Linkage to Care Intervention to Improve Post-Hospital Outcomes Among Children with Sickle Cell Disease in Tanzania: A Pilot Study

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We conducted a pilot study to determine the effectiveness of a linkage to care intervention with social workers to improve 12-month post-hospital mortality for children in Tanzania with sickle cell disease. Comparison was done with a historical cohort. Mortality was 6.7% in the interventional cohort compared with 19.2% (adjusted Hazard Ratio, 0.26; 95% CI, 0.08-0.83). *(J Pediatr 2021;232:290-3).*

Of the 300 000 children born with sickle cell disease (SCD) every year, 75% are in Africa.[1,2] It is estimated that 50%-80% of these children will die before adulthood.[3] Tanzania ranks third highest in terms of number of children born with SCD, and children with SCD have a 10-fold higher risk of early mortality from SCD than children in high-income countries.[2,4]

The period after hospital discharge carries significant risk for morbidity and mortality.[5] The term "post-hospital syndrome" describes an acquired, transient period of vulnerability following discharge.[6] Unique stressors such as sleep deprivation, poor nutrition, pain, and adverse effects of medications contribute to a state in which the patient is more vulnerable to decline, even after recovery from the initial illness. Among chronic diseases of childhood, SCD-related mortality is particularly high in the immediate months after a hospital discharge.[5,7,8] A promising intervention is linkage to care focused on the transition from hospital to home. The use of social workers have been successfully shown in studies of adults with chronic diseases like HIV to improve outcomes including linkage to clinic after hospitalization.[9,10] For children with SCD, increased clinic attendance has been shown to lower mortality.[11]

We conducted a pilot study to determine the effectiveness of a linkage to care intervention using social workers to improve post-hospital outcomes in children with SCD. This study builds on an earlier observational study in Tanzania conducted in 2014 in which children were followed for 12 months after discharge.[7] Our pilot study objective was to compare 12-month post-hospital mortality rates for children with SCD receiving a social worker intervention compared with historical controls.

aHR	adjusted Hazard Ratio
ARTAS	Antiretroviral Treatment and Access to Services
BMC	Bugando Medical Center
SCD	Sickle cell disease

Methods

Our pilot study was conducted at Bugando Medical Center (BMC) in Mwanza, Tanzania, the same site as the historical cohort study.[7] BMC has 3500 pediatric hospitalizations per year and the pediatric sickle cell clinic has more than 400 children enrolled.

Study Population

The historical cohort study had 57 children with SCD discharged from the hospital and followed for 12 months in 2014-2015. Similar to the historical cohort study, children in this pilot study were eligible for enrollment if they were hospitalized on the pediatric ward at BMC, known to have SCD or newly diagnosed with SCD. Using the same inclusion criteria as the historical cohort study, the guardian needed to be able to speak Kiswahili or English, be willing to provide locator information, and live within 10 miles of the hospital. The exclusion criteria were the same as the historical cohort study as well, which included children having significant cognitive or developmental impairment, and having any related illnesses associated with a survival of less than 12 months. In addition, for this pilot study children already receiving any assistance from a social worker or case manager were excluded.

Study Procedure and Intervention

We adapted the Antiretroviral Treatment and Access to Services (ARTAS) intervention for use in our

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interventional study for children with SCD.[12] ARTAS is a time-limited social worker intervention consisting of up to 5 sessions between a social worker and patient/family conducted over a 3-month period (**Figure**; available at www.jpeds.com). The first and second meeting sessions focus on building trust and identifying the patient's/family's strengths, needs, and barriers to accessing medical care. The third and fourth meeting sessions focus on goal setting and specific actions necessary to overcome personal and structural barriers to clinic attendance and adherence to medications. The fifth meeting session consists of a structured review process emphasizing the patient's/family's strengths and on transitioning the social worker's responsibilities to the medical team and family. The social worker received a 1-week training delivered by an investigator experienced with this intervention and a sickle cell clinician with material adapted from the ARTAS intervention manual.[12]

