Transforming Data to Action: Identifying delays and barriers to care in CHAMPS cases to inform child health interventions

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SUMMARY AND KEY TAKEAWAYS

This case study provides a retrospective review of Child Health and Mortality Prevention Surveillance (CHAMPS) cases in Mali, mapping routes of care—or each case's clinical pathway through the health system—in order to identify potential delays and barriers to seeking, providing, or escalating care for children under five years of age. Our results, investigating both formal and traditional healthcare systems during terminal illness, suggest specific improvements in both systems-level and community-level measures for prevention of child mortality in Bamako. These include reducing the time needed to escalate cases to a higher level of care; including delays in care due to treatment fees; enhancing emergency transport systems and reducing barriers to access transport services; educating parents on symptom severity and when to seek care; bolstering systems of care for children with chronic conditions; and continued attention to vaccinations. Investigation into safe sleep and SIDS-prevention strategies in Mali presents an additional opportunity to prevent child deaths.

BACKGROUND AND CONTEXT

Mali has the world's sixth highest under-five mortality rate (approximately 115 deaths per 1,000 live births) and hosts one of seven sites in the CHAMPS network (SOWC, 2016). CHAMPS is an ongoing study that determines causes of stillbirth and death in children under five years of age. In Mali, CHAMPS conducts minimally invasive tissue sampling (MITS) on deceased babies and children who meet age criteria and are residents of two quartiers in Bamako, Banconi and Djicoroni Para (Figure 1). Samples collected using MITS undergo various microbiology, molecular biology, and histopathology testing. These results, coupled with clinical data and verbal autopsy (VA) interviews, are reviewed by a panel of experts through the Determination of Cause of Death, or DeCoDe, process (Salzberg, 2019). For each case, DeCoDe panelists assign an immediate and underlying cause of death, identify pathogens or additional co-morbid conditions that may have contributed to the death, and comment on factors that could have prevented the death (Blau, 2019). CHAMPS informs public health action at local and national levels by identifying preventable deaths.

The decentralized health care system in Mali has a three-level, pyramidal structure for providing primary, secondary, and tertiary care (Figure 2). Primary care is provided at Community Health Centers (Centre de Santé Communautaire; or CSCOM) which are operated by Community Health Associations (Association de Santé Communautaire; or ASACO). CSCOMs refer patients to Referral Health Centers (Centres de Santé Référence; or CSRef), where secondary care is provided. Each of the six communes that make up the capital, Bamako, has one CSRef. Finally, tertiary care is provided at hospitals. Private facilities exist at all three levels.

Besides exemptions in fees for HIV/AIDS related-care, caesarean sections, and malaria treatment, Malian citizens are responsible for payment of most health services including medication, emergency transport, and medical equipment (Toure, 2015). This cost burden results in an underuse of services and delays in accessing care at facilities. Studies have demonstrated that subsidization of health care user fees and contact with community health workers leads to increased utilization of health services (Ponsar, 2011 & Johnson 2013).

