RESEARCH ARTICLE

Implications of delayed follow-up in pediatric post-discharge mortality research

Darla Leroux[1], Cherri Zhang[2], Clare Komugisha[3], Douglas Mwesigwa[3], Nathan Kenya Mugisha[3], Ivan Zhang[4], J. Mark Ansermino[2,5,6], Niranjan Kissoon[2,5,7], Jerome Kabakyenga[8,9], Matthew O. Wiens[2,3,6]*

1 Faculty of Health Sciences, Simon Fraser University, Burnaby, British Columbia, Canada, **2** Institute for Global Health, BC Children's & Women's Hospital, Vancouver, British Columbia, Canada, **3** Walimu, Unit 4, Coral Crescent, Kololo, Kampala, Uganda, **4** Faculty of Science, University of British Columbia, Vancouver, British Columbia, Canada, **5** BC Children's Hospital Research Institute, Vancouver, British Columbia, Canada, **6** Department of Anesthesiology, Pharmacology & Therapeutics, University of British Columbia, Vancouver, British Columbia, Canada, **7** Department of Paediatrics, Universtiy of British Columbia, Vancouver, Canada, **8** Department of Community Health, Faculty of Medicine, Mbarara University of Science and Technology, Mbarara, Uganda, **9** Maternal Newborn & Child Health Institute, Mbarara University of Science and Technology, Mbarara, Uganda

* matthew.wiens@bcchr.ca

Abstract

The primary objective of this analysis was to explore the characteristics of participants who we had difficulty following up within a cohort with minimal follow-up losses, and to assess the impact this difficulty had on post-discharge mortality. This secondary analysis was conducted using data from a prospective, observational cohort study of children under five who were admitted with suspected sepsis at six hospitals in Uganda. Participants' vital status was assessed through follow-up contact during three 2-month periods over a 6-month post-discharge observation time frame. For each period, follow-up difficulty was individually classified as "on-time" or "delayed". Follow-up was classified as "delayed" if completed more than 60 days after the scheduled contact; follow up within 60 days was considered "on-time". Logistic regression identified factors associated with follow-up difficulty, while Cox proportional hazard models evaluated the impact of follow-up difficulty on mortality and readmission. After being classified for difficulty across the three follow-up periods, 17,951 person-periods of observation were included. Of these, 3,392 (18.9%) were classified as delayed, and 14,559 (81.1%) were classified as on-time. Factors associated with delayed follow-up included malnutrition, HIV, respiratory distress, abnormal coma scale, low maternal education, long travel times, and unplanned discharge. Delayed follow-up did not significantly impact post-discharge mortality but reduced the likelihood of first readmission. Follow-up difficulty was common among children discharged from hospitals, particularly among socially vulnerable families but did not significantly impact post-discharge mortality. However, delayed follow-up

OPEN ACCESS

Citation: Leroux D, Zhang C, Komugisha C, Mwesigwa D, Mugisha NK, Zhang I, et al. (2026) Implications of delayed follow-up in pediatric post-discharge mortality research. PLoS One 21(11): e0362607. https://doi.org/10.1371/journal.pone.0362607

Editor: Inge Roggen, Universitair Kinderziekenhuis Koningin Fabiola: Hopital Universitaire des Enfants Reine Fabiola, BELGIUM

Received: October 2, 2025

Accepted: October 27, 2026

Published: November 24, 2026

Copyright: © 2026 Leroux et al. This is an open access article distributed under the terms of the Creative Commons Attribution License, which permits unrestricted use, distribution, and reproduction in any medium, provided the original author and source are credited.

Data availability statement: Study data is available upon request to the corresponding author or through the Pediatric Sepsis CoLab. The University of British Columbia Dataverse Collection: Pediatric Sepsis CoLab. Smart

Discharges Dataverse. Borealis. 2022. https://borealisdata.ca/dataverse/smart_discharge. Access to the de-identified data is granted on a case-by-case basis and will require the signing of a data sharing agreement, due to the sensitive nature of clinical data. The CoLab coordinator can be reached at sepsiscolab@bcchr.ca. Alternative contact is Mia Sheehan who can be reached at mia.sheehan@bcchr.ca.

Funding: The author(s) received no specific funding for this work.

Competing interests: The authors have declared that no competing interests exist.

was associated with reduced hospital readmission, possibly reflecting suboptimal care-seeking behaviour in these families.

Introduction

Over the last three decades significant progress has been made in reducing child mortality [1]. However, nearly five million children under five years die each year, primarily in low-and middle-income country (LMIC) settings [2]. In these settings, infectious diseases leading to sepsis are the major cause of death, with a significant proportion of these deaths occurring following hospital discharge [3,4].

