan children ages 1-5 years by analyzing verbal and social autopsies(VSA). Factors in the home, related to transport and to quality of care in the formal health sector (FHS) are thought to contribute to delays.

Design

We collected quantitative and qualitative cross-sectional data using the validated 2012 WHO VSA tool. Descriptive statistics were performed. We inductively and deductively coded narratives using the three delays model, conducted thematic content analysis and used convergent mixed-methods to synthesize findings.

Setting

The study was conducted in the catchment areas of two rural district hospitals in Rwanda - Kirehe and Southern Kayonza.

Participants

A caregiver for each child ages 1-5 years who died in our study area between March 2013 and February 2014 was interviewed.

Results

We analyzed 77 VSAs. Although 74% of children (N=57) had contact with the FHS before dying, the majority (59%, N=45) died at home. Many caregivers (44%, N=34) considered using traditional medicine and 23 (33%) actually did. Qualitative themes reflected difficulty recognizing the need for care, the importance of traditional medicine, especially for “poisoning”, and poor perceived quality of care. We identified an additional delay - phase 4 -which occurred after leaving formal healthcare facilities. These delays were caused by the caregivers’ unwillingness or inability to adhere to care plans.

Conclusion

Delays in deciding to seek care (phase 1) and receiving quality care in FHS (phase 3) dominated these narratives; delays in reaching a facility (phase 2) were rare. Failure to adhere to treatment plans after leaving facilities (phase 4) were an important additional delay. Improving quality of care, especially provider capacity to communicate danger signs/treatment plans and promote adherence in the presence of alternative explanatory models (traditional medicine) could help prevent childhood deaths.

Article Summary

Strengths and limitations

- The large qualitative and quantitative data set used to understand the experience of caregivers leading to the death of all children ages 1-5 years in this area of Rwanda is a strength of this study.
- As is the nature of qualitative research, these findings cannot be generalized beyond the study population, but may be used to guide similar explorations in comparable samples.
- The use of mixed methods and the unique caregiver perspectives allowed for the identification of an important additional source of delays that occurred after children left formal sector healthcare. We call these “phase 4 delays”.
- A strength of this study is that by characterizing a 4th delay, it adapts the three delays model of maternal mortality for use in understanding childhood mortality.

1
2
3
4
5
6
7
8
9
10 Competing interests – The authors declare no competing interests.

11 Funding – Doris Duke Charitable Foundation

12
13 Keywords – Community child health, pediatrics, qualitative research, quality in health care

14
15 Word Count: 3983

16 17 18 19 20 21 **BACKGROUND**

22 Rwanda has reduced under-five (U5) mortality by more than two-thirds since 2000, one
23 of only 12 low-income countries to achieve Millennium Development Goal (MDG) Four ¹⁻³. This
24 progress, though exceptional by most measures, mirrors a global trend of reduced childhood
25 mortality and epidemiological transition away from the most easily preventable causes of death ⁴.
26 As proficiency is gained in tackling the “low-hanging fruit” of child health, health systems must
27 turn their attention to solving the more complex problems that remain.

28
29
30
31
32 Despite Rwanda’s remarkable progress, a child is still ten times more likely to die before
33 their 5th birthday in Rwanda than in most high-income countries ⁵. Evidence from other low-
34 income countries suggests that the majority of these deaths will occur outside of a health facility
35 and that late care-seeking is a significant contributing factor ^{6,7}. Understanding family and
36 community contexts will thus be important for improvement ^{8,9}. What beliefs and behaviors exist
37 in homes and communities that delay care-seeking? What barriers do caregivers face when they
38 decide to seek care and what challenges might an increasingly capable but complex health
39 system pose for them?

40
41
42
43
44
45
46 These questions may best be answered by viewing health seeking pathways and the
47 health system from the perspective of its users, an area of scholarship that is poorly represented

1
2
3
4
5
6
7
8
9
10 in the literature in low-and middle- income countries (LMIC) ¹⁰. This study aims to address the
11 gap in knowledge by analyzing a verbal and social autopsy (VSA) data collected following all
12 deaths of children ages 1-5 years in two rural districts in Rwanda.

14 **METHODS**

16 *Setting*

18 During the study period, there were 23 health centers (HC) in Kirehe and Southern Kayonza
19 serving a population of 538,405. HCs are staffed by nurses and provide inpatient and outpatient
20 services ^{11,12}. Community health workers (CHWs) provide integrated community case
21 management of pediatric illnesses (c-IMCI) ¹³. They diagnose and treat pneumonia, diarrhea, and
22 malaria, monitor malnutrition and make referrals. An estimated average of one CHW serves 50
23 people under age 5; there are two cIMCI-trained CHWs per village ^{13,14}. Kirehe is served by one
24 district hospital and Kayonza by two. The study was conducted in the catchment area of one
25 hospital in Kirehe and another in Kayonza. Area households in the two districts are a median
26 3.5km from their closest HC ¹¹. Community based health insurance (CBHI also referred to as
27 “Mutuelle de Santé”, or “mutuelle”) was available in the study districts. It achieved over 90%
28 coverage in Rwanda overall (Makaka et al., 2012)

30 *Study design*

32 Data were collected through VSAs with caregivers of 259 U5s who died between March 2013
33 and February 2014. VSA is a process used to assign causes of death in cases where no standard
34 autopsy was done and social autopsy augments the structured interview of a verbal autopsy with
35 open-ended questions about the beliefs, decisions, and perspectives of those who cared for the
36 decedent ^{10,15-22}. Quantitative and qualitative data were collected during one visit with a family.
37 Deaths were identified through health records, RMOH reporting systems and the Monitoring of
38

1
2
3
4
5
6
7
8
9
10 Vital Events using Information Technology program in which CHWs reported vital events by
11 telephone. CHWs then helped locate families, and families who consented were interviewed
12 between 3 weeks and 1 year after the death. This paper is a sub-analysis of VSA data of children
13 between the ages of 1 year and 5 years. This age range was chosen because it encompasses
14 children with shared developmental characteristics, such as physical mobility, clinical
15 characteristics and illness patterns and social experiences, such as not yet being in the school
16 system.
17
18
19
20

21
22 Quantitative data were collected using the validated WHO 2012 verbal autopsy semi-
23 structured interview tool (InterVA4)²³ and supplemented by questions from the RMOH's Death
24 Audit Tool and the 2010 Rwanda Demographic and Health Survey. Trained interviewers used
25 hand held electronic devices and conducted semi-structured interviews in the local language,
26 Kinyarwanda. Informants were asked to describe events surrounding the death of the child.
27 Segments during which interviewees expanded on symptoms, decision-making, care-seeking and
28 perceptions of care received were transcribed and then back-transcribed from Kinyarwanda to
29 English for quality and accuracy review.
30
31
32
33
34

35 *Patient and Public Involvement*

36
37 The research question was informed by the work of Partners in Health/Inshuti Mu
38 Buzima (PIH/IMB) which has supported the Rwandan Ministry of Health (RMOH) to strengthen
39 health care delivery and systems in Kirehe and Southern Kayonza districts since 2005. This VSA
40 project was part of a larger initiative to better understand and reduce under five (U5) mortality.
41 Patients were not involved in the recruitment to and conduct of the study, nor were they involved
42 in the design of the study. However, as a service delivery organization, PIH/IMB has a deep
43 experience with patients and their families/caregivers, an experience that helped shape the study.
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60

1
2
3
4
5
6
7
8
9
10 Aggregated early results were shared with the MOH and IMB in a timely manner to facilitate
11 improved health care delivery.

12 *Analysis*

13
14 We used the three delays model ²⁴ as a framework to begin our thematic content analysis. This
15 model was originally developed to understand maternal mortality ²⁴. Phase 1 delays relate to
16 deciding to seek care, phase 2 delays occur while trying to reach a facility and Phase 3 delays
17 occur after arrival at a facility in the form of poor quality of care. We use the Lancet Global
18 Health Commission on High Quality Health Systems framework to understand high quality care.
19 Specifically, high quality care includes competent care and systems, positive user experience as
20 well as better health, confidence in the system and economic benefit²⁵.

21
22 A mix of inductive and deductive coding was used to develop a codebook ²⁶ which was
23 discussed and revised by an interdisciplinary team of researchers, physicians and public health
24 professionals. A sub-set of interviews (11) were double coded to ensure inter-rater reliability and
25 then the codebook was applied to the data set until saturation of codes was reached at 77
26 interviews. Iterative thematic analysis using coding, recoding, categorization and reorganization
27 was used to further develop the themes and generate hypotheses. Dedoose was used for
28 qualitative and mixed-methods analysis (Version 7.5.9, SocioCultural Research Consultants,
29 LLC, Los Angeles, CA).

30
31 The most likely cause of death (COD) was determined using InterVA4 ²³. COD and
32 sociodemographic variables from verbal autopsied were analyzed using descriptive statistics.
33 Quantitative analytics were performed using STATA version 14 (Copyright 1985-2015
34 StataCorp LP. College Station, TX).

35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60
6

Commented [SR1]: Will ask dom.

1
2
3
4
5
6
7
8
9
10 Associations between descriptive variables and qualitative themes were explored using a
11 convergent mixed-methods approach²⁷. This approach is recommended by experts to better
12 understand complex phenomenon, such as care seeking behavior because it helps uncover
13 patterns that may not have been accessible through only quantitative data analysis or only
14 qualitative data analysis²⁸. Excerpts were first organized by phase of delay and then divided by
15 quantitative variables. These variables were chosen based on hypotheses which were generated
16 during the qualitative analysis of the interviews. Thematic analysis of these sub-groups of
17 excerpts was conducted to identify divergent themes. Interviews were coded and analyzed until
18 saturation of codes was achieved, i.e. saturation was achieved when no new codes or ideas were
19 identified²⁹.
20
21
22
23
24
25
26

27 The study was approved by Rwanda National Ethics Committee and Partners Institutional
28 Review Board. Verbal consent was deemed permissible by both boards. A consent form was read
29 to potential participants in Kinyarwanda-speaking data collectors who also answered questions.
30 Participant were asked to verbally confirm that the consent was understood. Data collectors were
31 trained in sensitivity, patience and consideration with families who had lost a child. No
32 interviews were conducted during the three-week mourning period. Each interview was assigned
33 a number that matched with caregiver identifying information and was stored in a separate file in
34 a secure location. No individual identifiers were recorded on the data collection forms.
35
36
37
38
39
40

41 RESULTS

42 We identified 259 deaths of children ages 1 to 5 years (table 1). Saturation of codes was reached
43 at 77 interviews. The average age at death of the 77 children was 2.5 years. The majority were
44 male (57%) and 27% of mothers had no formal education. The average age of mothers of the
45 deceased was 31 years. One quarter of informants (29%) reported having no health insurance for
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60

1
2
3
4
5
6
7
8
9
10 the family. The leading cause of death was malaria (39%), then respiratory illness (14%), and
11 acute abdomen (14%).
12

13 Most children received some care from the formal health sector (FHS) - 61% from a HC
14 and 55% from a CHW. A CHW was the first point of contact for 46%. Nearly half of the
15 caregivers (34 of 77) considered consulting a traditional healer during the illness leading to the
16 index child's death; 33% actually did. The majority (59%) of children died at home.
17
18

19 *Phase 1 delays*, were raised during 54 VSAs. Caregivers, most commonly mothers,
20 frequently described "confusion" and "surprise" about their child's illness and said that they did
21 not know what to do or when to seek care. They also described domestic responsibilities that
22 constrained the ability to closely monitor children. For example, as women worked on their
23 farms, older children were left to tend younger children (table 2A).
24
25
26
27

28 The majority (63%, N=34) of VSA cases describing phase 1 delays also discussed
29 traditional medicine (TM), primarily for the diagnosis of "poisoning" which was described as
30 being caused by "nasty people" who wanted to do harm. The diagnosis was confirmed when
31 vomiting was induced by a liquid medication. Traditional healers were consulted either in
32 conjunction with the FHS (medical pluralism) or exclusively. Some respondents reported using
33 TM to "clear" the poison so that the FHS could be effective; others tried all available options
34 concurrently. Exclusive use of TM usually occurred if the caregiver was certain about the
35 diagnosis of poisoning (table 2B).
36
37
38
39
40
41
42

43 The majority of this sub-group of respondents (19/34) indicated that *only* TM could treat
44 poisoning. Beliefs and practices that supported exclusive use of TM for poisoning included
45 "admitting" severely ill children with poisoning to the house of a traditional healer and believing
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60

1
2
3
4
5
6
7
8
9
10 that FHS care for poisoned children, especially in the form of an injection, would kill the child
11 (table 2B).

12
13 Previous experiences with the health system or CBHI (being rejected for lack of
14 insurance or inability to pay out-of-pocket) shaped care-seeking decisions. Even those that did
15 have CBHI experienced administrative challenges to maintaining coverage. Beliefs about the
16 quality of the health system also shaped decisions to seek care (table 2C).

