Pediatric out-of-hospital deaths following hospital discharge: a mixed-methods study.

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Abstract

Background: Out-of-hospital death among children living in resource poor settings occurs frequently. Little is known about the location and circumstances of child death following a hospital discharge.

Objectives: This study aimed to understand the context surrounding out-of-hospital deaths and the barriers to accessing timely care for Ugandan children recently discharged from the hospital.

Methods: This was a mixed-methods sub-study within a larger cohort study of post-discharge mortality conducted in the Southwestern region of Uganda. Children admitted with an infectious illness were eligible for enrollment in the cohort study, and then followed for six months after discharge. Caregivers of children who died outside of the hospital during the six month post-discharge period were eligible to participate in this sub-study. Qualitative interviews and univariate logistic regression were conducted to determine predictors of out-of-hospital deaths.

Results: Of 1,242 children discharged, 61 died during the six month post-discharge period, with most (n=40, 66%) dying outside of a hospital. Incremental increases in maternal education were associated with lower odds of out-of-hospital death compared to hospital death (OR: 0.38, 95% CI: 0.19 – 0.81). The qualitative analysis identified health seeking behaviors and common barriers within the post-discharge period which delayed care seeking prior to death. For recently discharged children, caregivers often expressed hesitancy to seek care following a recent episode of hospitalization.

Conclusion: Mortality following discharge often occurs outside of a hospital context. In addition to resource limitations, the health knowledge and perceptions of caregivers can be influential to timely access to care. Interventions to decrease child mortality must consider barriers to health seeking among children following hospital discharge.

Keywords: Pediatrics, post-discharge mortality, Uganda, qualitative interviews, infectious diseas.

Introduction

Of the 6.3 million deaths among children under 5 years old, over half occur due to infectious diseases.[1] Some studies suggest that child mortality due to infectious diseases occurs disproportionately outside of the hospital, rather than in the hospital. A systematic review of pediatric post-discharge mortality found that rates of death after hospitalization often exceeded in-hospital mortality. Post-discharge deaths generally occurred early (within several weeks of discharge) and in many cases did not occur in hospitals.[4] A recent systematic analysis of severe acute respiratory infections (ARIs) in children under

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5 years found that although most episodes (62%) were treated in the hospital, 81% of the deaths from severe respiratory infection occurred outside of the hospital.[2] This study did not identify the proportion of out of hospital deaths which at some point received hospital care. This relationship is of critical importance since previous research has shown that most children who die following discharge do not successfully return to the hospital for care prior to death.[3]

Post-discharge death in children is increasingly being recognized as a major contributor to overall child mortality. Several factors, including inadequate health seeking behavior and poor access to hospital care, were responsible for the high occurrence of out of hospital death among children with ARIs.[2] Barriers to seeking care in Sub-Saharan Africa are complex and can include financial constraints, distance to health facilities, cultural practices, gender dynamics, limited knowledge or information, and health facility disincentives.[5,6] These barriers are thought to contribute to increased child mortality, for instance long distance from a health facility increased mortality risk by 17% in Tanzania.[7]

Malnutrition, previous hospitalizations and HIV are often identified as key risk factors for post-discharge mortality.[4] While these risk factors may assist clinicians in the identification of vulnerable children, many other contextual and social factors may contribute to post-discharge mortality.

Currently, little is known about the health seeking decisions made by caregivers following hospitalizations for acute illness. Further, the context surrounding out- of - hospital death has not been investigated in any research of post-discharge mortality. This oversight has important implications because understanding of the circumstances of post-discharge mortality and the barriers faced by caregivers is critical in the development of interventions aimed at reducing this burden. A focus on sub-Saharan Africa will become increasingly important, as the region is projected to account for 60% of all child deaths by 2030.[1] The objective of this study is to evaluate the context surrounding out of hospital deaths in children recently admitted for an infectious illness in Uganda, and to determine the most important barriers to seeking timely care in children who died out of hospital.