A major challenge in better elucidating the epidemiology of post-discharge mortality pertains to high rates of children who are lost to follow-up in post-discharge mortality research. These losses potentially limit the inferences which could be drawn from such data, since outcomes among those who are found may differ from outcomes among those who are lost to follow-up [5,6]. A systematic review previously conducted found substantial losses to follow-up across studies examining post-discharge mortality in children [7]. The review, which included 65 studies from 21 countries, found that rates of loss to follow-up from 0% to 49%, with a median of 11% [7]. This wide variation in loss to follow-up outlines the significant challenges in conducting such research in LMIC settings. While high rates of loss to follow-up have been a significant challenge in post-discharge mortality research, studies with minimal losses, alongside a grading of follow-up difficulty for those with successful follow-up, may offer important insights into the potential impact of losses, though no such studies have been published.

Studies within a programmatic context have shown that those lost to programmatic follow-up often have worse health outcomes compared to those retained in care, though non-research contexts may incur follow-up losses for different reasons [8,9]. Within both the HIV and TB context, those lost to follow up demonstrate worse outcomes (mortality and/or drug resistance), though this has not been evaluated in the context of general acute illness [8,9]. Through a better understanding of factors that influence ease of follow-up as well as the impact of loss to follow-up, we can inform future research and programs which rely on follow-up data. Therefore, the purpose of this study was to explore the characteristics of participants who were difficult to follow up with within a cohort with minimal follow-up losses, and to assess the impact of this difficult on post-discharge outcomes.

Methods

Study design and approval

This secondary analysis utilized data from a prospective, multisite, observational cohort study conducted across six hospitals in Uganda: Mbarara Regional Referral Hospital, Holy Innocents Children's Hospital, Masaka Regional Referral Hospital, Jinja Regional Referral Hospital, Uganda Martyrs' Ibanda Hospital, and Villa Maria Hospital. From July 2017 to March 2020, the study enrolled children under five years

of age who were admitted with suspected sepsis, defined as requiring hospital admission due to a suspected or proven infection. Comprehensive details on the study design, selection criteria, and data collection methods have been previously published [10]. The primary objective of this analysis was to explore the characteristics of participants who were difficult of follow-up, and to assess the impact difficulty had on post-discharge mortality.

Ethical approval for this study was obtained from the Mbarara University of Science and Technology Research Ethics Committee (15/10–16, 27-Jan-2017) and from the University of British Columbia–Children and Women's Health Centre of British Columbia Research Ethics Board (H16–02679, 09-May-2017). The reporting of this study follows the Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) guidelines [11].

Participants

This study enrolled children under the age of five who were admitted to hospital with confirmed or suspected sepsis infection. Children were excluded if they lived outside the hospital catchment area or were admitted for less than 24 hours, with trauma, or directly after birth without prior discharge. Parent or legal guardians provided written informed consent for all study participants.

Data collection

All clinical, sociodemographic, and outcome data were obtained from consenting participants by trained study nurses. Encrypted tablets were used to collect all study data, which was later stored in the Research Electronic Data Capture (REDCap) database, hosted by the BC Children's Hospital Research Institute (Vancouver, BC, Canada) [12].

To determine vital status, participants were contacted by field officers up to three times during the 6-month post-discharge period, at months two (telephone), four (telephone) and six (in-person or telephone). Follow-ups were not interventional in nature. The first attempt at follow-up was initiated within 7 days of the follow-up being due. If no contact was made, follow-up was re-attempted continuously until contact was made, or until the next contact became due (i.e., 2 months later). There was no upper limit to the number of attempts made to reach a study participant, nor were attempts limited to weekdays or daytime hours.

For 6-month in-person follow-up, address details captured during admission (for the purposes of follow-up) were used. Due to regional movement/migration (permanent and temporary), informal addresses, changes in phone numbers and other difficulties, in-person engagement was not always successful. Attempts at in-person follow-up continued for up to an additional 6-months using key follow-up data captured during the index admission (contact name, village chairperson, relatives, neighbours, etc.). With this approach losses to follow-up were low (1.9%), and also lower than most studies of a similar nature [7]. Among those who were successfully followed up, difficulty of follow-up was classified according to delays or missed interim follow-ups or delayed final follow-up.

Difficulty as an Exposure and Outcome

Follow-up difficulty was used as both an exposure and outcome variable. As an exposure, it was assessed as a potential risk factor for mortality and first hospital readmission. As an outcome it was used to identify risk factors associated with it.