17
18
19
20 *Phase 2 delays* were raised spontaneously by four of 77 informants. Transport barriers
21 included drivers refusing critically ill children and cost (table 2D). Many informants mentioned
22 waiting until morning to travel, but the safety of travelling at night was not discussed directly.
23 Some informants mentioned bypassing the closest facility and going to one they believed would
24 provide higher quality care.
25

26
27
28
29 *Phase 3 delays* were described in 57 of 77 (74%) cases. Despite Rwandan policy stating
30 that no critically ill child should be turned away, five respondents reported being denied
31 appropriate treatment in the FHS due to inability to pay (table 2E). Nearly all third phase
32 interviews mentioned poor quality of care (table 2F). A lack of FHS equipment, supplies,
33 medicine or providers were reported by very few informants (n=6) and the majority of these
34 excerpts related to CHWs. People describe “neglect”, being “ignored”, being “reprimanded” or
35 “shown contempt”. Long wait times were frequently mentioned. Leaving the FHS knowing a
36 child’s diagnosis or having a treatment plan, was common. Respondents reported poor technical
37 skills and decisions at the FHS. Informants also describe positive interactions with health care
38 professionals who “immediately” provided care or were empathic (table 2G), or went out of their
39 way to help. Services were sometimes described as “good” and “proper”.
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60

1
2
3
4
5
6
7
8
9
10 Informants reported barriers to successful care and treatment that did not fall into the
11 three phases during 28 VSAs. These occurred after a child left the formal sector and were related
12 to the willingness or capacity of caregivers to comply with FHS treatment plans. We are calling
13 these “phase 4 delays” (figure 1). Dissatisfaction with outcomes of care in the FHS (failed
14 treatment or inconclusive tests) led families to abandon the formal sector and seek care from
15 traditional healers (table 2H).
16
17
18
19

20 In seven cases FHS personnel referred families to TM because poor treatment response
21 was attributed to poisoning. Limited capacity to adhere to FHS treatment plans was linked to
22 financial barriers or poor communication; caregivers lacked clear instructions on how to
23 administer treatments or when to follow-up. Families were further challenged by needing to
24 make multiple trips to FHS facilities (table 2I).
25
26
27
28

29 A hypothesis-driven mixed methods analysis revealed several additional themes. First,
30 formal maternal education was associated with more active care-seeking language: “I decided”,
31 “I asked myself”, “I had the child tested”, “I suspected”. Those without formal education
32 disproportionately described delaying decisions in order to seek advice (table 3).
33
34
35

36 Second, children who died outside of a facility were *not* more likely to live far away from
37 a HC or discuss phase 2 delays but were more likely to have died while caregivers were
38 “preparing” to go the FHS. This theme is not present in the sub-set of children that died in the
39 FHS. Many caregivers of children who died at home actively made decisions to keep children at
40 home if they believed that death was imminent; death at home appeared to be a preference.
41 Those that did make it to a provider in the FHS but still had a child who died elsewhere,
42 described issues with adherence to formal sector provider recommendations and follow-up; 88%
43 of children whose caregivers discussed phase 4 delays did not die in the FHS (table 4). Several
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60

1
2
3
4
5
6
7
8
9 mixed methods sub-analyses were undertaken by cause of death. No convergent or divergent
10 themes were identifiable by this category of descriptors.
11

12
13 Finally, an analysis of excerpts by cause of death helped shed light on the fourth phase of
14 delay (table 5). Though diversion to the informal sector occurred across all causes of death, the
15 majority of cases of health care providers referring patients to traditional healers were in children
16 who died of something other than malaria. Those who died of malaria had caregivers who
17 described receiving “tablets”, waiting for them to take effect and having a child either die during
18 treatment or in the care of a traditional healer because the treatments were perceived to be
19 ineffective. They told of hesitating to take their child back to a facility despite recognizing a lack
20 of improvement during treatment. Whether this is because clear instructions for follow-up were
21 not given or not understood cannot be determined from the data. Sometimes this hesitation came
22 with an expressed fear of being judged for coming back too soon. Children without the diagnosis
23 of malaria were less likely to have been given “tablets” and more likely to experience delays
24 after leaving a health center related to searching for a treatment from multiple formal facilities or
25 from informal providers. Their decisions to seek alternatives were more likely to come
26 immediately after leaving the treatment facility.
27
28
29
30
31
32
33
34
35
36
37

38 **DISCUSSION**

39
40 We analyzed VSAs of 77 children ages 1-5 years in rural Rwanda and found that care-
41 seeking was dominated by challenges in deciding to seek care (phase 1) and in receiving high
42 quality care in the FHS (phase 3). Our respondents rarely mentioned challenges in reaching a
43 facility (phase 2). In addition to the three classic delays, we identified a domain that occurred
44 after sick children visited the FHS; phase 4 delays. The children in this sample either never made
45 it to a facility because of delays in deciding to seek care (phase 1) or were sent home after an
46
47
48
49
50
51

1
2
3
4
5
6
7
8
9
10 interaction with the FHS only to experience delays in follow-up care or adherence to treatment
11 (phase 4).
12

13 Phase 4 delays were related to caregiver unwillingness or inability to adhere to care plans
14 and often involved decisions to abandon formal sector care in favor of traditional medicine. This
15 phase was identified and characterized through the qualitative analysis of narratives and is
16 supported by descriptive data showing that 74% of children in our data set had contact with the
17 FHS, but 59% died at home. Phase 4 delays were closely linked to the ability of providers to
18 communicate care plans and danger signs, a shortcoming that is particularly dangerous in the
19 presence of a robust traditional medicine system that caregivers can turn to if interactions with
20 formal care are unsatisfactory or if the child is not improving as expected. The most common
21 cause of death in this sample, Malaria, appeared to be associated with fourth phase delays caused
22 by receiving treatment but not knowing when to return if treatment was not perceived to
23 be effective.
24
25
26
27
28
29
30
31

32 The majority of deaths were not associated with a single delay. This finding is consistent
33 with published literature on the three delays in maternal and child health ^{9,24,30}. Families
34 experienced complex care pathways that often began with partial information about child health
35 and required the ability to negotiate competing explanatory models ³¹. Explanatory models are
36 socio-culturally informed systems that explain illness and healing; in this population “poisoning”
37 appears to be a dominant construct. Those that did reach the FHS were sometimes turned away
38 for financial reasons. Though some informants described positive experiences with the FHS,
39 many did not. Children died while caregivers waited and families left facilities without knowing
40 why their child was sick or when to return. They made decisions to use TM or visited many FHS
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60

1
2
3
4
5
6
7
8
9 facilities. The complexity of care navigation was particularly challenging for families who
10 struggled with intersectional causes of disadvantage such as poverty and limited education.
11

12
13 A preference for dying at home, possibly due to indirect costs of facility death, may have
14 contributed to the high percent of children who died at home (59%). Caregivers of children who
15 died at home frequently described children dying while preparing to leave for the FHS
16 suggesting that the urgency of the illness was not well understood. Finally, TM was used by one
17 third of families and even recommended by FHS providers possibly augmenting out-of-facility
18 death rates. If poisoning was “confirmed” (often when a traditional healer induced vomiting),
19 some caregivers *only* used TM regardless of illness severity. Several practices made exclusive
20 (rather than complementary) TM use more likely; several critically ill children in this sample
21 were “admitted” to the homes of traditional healers for more intense treatment and some
22 informants believed that a poisoned child would be killed if treated in the FHS. This exclusive
23 pattern of TM use is found in the literature on epilepsy and tuberculosis in Rwanda ^{32,33}. Our data
24 does not allow us to determine which symptoms are locally understood as indicative of poisoning
25 in children, but according to Taylor (1988) the syndrome overlaps closely with features of
26 clinical dehydration. Perhaps the non-specific nature of symptoms of poisoning contributes to the
27 widespread use of TM in our study population.
28

29
30 Having TM as an alternative explanatory model ³¹ was particularly important when
31 caregivers were not satisfied with the care that they received at the FHS. A large portion of
32 fourth phase delays involved abandoning FHS treatment plans in favor of TM. Limited literature
33 is available on the nature or role of TM in Rwanda, due in part to only very recent efforts to
34 recognize and integrate this sector into the health system (Government of Rwanda, 2012). A
35 qualitative study of TM providers and their role in treating pregnant women estimated that there
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60

1
2
3
4
5
6
7
8
9
10 are up to two traditional providers in each village in Rwanda and that they are usually older
11 women who inherited the profession from their mothers³⁴. Only one study was identified that
12 specifically describes a Rwandan concept of poisoning³⁵. That work characterizes poisoning as a
13 humor that acts through the digestive tract and decreases blood volume, a description that seems
14 largely consistent with our findings.
15
16
17

18 In addition to helping us understand care-seeking in the community, our data also
19 describes a health system from the perspective of its users. Many informants consulted a CHW
20 as a first source of care, as recommended by the RMOH model of primary care. This shows that
21 the population accepts this cadre as an integral part of the Rwandan health care system.
22
23 However, families also encountered problems with CHWs – the majority of reports about limited
24 medications or human resources in our data set were about CHWs. These issues might make
25 CHWs a source of delay rather than an expansion of the healthcare web in Rwanda.
26
27
28
29

30 The experience of care at facilities is a significant challenge to informants in this dataset.
31
32 These Phase 3 themes are framed by the classic work on quality of care by Avedis Donabedian
33 of structure/inputs, processes and outcomes³⁶. The procedural elements of care (both technical
34 and interpersonal) are far more likely to be raised by our informants than the structure or inputs
35 of the FHS. Our informants describe how this quality impacts decisions to seek care as well as
36 how it impacts decisions to follow-through with treatment plans.
37
38
39
40

41 CBHI was widespread and highly valued by our informants. However, there were
42 implementation challenges. Informants discuss the high cost of insurance and share deeply
43 concerning narratives of being turned away from health facilities with critically ill children.
44
45 Caregivers also describe avoiding health facilities because of a fear of being turned away due to
46 not having health insurance.
47
48
49
50
51
52
53
54
55
56
57
58
59
60

1
2
3
4
5
6
7
8
9
10 As is the nature of qualitative research and despite census-level data, the themes arising
11 from this data cannot be assumed to be representative beyond the population studied. However,
12 our analysis of a large sample helps illuminate concepts that should be considered and explored
13 in parallel populations. Other limitations include variation in interviewing techniques due to
14 multiple research assistants in the field as well as variable transcription of narratives. We
15 minimized this issue through rigorous training of our research assistants, and regular research
16 team debriefings during data collection and processing. Though several techniques for
17 triangulating and identifying cases were used, it is possible that child death cases were missed
18 due to relocation or misclassification. This could lead to a selection bias because unidentified
19 cases may be systematically different from those that were analyzed (e.g. more remote, fewer
20 resources, less likely to seek care). Our community-based triangulation methods were designed
21 to capture the most marginalized families and to identify those that have left the catchment area
22 after a child's death. Finally, our study is not powered to draw statistical conclusions from the
23 descriptive data.
24
25
26
27
28
29
30
31
32
33
34

35 **CONCLUSION**

36
37 The patient narratives presented here describe the challenges that
38 families face at home, in their communities and with the health system to
39 provide their children with timely and appropriate medical care. Dramatic failures
40 or gross indiscretions are rare. Parents and families describe making the decisions they thought
41 were best and doing the most that they could despite barriers. The barriers and delays
42 experienced by caregivers in this dataset are concentrated in the first and third phase, with a
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60

1
2
3
4
5
6
7
8
9
10 significant contribution from delays occurring after leaving a formal facility, a category of
11 themes that we have termed phase 4 delays. Using a four delays framework may help more fully
12 characterize delays leading to the death of children in settings such as ours, because unlike
13 maternal cases, definitive treatment for children often occurs after seeing a provider.
14
15

16 Rwanda has made exceptional progress in child health, meeting and exceeding MDGs. In
17 order to maintain and accelerate this progress in the Sustainable Development Goals era, several
18 approaches could be considered. Healthcare service delivery needs to be consistently and reliably
19 aligned with national policies and would require improved facility-level accountability
20 mechanisms to ensure that patients are not denied care or otherwise treated unfairly. Continued
21 improvements in the quality of care, especially around provider competence in the areas of
22 patient-centered care and communication are necessary. Provider competencies should include
23 the ability to form healing partnerships with patients to prevent poor adherence and the ability to
24 explore and understand competing explanatory models that may cause delays in achieving good
25 health outcomes³⁷. Finally, in order for caregivers to be partners in child health, they must have
26 practical knowledge about appropriate care seeking and be empowered to use it to help their
27 children be healthy.
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60

List of abbreviations

CBHI – Community Based Health Insurance

CHW – Community Health Worker

c-IMCI – Community Integrated Management of Childhood Illness

COD – Cause of Death

FHS – Formal Health Sector

PIH/IMB – Partners in Health/Inshuti Mu Buzima

RMOH – Rwanda Ministry of Health

TM – Traditional Medicine

U5 – Under five

VSA – Verbal Social Autopsy

WHO – World Health Organization

Declarations

- Ethics approval and consent to participate - Study approval was received from the Rwanda National Ethics Committee and Partners Health Care
- Consent for publication – Consent forms are available upon request
- Availability of data and material – The datasets used and/or analyzed during the current study are available from the corresponding author.
- Author statement– Study oversight (LRH, NG), Study design (LRH, NG, DMK, LH), Data Collection (LH, DMK), Data coding (LH, SRD), Data analysis (SRD, LRH), Manuscript writing (SRD), Manuscript review (SRD, NG, LH, DMK, EN, CM, TB, LRH).
- Acknowledgments –The authors gratefully acknowledge the data collectors and study staff for their dedication to collecting the data with great sensitivity and compassion for the families

involved in this study. We would like to thank hospital leadership and staff from Rwinkwavu and Kirehe District Hospitals and the many health workers who have committed their lives to caring for families in Rwanda. Thank you also to Harvard Catalyst | The Harvard Clinical and Translational Science Center (National Center for Research Resources and the National Center for Advancing Translational Sciences, National Institutes of Health Award UL1 TR001102) via mixed methods consulting services from Rebekka M. Lee. (The content is solely the responsibility of the authors and does not necessarily represent the official views of Harvard Catalyst, Harvard University and its affiliated academic healthcare centers, or the National Institutes of Health.) We would also like to thank the Doris Duke Charitable Foundation's African Health Initiative funding for this project. Most importantly, we are incredibly grateful to the families and caregivers who generously shared their difficult stories with us to contribute to reducing U5 mortality in Rwanda.

References

1. Musafili A, Essén B, Baribwira C, Binagwaho A, Persson L-Å, Ekholm Selling K. Trends and social differentials in child mortality in Rwanda 1990–2010: results from three demographic and health surveys. *Journal of Epidemiology and Community Health* 2015; **69**(9): 834-40.
2. Persson LÅ, Rahman A, Peña R, Perez W, Musafili A, Hoa DP. Child survival revolutions revisited – lessons learned from Bangladesh, Nicaragua, Rwanda and Vietnam. 2017. p. 871-7.
3. UNICEF. Levels and Trends in Child Mortality. New York, NY: United Nations Children's Fund, 2015.
4. Liu L, Oza S, Hogan D, et al. Global, regional, and national causes of under-5 mortality in 2000–15: an updated systematic analysis with implications for the Sustainable Development Goals. *The Lancet* 2016; **388**(10063): 3027-35.
5. UNICEF. Levels and Trends in Child Mortality: Report 2015. Estimates Developed by the UN Inter-agency Group for Child Mortality Estimation. New York, NY: United Nations Children's Fund, 2015.
6. Bojalil R, Kirkwood BR, Bobak M, Guiscafre H. The relative contribution of case management and inadequate care - seeking behaviour to childhood deaths from diarrhoea and acute respiratory infections in Hidalgo, Mexico. *Tropical Medicine & International Health* 2007; **12**(12): 1545-52.