After the enrollment of a participant into this study, our social worker administered in Swahili a medical intake questionnaire and collected laboratory values from the medical charts recorded by the clinical team caring for the child. When the child was found appropriate for discharge by the clinical team, the social worker met with the child and parent or guardian for discharge counseling and education. After discharge, the 5 sessions would occur on average every 2 weeks either at the family's home, the clinic site, or a designated convenient location over the span of 3 months. Each meeting last 30-60 minutes. During all sessions, the social worker reminded families about upcoming clinic appointments, medication adherence for the child, and when to seek medical attention. The social worker was available by phone from 9 A.M. to 5 P.M. Monday to Friday to speak with families if they had questions or concerns. For the pilot study, we used 1 full-time social worker, who had a degree in social work, for all intervention activities. The social worker had on average 1-2 sessions per day to visit families. Depending on location and mode of transportation available, travel time could range upward of 1-2 hours 1 way for the social worker. The total cost of the intervention, for social worker salary, training, and transportation, totaled $US2000 over the course of the 3-month intervention period.

In the historical cohort study, the standard of care for children with SCD upon discharge was to follow-up in clinic within 2 weeks of discharge or sooner if necessary. No social worker support was provided.

Study Outcomes

The primary study outcome was mortality. Secondary study outcomes were clinic attendance (defined as 2 visits in the prior 3 months) and cumulative rate of readmission. These outcomes were measured at 3, 6, and 12 months after discharge. A phone call was made at these designated times and a standard set of questions including vital status of the child (alive/dead), clinic attendances, and readmissions. If the child had died, the date of death was also determined. Because our study was conducted in a low-resource setting where children commonly die outside the hospital setting and medical autopsies are not routinely available, we were not able to identify causes of death.

Data Analysis

Data was entered into Microsoft Excel (Microsoft) and analyzed using STATA version 14. Study participants lost to follow-up were censored at the last contact date. Cox regression analysis was used to calculate hazard ratios between the 2 cohorts. A 2-sided *P* value of less than .05 was regard as statistically significant. A sample size of 60 participants was chosen to match the historical cohort.

Ethical Considerations

The study was approved by Catholic University of Health and Allied Sciences/BMC (CREC/286/2018), Weill Cornell Medical College (1706018283) and the National Institute for Medical Research in Tanzania (NIMR/HQ/R.8c/Vol.II/317).

Results

Study Enrollment and Baseline Characteristics

From June 2018 to October 2018, 64 children with SCD were hospitalized on the pediatric ward at BMC. Three died during hospitalization. Of the 61 children screened, 2 declined participation. The remaining 59 children (92.1%) were

Table I. Baseline characteristics of study subjects

Variables	Historical cohort (n = 57)	Interventional cohort (n = 59)	*P* value
Female sex	22 (38.6)	28 (47.4)	.335
Age, months	76.8 ± 36.6	58.3 ± 51.1	.001
Education level of caretaker			
Did not complete primary education	6 (10.5)	5 (8.4)	.706
Completed primary education	27 (47.3)	32 (54.2)	.459
Completed secondary education or higher	14 (24.5)	22 (37.2)	.138
Hospitalized in the past 12 months	40 (83.3)	43 (74.1)	.253
HIV positive	0 (0)	0 (0)	N/A
Taking hydroxyurea	0 (0)	4 (6.7)	.045
Nutritional status			
Normal	15 (26.3)	24 (40.6)	.101
Mild malnutrition*	21 (36.8)	16 (27.1)	.261
Moderate malnutrition†	16 (28.0)	13 (22.0)	.261
Severe malnutrition‡	5 (8.7)	6 (10.1)	.797
Hemoglobin level, g/dL	5.6 ± 1.8	6.9 ± 1.9	<.001
Random blood glucose, mg/dL	5.6 ± 1.7	5.2 ± 0.8	.283
Duration of in-patient hospitalization, days	6.2 ± 4.3	6.5 ± 3.9	.449

Values are number (%) or mean ± SD.
*Weight-for-height Z score <–1 and ≥–2 SD.
†Weight-for-height Z score <–2 and ≥–3 SD.
‡Weight-for-height Z score <–3.