Methods
Population
This study was conducted on a sub-set of participants of a larger cohort study focused on determining predictors of post-discharge mortality among children admitted with infectious illness. A detailed review of the methods has been previously described.[8] Briefly, all children aged 6 months to 5 years admitted to Mbarara Regional Referral Hospital (MRRH) and Holy Innocents Children's Hospital (HICH) with a suspected or confirmed infectious illness were eligible for inclusion into the main study. All enrolled children had baseline characteristics measured which included clinical, laboratory and social variables. Patients received routine care during admission and were subsequently followed-up at 6 months post-discharge for a brief questionnaire to determine health status and health seeking during the post-discharge period.

An interim analysis of this study suggested that most post-discharge deaths occurred outside of the hospital context. The study protocol was, therefore, amended to conduct detailed qualitative interviews with families of study subjects who died during this period. The purpose of these interviews was to gain further insights into the circumstances behind these out- of- hospital deaths and to determine the most important barriers to seeking hospital care during the post-discharge period from the caregiver's perspective.

Eligibility
All subjects who were enrolled in the primary study and who died outside of the hospital during the 6 month post-discharge period were eligible for re-enrollment and re-consent. This amendment was approved by the institutional review boards at the Mbarara University of Science and Technology in Mbarara, Uganda and the University of British Columbia in Vancouver, BC.

Study procedure
The families of eligible subjects who died outside of the hospital during follow-up were contacted by phone and invited to participate in this study. If verbal consent was obtained, the primary caregiver was visited at their home and formally re-consented. A research nurse trained in qualitative methods administered a structured questionnaire recorded using a digital audio recorder (Table 1). The questionnaire consisted of eight open-ended questions related to events leading up to the child's death and subsequent probes. Questions sought to explore health seeking behavior and barriers to care just prior to death.

Analysis
Interviews were translated and transcribed from Runyankole-Rukiga into English. Thematic codebook development followed a standardized framework.[9] Through an iterative process, interviews were coded and analyzed for descriptive and interpretive themes. Descriptive themes included barriers to care and health seeking behavior during the post-discharge period, while interpretive themes focused on caregiver perspectives of child death and the role of the health care system. Thematic frequencies were generated to quantify medical symptoms, health seeking behavior, and barriers to care. Common themes were summarized to describe conceptual frameworks elicited by caregivers.

To determine if the demographic, social or environmental factors reported at admission were associated with out of hospital death (vs. in-hospital death), univariate logistic regression analysis was conducted. Analyses were limited to univariate analysis due to the relatively few outcomes available. All quantitative analyses were conducted using SAS 9.3 (Carey, NC).

Results
Participant characteristics
From the 1,307 children who were enrolled in the primary cohort study, 65 died during their initial admission. Of the 61 who died within six months following discharge from the hospital, the majority (n=40) died outside of the hospital without being readmitted. Among children who died at home the majority had discharge diagnoses of malaria, pneumonia, HIV and/or anemia.

Table 1. Structured interview questionnaire and probes

1. Tell me about the events leading up to the death of your child? Give as many details as you can think of.
   - What happened?
   - What were the initial symptoms and how did the illness progress?
2. Did you think of seeking care for your child?
3. What were the barriers/difficulties/challenges that prevented you (the parents/guardians) from going to the hospital/health facility to seek care?
4. Where exactly did the child die?
   - For instance, on the way to or at the hospital/health centre, at home, local clinic, another person's home (aunt, grandmother etc.) or with traditional healer.
5. Where was the child staying just prior to death?
   - Who was looking after the child at the time of becoming sick?
6. Did you (or the person caring for the child) notice that your child was very sick on this occasion?
   - If no, did your child appear healthy/well or like usual?
   - If yes, what were the things you noticed as being the signs your child was very sick?
7. What were the barriers/difficulties/challenges that prevented you (the parents/guardians) from going to the hospital/health facility to seek care?
8. Could anything have been done to help you or your child?
   - If yes, in your opinion, what could have been done?