7. Waiswa P, Kallander K, Peterson S, Tomson G, Pariyo GW. Using the three delays model to understand why newborn babies die in eastern Uganda.(Report). *Tropical Medicine and International Health* 2010; **15**(8): 964.
8. Noordam AC, Carvajal-Velez L, Sharkey AB, Young M, Cals JW. Care Seeking Behaviour for Children with Suspected Pneumonia in Countries in Sub-Saharan Africa with High Pneumonia Mortality. *PLoS One* 2015; **10**(2): urn:issn:1932-6203.
9. Ingabire CM, Kateera F, Hakizimana E, et al. Determinants of prompt and adequate care among presumed malaria cases in a community in eastern Rwanda: a cross sectional study.(Report). *Malaria Journal* 2016; **15**(228).
10. Bensaïd K, Yaroh AG, Kalter HD, et al. Verbal/Social Autopsy in Niger 2012–2013: A new tool for a better understanding of the neonatal and child mortality situation. *Journal of Global Health* 2016; **6**(1).
11. Manzi A, Magge H, Hedt-Gauthier BL, et al. Clinical mentorship to improve pediatric quality of care at the health centers in rural Rwanda: a qualitative study of perceptions and acceptability of health care workers. *BMC Health Services Research* 2014.
12. MOH R. Republic of Rwanda: Health System. 2014. <http://gov.rw/services/health-system/2016>.
13. Mugeni C, Levine AC, Munyaneza RM, et al. Nationwide implementation of integrated community case management of childhood illness in Rwanda. *Global health, science and practice* 2014; **2**(3): 328.
14. Mitsunaga T, Hedt-Gauthier B, Ngizwenayo E, et al. Data for Program Management: An Accuracy Assessment of Data Collected in Household Registers by Community Health Workers in Southern Kayonza, Rwanda. *J Community Health* 2015; **40**(4): 625-32.
15. Nonyane BAS, Kazmi N, Koffi AK, et al. Factors associated with delay in care-seeking for fatal neonatal illness in the Sylhet district of Bangladesh: results from a verbal and social autopsy study. *Journal of Global Health*; **6**(1).
16. Koffi AK, Maina A, Yaroh AG, Habi O, Bensaïd K, Kalter HD. Social determinants of child mortality in Niger: Results from the 2012 National Verbal and Social Autopsy Study. *Journal of Global Health*; **6**(1).
17. Kalter HD, Yaroh AG, Maina A, et al. Verbal/social autopsy study helps explain the lack of decrease in neonatal mortality in Niger, 2007–2010. *Journal of Global Health*; **6**(1).
18. Njuki R, Kimani J, Obare F, Warren C. Using verbal and social autopsies to explore health-seeking behaviour among HIV-positive women in Kenya: a retrospective study. *BMC Women's Health* 2014; **14**: 77.
19. Koffi Alain K, Babille M, Salgado R, Kalter Henry D, Black Robert E. Social autopsy for maternal and child deaths: a comprehensive literature review to examine the concept and the development of the method. *Population Health Metrics* 2011; **9**(1): 45.
20. D'ambrosio L, Byass P, Qomariyah SN, Ouédraogo M. A lost cause? Extending verbal autopsy to investigate biomedical and socio-cultural causes of maternal death in Burkina Faso and Indonesia. *Social Science & Medicine* 2010; **71**(10): 1728-38.
21. Hildenwall H, Tomson G, Kaija J, Pariyo G, Peterson S. " I never had the money for blood testing" – Caretakers' experiences of care-seeking for fatal childhood fevers in rural Uganda – a mixed methods study. *BMC International Health and Human Rights* 2008; **8**: 12-.
22. Kalter HD, Salgado R, Babille M, Koffi AK, Black RE. Social autopsy for maternal and child deaths: a comprehensive literature review to examine the concept and the development of the method. *Population Health Metrics* 2011; **9**: 45-.

- 1
2
3
4
5
6
7
8
9
10 23. Verbal autopsy standards: The 2012 WHO verbal autopsy instrument Release Candidate
11 1. Geneva, Switzerland: World Health, Organization, 2012.
- 12 24. Thaddeus S, Maine D. Too far to walk: Maternal mortality in context. *Social Science &*
13 *Medicine* 1994; **38**(8): 1091-110.
- 14 25. Kruk ME et al. High quality health systems—time for a revolution: Report of the Lancet
15 Global Health Commission on High Quality Health Systems in the SDG Era *Lancet Global*
16 *Health* 2018.
- 17 26. Maxwell JA. Qualitative research design : an interactive approach. 3rd ed. ed. Thousand
18 Oaks, Calif.; 2013.
- 19 27. Creswell J. A Concise Introduction To Mixed Methods Research. Los Angeles: Sage
20 Publications; 2015.
- 21 28. Curry LAMN-S. Mixed Methods in Health Sciences Research: A Practical Primer.
22 Applications and Illustrations of Mixed Methods Health Sciences Research
23 . Thousand Oaks: SAGE Publications, Inc.; 2017.
- 24 29. Saunders B, Sim J, Kingstone T, et al. Saturation in qualitative research: exploring its
25 conceptualization and operationalization. *Quality & Quantity* 2018; **52**(4): 1893-907.
- 26 30. Páfs J, Musafili A, Binder-Finnema P, Klingberg-Allvin M, Rulisa S, Essén B. Beyond the
27 numbers of maternal near-miss in Rwanda - a qualitative study on women's perspectives on access
28 and experiences of care in early and late stage of pregnancy. *BMC Pregnancy and Childbirth* 2016;
29 **16**.
- 30 31. Kleinman A, Eisenberg L, Good B. Culture, illness, and care: clinical lessons from
31 anthropologic and cross-cultural research. *Annals of internal medicine* 1978; **88**(2): 251.
- 32 32. Finel E. Fighting Against Epilepsy in Rwanda: An Efficient Patient Centred Experience,
33 2012.
- 34 33. Ecks S. Perceptions and beliefs about cough and tuberculosis and implications for TB
35 control in rural Rwanda. *The International Journal of Tuberculosis and Lung Disease* 2007;
36 **11**(10): 1108-13.
- 37 34. Beste J, Asanti D, Sirotnin N, Anastos K, Nathan L. Traditional Medicine Use in Pregnancy
38 in Rural Rwanda. 2012. p. S846-S7.
- 39 35. Taylor CC. The concept of flow in Rwandan popular medicine. *Social Science & Medicine*
40 1988; **27**(12): 1343-8.
- 41 36. Donabedian A. The Quality of Care: How Can It Be Assessed? *JAMA* 1988; **260**(12): 1743-
42 8.
- 43 37. Kleinman A, Benson P. Anthropology in the Clinic: The Problem of Cultural Competency
44 and How to Fix It (Essay). *PLoS Medicine* 2006; **3**(10): e294.
- 45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60

Table 1: Characteristics of pediatric autopsy cases in two rural districts of Rwanda, 2013-2014

	Analytical sample n=77		Full sample n=259	
	N	%	N	%
Child mean age (years)	2.5		2.6	
Maternal mean age (years)	31.9		31.6	
Child male	44	57	148	57
Mother with no formal education	18	27	77	31
Household more than 2 hours walking distance to facility	31	41	100	39
Household with no insurance coverage	22	29	54	21
Sought care from the formal health sector	57	74	204	80
Care Provider ^a				
Traditional healer	25	33	84	32
Community health worker	42	55	131	51
Health center	47	61	164	63
Hospital	14	18	66	25
First Contact Provider				
Community health worker	35	46	104	48
Health center	15	19	69	28
Traditional healer	9	12	30	14
Private pharmacy	2	2	3	1
Other	16	21	53	20
Site of Death				
Home	45	59	137	53
Hospital	7	9	46	18
Health center	10	13	27	10
Other	15	20	49	19
Causes of death				
Malaria	30	39	101	39
Acute abdomen	11	14	25	10
Acute respiratory infection, including pneumonia	11	14	30	12
Diarrheal disease	6	8	13	5
HIV/AIDS related death	6	8	32	12
Accidental drowning	3	4	5	2
Epilepsy	3	4	5	2
Transport accident	2	3	5	3
Other	5	6	43	16

a. May see multiple types of provider. b. The most likely cause of death (COD) was determined using InterVA4²³

Table 2: Key themes and supporting excerpts

Key Theme	Excerpts
Phase 1	
A. Constrained capacity to identify or understand illness	<p>i. <i>Her death confused me to some extent. I woke up in the morning and went to wash my clothes. When I came back, I washed her too – it was my first time to lose a child, so I was ignorant of what had happened – when I washed her, she didn't cry.</i> (Parent of 1yo girl who died of malaria)</p> <p>ii. <i>The death of the child should be known by his sister but, unfortunately, she is a child as well.</i> (Parent of 2yo boy who died of malaria)</p>
B. Traditional medicine	<p>i. <i>...we took the child to traditional healers who told me that the child had been poisoned. They kept giving the child herbal medications, promising me that the child would recover from poisoning. Despite this promise, the child's abdomen kept swelling and I thought to myself, "I have to take the child to the health facility." I took the child to [health facility x] and when I arrived, they put the child on supplemental oxygen therapy for nearly 3 weeks but the child's condition never improved.</i> (Parent of 1yo boy who died of pneumonia)</p> <p>ii. <i>As the other traditional healers had given the child medications which caused the child to vomit poison, I chose to take him back home in the hope that I would take him to [the health facility] and that it would be easy for them to help the child recover as the child had vomited the poison. After returning home, I immediately took him to the health facility but the child died on my way before reaching the health facility.</i> (Parent of 2yo boy who died of diarrhea)</p> <p>iii. <i>But as I told you, the child was poisoned. This is why I saw no need to take her to the health facility. I took her to the traditional healer and she died at the house of the traditional healer.</i> (Parent of 2yo girl who died of malaria)</p> <p>iv. <i>I refrained from taking the child to the health facility because I knew full well that many poisoned children had immediately died at the health facility after being given an injection.</i> (Parent of 3yo girl who died of trauma)</p>
C. Pre-existing beliefs about the health system	<p>i. <i>However, as we had no mutuelle, we were afraid of taking the baby to the health facility. I think this is the possible cause of the baby's death.</i> (Parent of 3yo boy who died of an acute abdomen)</p> <p>ii. <i>When you are not enrolled, you are obliged to wait and you may even die there.</i> (Parent of 1yo boy who died of malaria)</p> <p>iii. <i>I don't know what they are always busy doing! They are distracted by their own businesses! It is not easy to consult the health professional at [health facility X]</i> (Parent of 2yo boy who died of an acute abdomen)</p> <p>iv. <i>We are offered quality service at [health facility X] even if it is far. If we do not go to [health facility Y] it is not due to the distance but rather to poor service.</i> (Parent of 3yo boy who died of asthma)</p>
Phase 2	
D. Transportation challenges	<p>i. <i>I thought of going to [HF101] but this required hiring a moto taxi and, in our village, moto taxi drivers will not accept to transport you if you have a dying patient!</i> (Parent of 2yo boy who died of an acute abdomen)</p> <p>ii. <i>Unfortunately, on the date of the appointment, I didn't have any money at all, I didn't even have transportation ticket to go to [the health facility].</i> (Parent of 1yo boy who died of AIDS)</p>
Phase 3	

E. Financial barriers at point-of-care	<ul style="list-style-type: none"> i. <i>[The healthcare worker] then asked me, "Are you enrolled in mutuelle de santé? If you're not enrolled in mutuelle de santé, I can't do anything to help you."</i> (Parent of 3yo girl who died of pneumonia) ii. <i>As he wasn't enrolled in mutuelle de santé, they obliged us to pay Rwf 3000 before receiving him despite his being in a critical condition.</i> (Parent of 1yo boy who died of diarrhea) iii. <i>They refused to give me the transfer and the ambulance, simply because I didn't have money. So, they told me that they would give the child treatments. They gave her the treatments and then she died after a while.</i> (Parent of 1yo girl who died of pneumonia)
F. Poor quality of care	<ul style="list-style-type: none"> i. <i>I went to see a male CHW but I found that he was not around. I went to see another CHW and met him, but he told me "I don't have treatments. Yesterday I gave the last ones to a child who was ill.</i> (Family of 1yo girl who died of malaria) ii. <i>In fact they gave her a treatment when it was almost dawning. So, they gave her an injection and then, after a while – maybe they had gone to treat other patients – the child died.</i> (Parent of 1yo girl who died of pneumonia) iii. <i>Frankly speaking, there are instances where one goes to the health facility and your child's condition gets worse instead of improving because health professionals sometimes neglect patients. They sometimes delay providing us with treatment and show contempt for us thinking that they have more education than we have and they consider us peasants from rural areas. They even happen to deny us healthcare.</i> (Parent of 2yo girl who died of epilepsy) iv. <i>They didn't reveal to me anything regarding the child's illness. They only prescribed some tablets for the child.</i> (Parent of 3yo boy who died of malaria) v. <i>When I arrived there, health professionals were there. I said to one of them "As you can see, my child is in a critical condition. You should attend to him/her as a matter of urgency." He/she replied, "Under the current rules, no one can be allowed to go straight to the front of the queue. You have to bear with me and accept to queue." As I was queuing, the child immediately died in my arms. I thought that health professional has to be blamed for my child's death.</i> (Parent of 1yo boy who died of malaria) vi. <i>They discharged her and they told me to go home and give her pills. They discharged her although it was obvious that she was still very sick.</i> (Parent of 2yo girl who died of malaria)
G. Positive experiences with FHS	<ul style="list-style-type: none"> i. <i>There was a health professional by the name of "X" who was loved by all community members. When a patient was not enrolled in the community-based health insurance scheme, she volunteered to pay for his/her medical bills for the patient to repay after a certain period of time.</i> (Parent of 4yo girl who died of diarrhea) ii. <i>They properly care for patients and give them useful advice.</i> (Parent of 4yo girl who died of epilepsy)
Phase 4	
H. Dissatisfaction leads to traditional medicine	<ul style="list-style-type: none"> i. <i>...they gave me small tablets for the child. I gave the tablets to the child, but it didn't work. Seeing that, we decided to take the child to traditional healers.</i> (Parent of 2yo boy who died of malaria) ii. <i>.... As people often say, "you use tablets and if the child is not cured you tell yourself the baby must have been poisoned."</i> (Parent of 3yo girl who died of pneumonia) iii. <i>As the tablets that we had received from the health facility hadn't helped the child to recover, and instead caused the child's condition to deteriorate, I thought the child had an illness that would be treated by traditional healers and hence chose to return to traditional healers.</i> (Parent of 1yo boy who died of AIDS)
I. Home treatment plan failure	<ul style="list-style-type: none"> i. <i>I: Is it easy for you to access the meds once the doctor has prescribed them for you? R: It is a challenge because you cannot afford buying meds if you are not enrolled in the community-based health insurance scheme.</i> (Parent of 1yo boy who died of malaria) ii. <i>They gave me another appointment but told me that I had to pay bus fares on my own. And when I remembered the kind of life I had lived there, the medications that were prescribed to the child, the food and the financial means all that required, I noticed I was unable to secure all the money needed and I refrained from returning there. But apart from that, I could also see that the child had finished his/her journey on the earth.</i> (Parent of 3yo girl who died of pneumonia) iii. <i>He spent one week and one day without crying. Although they discharged us, he hadn't cried yet, even once. "Once he arrives in a cold place, he will cry", they told me as they discharged us. We spent a whole week before he cried. We noticed that the child was wasting away day after day. When I went to have him weighed, he would weigh 2 kilograms today, and next time he would weigh 1 kilogram and some grams.</i> (Parent of 1yo boy who died of AIDS)