Follow-up difficulty was categorized as "on-time" and "delayed". The group categorized as delayed was a proxy for those who might have been lost to follow-up in the absence of significant investment in the follow-up process, typical of some studies. Follow-up "on time" was defined as successful follow-up within 60 days of the scheduled follow-up date. Any follow-up in which the outcome, including death, was ascertained outside this window was classified as "delayed". Children with confirmed post-discharge death were not considered lost to follow-up, as their outcomes were ascertained and included in the analysis.

Statistical analysis

Since each follow-up episode was labelled as either "on-time" or "delayed", participants could have differential exposures of "delayed" vs "on-time" across the three follow-up periods. To account for this time-varying exposure, each 2-month period was considered as a separate observation period. Those who survived any given period were then re-evaluated in the next, each according to their exposure status. Thus, the primary unit of analysis was the person-period.

Counts and frequencies were reported for categorical variables, while medians and interquartile ranges (IQRs) were used for continuous variables. Logistic regression was conducted to determine the association between patient characteristics and follow-up difficulty, adjusting for age, sex, and site as fixed-effect covariates. Adjusted odds ratio (aOR) with 95% confidence intervals were reported and statistical significance was set at $p < 0.05$. A Cox proportional hazards model with time-varying covariates was employed to evaluate the impact of follow-up difficulty on post-discharge mortality and time to first readmission, using three start and stop times to account for the different observational periods.

All analyses were conducted using R-Studio version 4.4.0, with minimal missing data imputed using the k-nearest number method.

Results

Between July 2017 and March 2020, 6545 children were enrolled, of whom 6190 were discharged alive. Of these, 116 (1.9%) were lost to follow-up, and thus could not be included in the analysis for post-discharge mortality or time to first readmission, with only 6074 eligible for this analysis. Participant characteristics were generally comparable between children who were retained in follow-up and those lost to follow-up among delayed participants, minor differences were observed in some variables (S2 Table). After classification for difficulty across the three follow-up periods, 17,951 person-periods of observation were included. Of these, 3,392 (18.9%) were classified as delayed and 14,559 (81.1%) were classified as on-time, with period 2 bearing the highest proportion of delays (Fig 1). During the 6-month post-discharge period 376 participants died, of which 266 (70.7%) were within the first 60-day period. Of the 6074 participant, 1,104 experienced at least one hospital readmission during the 6-month post-discharge period.

Follow-up difficulty as an outcome

There were no observed sex differences between those who were delayed vs on time in their follow-up, though those who experienced delayed follow-up were younger (median 6.9 months, IQR: 1.7–17.0) compared to those who were on-time (median 9.7 months, IQR: 2.7–20.4) (S1 Table). In the analysis adjusted analyses for age, sex, and study site, several factors were found to be associated with follow-up difficulty (Table 1). Malnutrition, as measured by a MUAC of less than 110/115 mm (aOR=1.30, 1.17–1.45) and HIV (aOR=1.46, 1.18–1.78) were associated with higher odds of follow-up difficulty. Among the admission acuity variables assessed, respiratory distress (aOR=1.15, 1.04–1.26) and abnormal Blantyre coma scale (aOR=1.22, 1.07–1.39) were also associated with difficulty. Several sociodemographic factors were also associated with follow-up difficulty including longer travel times to reach the hospital (>2 hours; aOR=1.39, 95% CI 1.23–1.58), younger maternal age (aOR=0.98, 0.98–0.99; per year increase), low maternal education (aOR=1.94, 1.65–2.29), maternal HIV-positive status (aOR=1.38, 1.21–1.57), never using a bed net (aOR=1.36, 1.21–1.54), and not using treated water (aOR=1.42, 1.294–1.56). Unplanned discharge (aOR=1.72, 1.55–1.92) was also strongly associated with a more difficult follow-up.

Follow-up difficulty on mortality and readmission

The impact of delayed follow-up was not found to be associated with the risk of post-discharge mortality (aHR 0.97, 95% CI: 0.75–1.26). However, delayed follow-up was associated with a lower likelihood of a first readmission to the hospital (aHR = 0.53, 95% 0.44–0.64).