In order to identify potential delays and barriers to seeking, providing, or escalating care that could have contributed to death in children under five, this case study outlines the contacts that CHAMPS cases had with the formal and traditional healthcare system in Mali during terminal illness.
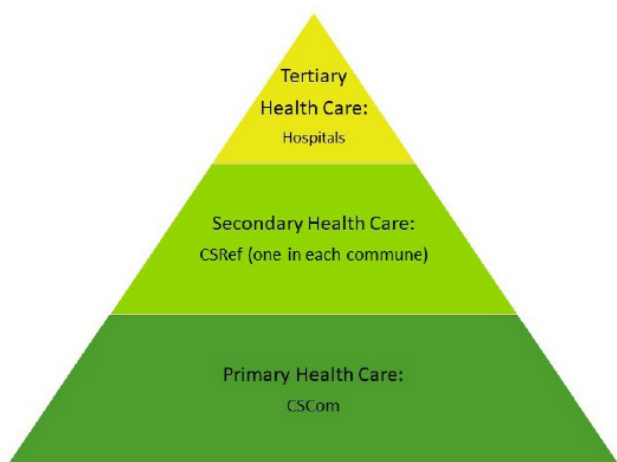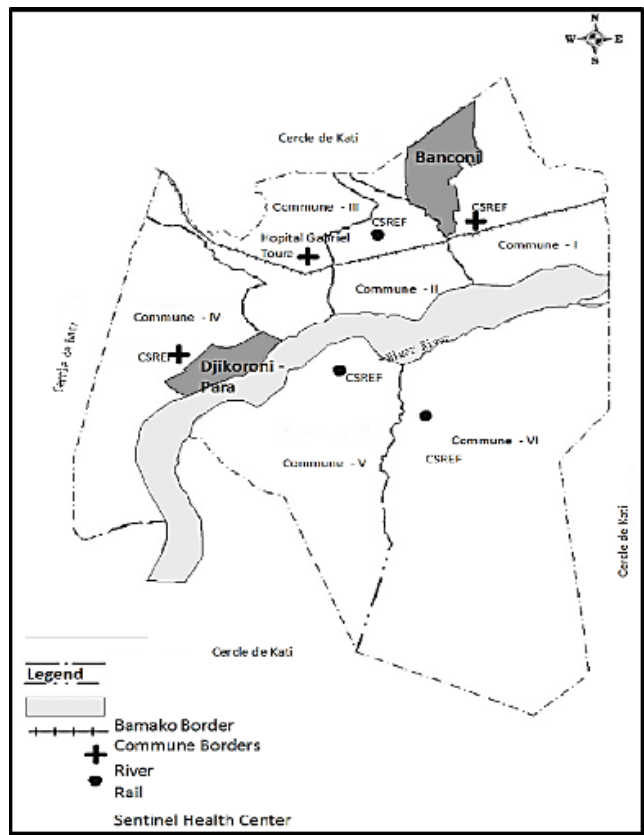

Figure 1: Map of Bamako, Mali. The CHAMPS catchment area, the quartiers of Djicoroni Para and Banconi are shaded in gray

Figure 2: Formal healthcare system structure in Bamako, Mali

METHODS

From January 2018 through December 2019, DeCoDe panelists determined causes of death for 128 Malian cases. In order to focus on post-natal contact with the healthcare system rather than antenatal and obstetric care, stillbirths (n=47) and children less than 24 hours of age (n=18) were excluded from this analysis. Sixty-three cases were aged 24 hours to 60 months; two of these were excluded from this analysis, as one case had no data available on clinical course and the other case was awaiting re-adjudication based on new test results. A retrospective review of the clinical records, verbal autopsies, and DeCoDe findings (including causes of death, notes on preventability of death, and observations of delays in care by DeCoDe panelists) for the remaining 61 cases were conducted by two researchers; their aims were to reconstruct each case's interactions with both the formal and traditional health systems throughout the course of illness and identify any potential delays in care.

Table 1: Definition of each step within the routes of care. These definitions are based on the structure of the Malian health system.

Step in the Route of Care	Definition
Primary Care Facility	Primary care facilities include Community Health Centers (Centres de Santé Communautaire; CSCom), medical cabinets, and clinics.
Secondary Care Facility	Referral Health Centers (Centres de Santé Référence; CSRef), are public secondary care facilities in Mali. There are 6 CSRefs in Bamako, one within each commune.
Tertiary Care Facility	Public or private hospitals in Bamako provide tertiary level care. Hospitals in Bamako include L'hôpital Gabriel Touré (HGT), Polyclinique Pasteur, L'hôpital Luxembourg, Centre Hospitalier Universitaire du Point G, Hôpital du Mali, and Golden Life American Hospital.
Ambulatory	Outpatient visits at a secondary care facility (CSRef) or tertiary care hospital.
Inpatient	Inpatient stays/admissions at a secondary care facility (CSRef) or tertiary care hospital.
Traditional Healer	Documented visit with a traditional healer (distinct from use of traditional treatment).
Transport	Deaths in transport are those which occurred en route from home to a facility, en route from referring facility to receiving facility (including detours), or at a facility, but before evaluation by a health care worker took place.