Table 3: Phase 1 mixed-methods themes and excerpts for maternal education

	No formal maternal education	Some formal maternal education
Phase 1 excerpts by maternal education	<p>Those who were with me, told me, "Hurry up and, if he is still breathing by the time you reach home, take him immediately to the health facility for them to find out the cause of the child's death." (Parent of 2yo boy who died of malaria)</p> <p>"Let's go to see the father's child in the farm so that he can help me to take the child to the health facility and to avoid that the child's condition to deteriorate at home." (Parent of 4yo girl who died of malaria)</p> <p>I ran to the other neighbors who were digging the fields and told them, "Look! My child is dying and h/s was healthy when I brought him." (Parent of 2yo boy who died of malaria)</p> <p>If I had known what illness the child had I would have sought treatment for the child. Some of my neighbors could say that the child was suffering from malnutrition whilst others suspected the child had been given poison. People in rural areas are always inclined to speculate on all that happens. (Parent of 4yo girl who died of AIDS)</p> <p>I sought advice from my fellow mothers asking them, "My child has a horrible smell in his/her nose. What can I do?" (Parent of 1yo boy who died of AIDS)</p>	<p>Seeing that, I asked myself the following question: why is my child passing such things in stool while I've administered medications to the child? I put the child on my back and came back home thinking that, "Let me administer the medications to the child. If the medications don't work, I will take the child to traditional healers for them to find out what illness the child has." (Parent of 1yo boy who died of malaria)</p> <p>When the child started getting ill, I had the child tested for a folk illness known as uburo. I first took the child to the traditional healer and then to the health facility. (Parent of 3yo boy who died of malaria)</p> <p>The child did not have any accident. I thought my child was given poison by malicious people, who did so secretly during our visit. (Parent of 2yo boy who died of an acute abdomen)</p> <p>It wasn't until late that night that I suspected that the child was given poison. However, I said to myself, "I need to take the child to the health facility first because it might be that the child has abdominal pain because of malaria. If I arrive at the health facility and the child tests negative for malaria, I will decide to take her to traditional healers." The child died before taking any medications (Parent of 3yo female who died of an acute abdomen)</p> <p>One evening in that same year, the child developed a folk illness known as igishikuzi. Seeing that, I administered meds to the</p>

		<p><i>child. After taking the meds, the child moderately recovered. As the child appeared to have moderately recovered, I decided to leave home for work. As I was preparing to leave, the child's illness suddenly came back again. After realizing that it was the same illness, I thought to myself, "I have to give the child the meds I have given him before." As I was preparing for going to pick up meds for the child, he immediately died. (Parent of 2yo boy who died of epilepsy)</i></p>
--	--	--

Table 4: phase 1 mixed methods themes and excerpts for place of death

	Did not die in a facility	Died in a facility
Phase 1 excerpts by place of death	<p><i>As I was working in the fields, I realized that the child was in a critical condition and rushed back home. As I was preparing for going to seek treatment for him, the child died. To be frank, the child wasn't taken to the health facility or the CHWs. As you can see, the child's death came suddenly. (Parent of 2yo boy who died of epilepsy)</i></p> <p><i>When I took the child to the CHW, I was told that medications were not available. I came back home. As I was preparing to go there in the morning, the child immediately died. (Parent of 3yo girl who died of an acute abdomen)</i></p> <p><i>While I was thinking about that, I washed myself, and washed him too. By the time I wanted to carry him on my back, he died on the spot. (Parent of 1yo boy who died of malaria)</i></p> <p><i>I immediately bathed the child and then applied body lotion to the child's entire body. I then washed my body after which this one (her husband) arrived. The child immediately started falling into agony and died. It was around 8.00pm. (Parent of 3yo boy with an unknown cause of death)</i></p> <p><i>He will not recover but he will die at home at least. I wondered, "Shall I take a dead child to the health facility? What shall I say? What shall I do since the child did not have any fever?" I eventually put the baby on my</i></p>	<p>Theme not present</p>

	<p><i>back. They said, "Wash yourself and go even if it is almost over...I washed myself hastily and sought some clothes to dress the child. When I was ready, my mother said to me, "No need for the clothes: he has just died." I threw the clothes to them. (Parent of 2yo boy who died of malaria)</i></p> <p><i>As I was preparing to take the baby to the health facility early in the morning, the baby passed away. (Parent of 1yo girl who died of malaria)</i></p> <p><i>However, the child refused to eat and chose to go to bed. I asked myself, "Is this child suffering from intestinal parasites? Is he/she ill?" I immediately bathed the children and clothed them and then went to the nearest shop to buy juice and 2 biscuits for them. When I tried to give them the juice and biscuits, the children appeared to have no appetite. Even the juice and biscuits were still here after the burial of the child. (Parent of 3yo boy who died of an acute abdomen)</i></p>	
--	--	--

Table 5: Phase 4 mixed methods themes and excerpts for malaria diagnosis

	Malaria	Diagnosis other than malaria
Phase 4 excerpts by COD (Malaria)	<p>When I arrived, they gave me small tablets for the child. I gave the tablets to the child, but it didn't work. Seeing that, we decided to take the child to traditional healers. 2Apr_KACA102040WI</p> <p>The child was yet to take traditional medications when h/s died. This is because I started by administering the baby medications prescribed by health professionals. 18Jun_KACA118060WI</p> <p>He/she finished the meds but he/she didn't recover. Then we said, "The child might have been given poison. Let's go for checking." When we had checked, we found that the child had been poisoned but it was too late to save his/her life. He/she died that night. 26Aug_KICA226080DK</p>	<p>They performed malaria test but the child tested negatively for malaria. Following this, they asked me to take the child to the people who could perform consultations on the child to see if he/she had "ikimoso". 1Apr_KICA201040AU</p> <p>The child fell ill but his/her condition didn't severely deteriorated. I took the child to the public health facility and then to the private health facility. The child's illness persisted to such an extent that he/she couldn't eat anything at all! I tried to seek treatment for the child but to no avail. 29Jul_KACA229070MA</p> <p>Seeing that, we took the child back to the health facility. When we arrived, health professionals said to us, "You need to consult traditional healers." 26Mar_KICA226030PK</p>

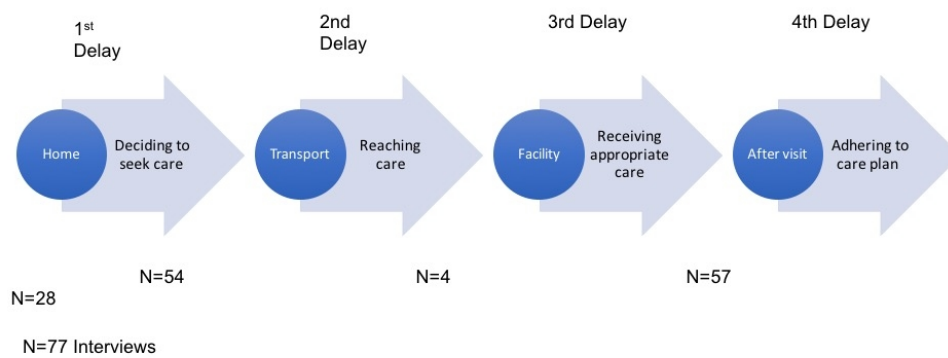
1
2
3
4
5
6
7
8
9
10
11
12
13
14
15
16
17
18
19
20
21
22
23
24
25
26
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47

Phase 3 excerpts by COD domain	No divergent themes	
---	---------------------	--

For peer review only

1
2
3
4
5
6
7
8
9
10
11
12
13
14
15
16
17
18
19
20
21
22
23
24
25
26
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60

Figure 1: Four phases of delay



82x81mm (300 x 300 DPI)

BMJ Open

The Four Delays of Child Mortality in Rwanda: A Mixed-Methods Analysis of Verbal Social Autopsies

Journal:	<i>BMJ Open</i>
Manuscript ID	bmjopen-2018-027435.R1
Article Type:	Research
Date Submitted by the Author:	31-Jan-2019
Complete List of Authors:	Roder-DeWan, Sanam; Harvard University T H Chan School of Public Health, Global Health and Population; Ifakara Health Institute Gupta, Neil; Brigham and Women's Hospital, Global Health Equity; Partners in Health/Inshuti Mu Buzima Kagabo, Daniel; Partners in Health/Inshuti Mu Buzima Habumugisha, Lameck; Partners in Health/Inshuti Mu Buzima Nahimana, Evrard; Partners in Health/Inshuti Mu Buzima Mugeni, Catherine; Maternal Child and Community Health Rwanda Biomédical Center, Rwanda Ministry of Health Bucyana, Tatien; Maternal Child and Community Health Rwanda Biomédical Center, Rwanda Ministry of Health Hirschhorn, Lisa; Ariadne Labs; Northwestern University Feinberg School of Medicine
Primary Subject Heading:	Health services research
Secondary Subject Heading:	Paediatrics, Global health, Qualitative research
Keywords:	PAEDIATRICS, Community child health < PAEDIATRICS, Quality in health care < HEALTH SERVICES ADMINISTRATION & MANAGEMENT, QUALITATIVE RESEARCH

SCHOLARONE™
Manuscripts

The Four Delays of Child Mortality in Rwanda: A Mixed-Methods Analysis of Verbal Social

Autopsies

Authors:

Sanam Roder-DeWan - Harvard Chan School of Public Health, 677 Huntington Avenue, Boston, MA, USA; Ifakara Health Institute, Dar es Salaam, Tanzania, roderdewan@mail.harvard.edu (corresponding author)

Neil Gupta-Division of Global Health Equity, Brigham & Women's Hospital, 75 Francis St. Boston, MA USA; Partners In Health / Inshuti Mu Buzima, Rwinkwavu, Rwanda, ngupta@pih.org

Daniel M. Kagabo- Partners In Health / Inshuti Mu Buzima, Rwinkwavu, Rwanda, dankagabo@gmail.com

Lameck Habumugisha- Partners In Health / Inshuti Mu Buzima, Rwinkwavu, Rwanda, habumugisha4@gmail.com

Evrard Nahimana- Partners In Health / Inshuti Mu Buzima, Rwinkwavu, Rwanda, enahimana@pih.org

Catherine Mugeni-Maternal Child and Community Health, Rwanda Biomedical Center, Rwanda Ministry of Health, KN 3 Rd, Kigali, Rwanda, cmugeni@gmail.com

Tatien Bucyana- Maternal Child and Community Health Rwanda Biomedical Center, Rwanda Ministry of Health, KN 3 Rd, Kigali, Rwanda, tbucyana@yahoo.fr

Lisa R. Hirschhorn- Northwestern University, 633 N. Saint Clair Street, 19th Floor Chicago, IL, USA, lisa.hirschhorn@northwestern.edu

1 ABSTRACT

2 Objectives

3 We sought to elucidate healthcare-seeking patterns and delays in obtaining effective treatment
4 for rural Rwandan children ages 1-5 years by analyzing verbal and social autopsies(VSA).
5 Factors in the home, related to transport and to quality of care in the formal health sector (FHS)
6 are thought to contribute to delays.

7 Design

8 We collected quantitative and qualitative cross-sectional data using the validated 2012 WHO
9 VSA tool. Descriptive statistics were performed. We inductively and deductively coded
10 narratives using the three delays model, conducted thematic content analysis and used
11 convergent mixed-methods to synthesize findings.

12 Setting

13 The study was conducted in the catchment areas of two rural district hospitals in Rwanda -
14 Kirehe and Southern Kayonza. Participants were caregivers of children ages 1-5 years who died
15 in our study area between March 2013 and February 2014.

16 Results

17 We analyzed 77 VSAs. Although 74% of children (N=57) had contact with the FHS before
18 dying, most (59%, N=45) died at home. Many caregivers (44%, N=34) considered using
19 traditional medicine and 23 (33%) actually did. Qualitative themes reflected difficulty
20 recognizing the need for care, the importance of traditional medicine, especially for “poisoning”,
21 and poor perceived quality of care. We identified an additional delay - phase 4 - which occurred
22 after leaving formal healthcare facilities. These delays were caused by caregiver unwillingness or
23 inability to adhere to care plans.

24 Conclusion

25 Delays in deciding to seek care (phase 1) and receiving quality care in FHS (phase 3) dominated
26 these narratives; delays in reaching a facility (phase 2) were rarely discussed. Failure to adhere to
27 treatment plans after leaving facilities (phase 4) were an important additional delay. Improving
28 quality of care, especially provider capacity to communicate danger signs/treatment plans and
29 promote adherence in the presence of alternative explanatory models informed by traditional
30 medicine, could help prevent childhood deaths.

32 Article Summary

33 *Strengths and limitations*

- 34 • The large qualitative and quantitative data set used to understand the experience of
35 caregivers leading to the death of all children ages 1-5 years in this area of Rwanda is a
36 strength of this study.
- 37 • As is the nature of qualitative research, these findings cannot be generalized beyond the
38 study population, but may be used to guide similar explorations in comparable samples.
- 39 • The use of mixed methods and the unique caregiver perspectives allowed for the
40 identification of an important additional source of delays that occurred after children left
41 formal sector healthcare. We call these “phase 4 delays”.
- 42 • A strength of this study is that by characterizing a 4th delay, it adapts the three delays
43 model of maternal mortality for use in understanding childhood mortality.