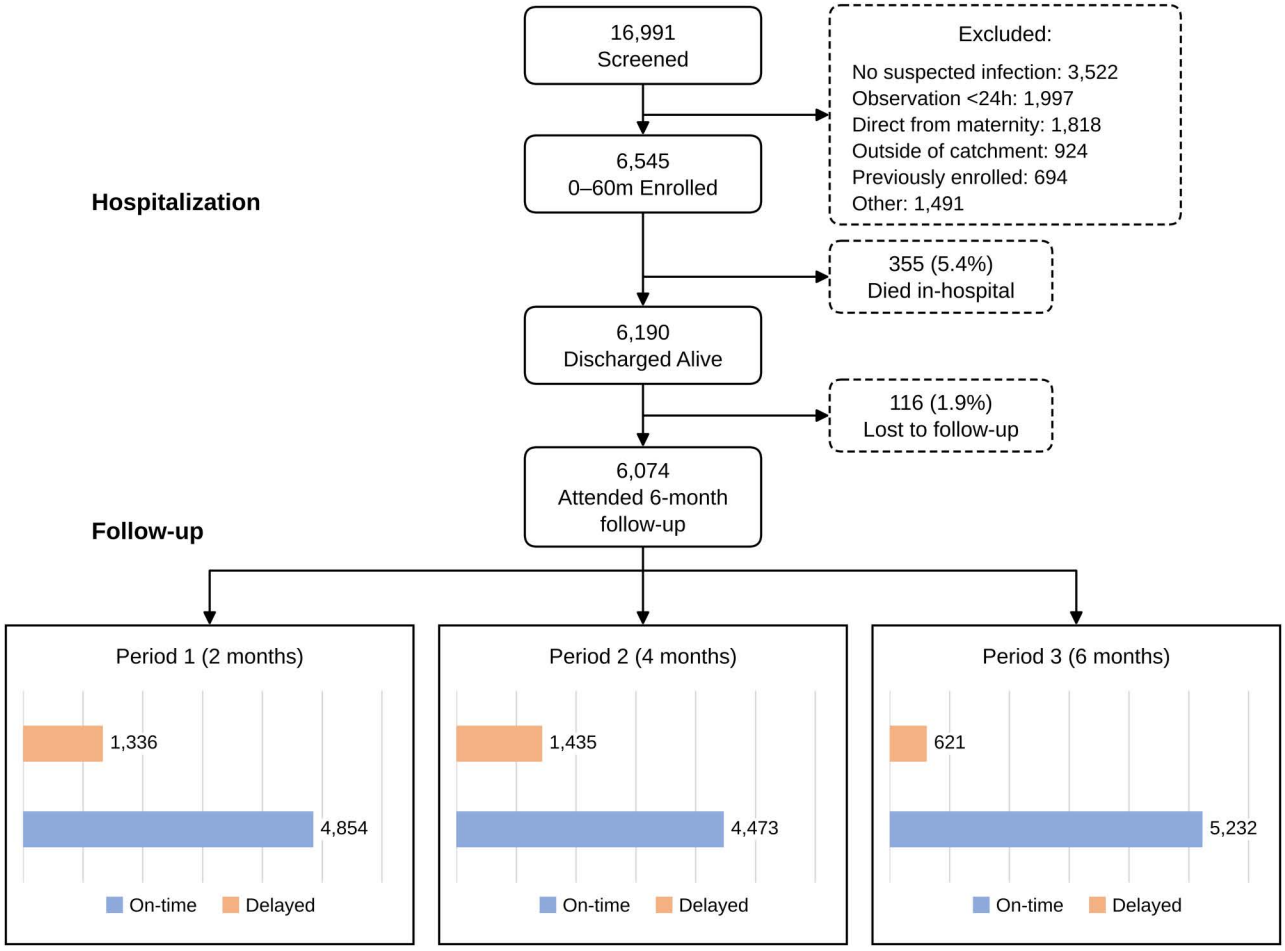

Fig 1. Participant flowchart. Flow diagram illustrating screening, exclusions, enrollment, and follow-up of study participants.

https://doi.org/10.1371/journal.pone.0362607.g001

Discussion

Difficult to follow-up study participants, defined in this study by a 60-day delay in contact, was common, affecting nearly 20% of study participants. This affirms the challenging nature of research focusing on follow-up during the post-discharge period, a challenge likely magnified in real-world clinical practice. As an exposure, we found no significant impact on post-discharge mortality, suggesting that studies of post-discharge mortality are unlikely to be substantially biased due to imperfect follow-up rates. While losses to follow-up did not appear to substantially impact post-discharge mortality, our analysis demonstrated that several factors, particularly those related to social vulnerability, were associated with difficulty in follow-up. Our findings bear relevance to global health researchers and policymakers, who must understand the relevance of losses to follow-up in existing research and surveillance.