Table II. Comparison of Outcomes Between Historical Cohort (n = 57) and Interventional Cohort (n = 59) at 3, 6, and 12 months after discharge

Outcomes	Historical cohort, No. (%)	Interventional cohort, No. (%)	aHR* (95% CI)	*P* value
3 months (intervention period)				
Dead	6 (10.5)	3 (5.0)	0.91 (0.29-4.03)	.902
Clinic attendance†	11 (19.2)	56 (94.9)	13.19 (3.98-43.66)	<.001
Cumulative rate of readmission	8 (14.0)	13 (22.0)	2.24 (0.87-5.77)	.139
6 months				
Cumulative dead	8 (14.0)	4 (6.7)	0.45 (0.13-1.50)	.196
Clinic attendance†	31 (54.3)	55 (93.2)	6.13 (2.00-18.76)	.001
Cumulative rate of readmission	21 (36.8)	33 (55.9)	1.71 (0.93-3.13)	.085
12 months				
Cumulative dead	11 (19.2)	4 (6.7)	0.26 (0.08-0.83)	.023
Clinic attendance†	26 (45.6)	55 (93.2)	7.05 (2.39-20.77)	<.001
Cumulative rate of readmission	36 (50.8)	45 (70.4)	1.17 (0.73-1.87)	.543

*Adjusted for age, hydroxyurea, and hemoglobin level.
†At least twice within the past 3 months.

enrolled into the study. Baseline characteristics of both the historical cohort and the interventional cohort are described in Table I.

Intervention and Outcomes

Of the 59 children enrolled, 3 children (5.0%) died during the 3-month intervention period, and the remaining 56 children completed all 5 sessions (Table II). No children were lost to follow-up during the intervention period.

The post-hospital mortality at 12 months was 4 of 59 (6.7%) (Table II). The 4 deaths occurred on post-discharge days 4, 39, 68, and 153. Adjusting for differences in age, hydroxyurea, and hemoglobin level, mortality in the interventional cohort was significantly lower than the 19.2% observed in the historical cohort (adjusted Hazard Ratio [aHR], 0.26; 95% CI, 0.08-0.83; $P = .023$). At 12 months, the clinic attendance rate was 45.6% in the historical cohort compared with 93.2% in the interventional cohort (aHR, 7.05; 95% CI, 2.39-20.77; $P < .001$), and the cumulative rate of readmission was 50.8% in the historical cohort compared with 70.4% in the interventional cohort (aHR, 1.17; 95% CI, 0.73-1.87; $P = .543$).

Discussion

Our pilot study illustrates the potential impact of a time-limited linkage to care intervention using social workers on post-hospitalization outcomes for children living in low-resource settings. In our pilot study targeting children with SCD, we successfully reduced 12-month post-hospital mortality by more than 60% compared with historical controls. The challenges faced by children with SCD are similar to those faced by other children with chronic medical conditions who live in low-resource settings. Death is unfortunately common during the period immediately after hospital discharge, but often goes under-recognized because it occurs outside the doors of the acute care center and before a child enters an outpatient clinic that might become their medical home. Post-hospital follow-up is a vital but often neglected step in the cascade of care system.

Successful linkage to care after hospital discharge has been shown to improve outcomes; however, it must include consistent clinic attendance.[13,14] Our intervention improved clinic attendance during the 3-month intervention period and had a sustained effect that persisted throughout the 12-month study period, possibly owing to the counseling provided by the social worker regarding clinic attendance and medication adherence. This point is especially important for individuals with chronic diseases, like SCD or HIV, which require the maintenance of long-term prophylactic regimens rather than the completion of a brief treatment directed at an acute disease. For example, Uyoga et al demonstrated that children with SCD in rural Kenya who enrolled in the SCD clinic after diagnosis had a mortality rate that was less than one-half that of those who did not.[11] Children who are first diagnosed during a hospitalization derive particular benefit with the early, repetitive interactions of a social worker, who equips families to establish care and forge a strong connection to the healthcare system.