44 Competing interests – The authors declare no competing interests.

1
2
3 1 Funding – Doris Duke Charitable Foundation

4
5 2 Keywords – Community child health, pediatrics, qualitative research, quality in health care

6
7 3
8 4 Word Count: 3983

9
10
11 5
12 6
13 7
14 8
15 9
16 10
17 11 **BACKGROUND**

18
19 12 Rwanda has reduced under-five (U5) mortality by more than two-thirds since 2000, one
20
21 13 of only 12 low-income countries to achieve Millennium Development Goal (MDG) Four ¹⁻³. This
22
23 14 progress, though exceptional by most measures, mirrors a global trend of reduced childhood
24
25 15 mortality and epidemiological transition away from the most easily preventable causes of death ⁴.
26
27 16 As proficiency is gained in tackling the “low-hanging fruit” of child health, health systems must
28
29 17 turn their attention to solving the more complex problems that remain.

30
31 18 Despite Rwanda’s remarkable progress, a child is still ten times more likely to die before
32
33 19 their 5th birthday in Rwanda than in most high-income countries ⁵. Evidence from other low-
34
35 20 income countries suggests that the majority of these deaths will occur outside of a health facility
36
37 21 and that late care-seeking is a significant contributing factor ^{6,7}. Understanding family and
38
39 22 community contexts will thus be important for improvement ^{8,9}. What beliefs and behaviors exist
40
41 23 in homes and communities that delay care-seeking? What barriers do caregivers face when they
42
43 24 decide to seek care and what challenges might an increasingly capable but complex health
44
45 25 system pose for them?

46
47
48
49 26 These questions may best be answered by viewing health seeking pathways and the
50
51 27 health system from the perspective of its users, an area of scholarship that is poorly represented
52
53 28 in the literature in low-and middle- income countries (LMIC) ¹⁰. This study aims to address the

1 gap in knowledge by analyzing verbal and social autopsy (VSA) data collected following all
2 deaths of children ages 1-5 years in two rural districts in Rwanda.

3 **METHODS**

4 *Setting*

5 During the study period, there were 23 health centers (HC) in Kirehe and Southern Kayonza
6 serving a population of 538,405. HCs are staffed by nurses and provide inpatient and outpatient
7 services ^{11,12}. Community health workers (CHWs) provide integrated community case
8 management of pediatric illnesses (c-IMCI) ¹³. They diagnose and treat pneumonia, diarrhea, and
9 malaria, monitor malnutrition and make referrals. An estimated average of one CHW serves 50
10 people under age 5; there are two cIMCI-trained CHWs per village ^{13,14}. Kirehe is served by one
11 district hospital and Kayonza by two. The study was conducted in the catchment area of one
12 hospital in Kirehe and another in Kayonza. Area households in the two districts are a median
13 3.5km from their closest HC ¹¹. Community based health insurance (CBHI also referred to as
14 “Mutuelle de Santé”, or “mutuelle”) was available in the study districts. It achieved over 90%
15 coverage in Rwanda overall (Makaka et al., 2012). The catchment area for this study is rural and
16 the majority of families rely on subsistence agriculture. Paved roads connect the main towns, and
17 unpaved roads extend to most communities. Homes are predominantly made of natural materials
18 such as earth and thatch and few communities have access to electricity. According to the 2014
19 Rwandan Demographic and Health Survey, nearly 40% of the population lives below the poverty
20 line, though nearly all women in Kirehe and Kayonza work in agriculture. Educational
21 attainment is low in both areas, with most women not having completed primary school.¹⁵

22 *Study design*

1
2
3 1 Data were collected through VSAs with caregivers of 259 U5s who died between March 2013
4
5 2 and February 2014. VSA is a process used to assign causes of death in cases where no standard
6
7 3 autopsy was done and social autopsy augments the structured interview of a verbal autopsy with
8
9 4 open-ended questions about the beliefs, decisions, and perspectives of those who cared for the
10
11 5 decedent^{10,16-23}. Quantitative and qualitative data were collected during one visit with a family.
12
13 6 Deaths were identified through health records, RMOH reporting systems and the Monitoring of
14
15 7 Vital Events Using Information Technology program in which CHWs reported vital events by
16
17 8 telephone. CHWs then helped locate families, and families who consented were interviewed
18
19 9 between 3 weeks and 1 year after the death. The minimum waiting period of 3 weeks was
20
21 10 selected considering the Rwandan custom of a formal 1-week mourning period and literature
22
23 11 from other countries suggesting that several weeks is an appropriate delay^{24,25}. Importantly,
24
25 12 families could decline participation and could choose a time for the interview if they consented.
26
27 13 This paper is a sub-analysis of VSA data of children between the ages of 1 year and 5 years. This
28
29 14 age range was chosen because it includes children with shared developmental characteristics
30
31 15 (e.g. the ability to crawl/walk), clinical characteristics (e.g. causes of pneumonia), and social
32
33 16 experiences (e.g. not being in primary school).

34
35
36
37
38
39
40 17 Quantitative data were collected using the validated WHO 2012 verbal autopsy semi-
41
42 18 structured interview tool (InterVA4)²⁶ and supplemented by questions from the RMOH's Death
43
44 19 Audit Tool and the 2010 Rwanda Demographic and Health Survey. Trained interviewers used
45
46 20 handheld electronic devices and conducted semi-structured interviews in the local language,
47
48 21 Kinyarwanda. Informants were asked to describe events surrounding the death of the child.
49
50 22 Segments during which interviewees expanded on symptoms, decision-making, care-seeking and
51
52
53
54
55
56
57
58
59
60

1 perceptions of care received were transcribed and then back-transcribed from Kinyarwanda to
2 English for quality and accuracy review.

3 *Patient and Public Involvement*

4 The research question was informed by the work of Partners in Health/Inshuti Mu
5 Buzima (PIH/IMB) which has supported the Rwandan Ministry of Health (RMOH) to strengthen
6 health care delivery and systems in Kirehe and Southern Kayonza districts since 2005. This VSA
7 project was part of a larger initiative to better understand and reduce under five (U5) mortality.
8 Patients were not involved in the recruitment to and conduct of the study, nor were they involved
9 in the design of the study. However, as a service delivery organization, PIH/IMB has a deep
10 experience with patients and their families/caregivers, an experience that helped shape the study.
11 Aggregated early results were shared with the MOH and IMB in a timely manner to facilitate
12 improved health care delivery.

13 *Analysis*

14 We used the three delays model²⁷ as a framework to begin our thematic content analysis. This
15 model was originally developed to understand maternal mortality²⁷. Phase 1 delays relate to
16 deciding to seek care, phase 2 delays occur while trying to reach a facility and Phase 3 delays
17 occur after arrival at a facility in the form of poor quality of care. We use the Lancet Global
18 Health Commission on High Quality Health Systems framework to understand high quality care.
19 Specifically, high quality care includes competent care and systems, positive user experience as
20 well as better health, confidence in the system and economic benefit²⁸.

21 A mix of inductive and deductive coding was used to develop a codebook²⁹ which was
22 discussed and revised by an interdisciplinary team of researchers, physicians and public health
23 professionals. A sub-set of interviews (11) were double coded to ensure inter-rater reliability and

1 then the codebook was applied to the data set until saturation of codes was reached at 77
2
3 interviews. Iterative thematic analysis using coding, recoding, categorization and reorganization
4
5 was used to further develop the themes and generate hypotheses. Dedoose was used for
6
7 qualitative and mixed-methods analysis (Version 7.5.9, SocioCultural Research Consultants,
8
9 LLC, Los Angeles, CA).
10
11
12
13

14 The most likely cause of death (COD) was determined using InterVA4²⁶. COD and
15
16 sociodemographic variables from verbal autopsied were analyzed using descriptive statistics.
17
18 Quantitative analytics were performed using STATA version 14 (Copyright 1985-2015
19
20 StataCorp LP. College Station, TX).
21
22
23

24 Associations between descriptive variables and qualitative themes were explored using a
25
26 convergent mixed-methods approach³⁰. This approach is recommended by experts to better
27
28 understand complex phenomenon, such as care seeking behavior, because it helps uncover
29
30 patterns that may not have been accessible through only quantitative data analysis or only
31
32 qualitative data analysis³¹. Excerpts were first organized by phase of delay and then divided by
33
34 quantitative variables. These variables were chosen based on hypotheses which were generated
35
36 during the qualitative analysis of the interviews. Hypotheses included 1) maternal education
37
38 impacts care-seeking by giving caregivers more access to accurate health information, 2)
39
40 children who died at home experienced more phase 1 delays, 3) less common causes of death are
41
42 associated with more phase 3 delays. Thematic analysis of these sub-groups of excerpts was
43
44 conducted to identify divergent themes. Interviews were coded and analyzed until saturation of
45
46 codes was achieved, i.e. saturation was achieved when no new codes or ideas were identified³².
47
48
49
50

51 The study was approved by Rwanda National Ethics Committee and Partners Institutional
52
53 Review Board. Verbal consent was deemed permissible by both boards. A consent form was read
54
55
56
57
58
59
60

1 to potential participants by Kinyarwanda-speaking data collectors who also answered questions.
2 Participants were asked to verbally confirm that the consent was understood. Data collectors
3 were trained in sensitivity, patience and consideration with families who had lost a child. No
4 interviews were conducted during the three -week mourning period. Each interview was assigned
5 a number that matched with caregiver identifying information and was stored in a separate file in
6 a secure location. No individual identifiers were recorded on the data collection forms.

7 **RESULTS**

8 We identified 259 deaths of children ages 1 to 5 years (table 1). Saturation of codes was reached
9 at 77 interviews. The average age at death of the 77 children was 2.5 years. The majority were
10 male (57%) and 27% of mothers had no formal education. The average age of mothers of the
11 deceased was 31 years. One quarter of informants (29%) reported having no health insurance for
12 the family. The leading cause of death was malaria (39%), then respiratory illness (14%), and
13 acute abdomen (severe abdominal pain usually requiring surgery) at 14%.

14 Most children received some care from the formal health sector (FHS) - 61% from a HC
15 and 55% from a CHW. A CHW was the first point of contact for 46%. Nearly half of the
16 caregivers (34 of 77) considered consulting a traditional healer during the illness leading to the
17 index child's death; 33% actually did. The majority (59%) of children died at home.

18 *Phase 1 delays*, were raised during 54 VSAs. Caregivers, most commonly mothers,
19 frequently described “confusion” and “surprise” about their child's illness and said that they did
20 not know what to do or when to seek care. They also described domestic responsibilities that
21 constrained the ability to closely monitor children. For example, as women worked on their
22 farms, older children were left to tend younger children (table 2A).

1 The majority (63%, N=34) of VSA cases describing phase 1 delays also discussed
2 traditional medicine (TM), primarily for the diagnosis of “poisoning” which was described as
3 being caused by “nasty people” who wanted to do harm. The diagnosis was confirmed when
4 vomiting or diarrhea was induced by a liquid medication. Traditional healers were consulted
5 either in conjunction with the FHS (medical pluralism) or exclusively. Some respondents
6 reported using TM to “clear” the poison so that the FHS could be effective; others tried all
7 available options concurrently. Exclusive use of TM usually occurred if the caregiver was certain
8 about the diagnosis of poisoning (table 2B).

9 The majority of this sub-group of respondents (19/34) indicated that *only* TM could treat
10 poisoning. Beliefs and practices that supported exclusive use of TM for poisoning included
11 “admitting” severely ill children with poisoning to the house of a traditional healer and believing
12 that FHS care for poisoned children, especially in the form of an injection, would kill the child
13 (table 2B).

14 Previous experiences with the health system or CBHI (being rejected for lack of
15 insurance or inability to pay out-of-pocket) shaped care-seeking decisions. Even those that did
16 have CBHI experienced administrative challenges to maintaining coverage. Beliefs about the
17 quality of the health system also shaped decisions to seek care (table 2C).

18 *Phase 2 delays* were raised spontaneously by four of 77 informants. Transport barriers
19 included drivers refusing critically ill children and cost (table 2D). Many informants mentioned
20 waiting until morning to travel, but the safety of travelling at night was not discussed directly.
21 These informants may be referring to phase 2 delays, but this cannot be determined from the
22 narratives. Some informants mentioned bypassing the closest facility and going to one they
23 believed would provide higher quality care.

1 *Phase 3 delays* were described in 57 of 77 (74%) cases. Despite Rwandan policy stating
2 that no critically ill child should be turned away, five respondents reported being denied
3 appropriate treatment in the FHS due to inability to pay (table 2E). Nearly all third phase
4 interviews mentioned poor quality of care (table 2F). A lack of FHS equipment, supplies,
5 medicine or providers were reported by very few informants (n=6) and the majority of these
6 excerpts related to CHWs. People describe “neglect”, being “ignored”, being “reprimanded” or
7 “shown contempt”. Long wait times were frequently mentioned. Leaving the FHS knowing a
8 child’s diagnosis or having a treatment plan, was common. Respondents reported poor technical
9 skills and decisions at the FHS. Informants also describe positive interactions with health care
10 professionals who “immediately” provided care or were empathic (table 2G), or went out of their
11 way to help. Services were sometimes described as “good” and “proper”.

12 Informants reported barriers to successful care and treatment that did not fall into the
13 three phases during 28 VSAs. These occurred after a child left the formal sector and were related
14 to the willingness or capacity of caregivers to comply with FHS treatment plans. We are calling
15 these “phase 4 delays” (figure 1). Dissatisfaction with outcomes of care in the FHS (failed
16 treatment or inconclusive tests) led families to abandon the formal sector and seek care from
17 traditional healers (table 2H).

18 In seven cases FHS personnel referred families to TM because poor treatment response
19 was attributed to poisoning. Limited capacity to adhere to FHS treatment plans was linked to
20 financial barriers or poor communication; caregivers lacked clear instructions on how to
21 administer treatments or when to follow-up. Families were further challenged by needing to
22 make multiple trips to FHS facilities (table 2I).

1
2
3 1 A hypothesis-driven mixed methods analysis revealed several additional themes. First,
4
5 2 formal maternal education was associated with more active care-seeking language: “I decided”,
6
7 3 “I asked myself”, “I had the child tested”, “I suspected”. Those without formal education
8
9 4 disproportionately described delaying decisions in order to seek advice (table 3).