Several factors related to social vulnerability significantly increased the likelihood of follow-up difficulty for children under five discharged from hospitals in Uganda. Longer travel times to healthcare facilities appeared as a risk factor, emphasizing the challenges faced by families who live in rural or remote areas [13–16]. Another factor associated with increased follow-up difficulty includes lower maternal education levels suggesting that limited health literacy and awareness significantly influence health-seeking behaviors and adherence to follow-up schedules [14,15,17–19]. Mothers who

Table 1. Factors associated with follow-up difficulty 6-months post-discharge.

	aOR (95% CI)
Demographic variables	
Sex, male	0.98 (0.91–1.07)
Age at admission (months)	**0.99 (0.98–0.99)**
Admission Anthropometry	
MUAC [a]	
<110/<115	**1.30 (1.17–1.45)**
110-120 / 115-125	**1.18 (1.06–1.30)**
>120/>125	Ref
Weight for age Z-scores	
<−3	**1.13 (1.01–1.26)**
−3 to −2	**1.13 (1.01–1.26)**
>-2	Ref
Length for age Z-scores	
<−3	**1.17 (1.04–1.32)**
−3 to −2	1.06 (0.94–1.19)
>-2	ref
BMI Z-scores	
<−3	**1.14 (1.03–1.27)**
−3 to −2	1.05 (0.93–1.17)
>-2	ref
Weight for length Z-scores	
<−3	1.10 (0.99–1.22)
−3 to −2	1.07 (0.95–1.19)
>-2	ref
Admission Clinical Assessment	
How long since last admission	
Never	ref
<1 month	1.04 (0.92–1.18)
1 month – 1 year	**0.86 (0.77–0.96)**
>1 year	0.88 (0.71–1.08)
Care sought for current illness prior to admission	1.08 (0.99–1.17)
Referral	**1.09 (1.01–1.19)**
SpO_2	1.00 (0.99–1.01)
Heart Rate	1.00 (1.00–1.00)
Respiratory Rate	1.00 (1.00–1.00)
Systolic BP	1.00 (1.00–1.00)
Diastolic BP	1.00 (0.99–1.00)
Temperature	
<36·5	0.99 (0.87–1.12)
36·5-37·5	ref
>37.6	**0.91 (0.84–0.99)**
Respiratory distress	**1.15 (1.04–1.26)**
Capillary refill ≥3 seconds	1.08 (0.95–1.22)
Abnormal Blantyre Coma Scale	**1.22 (1.07–1.39)**
Malaria test positive	1.07 (0.97–1.19)
HIV RDT test positive	**1.46 (1.18–1.78)**
Lactate (mmol/L)	1.00 (0.98–1.02)

(Continued)

Table 1. (Continued)

	aOR (95% CI)
Glucose (mmol/L)	
<2.5	0.89 (0.69–1.13)
2.5-8.3	ref
>8.3	0.92 (0.81–1.04)
Maternal and social characteristics	
Time to reach hospital	
<30 min	ref
30 min-1h	1.07 (0.96–1.19)
1-2h	**1.16 (1.04–1.30)**
>2h	**1.39 (1.23–1.58)**
Distance to facility (km)	1.01 (1.00–1.01)
Maternal age (years)	**0.98 (0.98–0.99)**
Household size	0.98 (0.96–1.00)
Maternal education	
No school/ ≤ P3	**1.94 (1.65–2.29)**
P4-P7	**1.68 (1.47–1.92)**
S1-S6.	**1.37 (1.20–1.57)**
Post-Secondary	ref
Maternal HIV status	
Negative	ref
Positive	**1.38 (1.21–1.57)**
Bed net use	
Never	**1.36 (1.21–1.54)**
Sometimes	**1.20 (1.05–1.38)**
Always	ref
Boil/disinfect/filter water	**1.42 (1.29–1.56)**
Discharge characteristics	
Length of stay (days)	1.00 (1.00–1.01)
Discharge status	
Routine discharge	ref
Referred to higher level of care	**1.44 (1.15–1.78)**
Unplanned discharge	**1.72 (1.55–1.92)**
Feeding at discharge	
Feeding well	ref
Feeding poorly	**1.24 (1.07–1.43)**

Data is in n (%) or median (IQR). [a]MUAC thresholds are given in mm for the 0 to <6month cohort and for the 6–60-month cohort. Abbreviations: MUAC = middle-upper-arm circumference; BP = blood pressure; HIV = human immunodeficiency virus; RDT = rapid diagnostic test; SpO = oxygen saturation; P = primary school, where the following number represents years of school; S = secondary school, where following numbers represent years of school; h = hours; km = kilometer; aOR = adjusted odds ratio; CI = confidence interval; ref = reference.

https://doi.org/10.1371/journal.pone.0362607.t001

were HIV-positive were associated with increased follow-up difficulty, further displaying the compounded vulnerabilities faced by those with follow-up difficulty [20]. Socioeconomic factors, such as lack of bed net use and inadequate water treatment practices, further contribute to the vulnerability profile of families who experience follow-up difficulty. These findings suggest that socially vulnerable families – those who live distant from health facilities, have lower education levels,

face health challenges, and lack basic resources – are at a higher risk of follow-up difficulty. This pattern of vulnerability is consistent with prior research in LMICs, where social determinants of health frequently influence healthcare access and utilization [21]. Public health initiatives aimed at improving healthcare access, enhancing health literacy, and promoting timely care-seeking behaviours may mitigate these barriers to some extent.