Table 2: Categorization of delays in and barriers to care in this case study

Type of Delay or Barrier	Expanded Definition/Examples
Potential delay or absence in escalation of care at a facility	• Delay in referral from facility to higher-care facility • Delay in either prescription or acquisition of medication • Lack of adequate support or resources in the hospital
Inadequate support or absence of support during transport	• Death en route from home to facility • After a referral, death before arrival at receiving facility • Death at facility before evaluation or initiation of testing/treatment (not including resuscitation measures taken on arrival, after death, without any response)
Premature facility discharge or leaving against medical advice	• Facility discharge of a child in unstable condition • Family left against medical advice or could not continue care because of resource constraints
Potential delay in seeking adequate clinical care	• Delayed recognition of symptom onset or severity of symptoms, or delayed care-seeking for recognized symptoms • Death at home with reported signs of serious illness • Care sought from a traditional healer before the formal health sector (perceived incongruity between traditional healing practices and clinical medical care) • Death at home after traditional healer visit or after traditional medication administration • Outpatient care followed by worsening of symptoms and death at home
Care system gaps related to diagnosis or management of chronic or pre-existing condition	• Child's pre-existing or chronic condition (e.g. HIV; malnutrition), which was determined during DeCoDe to contribute to death, had been diagnosed prior to death, but was not appropriately managed through the healthcare system • Child's pre-existing or chronic condition (e.g. HIV; malnutrition), which was determined during DeCoDe to contribute to death, had not been diagnosed pre-mortem, but could have been identified and treated during documented clinical visits

Delineating Contacts With the Healthcare System

Each case's clinical pathway, or "documented route of care", through both the formal and traditional healthcare systems during terminal illness was outlined in a Sankey Diagram (The Sankey Diagram Generator, Acquire Procurement Services, Brisbane, Australia) (Snavely, 2018). Each route is broken down into various "steps." The first step in the route of care represents the location where symptoms related to the acute, terminal illness started. For all early neonates (less than seven days old at the time of death), the first step represents place of birth. Each subsequent step represents the next location during the child's fatal illness. The last step in the route is defined as the location of death or, in cases where death occurred during transport, the facility to which the case was being transported. The steps in each route were categorized based on the structure of the Malian health system (Table 1).

Identifying Potential Delays in Care

In reviewing case documents, including the assessment from DeCoDe panelists on whether the death was preventable, common categories of delays in care emerged (Table 2). These categories build upon the "three delays model" of delays implicated in pregnancy-related mortality (delays in seeking care, reaching adequate care, and receiving adequate care) (Snavely 2018). Our expanded categories include systems-level transportation issues (including between facilities), escalation of care or discharge from care at facilities, and systems-level management of chronic child health needs.

For each case, we classified potential barriers or delays in seeking or receiving care according to these categories. It should be noted that these delays are often multifactorial. They do not necessarily imply negligence of facility staff, inappropriate provision of care at facilities, or negligence of cases' guardians; rather, they reflect cumulative, systemic barriers to accessing life-saving health care.

Figure 3: Age classification at the time of death of 61 deceased children (aged 24 hours - 59 months) identified through child mortality surveillance in Bamako, Mali, 2018-2019
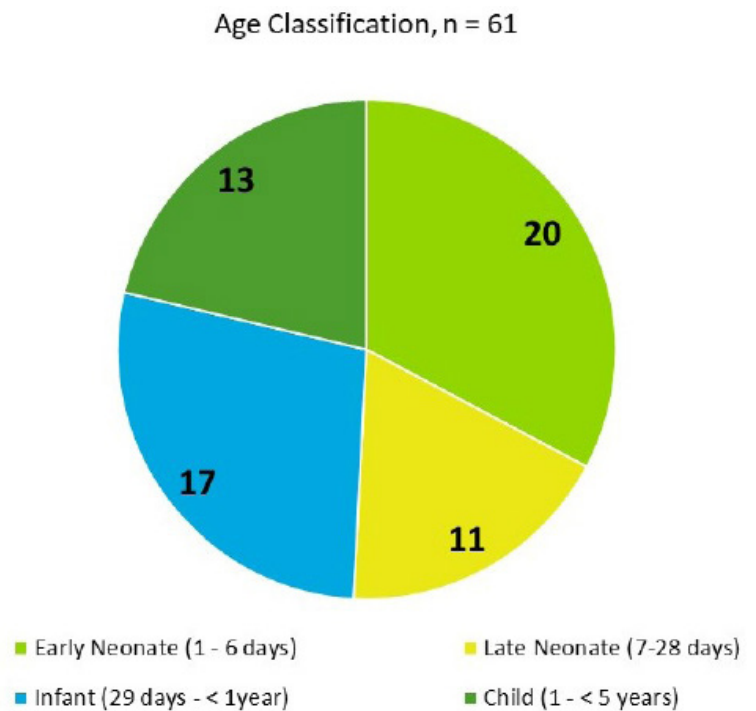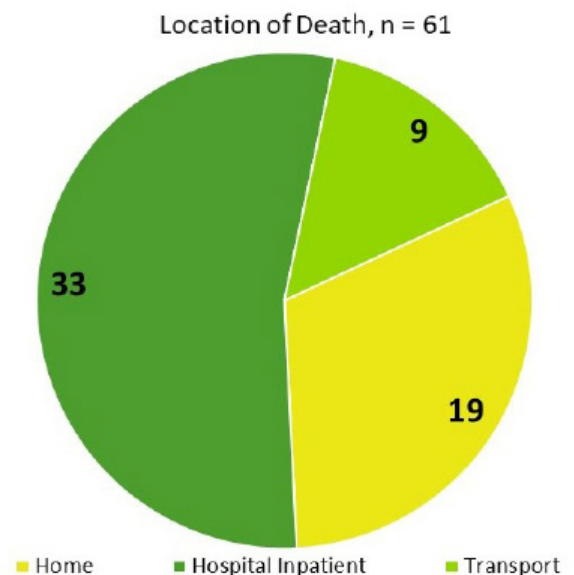