10
11
12 5 Second, children who died outside of a facility were *not* more likely to live far away from
13
14 6 a HC or discuss phase 2 delays but were more likely to have died while caregivers were
15
16 7 “preparing” to go the FHS. This theme is not present in the sub-set of children that died in the
17
18 8 FHS. Many caregivers of children who died at home actively made decisions to keep children at
19
20 9 home if they believed that death was imminent; death at home appeared to be a preference.
21
22 10 Those that did make it to a provider in the FHS but still had a child who died elsewhere,
23
24 11 described issues with adherence to formal sector provider recommendations and follow-up; 88%
25
26 12 of children whose caregivers discussed phase 4 delays did not die in the FHS (table 4). Several
27
28 13 mixed methods sub-analyses were undertaken by cause of death. No convergent or divergent
29
30 14 themes were identifiable by this category of descriptors.

31
32
33 15 Finally, an analysis of excerpts by cause of death helped shed light on the fourth phase of
34
35 16 delay (table 5). Though diversion to the informal sector occurred across all causes of death, the
36
37 17 majority of cases of health care providers referring patients to traditional healers were in children
38
39 18 who died of something other than malaria. Those who died of malaria had caregivers who
40
41 19 described receiving “tablets”, waiting for them to take effect and having a child either die during
42
43 20 treatment or in the care of a traditional healer because the treatments were perceived to be
44
45 21 ineffective. They told of hesitating to take their child back to a facility despite recognizing a lack
46
47 22 of improvement during treatment. Whether this is because clear instructions for follow-up were
48
49 23 not given or not understood cannot be determined from the data. Sometimes this hesitation came
50
51
52
53
54
55
56
57
58
59
60

1 with an expressed fear of being judged for coming back too soon. Children without the diagnosis
2 of malaria were less likely to have been given “tablets” and more likely to experience delays
3 after leaving a health center related to searching for a treatment from multiple formal facilities or
4 from informal providers. Their decisions to seek alternatives were more likely to come
5 immediately after leaving the treatment facility.

6 7 **DISCUSSION**

8 We analyzed VSAs of 77 children ages 1-5 years in rural Rwanda and found that care-
9 seeking was dominated by challenges in deciding to seek care (phase 1) and in receiving high
10 quality care in the FHS (phase 3). Our respondents rarely mentioned challenges in reaching a
11 facility (phase 2), though it is unclear whether the common experience of waiting until morning
12 to travel was related to difficulty securing transport. In addition to the three classic delays, we
13 identified a domain that occurred after sick children visited the FHS; phase 4 delays. The
14 children in this sample either never made it to a facility because of delays in deciding to seek
15 care (phase 1) or were sent home after an interaction with the FHS only to experience delays in
16 follow-up care or adherence to treatment (phase 4).

17 Phase 4 delays were related to caregiver unwillingness or inability to adhere to care plans
18 and often involved decisions to abandon formal sector care in favor of traditional medicine. This
19 phase was identified and characterized through the qualitative analysis of narratives and is
20 supported by descriptive data showing that 74% of children in our data set had contact with the
21 FHS, but 59% died at home. Phase 4 delays were closely linked to the ability of providers to
22 communicate care plans and danger signs, a shortcoming that is particularly dangerous in the
23 presence of a robust traditional medicine system that caregivers can turn to if interactions with
24 formal care are unsatisfactory or if the child is not improving as expected. The most common

1 cause of death in this sample, malaria, appeared to be associated with fourth phase delays caused
2 by receiving treatment but not knowing when to return if treatment was not perceived to be
3 effective.

4 The majority of deaths were not associated with a single delay (see table 6). This finding
5 is consistent with published literature on the three delays in maternal and child health ^{9,27,33}.
6 Families experienced complex care pathways that often began with partial information about
7 child health and required the ability to negotiate competing explanatory models ³⁴. Explanatory
8 models are socio-culturally informed systems that explain illness and healing; in this population
9 “poisoning” appears to be a dominant construct. Those that did reach the FHS were sometimes
10 turned away for financial reasons. Though some informants described positive experiences with
11 the FHS, many did not. Children died while caregivers waited and families left facilities without
12 knowing why their child was sick or when to return. They made decisions to use TM or visited
13 many FHS facilities. The complexity of care navigation was particularly challenging for families
14 who struggled with intersectional causes of disadvantage such as poverty and limited education.

15 A preference for dying at home, possibly due to indirect costs of facility death, may have
16 contributed to the high percent of children who died at home (59%). Caregivers of children who
17 died at home frequently described children dying while preparing to leave for the FHS
18 suggesting that the urgency of the illness was not well understood. Finally, TM was used by one
19 third of families and even recommended by FHS providers possibly augmenting out-of-facility
20 death rates. If poisoning was “confirmed” (often when a traditional healer induced vomiting),
21 some caregivers *only* used TM regardless of illness severity. Several practices made exclusive
22 (rather than complementary) TM use more likely; several critically ill children in this sample
23 were “admitted” to the homes of traditional healers for more intense treatment and some

1 informants believed that a poisoned child would be killed if treated in the FHS. This exclusive
2 pattern of TM use is found in the literature on epilepsy and tuberculosis in Rwanda ^{35,36}. Our data
3 does not allow us to determine which symptoms are locally understood as indicative of poisoning
4 in children, but according to Taylor (1988) the syndrome overlaps closely with features of
5 clinical dehydration. Perhaps the non-specific nature of symptoms of poisoning contributes to the
6 widespread use of TM in our study population.

7 Having TM as an alternative to shape an individual's explanatory model ³⁴ was
8 particularly important when caregivers were not satisfied with the care that they received at the
9 FHS. A large portion of fourth phase delays involved abandoning FHS treatment plans in favor
10 of TM. Limited literature is available on the nature or role of TM in Rwanda, due in part to only
11 very recent efforts to recognize and integrate this sector into the health system (Government of
12 Rwanda, 2012). A qualitative study of TM providers and their role in treating pregnant women
13 estimated that there are up to two traditional providers in each village in Rwanda and that they
14 are usually older women who inherited the profession from their mothers ³⁷. Only one study was
15 identified that specifically describes a Rwandan concept of poisoning ³⁸. That work characterizes
16 poisoning as a humor that acts through the digestive tract and decreases blood volume, a
17 description that seems largely consistent with our findings.

18 In addition to helping us understand care-seeking in the community, our data also
19 describes a health system from the perspective of its users. Many informants consulted a CHW
20 as a first source of care, as recommended by the RMOH model of primary care. This shows that
21 the population accepts this cadre as an integral part of the Rwandan health care system.
22 However, families also encountered problems with CHWs – the majority of reports about limited

1 medications or human resources in our data set were about CHWs. These issues might make
2 CHWs a source of delay rather than an expansion of the healthcare web in Rwanda.

3 The experience of care at facilities is a significant challenge to informants in this dataset.

4 These Phase 3 themes are framed by the classic work on quality of care by Avedis Donabedian
5 of structure/inputs, processes and outcomes³⁹. The procedural elements of care (both technical
6 and interpersonal) are far more likely to be raised by our informants than the structure or inputs
7 of the FHS. Our informants describe how this quality impacts decisions to seek care as well as
8 how it impacts decisions to follow-through with treatment plans.

9 CBHI was widespread and highly valued by our informants. However, there were
10 implementation challenges. Informants discuss the high cost of insurance and share deeply
11 concerning narratives of being turned away from health facilities with critically ill children.
12 Caregivers also describe avoiding health facilities because of a fear of being turned away due to
13 not having health insurance.

14 As is the nature of qualitative research and despite census-level data, the themes arising
15 from this data cannot be assumed to be representative beyond the population studied. However,
16 our analysis of a large sample helps illuminate concepts that should be considered and explored
17 in parallel populations. Other limitations include variation in interviewing techniques due to
18 multiple research assistants in the field as well as variable transcription of narratives. We
19 minimized this issue through rigorous training of our research assistants, and regular research
20 team debriefings during data collection and processing. Though several techniques for
21 triangulating and identifying cases were used, it is possible that child death cases were missed
22 due to relocation or misclassification. This could lead to a selection bias because unidentified
23 cases may be systematically different from those that were analyzed (e.g. more remote, fewer

1 resources, less likely to seek care). Our community-based triangulation methods were designed
2 to capture the most marginalized families and to identify those that have left the catchment area
3 after a child's death. Finally, our study is not powered to draw statistical conclusions from the
4 descriptive data.

6 CONCLUSION

7 The patient narratives presented here describe the challenges that families face at home,
8 in their communities and with the health system to provide their children with timely and
9 appropriate medical care. Dramatic failures or gross indiscretions are rare. Parents and families
10 describe making the decisions they thought were best and doing the most that they could despite
11 barriers. The barriers and delays described by caregivers in this dataset are concentrated in the
12 first and third phase, with a significant contribution from delays occurring after leaving a formal
13 facility, a category of themes that we have termed phase 4 delays. Using a four delays framework
14 may help more fully characterize delays leading to the death of children in settings such as ours,
15 because unlike maternal cases, definitive treatment for children often occurs after seeing a
16 provider.

17 Rwanda has made exceptional progress in child health, meeting and exceeding MDGs. In
18 order to maintain and accelerate this progress in the Sustainable Development Goals era, several
19 approaches could be considered. Healthcare service delivery needs to be consistently and reliably
20 aligned with national policies and would require improved facility-level accountability
21 mechanisms to ensure that patients are not denied care or otherwise treated unfairly. Continued
22 improvements in the quality of care, especially around provider competence in the areas of
23 patient-centered care and communication are necessary. Provider competencies should include

1
2
3 1 the ability to form healing partnerships with patients to prevent poor adherence and the ability to
4
5 2 explore and understand competing explanatory models that may cause delays in achieving good
6
7 3 health outcomes⁴⁰. Finally, in order for caregivers to be partners in child health, they must have
8
9
10 4 practical knowledge about appropriate care seeking and be empowered to use it to help their
11
12 5 children be healthy.
13
14
15
16
17
18
19
20
21
22
23
24
25
26
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60

For peer review only

1
2
3 1
4 2
5
6
7
8
9
10 3 **List of abbreviations**

- 11
12 4 CBHI – Community Based Health Insurance
13
14 5 CHW – Community Health Worker
15
16 6 c-IMCI – Community Integrated Management of Childhood Illness
17
18
19 7 COD – Cause of Death
20
21 8 FHS – Formal Health Sector
22
23 9 PIH/IMB – Partners in Health/Inshuti Mu Buzima
24
25
26 10 RMOH – Rwanda Ministry of Health
27
28 11 TM – Traditional Medicine
29
30 12 U5 – Under five
31
32 13 VSA – Verbal Social Autopsy
33
34
35 14 WHO – World Health Organization
36
37
38
39

40 16 **Declarations**

- 41
42
43 17• Ethics approval and consent to participate - Study approval was received from the Rwanda
44 National Ethics Committee and Partners Health Care
45
46 19• Consent for publication – Consent forms are available upon request
47
48 20• Availability of data and material – The datasets used and/or analyzed during the current study are
49 available from the corresponding author.
50
51 22• Author statement– Study oversight (LRH, NG), Study design (LRH, NG, DMK, LH), Data
52 Collection (LH, DMK), Data coding (LH, SRD), Data analysis (SRD, LRH), Manuscript writing
53 (SRD), Manuscript review (SRD, NG, LH, DMK, EN, CM, TB, LRH).
54
55 25• Acknowledgments –The authors gratefully acknowledge the data collectors and study staff for
56 their dedication to collecting the data with great sensitivity and compassion for the families
57
58
59
60

1 involved in this study. We would like to thank hospital leadership and staff from Rwinkwavu and
2 Kirehe District Hospitals and the many health workers who have committed their lives to caring
3 for families in Rwanda. Thank you also to Harvard Catalyst | The Harvard Clinical and
4 Translational Science Center (National Center for Research Resources and the National Center
5 for Advancing Translational Sciences, National Institutes of Health Award UL1 TR001102) via
6 mixed methods consulting services from Rebekka M. Lee. (The content is solely the
7 responsibility of the authors and does not necessarily represent the official views of Harvard
8 Catalyst, Harvard University and its affiliated academic healthcare centers, or the National
9 Institutes of Health.) We would also like to thank the Doris Duke Charitable Foundation's
10 African Health Initiative funding for this project. Most importantly, we are incredibly grateful to
11 the families and caregivers who generously shared their difficult stories with us to contribute to
12 reducing U5 mortality in Rwanda.

References

1. Musafili A, Essén B, Baribwira C, Binagwaho A, Persson L-Å, Ekholm Selling K. Trends and social differentials in child mortality in Rwanda 1990–2010: results from three demographic and health surveys. *Journal of Epidemiology and Community Health* 2015; **69**(9): 834-40.
2. Persson LÅ, Rahman A, Peña R, Perez W, Musafili A, Hoa DP. Child survival revolutions revisited – lessons learned from Bangladesh, Nicaragua, Rwanda and Vietnam. 2017. p. 871-7.
3. UNICEF. Levels and Trends in Child Mortality. New York, NY: United Nations Children's Fund, 2015.
4. Liu L, Oza S, Hogan D, et al. Global, regional, and national causes of under-5 mortality in 2000–15: an updated systematic analysis with implications for the Sustainable Development Goals. *The Lancet* 2016; **388**(10063): 3027-35.
5. UNICEF. Levels and Trends in Child Mortality: Report 2015. Estimates Developed by the UN Inter-agency Group for Child Mortality Estimation. New York, NY: United Nations Children's Fund, 2015.
6. Bojalil R, Kirkwood BR, Bobak M, Guiscafre H. The relative contribution of case management and inadequate care - seeking behaviour to childhood deaths from diarrhoea and acute respiratory infections in Hidalgo, Mexico. *Tropical Medicine & International Health* 2007; **12**(12): 1545-52.