Certain indicators of illness acuity at admission were also associated with follow-up difficulty. In this secondary analysis of post-discharge mortality, it is interesting to note that there is significant overlap between risk factors for follow-up difficulty and risk factors for mortality. Mortality, like follow-up difficulty has been shown to be driven largely by malnutrition, illness acuity and social vulnerability. While this suggests that this analysis may have not been sufficiently powered to detect an impact on mortality, it is also reassuring that such impacts are not likely to be significantly larger than the risk contained within the upper confidence limit of the effect estimate. This finding is important in the interpretation of studies evaluating post-discharge mortality that also have high rates of follow-up losses, and suggests while the mortality estimates are unlikely to suffer from a major bias, the baseline features of those who die may be subject to bias.

This study showed that delayed follow-up was significantly associated with a reduced likelihood of a child being readmitted to the hospital. This result may suggest that those who experience follow-up difficulty may engage in delayed or untimely care-seeking behaviour. This is supported by a recent study showing that hospital readmission often reflects health-seeking behaviour rather than severity of recurrent illness [22]. Caregiver perceptions of illness severity may also play a role in follow-up adherence. In a previous study, it was shown that even with symptoms present some caregivers believed that the child would improve, reducing their likelihood of seeking care [23]. Although not measured in our study, psychological morbidity following critical childhood illness, including symptoms of anxiety, depression, and post-traumatic stress, has been described among survivors and families and are associated with impaired functioning [24]. Avoidance symptoms have been reported as part of post-traumatic stress responses after critical illness and may be relevant to understanding difficulties with follow-up; however, whether these psychological factors influence delayed follow-up among pediatric sepsis survivors in LMICs remains unclear [24]. Our findings further highlight the impact of social vulnerabilities, suggesting that the delayed follow-up group represents those patients who are less likely to interact with hospital services.

While the impact on rare outcomes such as mortality may be relatively minor, missing post-discharge follow-up data may still be an important source of bias within a research or surveillance context. The fact that follow-up difficulty was largely associated with social vulnerability suggests missingness of these data can affect case-mix, disproportionately affecting the distribution of certain variables within the study sample, and thereby potentially biasing study findings. Therefore, it is important for researchers and policymakers to consider how losses to follow-up might influence their findings and the subsequent interpretations of the data. Future research should explore strategies to reduce these biases, such as using sensitivity analyses or considering alternative methods for handling missing data, to enhance the robustness and generalizability of findings.

This study has several limitations. First, this study was itself subject to follow-up losses, potentially biasing the inferences drawn if those who were actually lost to follow-up differ systematically from those who were merely difficult to follow-up but were not lost. However, this only applied to 116 (1.9%) of children, which is not likely to have had a major impact on our results. Further, our focus on those difficult to follow-up rather than those completely lost allows for valuable insights into the challenges faced by a significant portion of the study population. Second, since mortality was a relatively rare outcome, this study was not sufficiently powered to detect very small differences in mortality between exposures. With our sample size, however, we can with reasonable confidence rule out major impacts on mortality beyond approximately a 25% increase among these children, representing the upper confidence limit of our effect estimate. Given that this would only affect a minority of children, its overall impact would be small. Third, our findings may not be fully generalizable to children not participating in research, as those enrolled in structured follow-up studies may receive more intensive contact than patients in routine clinical care, which may influence both follow-up behaviour and post-discharge outcomes. Follow-up in this study was conducted for outcome ascertainment within a research context, rather than

representing clinical follow-up for ongoing care. However, many of the factors associated with follow-up difficulty, such as social vulnerabilities and illness acuity, are likely to be relevant in routine care, suggesting that our findings may provide insight into the factors shaping post-discharge follow-up in similar settings. Lastly, our metric of follow-up difficulty may not be the ideal metric to identify those that are actually lost to follow-up in other studies. Losses to follow-up are naturally heterogeneous events caused by a multitude of factors. Further work on the specific causal mechanisms of such losses has not been sufficiently explored. While this study identified risk factors, these remain only associations and not necessarily causal factors. This study did not elicit details on the specific challenges related to follow-up difficulty, something which future studies could consider incorporating into their case report forms.