Age Classification, n = 61

- ■ Early Neonate (1 - 6 days)
- ■ Late Neonate (7-28 days)
- ■ Infant (29 days - < 1year)
- ■ Child (1 - < 5 years)

Figure 4: Location at the time of death of 61 deceased children (aged 24 hours - 59 months) identified through child mortality surveillance in Bamako, Mali, 2018-2019

Location of Death, n = 61

- ■ Home
- ■ Hospital Inpatient
- ■ Transport

FINDINGS
Summary

The age classification and location of deaths of the 61 cases evaluated are presented in Figures 3 and 4, respectively. Of the deaths included in this evaluation, 20 (33%) occurred in the early neonatal period (1-6 days), 11 (18%) occurred in the late neonatal period (7-28 days), 17 (28%) occurred in infancy (29 days up to 1 year), and 13 (21%) occurred in children aged 12 months up to 5 years (Figure 3). Thirty-three cases (54%) died in the hospital, 19 (31%) died at home, and 9 (15%) died in transport either to a facility or between facilities (Figure 4). Thirty-four cases were female (56%). Discrepancies between information from the clinical record and verbal autopsy were noted in 21 cases (34%). Two case records (3%) had incomplete or missing information about locations of contact with the health system; 24 case records (29%) lacked complete date and/or time information for contacts with the health system.

Routes of Care

The documented routes of care of each case through the healthcare system are presented in the Sankey diagrams in Figure 5. Eighteen of the 61 cases (30%) – including 13 early neonatal deaths and 5 late neonatal deaths—were never discharged from facility care: they were born and died at the same facility or a referral facility. Of the remaining 43 cases, the number of contacts within the traditional or formal health sectors ranged from 0 to 6. The median number of contacts was 2.

Early neonates (Figure 5a). The 20 neonates who died within 1-6 days of age were all delivered at a facility: 14 (70%) at a primary level care facility, 4 (20%) at a secondary level facility, and 2 (10%) at a hospital. Seven (35%) were discharged home from facility whereas 13 (65%) were referred to a higher level of care and died without leaving the healthcare system. One case died at the facility of birth. The maximum number of documented steps in the children's routes before death was 5, and the median number of steps was 3. In some cases, care was escalated from primary, to secondary, and then to tertiary care prior to death. Two cases (10%) died in transport, one during interfacility transport and one during transport from home to a primary care facility. None of the cases were taken to traditional healers for care.

Late neonates (Figure 5b). Of the 11 neonates who died between 7-28 days old, seven (64%) showed conditions leading to death beginning in a primary care facility (noted as Step 1 of their route). Of the remaining 4 (36%) who were discharged home after birth as healthy neonates, 3 developed symptoms of illness and returned to the healthcare system while 1 died at home with a cause of death designated as sudden infant death syndrome (SIDS) by the DeCoDe panel. The maximum number of steps in the routes was 5, and the median number of steps was 2. No patients died in transport. For one case, care was sought from a traditional healer after the neonate was discharged home from a secondary care facility; the neonate ultimately died at home.