- 1 7. Waiswa P, Kallander K, Peterson S, Tomson G, Pariyo GW. Using the three delays model
2 to understand why newborn babies die in eastern Uganda.(Report). *Tropical Medicine and*
3 *International Health* 2010; **15**(8): 964.
- 4 8. Noordam AC, Carvajal-Velez L, Sharkey AB, Young M, Cals JWL. Care Seeking
5 Behaviour for Children with Suspected Pneumonia in Countries in Sub-Saharan Africa with High
6 Pneumonia Mortality. *PLoS One* 2015; **10**(2): urn:issn:1932-6203.
- 7 9. Ingabire CM, Kateera F, Hakizimana E, et al. Determinants of prompt and adequate care
8 among presumed malaria cases in a community in eastern Rwanda: a cross sectional
9 study.(Report). *Malaria Journal* 2016; **15**(228).
- 10 10. Bensaïd K, Yaroh AG, Kalter HD, et al. Verbal/Social Autopsy in Niger 2012–2013: A
11 new tool for a better understanding of the neonatal and child mortality situation. *Journal of Global*
12 *Health* 2016; **6**(1).
- 13 11. Manzi A, Magge H, Hedt-Gauthier BL, et al. Clinical mentorship to improve pediatric
14 quality of care at the health centers in rural Rwanda: a qualitative study of perceptions and
15 acceptability of health care workers. *BMC Health Services Research* 2014.
- 16 12. MOH R. Republic of Rwanda: Health System. 2014. [http://gov.rw/services/health-](http://gov.rw/services/health-system/2016)
17 [system/2016](http://gov.rw/services/health-system/2016)).
- 18 13. Mugeni C, Levine AC, Munyaneza RM, et al. Nationwide implementation of integrated
19 community case management of childhood illness in Rwanda. *Global health, science and practice*
20 2014; **2**(3): 328.
- 21 14. Mitsunaga T, Hedt-Gauthier B, Ngizwenayo E, et al. Data for Program Management: An
22 Accuracy Assessment of Data Collected in Household Registers by Community Health Workers
23 in Southern Kayonza, Rwanda. *J Community Health* 2015; **40**(4): 625-32.
- 24 15. National Institute of Statistics of R, Ministry of F, Economic PR, Ministry of HR,
25 International ICF. Rwanda Demographic and Health Survey 2014-15. Kigali, Rwanda: National
26 Institute of Statistics of Rwanda, Ministry of Finance and Economic Planning/Rwanda, Ministry
27 of Health/Rwanda, and ICF International, 2016.
- 28 16. Nonyane BAS, Kazmi N, Koffi AK, et al. Factors associated with delay in care-seeking
29 for fatal neonatal illness in the Sylhet district of Bangladesh: results from a verbal and social
30 autopsy study. *Journal of Global Health*; **6**(1).
- 31 17. Koffi AK, Maina A, Yaroh AG, Habi O, Bensaïd K, Kalter HD. Social determinants of
32 child mortality in Niger: Results from the 2012 National Verbal and Social Autopsy Study. *Journal*
33 *of Global Health*; **6**(1).
- 34 18. Kalter HD, Yaroh AG, Maina A, et al. Verbal/social autopsy study helps explain the lack
35 of decrease in neonatal mortality in Niger, 2007–2010. *Journal of Global Health*; **6**(1).
- 36 19. Njuki R, Kimani J, Obare F, Warren C. Using verbal and social autopsies to explore health-
37 seeking behaviour among HIV-positive women in Kenya: a retrospective study. *BMC Women's*
38 *Health* 2014; **14**: 77.
- 39 20. Koffi Alain K, Babilie M, Salgado R, Kalter Henry D, Black Robert E. Social autopsy for
40 maternal and child deaths: a comprehensive literature review to examine the concept and the
41 development of the method. *Population Health Metrics* 2011; **9**(1): 45.
- 42 21. D'ambruoso L, Byass P, Qomariyah SN, Ouédraogo M. A lost cause? Extending verbal
43 autopsy to investigate biomedical and socio-cultural causes of maternal death in Burkina Faso and
44 Indonesia. *Social Science & Medicine* 2010; **71**(10): 1728-38.

- 1
2
3 1 22. Hildenwall H, Tomson G, Kaija J, Pariyo G, Peterson S. " I never had the money for blood
4 2 testing" – Caretakers' experiences of care-seeking for fatal childhood fevers in rural Uganda – a
5 3 mixed methods study. *BMC International Health and Human Rights* 2008; **8**: 12-.
- 6 4 23. Kalter HD, Salgado R, Babilie M, Koffi AK, Black RE. Social autopsy for maternal and
7 5 child deaths: a comprehensive literature review to examine the concept and the development of
8 6 the method. *Population Health Metrics* 2011; **9**: 45-.
- 9 7 24. Bentley B, O'Connor M. Conducting research interviews with bereaved family carers:
10 8 when do we ask? *Journal of palliative medicine* 2015; **18**(3): 241-5.
- 11 9 25. Dwyer SC, Jackson M. Qualitative bereavement research: incongruity between the
12 10 perspectives of participants and research ethics boards AU - Buckle, Jennifer L. *International
13 11 Journal of Social Research Methodology* 2010; **13**(2): 111-25.
- 14 12 26. Verbal autopsy standards: The 2012 WHO verbal autopsy instrument Release Candidate
15 13 1. Geneva, Switzerland: World Health, Organization, 2012.
- 16 14 27. Thaddeus S, Maine D. Too far to walk: Maternal mortality in context. *Social Science &
17 15 Medicine* 1994; **38**(8): 1091-110.
- 18 16 28. Kruk ME et al. High quality health systems—time for a revolution: Report of the Lancet
19 17 Global Health Commission on High Quality Health Systems in the SDG Era *Lancet Global
20 18 Health* 2018.
- 21 19 29. Maxwell JA. Qualitative research design : an interactive approach. 3rd ed. ed. Thousand
22 20 Oaks, Calif.; 2013.
- 23 21 30. Creswell J. A Concise Introduction To Mixed Methods Research. Los Angeles: Sage
24 22 Publications; 2015.
- 25 23 31. Curry LAMN-S. Mixed Methods in Health Sciences Research: A Practical Primer.
26 24 Applications and Illustrations of Mixed Methods Health Sciences Research
27 25 . Thousand Oaks: SAGE Publications, Inc.; 2017.
- 28 26 32. Saunders B, Sim J, Kingstone T, et al. Saturation in qualitative research: exploring its
29 27 conceptualization and operationalization. *Quality & Quantity* 2018; **52**(4): 1893-907.
- 30 28 33. Pâfs J, Musafili A, Binder-Finnema P, Klingberg-Allvin M, Rulisa S, Essén B. Beyond the
31 29 numbers of maternal near-miss in Rwanda - a qualitative study on women's perspectives on access
32 30 and experiences of care in early and late stage of pregnancy. *BMC Pregnancy and Childbirth* 2016;
33 31 **16**.
- 34 32 34. Kleinman A, Eisenberg L, Good B. Culture, illness, and care: clinical lessons from
35 33 anthropologic and cross-cultural research. *Annals of internal medicine* 1978; **88**(2): 251.
- 36 34 35. Finel E. Fighting Against Epilepsy in Rwanda: An Efficient Patient Centred Experience,
37 35 2012.
- 38 36 36. Ecks S. Perceptions and beliefs about cough and tuberculosis and implications for TB
39 37 control in rural Rwanda. *The International Journal of Tuberculosis and Lung Disease* 2007;
40 38 **11**(10): 1108-13.
- 41 39 37. Beste J, Asanti D, Sirotin N, Anastos K, Nathan L. Traditional Medicine Use in Pregnancy
42 40 in Rural Rwanda. 2012. p. S846-S7.
- 43 41 38. Taylor CC. The concept of flow in Rwandan popular medicine. *Social Science & Medicine*
44 42 1988; **27**(12): 1343-8.
- 45 43 39. Donabedian A. The Quality of Care: How Can It Be Assessed? *JAMA* 1988; **260**(12): 1743-
46 44 8.
- 47 45 40. Kleinman A, Benson P. Anthropology in the Clinic: The Problem of Cultural Competency
48 46 and How to Fix It (Essay). *PLoS Medicine* 2006; **3**(10): e294.

1
2
3
4
5
6
7
8
9
10
11
12
13
14
15
16
17
18
19
20
21
22
23
24
25
26
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60

1

2

3

For peer review only

Table 1: Characteristics of pediatric autopsy cases in two rural districts of Rwanda, 2013-2014

	Analytical sample n=77		Full sample n=259	
Child mean age (years)	2.5		2.6	
Maternal mean age (years)	31.9		31.6	
	N	%	N	%
Child male	44	57	148	57
Mother with no formal education	18	27	77	31
Household more than 2 hours walking distance to facility	31	41	100	39
Household with no insurance coverage	22	29	54	21
Sought care from the formal health sector	57	74	204	80
Care Provider ^a				
Traditional healer	25	33	84	32
Community health worker	42	55	131	51
Health center	47	61	164	63
Hospital	14	18	66	25
First Contact Provider				
Community health worker	35	46	104	48
Health center	15	19	69	28
Traditional healer	9	12	30	14
Private pharmacy	2	2	3	1
Other	16	21	53	20
Site of Death				
Home	45	59	137	53
Hospital	7	9	46	18
Health center	10	13	27	10
Other	15	20	49	19
Causes of death				
Malaria	30	39	101	39
Acute abdomen	11	14	25	10
Acute respiratory infection, including pneumonia	11	14	30	12
Diarrheal disease	6	8	13	5
HIV/AIDS related death	6	8	32	12
Accidental drowning	3	4	5	2
Epilepsy	3	4	5	2
Transport accident	2	3	5	3
Other	5	6	43	16

a. May see multiple types of provider. b. The most likely cause of death (COD) was determined using InterVA4²⁶

Table 2: Key themes and supporting excerpts

Key Theme	Excerpts
Phase 1	
A. Constrained capacity to identify or understand illness	<p>i. <i>Her death confused me to some extent. I woke up in the morning and went to wash my clothes. When I came back, I washed her too – it was my first time to lose a child, so I was ignorant of what had happened – when I washed her, she didn't cry.</i> (Parent of 1yo girl who died of malaria)</p> <p>ii. <i>The death of the child should be known by his sister but, unfortunately, she is a child as well.</i> (Parent of 2yo boy who died of malaria)</p>
B. Traditional medicine	<p>i. <i>...we took the child to traditional healers who told me that the child had been poisoned. They kept giving the child herbal medications, promising me that the child would recover from poisoning. Despite this promise, the child's abdomen kept swelling and I thought to myself, "I have to take the child to the health facility." I took the child to [health facility x] and when I arrived, they put the child on supplemental oxygen therapy for nearly 3 weeks but the child's condition never improved.</i> (Parent of 1yo boy who died of pneumonia)</p> <p>ii. <i>As the other traditional healers had given the child medications which caused the child to vomit poison, I chose to take him back home in the hope that I would take him to [the health facility] and that it would be easy for them to help the child recover as the child had vomited the poison. After returning home, I immediately took him to the health facility but the child died on my way before reaching the health facility.</i> (Parent of 2yo boy who died of diarrhea)</p> <p>iii. <i>But as I told you, the child was poisoned. This is why I saw no need to take her to the health facility. I took her to the traditional healer and she died at the house of the traditional healer.</i> (Parent of 2yo girl who died of malaria)</p> <p>iv. <i>I refrained from taking the child to the health facility because I knew full well that many poisoned children had immediately died at the health facility after being given an injection.</i> (Parent of 3yo girl who died of trauma)</p>
C. Pre-existing beliefs about the health system	<p>i. <i>However, as we had no mutuelle, we were afraid of taking the baby to the health facility. I think this is the possible cause of the baby's death.</i> (Parent of 3yo boy who died of an acute abdomen)</p> <p>ii. <i>When you are not enrolled, you are obliged to wait and you may even die there.</i> (Parent of 1yo boy who died of malaria)</p> <p>iii. <i>I don't know what they are always busy doing! They are distracted by their own businesses! It is not easy to consult the health professional at [health facility X]</i> (Parent of 2yo boy who died of an acute abdomen)</p> <p>iv. <i>We are offered quality service at [health facility X] even if it is far. If we do not go to [health facility Y] it is not due to the distance but rather to poor service.</i> (Parent of 3yo boy who died of asthma)</p>
Phase 2	
D. Transportation challenges	<p>i. <i>I thought of going to [HF101] but this required hiring a moto taxi and, in our village, moto taxi drivers will not accept to transport you if you have a dying patient!</i> (Parent of 2yo boy who died of an acute abdomen)</p> <p>ii. <i>Unfortunately, on the date of the appointment, I didn't have any money at all, I didn't even have transportation ticket to go to [the health facility].</i> (Parent of 1yo boy who died of AIDS)</p>
Phase 3	