In conclusion, this study provides valuable insights into the social and clinical features associated with follow-up difficulty among children discharged from the hospital. While follow-up difficulty was observed to be common, its impact on post-discharge mortality was not significant. Learning health systems need robust data to improve the quality of care. Monitoring post-discharge status is crucial to improve outcomes. This study provides insight into the challenges of following up with specific populations that may require enhanced efforts in real-world settings.

Supporting information

S1 Table. Comparing patient characteristics across three follow-up periods.
(PDF)

S2 Table. Comparison of patient characteristics among participants classified as delayed but retained in follow-up versus delayed and lost to follow-up, across three follow-up periods.
(PDF)

Acknowledgments

We gratefully acknowledge thank the patient participants and staff involved in the Smart Discharges program in Uganda, whose contributions made this study possible.

Author contributions

Conceptualization: Clare Komugisha, Nathan Kenya Mugisha, Niranjan Kissoon, Jerome Kabakyenga, Matthew O. Wiens.

Data curation: Cherri Zhang.

Formal analysis: Darla Leroux, Cherri Zhang, Matthew O. Wiens.

Investigation: Jerome Kabakyenga, Matthew O. Wiens.

Methodology: Darla Leroux, Cherri Zhang, Matthew O. Wiens.

Visualization: Darla Leroux.

Writing – original draft: Darla Leroux, Matthew O. Wiens.

Writing – review & editing: Darla Leroux, Cherri Zhang, Clare Komugisha, Douglas Mwesigwa, Nathan Kenya Mugisha, Ivan Zhang, J Mark Ansermino, Niranjan Kissoon, Jerome Kabakyenga, Matthew O. Wiens.

References

1. World Health Organization. Child mortality and causes of death. https://www.who.int/data/gho/data/themes/topics/topic-details/GHO/child-mortality-and-causes-of-death Accessed 2024 November 19.
2. United Nations Inter-Agency Group for Child Mortality Estimation. Levels and trends in child mortality: report 2022. 2022. https://data.unicef.org/wp-content/uploads/2023/01/UN-IGME-Child-Mortality-Report-2022_Final-online-version_9Jan.pdf