Our linkage to care intervention using social workers was feasible for children and families to accommodate. Aside from the children who died before the end of the 3-month intervention period, 100% of our participants were able to complete the 5 sessions after discharge, which supports the interventions feasibility. Families reported a positive experience with the social worker in helping them overcome barriers to care (Table III; available at www.jpeds.com). These common barriers to clinic attendance may be amenable to more targeted strategies, such as mobile phone messages to remind families of upcoming appointments. Social workers are an essential cadre of healthcare professionals who already exist in many healthcare systems, even in low-resource settings. Expanding their role beyond the hospital walls to include postdischarge care could significantly improve outcomes for patients during the tenuous transition from hospital to home, when discharged patients

can experience generalized risk for numerous adverse health events.[6] Social workers are well-equipped to connect families struggling with income or social support to job employment/welfare organizations and religious/social organizations to provide assistance in these critical areas of daily living that have an impact on ability to access appropriate medical care. Although our study was conducted with social workers, the material reviewed during the post-hospital sessions could easily be facilitated by other cadres of healthcare workers like nurses, case managers, or community health leaders that might be more cost-effective in settings with limited resources.

In our study, it was observed that the cumulative rates of readmission for the interventional cohort were higher compared with the historical cohort. Uyoga et al found that readmissions among children attending a SCD clinic was more than twice that of participants who were not attending the clinic.[11] For our results, we speculate that, because of the social worker's teaching and education to families about their child's condition, this led to a greater parental awareness of when to bring a sick child to the hospital for evaluation. Although we did not collect any family financial data, financial instability could affect the rates of readmission for children. Families who do not have the means to pay for hospitalizations may, therefore, decide not to bring their child to the hospital.

Our pilot study has limitations. First, we have a small sample size that limits the ability of this study to make vigorous comparisons. We also compared 2 cohort groups that were enrolled several years apart and vary in some variables. Secular changes in healthcare may have explained some of the differences in outcomes that we observed. Another limitation is that our study took place at only one public hospital in Africa. Future studies should include a randomized controlled social worker intervention vs current standard of care.

In conclusion, we found that implementing a low-cost linkage to care intervention using social workers during the first 3 months after discharge for children with SCD can significantly reduce post-hospital mortality by over 60% and significantly improve clinic attendance up to 1 year after discharge. Further research should be directed at implementing a linkage to care intervention on a broader scale for children in low-resource settings. The postdischarge period is an opportune time to intervene and link children to clinic, and hence reduce overall child mortality. ■

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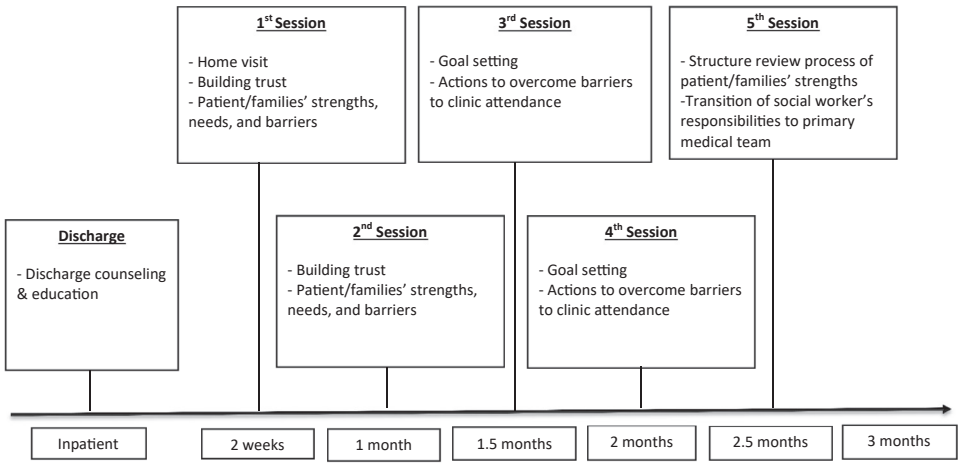

Figure. Key components of our 3-month, 5-session linkage to care intervention using a social worker.

Table III. Key barriers to clinic attendance and strategies used by the social worker to overcome these barriers

Barriers	Strategies
Unemployment/no income	Connect parents to local job employment/social welfare organizations Meet with former employers to discuss re-employment
Failure to remember appointments	Text/call family several days before appointment to remind family of their appointment Schedule patients' appointment on recurring schedule (ie, every second Friday each month at 9 A.M.)
Lack of social support	Encourage family to seek out close relationships within family, relatives, or neighbors to disclose child's health Connect to local religious/social organizations