Infants and children (Figure 5c). Terminal illnesses were documented to have commenced at home for all 30 infant and child mortality cases investigated in this study. The number of steps along the routes ranged from 0 to 10, and the median number of steps was 5. Seven deaths (23%) occurred at home prior to any contact

Table 3: Enumeration of the type(s) of delays or barriers (n=57) experienced by 33 cases. Some cases experienced multiple delays or barriers

Type of Delay or Barrier	Number of instances
Potential delay or absence in escalation of care at a facility	9
Inadequate support or absence of support during transport	11
Premature facility discharge or leaving against medical advice	10
Potential delay in seeking adequate clinical care	18
Care system gaps related to diagnosis or management of chronic or pre-existing condition	9

with the healthcare system; the cause of death for 4 of these cases was designated as SIDS by the DeCoDe panel; the remaining 3 cases had symptoms of illness which were identified and managed at home prior to death. Care was sought from a traditional healer as the first contact in 5 cases (17%), with 12 total instances of care sought from a traditional healer. Seven cases (23%) died in transport to a facility: 3 of these were traveling from home and the remaining 4 were traveling between facilities. One case's documented trajectory includes 10 steps and 6 points of contact with the healthcare system prior to death in a tertiary care facility.

Deaths at Home and Deaths in Transport

Of the 19 children who died at home, 11 (58%) had received care for their illness at a facility prior to death. Of the nine cases who died in transport, three were traveling from home to a facility while the remainder were traveling from facility to facility; this included two children who died at the receiving facility before evaluation by a healthcare worker and one child who died when the family took a detour to their home to make financial arrangements on the way to the referral hospital. Of the eight cases (13%) who died at home and did not seek or receive care immediately preceding death, five deaths were attributed to SIDS.

Traditional Healer Visits, Traditional Medications, and Self-Medication

Thirteen cases (21%) were taken to a traditional healer during the illness leading up to their death; five of these cases visited a traditional healer prior to seeking treatment within the formal health sector. In total, 18 (30%) of the 61 cases had documented use of traditional medications during the terminal illness.

Use of medication or traditional therapies that were not prescribed by a healthcare worker or traditional healer was noted in eight (13%) cases, one with antibiotics, one with an unspecified syrup, and the remaining six cases with traditional therapies.

Delays in and Barriers to Care

Of the 61 cases, 33 (54%) experienced at least one of the delays or barriers to accessing care defined in this case study. Nineteen cases (31%) faced two or more barriers. In total, 57 total potential barriers were identified for the 61 cases (Table 3). The instances of these barriers across all 33 cases, some of whom experienced multiple barriers, are summarized in Table 3.

Preventable Deaths

Overall, 30 cases (49%) were assessed as preventable by DeCoDe panelists during cause of death adjudication. Of these, 12 cases did not experience the barriers defined in this case study but were instead deemed preventable either by increased pregnancy/obstetric monitoring, improved support of premature neonates, improved infection control, or parental education on signs of severe illness and escalation of symptoms. Panelists also noted that two cases that experienced these barriers could have been prevented with appropriate vaccination. DeCoDe panelists' assessment of whether a death is preventable considers the local context and current state of the health system as well as the cause of death. Some of the cases who faced structural barriers to care may not have been considered preventable in the current context of the health care system in Bamako. Delineating routes of care and contacts with the healthcare system provides additional information on opportunities to intervene on so-called "upstream" structural factors that strengthen health systems and prevent untimely deaths.

Figures 5a, 5b, 5c: Sankey Diagrams

The first step in the Sankey Diagram represents the location where symptoms related to the terminal illness started. For all early neonates, the first step represents place of birth. The number on each vertical bar, or location, indicates the number of cases who presented to that location. The thickness of the lines which flow between steps indicate the proportion of cases moving from one location to another. Dark gray lines between locations represent deaths which occurred en route from the starting step to the subsequent step. Deaths are represented by the cessation of flows, resulting in the Sankey Diagram narrowing from the first to the last step. The last step in each individual route is defined as the location of death or, in cases where death occurred during transport, the facility to which the case was being transported.