3. Childhood Acute Illness and Nutrition (CHAIN) Network. Childhood mortality during and after acute illness in Africa and south Asia: a prospective cohort study. Lancet Glob Health. 2022;10(5):e673–84. https://doi.org/10.1016/S2214-109X(22)00118-8 PMID: 35427524
4. Madrid L, Casellas A, Sacoor C, Quintó L, Sitoe A, Varo R, et al. Postdischarge Mortality Prediction in Sub-Saharan Africa. Pediatrics. 2019;143(1):e20180606. https://doi.org/10.1542/peds.2018-0606 PMID: 30552144
5. Wiens MO, Pawluk S, Kissoon N, Kumbakumba E, Ansermino JM, Singer J, et al. Pediatric post-discharge mortality in resource poor countries: a systematic review. PLoS One. 2013;8(6):e66698. https://doi.org/10.1371/journal.pone.0066698 PMID: 23825556
6. Nemetchek B, English L, Kissoon N, Ansermino JM, Moschovis PP, Kabakyenga J, et al. Paediatric postdischarge mortality in developing countries: a systematic review. BMJ Open. 2018;8(12):e023445. https://doi.org/10.1136/bmjopen-2018-023445 PMID: 30593550
7. Knappett M, Nguyen V, Chaudhry M, Trawin J, Kabakyenga J, Kumbakumba E, et al. Pediatric post-discharge mortality in resource-poor countries: a systematic review and meta-analysis. EClinicalMedicine. 2023;67:102380. https://doi.org/10.1016/j.eclinm.2023.102380 PMID: 38204490
8. Geng EH, Odeny TA, Lyamuya R, Nakiwogga-Muwanga A, Diero L, Bwana M, et al. Retention in Care and Patient-Reported Reasons for Undocumented Transfer or Stopping Care Among HIV-Infected Patients on Antiretroviral Therapy in Eastern Africa: Application of a Sampling-Based Approach. Clin Infect Dis. 2016;62(7):935–44. https://doi.org/10.1093/cid/civ1004 PMID: 26679625
9. Kendall EA, Theron D, Franke MF, van Helden P, Victor TC, Murray MB, et al. Alcohol, hospital discharge, and socioeconomic risk factors for default from multidrug resistant tuberculosis treatment in rural South Africa: a retrospective cohort study. PLoS One. 2013;8(12):e83480. https://doi.org/10.1371/journal.pone.0083480 PMID: 24349518
10. Wiens MO, Bone JN, Kumbakumba E, Businge S, Tagoola A, Sherine SO, et al. Mortality after hospital discharge among children younger than 5 years admitted with suspected sepsis in Uganda: a prospective, multisite, observational cohort study. Lancet Child Adolesc Health. 2023;7(8):555–66. https://doi.org/10.1016/S2352-4642(23)00052-4 PMID: 37182535
11. von Elm E, Altman DG, Egger M, Pocock SJ, Gøtzsche PC, Vandenbroucke JP, et al. The Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) statement: guidelines for reporting observational studies. Lancet. 2007;370(9596):1453–7. https://doi.org/10.1016/S0140-6736(07)61602-X PMID: 18064739
12. Harris PA, Taylor R, Thielke R, Payne J, Gonzalez N, Conde JG. Research electronic data capture (REDCap)--a metadata-driven methodology and workflow process for providing translational research informatics support. J Biomed Inform. 2009;42(2):377–81. https://doi.org/10.1016/j.jbi.2008.08.010 PMID: 18929686
13. Shargie EB, Lindtjørn B. Determinants of treatment adherence among smear-positive pulmonary tuberculosis patients in Southern Ethiopia. PLoS Med. 2007;4(2):e37. https://doi.org/10.1371/journal.pmed.0040037 PMID: 17298164
14. Milambo JPM, Cho K, Okwundu C, Olowoyeye A, Ndayisaba L, Chand S, et al. Newborn follow-up after discharge from a tertiary care hospital in the Western Cape region of South Africa: a prospective observational cohort study. Glob Health Res Policy. 2018;3:2. https://doi.org/10.1186/s41256-017-0057-4 PMID: 29372186
15. Titaley CR, Dibley MJ, Roberts CL. Factors associated with non-utilisation of postnatal care services in Indonesia. J Epidemiol Community Health. 2009;63(10):827–31. https://doi.org/10.1136/jech.2008.081604 PMID: 19414443
16. Karra M, Fink G, Canning D. Facility distance and child mortality: a multi-country study of health facility access, service utilization, and child health outcomes. Int J Epidemiol. 2017;46(3):817–26. https://doi.org/10.1093/ije/dyw062 PMID: 27185809
17. English L, Kumbakumba E, Larson CP, Kabakyenga J, Singer J, Kissoon N, et al. Pediatric out-of-hospital deaths following hospital discharge: a mixed-methods study. Afr Health Sci. 2016;16(4):883–91. https://doi.org/10.4314/ahs.v16i4.2 PMID: 28479878
18. Kanté AM, Chung CE, Larsen AM, Exavery A, Tani K, Phillips JF. Factors associated with compliance with the recommended frequency of postnatal care services in three rural districts of Tanzania. BMC Pregnancy Childbirth. 2015;15:341. https://doi.org/10.1186/s12884-015-0769-8 PMID: 26689723
19. Bigna JJR, Noubiap JJN, Plottel CS, Kouanfack C, Koulla-Shiro S. Factors associated with non-adherence to scheduled medical follow-up appointments among Cameroonian children requiring HIV care: a case-control analysis of the usual-care group in the MORE CARE trial. Infect Dis Poverty. 2014;3(1):44. https://doi.org/10.1186/2049-9957-3-44 PMID: 25671122
20. Braitstein P, Katshcke A, Shen C, Sang E, Nyandiko W, Ochieng VO, et al. Retention of HIV-infected and HIV-exposed children in a comprehensive HIV clinical care programme in Western Kenya. Trop Med Int Health. 2010;15(7):833–41. https://doi.org/10.1111/j.1365-3156.2010.02539.x PMID: 20487430
21. Kissoon N, Carapetis J. Pediatric sepsis in the developing world. J Infect. 2015;71 Suppl 1:S21-6. https://doi.org/10.1016/j.jinf.2015.04.016 PMID: 25917800
22. Zhang C, Kissoon N, Ansermino JM, Nguyen V, Kumbakumba E, Bushige S. Diverging pathways: exploring the interplay between hospital readmission and post-discharge mortality in pediatric sepsis in low-income settings. Preprint. 2025. https://ssrn.com/abstract=5191113
23. Behan J, Kabajaasi O, Derksen B, Sendegye G, Kugumikiriza B, Komugisha C, et al. Caregivers' and nurses' perceptions of the Smart Discharges Program for children with sepsis in Uganda: A qualitative study. PLoS One. 2024;19(10):e0307089. https://doi.org/10.1371/journal.pone.0307089 PMID: 39356657
24. Ko MSM, Lee WK, Sultana R, Murphy B, Heng KYC, Loh SW, et al. Psychological Outcomes in Families of PICU Survivors: A Meta-Analysis. Pediatrics. 2024;154(1):e2023064210. https://doi.org/10.1542/peds.2023-064210 PMID: 38916047