For mothers, the mean age was 29 years, and 35 (87%) had either no formal education or only primary education (Table 2).

Table 2. Participant characteristics of children who died following discharge

Variable	Mean ± SD or N (%)
Age (months)	19.2 ± 14.2
Sex	
Male	22 (55.0%)
Female	18 (45.0%)
Discharge Diagnoses*	
Malaria	14 (35.0%)
Pneumonia	16 (40.0%)
Diarrhea	3 (7.5%)
Meningitis	3 (7.5%)
Malnutrition	6 (15%)
Tuberculosis	1 (2.5%)
Respiratory infection	2 (5.0%)
Sepsis	2 (5.0%)
Bronchiolitis	1 (2.5%)
Anemia	7 (17.5%)
Other	6 (15%)
Distance to hospital	
< 30 minutes	6 (15.0%)
30 minutes – 1 hour	7 (17.5%)
> 1 hour	27 (67.5%)
HIV status	
Child HIV+	7 (17.5%)
Maternal HIV+	6 (15.0%)
Maternal age (years)	29.0 ± 7.25
Maternal education	
< Primary 3	12 (30.0%)
Primary 3 – primary 7	22 (55.0%)
Secondary	5 (12.5%)
Post-secondary	1 (2.5%)
Water supply	
Municipal water	6 (15.0%)
Protected spring	4 (10.0%)
Bore hole	6 (15.0%)
Fast running stream	1 (2.5%)
Slow stream	1 (2.5%)
Shallow well	21 (52.5%)
Bed net use (child)	
Always	15 (37.5%)
Sometimes	12 (30.0%)
Never	13 (32.5%)

*Some participants had concurrent diagnoses; hence the total number of diagnoses is greater than the sample

The participant population was also characterized by their home environment. Most caregivers (n=27, 67.5%) lived more than one hour from the hospital. For most, their water supply came from shallow wells, and approximately one-third of children always slept under a bed net.

Post-discharge mortality
Among 40 children who died out- of- hospital post discharge, 31 (77.5%) were staying with both parents just prior to death. Over half of post-discharge child mortality occurred at home (n= 24, 60%), while another one-third (n= 11, 27.5%) on the way to or upon reaching a medical facility. The remaining children died at or on the way to church, to stay with family, or home from the hospital.

Factors associated with out of hospital death
Several social and environmental factors described the context within which children died outside the hospital, rather than reaching the hospital (Table 3).

Table 3. Predictors of out of hospital death (n=40) among children who died post-discharge (n=61)

Variable	OR (95% CI)	p-value
Sex (ref = male)	1.10 (0.38 – 3.19)	0.86
Age (per 1 month increase)	1.04 (0.99 – 1.10)	0.12
HIV positive	1.33 (0.31 – 5.86)	0.70
Bed net use (ref = always)		
Sometimes	6.40 (1.22 – 33.47)	0.03
Never	8.00 (1.56 – 41.03)	0.01
Maternal education (ref = < P3)		
P4 - P7	0.35 (0.07 – 1.87)	0.22
S1 - S6	0.19 (0.03 – 1.40)	0.10
Post-secondary	0.04 (0.00 – 0.54)	0.02
Maternal education (per category increase)	0.38 (0.19 – 0.79)	0.009
Distance (ref = <30 minutes)		
30 – 60 minutes	4.00 (0.62 – 25.96)	0.15
> 60 minutes	3.20 (0.92 – 11.12)	0.07
Maternal HIV status (ref = negative)		
Positive	1.38 (0.32 – 6.05)	0.67
Unknown	1.21 (0.27 – 5.42)	0.80
Water source (ref = municipal water)		
Protected spring	12.00 (1.20 – 120.08)	0.03
Bore hole	8.00 (0.75 – 85.73)	0.09
Fast running stream	NA	NA
Slow stream	NA	NA
Shallow well	10.50 (2.58 – 42.68)	0.001
Early death (ref=<30days)	1.92 (0.65 – 5.68)	0.24
Discharged against medical advice	1.05 (0.33 – 3.33)	0.95
Length of stay (ref =<3 days)		
3-5 days	1.15 (0.24 – 5.39)	0.86
> 5 days	0.72 (0.20 – 2.59)	0.61