Figure 5a. Routes of care for early neonates (n=20). Step 1 for each early neonate represents their location of birth. .
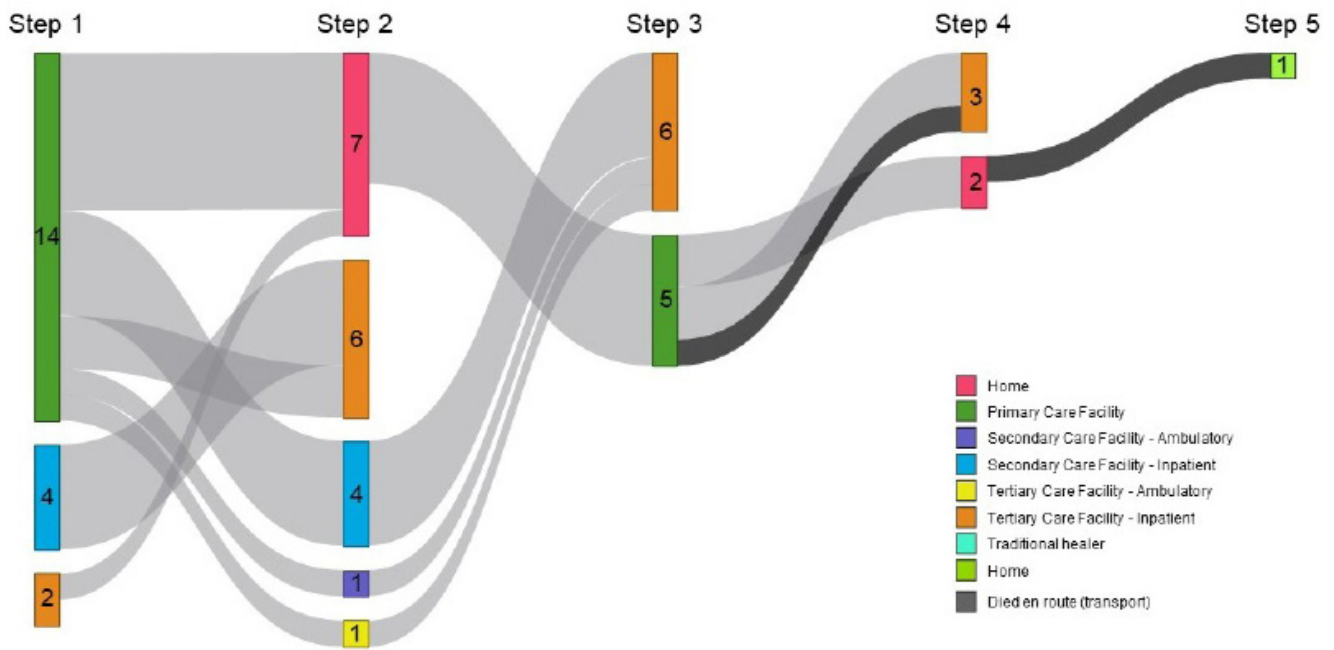
Figure 5b. Routes of care for late neonates (n=11). Step 1 represents the location where the child's illness began (either at facility of birth or if released after birth, then at home)