E. Financial barriers at point-of-care	<p>i. <i>[The healthcare worker] then asked me, “Are you enrolled in mutuelle de santé? If you’re not enrolled in mutuelle de santé, I can’t do anything to help you.”</i> (Parent of 3yo girl who died of pneumonia)</p> <p>ii. <i>As he wasn’t enrolled in mutuelle de santé, they obliged us to pay Rwf 3000 before receiving him despite his being in a critical condition.</i> (Parent of 1yo boy who died of diarrhea)</p> <p>iii. <i>They refused to give me the transfer and the ambulance, simply because I didn’t have money. So, they told me that they would give the child treatments. They gave her the treatments and then she died after a while.</i> (Parent of 1yo girl who died of pneumonia)</p>
F. Poor quality of care	<p>i. <i>I went to see a male CHW but I found that he was not around. I went to see another CHW and met him, but he told me “I don’t have treatments. Yesterday I gave the last ones to a child who was ill.</i> (Family of 1yo girl who died of malaria)</p> <p>ii. <i>In fact they gave her a treatment when it was almost dawning. So, they gave her an injection and then, after a while – maybe they had gone to treat other patients – the child died.</i> (Parent of 1yo girl who died of pneumonia)</p> <p>iii. <i>Frankly speaking, there are instances where one goes to the health facility and your child’s condition gets worse instead of improving because health professionals sometimes neglect patients. They sometimes delay providing us with treatment and show contempt for us thinking that they have more education than we have and they consider us peasants from rural areas. They even happen to deny us healthcare.</i> (Parent of 2yo girl who died of epilepsy)</p> <p>iv. <i>They didn’t reveal to me anything regarding the child’s illness. They only prescribed some tablets for the child.</i> (Parent of 3yo boy who died of malaria)</p> <p>v. <i>When I arrived there, health professionals were there. I said to one of them “As you can see, my child is in a critical condition. You should attend to him/her as a matter of urgency.” He/she replied, “Under the current rules, no one can be allowed to go straight to the front of the queue. You have to bear with me and accept to queue.” As I was queuing, the child immediately died in my arms. I thought that health professional has to be blamed for my child’s death.</i> (Parent of 1yo boy who died of malaria)</p> <p>vi. <i>They discharged her and they told me to go home and give her pills. They discharged her although it was obvious that she was still very sick.</i> (Parent of 2yo girl who died of malaria)</p>
G. Positive experiences with FHS	<p>i. <i>There was a health professional by the name of “X” who was loved by all community members. When a patient was not enrolled in the community-based health insurance scheme, she volunteered to pay for his/her medical bills for the patient to repay after a certain period of time.</i> (Parent of 4yo girl who died of diarrhea)</p> <p>ii. <i>They properly care for patients and give them useful advice.</i> (Parent of 4yo girl who died of epilepsy)</p>
Phase 4	
H. Dissatisfaction leads to traditional medicine	<p>i. <i>...they gave me small tablets for the child. I gave the tablets to the child, but it didn’t work. Seeing that, we decided to take the child to traditional healers.</i> (Parent of 2yo boy who died of malaria)</p> <p>ii. <i>.... As people often say, “you use tablets and if the child is not cured you tell yourself the baby must have been poisoned.”</i> (Parent of 3yo girl who died of pneumonia)</p> <p>iii. <i>As the tablets that we had received from the health facility hadn’t helped the child to recover, and instead caused the child’s condition to deteriorate, I thought the child had an illness that would be treated by traditional healers and hence chose to return to traditional healers.</i> (Parent of 1yo boy who died of AIDS)</p>
I. Home treatment plan failure	<p>i. <i>I: Is it easy for you to access the meds once the doctor has prescribed them for you? R: It is a challenge because you cannot afford buying meds if you are not enrolled in the community-based health insurance scheme.</i> (Parent of 1yo boy who died of malaria)</p> <p>ii. <i>They gave me another appointment but told me that I had to pay bus fares on my own. And when I remembered the kind of life I had lived there, the medications that were prescribed to the child, the food and the financial means all that required, I noticed I was unable to secure all the money needed and I refrained from returning there. But apart from that, I could also see that the child had finished his/her journey on the earth.</i> (Parent of 3yo girl who died of pneumonia)</p> <p>iii. <i>He spent one week and one day without crying. Although they discharged us, he hadn’t cried yet, even once. “Once he arrives in a cold place, he will cry”, they told me as they discharged us. We spent a whole week before he cried. We noticed that the child was wasting away day after day. When I went to have him weighed, he would weigh 2 kilograms today, and next time he would weigh 1 kilogram and some grams.</i> (Parent of 1yo boy who died of AIDS)</p>

Table 3: Phase 1 mixed-methods themes and excerpts for maternal education

	No formal maternal education	Some formal maternal education
Phase 1 excerpts by maternal education	<p><i>Those who were with me, told me, "Hurry up and, if he is still breathing by the time you reach home, take him immediately to the health facility for them to find out the cause of the child's death."</i> (Parent of 2yo boy who died of malaria)</p> <p><i>"Let's go to see the father's child in the farm so that he can help me to take the child to the health facility and to avoid that the child's condition to deteriorate at home."</i> (Parent of 4yo girl who died of malaria)</p> <p><i>I ran to the other neighbors who were digging the fields and told them, "Look! My child is dying and h/s was healthy when I brought him."</i> (Parent of 2yo boy who died of malaria)</p> <p><i>If I had known what illness the child had I would have sought treatment for the child. Some of my neighbors could say that the child was suffering from malnutrition whilst others suspected the child had been given poison. People in rural areas are always inclined to speculate on all that happens.</i> (Parent of 4yo girl who died of AIDS)</p> <p><i>I sought advice from my fellow mothers asking them, "My child has a horrible smell in his/her nose. What can I do?"</i> (Parent of 1yo boy who died of AIDS)</p>	<p><i>Seeing that, I asked myself the following question: why is my child passing such things in stool while I've administered medications to the child? I put the child on my back and came back home thinking that, "Let me administer the medications to the child. If the medications don't work, I will take the child to traditional healers for them to find out what illness the child has."</i> (Parent of 1yo boy who died of malaria)</p> <p><i>When the child started getting ill, I had the child tested for a folk illness known as uburo. I first took the child to the traditional healer and then to the health facility.</i> (Parent of 3yo boy who died of malaria)</p> <p><i>The child did not have any accident. I thought my child was given poison by malicious people, who did so secretly during our visit.</i> (Parent of 2yo boy who died of an acute abdomen)</p> <p><i>It wasn't until late that night that I suspected that the child was given poison. However, I said to myself, "I need to take the child to the health facility first because it might be that the child has abdominal pain because of malaria. If I arrive at the health facility and the child tests negative for malaria, I will decide to take her to traditional healers." The child died before taking any medications</i> (Parent of 3yo female who died of an acute abdomen)</p> <p><i>One evening in that same year, the child developed a folk illness known as igishikuzi. Seeing that, I administered meds to the</i></p>

		<p><i>child. After taking the meds, the child moderately recovered. As the child appeared to have moderately recovered, I decided to leave home for work. As I was preparing to leave, the child's illness suddenly came back again. After realizing that it was the same illness, I thought to myself, "I have to give the child the meds I have given him before." As I was preparing for going to pick up meds for the child, he immediately died. (Parent of 2yo boy who died of epilepsy)</i></p>
--	--	--

Table 4: Phase 1 mixed methods themes and excerpts for place of death

	Did not die in a facility	Died in a facility
<p>Phase 1 excerpts by place of death</p>	<p><i>As I was working in the fields, I realized that the child was in a critical condition and rushed back home. As I was preparing for going to seek treatment for him, the child died. To be frank, the child wasn't taken to the health facility or the CHWs. As you can see, the child's death came suddenly. (Parent of 2yo boy who died of epilepsy)</i></p> <p><i>When I took the child to the CHW, I was told that medications were not available. I came back home. As I was preparing to go there in the morning, the child immediately died. (Parent of 3yo girl who died of an acute abdomen)</i></p> <p><i>While I was thinking about that, I washed myself, and washed him too. By the time I wanted to carry him on my back, he died on the spot. (Parent of 1yo boy who died of malaria)</i></p> <p><i>I immediately bathed the child and then applied body lotion to the child's entire body. I then washed my body after which this one (her husband) arrived. The child immediately started falling into agony and died. It was around 8.00pm. (Parent of 3yo boy with an unknown cause of death)</i></p> <p><i>He will not recover but he will die at home at least. I wondered, "Shall I take a dead child to the health facility? What shall I say? What shall I do since the child did not have any fever?" I eventually put the baby on my</i></p>	<p>Theme not present</p>

	<p><i>back. They said, "Wash yourself and go even if it is almost over...I washed myself hastily and sought some clothes to dress the child. When I was ready, my mother said to me, "No need for the clothes: he has just died." I threw the clothes to them. (Parent of 2yo boy who died of malaria)</i></p>	
	<p><i>As I was preparing to take the baby to the health facility early in the morning, the baby passed away. (Parent of 1yo girl who died of malaria)</i></p>	
	<p><i>However, the child refused to eat and chose to go to bed. I asked myself, "Is this child suffering from intestinal parasites? Is he/she ill?" I immediately bathed the children and clothed them and then went to the nearest shop to buy juice and 2 biscuits for them. When I tried to give them the juice and biscuits, the children appeared to have no appetite. Even the juice and biscuits were still here after the burial of the child. (Parent of 3yo boy who died of an acute abdomen)</i></p>	

Table 5: Phase 4 mixed methods themes and excerpts for malaria diagnosis

	Malaria	Diagnosis other than malaria
Phase 4 excerpts by COD (Malaria)	<p>When I arrived, they gave me small tablets for the child. I gave the tablets to the child, but it didn't work. Seeing that, we decided to take the child to traditional healers. Parent of a 2yo boy who died of Malaria.</p> <p>The child was yet to take traditional medications when h/s died. This is because I started by administering the baby medications prescribed by health professionals. Parent of a 1yo boy who died of Malaria</p> <p>He/she finished the meds but he/she didn't recover. Then we said, "The child might have been given poison. Let's go for checking." When we had checked, we found that the child had been poisoned but it was too late to save his/her life. He/she died that night. Parent of a 1yo boy who did of Malaria (Kirehe)</p>	<p>They performed malaria test but the child tested negatively for malaria. Following this, they asked me to take the child to the people who could perform consultations on the child to see if he/she had "ikimoso". Parent of a 3yo boy who died of diarrhea.</p> <p>The child fell ill but his/her condition didn't severely deteriorated. I took the child to the public health facility and then to the private health facility. The child's illness persisted to such an extent that he/she couldn't eat anything at all! I tried to seek treatment for the child but to no avail. Parent of a 4yo girl who died of HIV/AIDS</p>

1
2
3
4
5
6
7
8
9
10
11
12
13
14
15
16
17
18
19
20
21
22
23
24
25
26
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47

Phase 3 excerpts by COD domain	No divergent themes	
--------------------------------	---------------------	--

Table 6: Illustrative care-seeking narrative

On 10 August, the child had his/her first birthday and had never had any problem since birth. In September, the child started having a cough and fever. And whenever the child had cough and fever, I rushed to CHWs who gave me tablets for the child. As the tablets didn't help they finally referred me to the health facility. When I then went to the health Center, one of the health professionals I found there told me, "You have to take the child to your nearest health center for TB test." He/she said this based on the signs I had recounted to him/her. And when I took the child to my nearest health center, they didn't perform TB test. The child became sickly such that I was obliged to go to the health facility every week.

When people saw that, they told me the child was victim of poisoning and asked me to take the child to those people who would pray for his/her recovery. When they told me that the child was suffering from poisoning, I took him/her to traditional healers who gave medications to the child. I went to see them and spent there 2 weeks. After taking such medications, the child started having diarrhea following which traditional healers told me, "The child has been poisoned." The traditional healers added, "As the child has started having diarrhea after being given medications, it means that poison has been removed from the baby's body. Now, you have to take the child to the health facility for him/her to be put on drip so that the level of water in his/her body can be increased."

I arrived here [home] on a Saturday and spent the following Sunday here [home]. On the following Monday, I said to myself, "I have to wash my clothes as I need to take the child to the health facility." However, the child's hair had started becoming very fine as if the child had kwashiorkor. The CHW said to me, "The child appears to be in a critical condition and I have to give you a referral note so that you can take him/her to the health facility." The CHW reported that the child was suffering from malnutrition. However, I had adequate foods for my child. I had beans and often bought small fish commonly known as "indagara". I also used to buy soybeans and give the child porridge made up of a mixture of many ingredients. I had enough foods to feed my child.

As the child's condition became very critical, I took the child to [HF X]. And when I arrived there, a health professional rushed to call an ambulance upon looking at the child. When I took the child to the health facility, a health professional checked the palms of the child's hands and his/her eyes and concluded that the child had anemia. They immediately referred me to [HF Y].

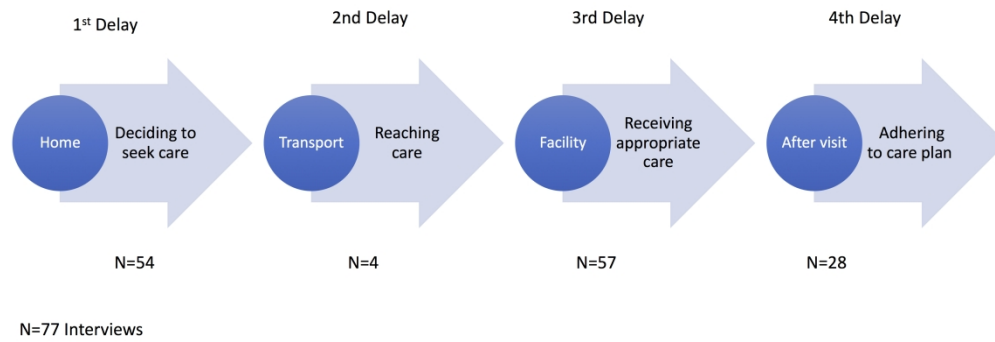
1
2
3
4 I went to [HF Y] nearly two months after the child started having cough. Even if I used to take the child to those who would pray
5 for him/her, I didn't neglect seeking treatment from the health facility. But when I arrived at [HF Y], they performed blood tests on
6 the child and when I asked health professionals to disclose to me the test results, they said to me that the child was suffering from
7 malnutrition. I went to [HF Y] on the 26th day and stayed there for 23 days. This often happens when one is at the health facility.
8 Whenever the child's condition became critical, I went to alert them but they appeared not to be interested in what I was telling
9 them. If they had taken care of the child, I wouldn't have stayed for as many days at [HF Y]. But the child's condition started
10 becoming very critical when I was still at [HF Y]. At the end of these 23 days, they told me that I had to take the child to Kigali.
11
12

13 We left [HF Y] around noon and reached Kigali around 4.00 pm. When we arrived, they laid the child on the bed and was
14 examined. The child lost weight. This is because when I took the child to the health facility for his/her 9-month vaccination, the
15 child weighed 10 kg. And when the child started getting ill, his/her weight decreased to 8 kg and then to 7 kg. The child weighed
16 6.3 kg at death. They then started feeding the child on milk. I remember that it was on a Thursday. On the following Sunday, they
17 stopped giving milk to the child and started feeding him/her on porridge. They started giving me porridge and mashed foods as well
18 as tree tomatoes for the child. I stayed there several days.
19
20

21 However, there later came a time when the child's condition started becoming very critical and the child would wake up
22 every night crying out in pain. On the following Monday, I went [back] to Kigali where they performed tests on the child and when
23 I asked them, "What illness does the child have?", they turned a deaf ear to me. Around 7.00 one of the health professionals came to
24 me and told me, "the child has little chance of survival. As you can see, the child is in a very critical condition. We're very sorry
25 for that." I too was realizing that the child was going to die. I asked him/her, "What illness does the child have?" He/she told me
26 that the child has pneumonia and that it was too late to save his/her life. It's really unclear to me which of these illnesses killed the
27 child.
28
29

30 Parent of a 1.5 year old boy who died of AIDS
31

32 *Note: minor adjustments in the order of the narrative were necessary to make the order of health facilities clear to the reader.*
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47



25
26
27
28
29

Caption: Figure 1: Four phases of delay Legend: The graphic illustrates four phases of delay, starting with the 1st delay in deciding to seek care. Once decisions to seek care have been made, phase 2 delays in reaching formal care may be experienced. Those who arrive at a facility may experience phase 3 delays in receiving timely and appropriate care. The fourth phase occurs after patients have left formal care and involves challenges in adhering to the prescribed care plan.

30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60

338x190mm (300 x 300 DPI)