Maternal education was significantly associated with odds of out- of- hospital death, such that those with post-secondary school education had a 96% lower odds of their children dying outside the hospital than those with only some or no primary school education (OR 0.04; 95% CI 0.00 – 0.59). The odds of the child dying outside the hospital decreased by 62% with each additional level of maternal education, from primary to secondary to post-secondary (OR 0.38; 95% CI 0.19 – 0.81). Of borderline statistical significance, children who lived more than 1 hour from the admitting facility had an odds ratio of dying of 3.20 (95% CI 0.92 – 11.12).

Within the home environment, bed net use and water source were also associated with increased odds of death

outside the hospital. Children who never used bed nets had much higher odds of out of hospital death than those who used bed nets (OR 8.00; 95% CI 1.56 – 41.03). Similarly, the odds of dying outside the hospital for children with a shallow well as their primary water source were 10.5 times the odds of those with municipal water as their primary source (OR 10.50; 95% CI 2.58 – 42.68). The sex, age, and HIV status of the child did not appear to be associated with out of hospital death, although the small sample does not rule out type II error.

Among children who died, the median duration of hospital stay during the initial admission was 4.5 days, with half of all deaths occurring within 30 days following discharge. Approximately one-third of caregivers (n=12, 30%) removed their child from the hospital against med-

ical advice. However, leaving against medical advice was not associated with an increased risk of out of hospital death (OR 0.97; 95% CI 0.30-3.11).

Health seeking behavior

Almost all caregivers considered seeking care for their child prior to death (n=36, 90%), but a small minority did not consider additional care due to monetary expense, recent discharge from the hospital, or lack of previous improvement. One caregiver explained: "*Since I had just been discharged from a big hospital, [I] did not think of seeking any other care.*" Of the 36 caregivers who considered seeking care, only 30 caregivers actually did so. Common limitations included transportation costs and arrangements. Among caregivers who did not access care, the majority had children who died within 24 hours of noticeable symptoms. One caregiver reported, "*If the sickness was not sudden, they would have taken the child back to Mbarara… but it wasn't possible because the child died within a short time.*"

Most caregivers sought multiple means of addressing the child's illness, including home remedies, traditional medicine, health centers, hospitals, and divine intervention.

Initial point of care, indicating the first care seeking behavior after noticing symptoms, varied among caregivers. Some sought care at hospitals, while others went to health centers or utilized traditional medicine. When people took their child to traditional healers or herbalists but noticed no improvement, they often turned to hospitals or health centers for healing. For example, one caregiver said: "*Child was taken to the herbalist who excised the enlarged lymph nodes and gave herbs for the enlarged spleen. I noted no improvement, [so] decided to take him to the nearby health center.*"

Common barriers to care

Financial constraints were the most common barrier to seeking care at a medical facility. This barrier often presented as limited transportation options, which became particularly important when the child's health deteriorated during the night. Lack of paternal support also played a significant role in financial instability for some caregivers. Notably, if a caregiver did not observe their child improving after one or multiple visits to a medical facility, they were less likely to return just prior to the death of their child. Approximately one-third of caregivers (n=15, 37.5%) reported no barriers to seeking care at a medical facility (Table 4).

Table 4. Illustrative quotes of barriers to care identified through interviews

Barriers to Care	Quote
Monetary constraints	*I took her to the nearby clinic and was seen by a nurse who referred us to the hospital. However, due to lack of money, I went back home.*
Transportation	*The cars in this place do not travel at night, starting from midnight to 5 am. Before that time, the only option is hiring which was too expensive for us, so this caused a delay to reach the hospital.*
Recent hospital visit	*I only delayed to take him to the hospital because I thought that maybe the sickness was the effect of drugs he had received in the hospital… but he kept getting worse.*
No notable improvement	*As for the health center which was near me, I had been going there with no improvement, so I did not see any need to go back.*

Though many barriers were mentioned, two responses were commonly given when asked if anything could have been done to help the child. Caregivers focused on the need for affordable transport options and access to improved health care services. One father said "*if they had fast means to take their child to hospital, maybe the child's life would have been saved.*" Distance and road infrastructure contributed to limited transport, as one mother described, "*the road was so flooded that she failed to get means to reach the hospital in time.*" In addition, caregivers often felt access to better health care – through more services or larger medical centers – would have helped their child, wishing they had "*the money to take [their child] to bigger hospitals for more tests.*"

Role of the hospital experience

The in-patient experience reportedly had some influence on post-discharge mortality and health seeking behavior. Several caregivers reported that their child was initially discharged from the hospital while still sick and exhibiting symptoms, such as vomiting, diarrhea, severe weakness or convulsions. Among those who returned to a health facility prior to death, some felt the hospital failed to effectively care for their child, while others indicated the health care workers tried their best. Interestingly, negative in-patient experiences did not always decrease overall perceptions of the health care provided. For one family, they described how the "*process of referral was delayed*

by health workers… [and] during this time the child's condition continued to worsen (convulsing and started bleeding through the nose and mouth)." However, they felt that *"the health workers in the hospital did their best and gave all possible care."*

Some caregivers said recent care/discharge or an impending follow-up appointment delayed them from returning, even when their child's symptoms worsened. For example, one caregiver explained: *"the child developed difficulty in breathing, sharp pains and was complaining of thirst… [but] they thought the child would become better since she was on medication they were given at discharge from the hospital."* Though symptoms were present, they were discounted or considered likely to improve or not recognized as severe enough to seek immediate care.

Acceptance of child mortality

Many caregivers expressed acceptance of their child's death. Half of all caregivers (n=18, 45%) said nothing could have been done to help their child. These caregivers commonly mentioned that the illness was "incurable". Solace seemed to come from the belief that all avenues of care had been pursued. Caregivers noted that *"all the possible measures and assistance were given by both the health workers and the neighbors."* Many tended to focus on what had been done for the child, rather than what could have been done, especially if additional measures were unavailable. Through various expressions, caregivers stated that *"[their child] died a natural death like any other person can die."*

Notably, religion seemed to play a dichotomous role as both curative prior to death and consoling following death. Some caregivers took their child to church or religious leaders for prayers, as a means of addressing their illness. One caregiver felt that, *"if the child had been taken to a prayer palace in Kampala, he would have survived."* Others used a religious framework to explain their child's passing. Many noted that *"it was God's Plan that [their child] pass on at that time."* To cultivate acceptance, caregivers often focused on the actions taken to help the child and acknowledged *"the rest was God's Plan."*

Discussion

This study examined the context of post-discharge deaths occurring outside of a hospital and determined important barriers to seeking timely medical care in critically ill children during the post-discharge period. We found that most caregivers pursued multiple avenues of care for their child, but in many cases, the child's health deteriorated quickly. Common barriers, such as limited transportation and monetary constraints, delayed care seeking prior to death. For recently discharged children, the caregivers often expressed hesitancy to seek immediate care. Upon leaving the hospital, many perceived that the child was cured or on trajectory for recovery, even with persisting symptoms. Recognition of preliminary symptoms or improved modalities of reaching care could enable earlier heath seeking behavior.

These interviews also demonstrated that health care access extends beyond resource limitations; this study identified important social and environmental risk factors associated with out- of- hospital deaths during the post-discharge period. We found that factors, such as maternal education, water source, and bed net use, were predictive of out- of- hospital death. Other home characteristics have been shown to increase the odds of under-five mortality as well, including large family size, poor birth spacing, poor sanitation, and living in a rural environment.[10-12] Though these aspects may not directly influence child mortality, they likely reflect the socioeconomic status and difficult circumstances within which these families are embedded.

In addition, caregiver attitudes and perceptions were important to health seeking, as they played a significant role in conceptualizing likelihood of recovery and availability of opportunities. When asked what could have saved their child, many caregivers chose to focus on steps that were taken, resources that were accessed, or help that was given, rather than hypothetical areas of improvement. Some wished for access to better health services existing elsewhere, but few focused on potential changes in their immediate environment or health system. With a fatalistic undertone, caregivers often expressed an acceptance of death and the medical resources surrounding them. Perception of the possible or the changeable may have been stifled by previous experiences, limited control, and the larger social context. Given complex weaknesses in the health system, caregivers may not have been aware of systemic solutions to prevent these out of hospital deaths, and additional studies are needed in this area.

Studies suggest that limited access to health care in developing countries, resulting from delayed health care seeking or none at all, may be an important determinant of child mortality.[13] Delayed health seeking behavior, ob-

served in our study among others, often stems from poor symptom recognition and caregiver perceptions of health resources.[13-16] Previous studies of acute child illnesses indicate that danger symptoms and disease severity are often not recognized by caregivers.[17-19] A cross-sectional study in Burkina Faso found that clinically defined diarrhea was recognized by only 55% of caregivers of whom only half then sought care for their child, indicating deficits in the perceived severity of the illness.[20] In addition to perceptions about the illness itself, the perceived etiology, anticipated quality of care, and estimated distance to the health facility influence health seeking behavior, but their relative contributions are less studied.[21]

Caregiver knowledge about health has been shown to protect against child death.[12,22] Our study, among others, found that maternal education was incrementally correlated with decreased odds of out- of- hospital death and infection.[23] Aligning with evidence from the literature, post-discharge interventions should be developed and implemented for children at risk of out- of- hospital death. An emphasis on developing health knowledge and perceptions of caregivers has the potential to greatly impact child disease and mortality. Given the identified barriers, delayed health seeking could be improved through providing health education to caregivers on early warning symptoms or through establishment of routine post-discharge care, utilizing the available out-patient heath infrastructure (such as post-discharge follow-up at nearby health centers).

Limitations

Some limitations to the study design should be considered when interpreting results. The sample size was relatively small for quantitative analysis, making the results vulnerable to Type II error. Therefore, only very strong associations were detected. Despite the small sample size, we found several variables with high odds ratios for out- of- hospital death. Another limitation is the external validity of this study. Our sample was derived from a single region of Uganda and included only discharged patients from two hospitals. However, the experiences of patients and caregivers from other hospitals and in other countries are reported similar to what we found.[19,24] Our sampled hospitals included a typical regional government hospital, similar to others in East Africa, and a private mission hospital. This mixture of health facilities provides as diverse a sample as could be derived from a single area. Further,

as this qualitative survey was administered near the end of an ongoing study, differential recall, between caregivers whose children recently died compared to those whose children died earlier during the study, may have played a role in the kinds of events which were reported. However, this study used very general questions, and due to the importance of the events, it is unlikely that significant details were forgotten. Finally, this study did not directly ask about facilitators to health care seeking, which is an important aspect for overcoming barriers.

Conclusion

Out of hospital death is an important contributor to overall mortality in children discharged from hospital. Barriers contributing to death outside of hospitals are complex and include financial constraints for transportation, delayed care seeking, and a general unawareness of the risk surrounding the post-discharge period. These occur in the context of poor maternal education and environmental conditions. Interventions aimed at improving both the social context (eg. maternal education) and the health system (eg. emergency transport, post-discharge follow-up) may help to alleviate some of this burden.

Conflict of interest

None to declare.

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