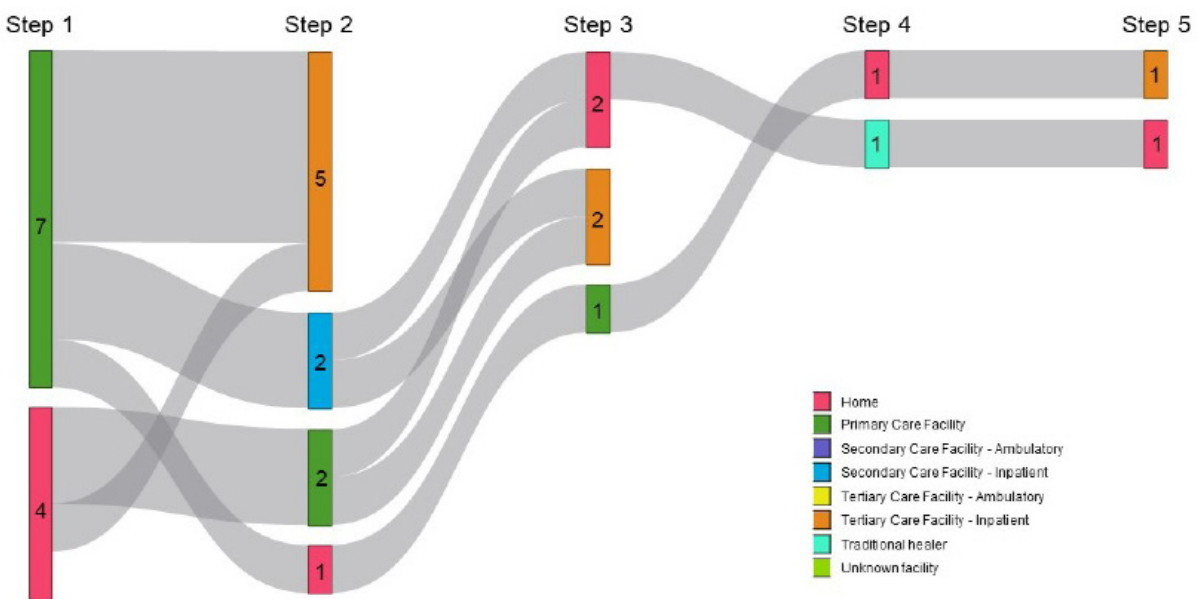
Figure 5c. Routes of care for infants and children (n=30). Step 1 represents the location where the child's illness began.
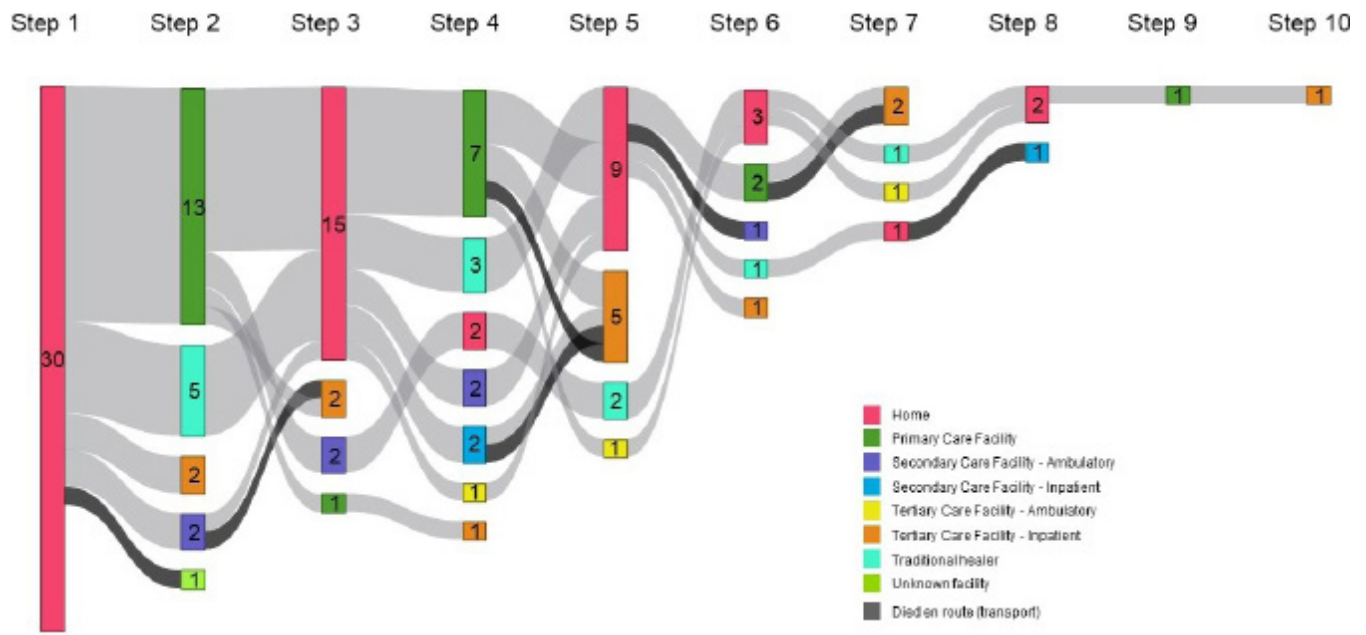
Table 4: Recommendations and potential points of interventions to address broad categories of delays or barriers

Delay or Barrier	Recommendations for points of intervention: Opportunities to translate CHAMPS Data to Action
Potential delay or absence in escalation of care at a facility	• Conduct routine facility-based focus groups and training sessions • Improve triage at facilities • Address the requirement for upfront payment for medical care, which currently delays/prohibits immediate or emergency care
Inadequate support or absence of support during transport	• Increase availability of functional ambulances • Improve equipment in ambulances • Set up a formalized network of paramedics (currently there is a lack of structured paramedic services) • Improve triage at facility
Premature facility discharge or leaving against medical advice	• Conduct routine facility-based focus groups and training sessions, including discharge planning checklists and routine guidance on when to return to care • Address the requirement for upfront payment for medical care, which currently prohibits continued care

Potential delay in seeking adequate care	• Parent education on severity signs and escalation of symptoms
	• Conduct routine facility-based focus groups and training sessions, focusing on effective messaging strategies
	• Establish or strengthen collaborations between traditional healers and clinical health facilities:
	    • Healers can escalate care and refer for clinical care as needed
	    • Healers can educate parents (effective messaging strategies)

Care system gaps related to diagnosis or management of chronic or pre-existing condition	• Bolster the existing follow-up system for chronically ill or malnourished children (ensure wellness checks are conducted routinely) • Increase the number of community health workers associated with various CSComs. These community health workers track the health of children within their communities • Enhance partnerships between traditional healers and formal health system to support family goals of care
Panelists noted death was preventable with vaccines	• Increased vaccine coverage • Conduct routine facility-based focus groups and training sessions on encouraging vaccination and connecting parents with vaccination sites (especially at hospitals, where vaccinations are not usually conducted)

Conclusions and Recommendations
Limitations and Futher Directions

Due to limitations surrounding the completeness of data, findings should be interpreted with caution. Given the limitations of clinical records and verbal autopsy interview data, it was not possible to assess the time course of illness or the duration at each step in the route of care. Likewise, assessment of whether parents and healthcare workers identified signs and symptoms as illness progressed, and assessment of attempted treatments or interventions, were limited to those reported or documented for each case. This analysis cannot determine if, in the absence of the noted delays and barriers to accessing care, outcomes for individual cases would have changed.

Nevertheless, these analyses present a landscape of the interactions between patient and health systems, highlighting discrete points of contact and points of opportunity along the spectrum of care prior to child death. Reviewing each case and each point of contact helps identify where educational interventions and health systems-level interventions could be applied in order to offer opportunities to bolster care, support families and healthcare workers, strengthen health systems, and, ultimately, save children's lives.

In contrast to some cause-specific mortality prevention efforts, opportunities for public health system interventions may be relevant across multiple causes of death for which life-saving medical treatment or known strategies for prevention exist.

Our findings suggest that in Bamako, such systems-level opportunities for intervention to reduce child mortality include:

- Reducing the time in escalation to a higher level of care (including removing cost as a barrier to care for parents and delineating facility-level barriers to referral for clinical service providers)
- Enhancing emergency transport systems and reducing barriers for access to transport services
- Emphasizing return-to-care precautions and safe discharge at facilities
- Educating parents on symptom severity and when to access care
- Investment in care of chronic conditions
- Continuing to emphasize vaccination towards prevention of vaccine-preventable diseases, including partnering with the Expanded Programme on Immunization (EPI), childhood immunization programs and community immunization champions (Table 4).

In addition, because of the deaths at home attributed to SIDS, findings suggest value in further research on strategies to prevent SIDS and educate parents on safe sleep in the Malian context. Across each realm of intervention, further understanding of the multi-layered choices, challenges, and constraints of parents, healthcare workers, and administrators will guide mortality prevention efforts.

While limited, these findings may empower healthcare providers, hospital administrators, and public health officials with actionable interventions and areas for further investigation to address locally-significant barriers and delays in access to care. This type of mapping analysis may be useful for other research teams seeking to understand the interface of child mortality cases and their contacts with the healthcare system, helping them identify opportunities for intervention. The results of this case study and the recommendations for public health intervention will be presented to the Malian Ministry of Health and other external stakeholders.

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Acknowledgments

The authors thank the following individuals for their contributions to the development of this case study: