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Brought in dead cases to a tertiary referral paediatric emergency department in India: a prospective qualitative study

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ABSTRACT

Objectives Brought in dead (BID) presentation is profoundly related to prehospital variables including disease-related determinants and social and system-related factors. Identifying these factors would help us recognise various gaps in health services.

Setting Tertiary paediatric emergency department (ED) in north India.

Patients Children aged 12 years or younger presented in cardiac arrest between April 2016 and March 2017 were prospectively enrolled irrespective of outcome of cardiopulmonary resuscitation (CPR). Data were collected from multiple sources including referral documents, direct interview from parents and field observations at the referring facility.

Results Of 100 BID cases enrolled, 55 were neonates. Low birth weight (n=43, 78%) and malnutrition (n=31, 69%) were respectively common in neonates and postneonatal children. The most frequent symptom was breathing difficulty (n=80). Common diagnoses included respiratory distress syndrome (n=21, 38%), birth asphyxia (n=19, 35%) and sepsis (n=11, 20%) in neonates, and pneumonia (n=11, 25%), congenital heart disease (n=6, 13%) and acute gastroenteritis (n=5, 11%) in postneonatal children. Eighty-nine cases were referred from another healthcare facility, majority after first healthcare contact (n=77, 87%). Progressive severity of illness (n=61, 71%) and lack of expertise for acute care (n=35, 39%) were the common reasons for referral. Ambulance (n=77) was the most common mode of transport; median (IQR) distance and duration of travel were 80 (25–111.5) km and 120 (60–180) min, respectively. Respiratory support during transport included supplemental nasal oxygen (n=41, 46%) and bag and tube ventilation (n=30, 34%). Clinical deterioration was recognised in 62 children during transport, only five received CPR en route. Ninety-five children underwent CPR at the referral centre, two had return of spontaneous circulation.

Conclusion Social and system-related factors contribute to children presenting to ED in BID state. Streamlining the referral process and linking transport to hospital care could reduce decompensated referrals and thereby decrease child mortality.

What is known about the subject?

► Hospital-based data have mainly focused on disease-specific mortality in children.
► Complications of prematurity, diarrhoea and pneumonia are the leading causes of neonatal and child deaths.
► Children who are brought in dead to hospitals in low middle-income countries represent deaths due to complex interplay of disease-related determinants with social/system-based factors.

What this study adds?

► About 3% of emergency department admissions were brought in dead; half were neonates.
► Referral and transport was found to be the weakest system.
► Lack of prereferral communication, poor documentation and inadequate transport services to address resuscitation needs were the common factors identified in children with decompensated referrals.

INTRODUCTION

Low and middle-income countries (LMIC) like India face unique challenges in the healthcare sector. Growing population and limited ability to expand healthcare resources puts the vulnerable age groups of neonates and young children at high risk for morbidity and mortality. Although global estimates of under-five mortality have shown a substantial decline over the past two decades, the United Nations' Millennium Development Goal of reducing under-five deaths by two-thirds could not be met in 2015.[1] The failure was mainly due to the slower progress, high mortality rate and low resource and fund allocation in countries from sub-Saharan Africa and south Asia including India. India contributed to nearly 21% of the global under-five child deaths.[2 3] Under-five mortality is an incisive indicator of a nation's progress and a crucial affirmation of its priorities and values. Therefore, in LMIC with high under-five mortality, it is imperative to introspect the deficiencies

in healthcare delivery as a major portion of these deaths are preventable. Hospital-based data have mainly focused on disease-specific mortality in children. WHO data and several other studies have listed preterm birth complications, pneumonia, diarrhoea and malaria as the top causes for neonatal and child mortality.[2 4–8] Most child deaths are impacted by a chain of events including social, cultural, environmental and healthcare-related factors and not merely by the medical disease that is usually assigned as the cause of death. Very few studies have explored these system-based non-biological factors that are often preventable or modifiable.[6 9]

Brought in dead (BID) or dead on arrival cases are those who are brought to a health facility in cardiac arrest requiring cardiopulmonary resuscitation (CPR).[10 11] BID presentation at tertiary care level is related to prehospital variables including disease-related determinants, social and system-related factors and referral and transport system. Identifying these factors would place health system within the broader and bigger context of social determinants of health and help us recognise various gaps in health services. On this premise, we conducted this qualitative phenomenology study on BID cases presenting to our emergency department (ED) to determine disease-related and system-based causes for such presentations.

MATERIALS AND METHODS
Enrolment
This prospective qualitative study was conducted in the ED of a tertiary care referral hospital in north India between April 2016 and March 2017. Consecutive children aged 12 years or younger who presented in cardiac arrest or cardiopulmonary failure were enrolled irrespective of outcome of CPR after obtaining written informed consent from parents or guardian. Children who sustained trauma in a road traffic accident or natural disasters were excluded.

Patient and public involvement
We did not directly involve parents and public in the design of the study.

Data collection
The information required for the study was obtained from multiple sources which included referral documents, direct interview and field observations. Lead and corresponding authors (PK1 and KN) were responsible for conducting semistructured interviews. Parents/guardian were approached for consent shortly after declaration of the outcome of CPR in ED. Although no specific relationship was established prior to conducting interviews, the participants were informed about the authors' professional background, objectives of the study and outline of the nature of interview. Authors PK1, KN and MJ were involved in field visits. Data collection began immediately after enrolment and the entire process for each case was completed within 4 weeks of enrolment.

Interview
Interview of the parents/guardian was conducted for information regarding their socioeconomic background, history of presenting illness and caregiver's knowledge and awareness towards the illness. For this purpose, the actual sequence of events as narrated by the parents from the point when the child had become symptomatic at home to the point of presentation to ED was noted. A predesigned semistructured questionnaire was used to record the information (online supplementary material). The questionnaire also included elements described in WHO verbal autopsy standards.[12] The entire process of interview was completed in 20–30 min. In situations where obtaining complete information was not possible immediately, telephonic interview or home visit at a later point was arranged after parent's consent. Member check at the conclusion of the interview was not done as we felt it was difficult to perform due to sensitivity of the content and it demanded additional time.

Field visits
Investigators made field visits to the referring hospitals and clinics for direct observations and assessment of the diagnostic, treatment and transport facilities available at the centre. Treating physicians were interviewed after obtaining informed consent and details regarding the diagnosis, management and referral process were ascertained. All personal or individual specific data from the direct interview were deidentified and kept strictly confidential.

Using the information obtained, a detailed timeline of events was generated for each patient; variables were grouped into three major themes: (1) prehospital determinants (social and disease-related factors), (2) health system-based factors, and (3) referral factors.

During enrolment, we observed that a significant proportion of BID cases were neonates. Data saturation was planned to be achieved based on sizeable representation of postneonatal children and non-emergence of new information related to social, health system and referral factors. We allowed for iterative adjustments between interview and field visits to ensure that the data collected from referring hospitals reflect the emergent pattern from interviews.

Statistical analysis
Authors PK1 and KN compiled, coded and analysed the data. Majority of the data were arranged in prefigured deductive codes derived from the semistructured data collection instrument. This was supplemented by inductive codes emerged from new topics. Descriptive statistics were used to present the data under different themes. Categorical variables are mainly presented as proportions. Continuous variables are presented as mean and SDs (normally distributed data) or as median and IQR

(non-parametric data). Statistical Package for Social Sciences (SPSS) V.20.0 for Windows (SPSS, IBM) was used for analysis.

RESULTS

Demographic and social factors

We screened 4364 admissions during the study period and 137 (3%) children were brought in dead to ED. Thirty-seven children were excluded due to challenges in obtaining consent or declined consent. Of 100 BID cases enrolled, more than half (n=55) were neonates. Two-thirds of all neonates (n=37, 67%) presented within the first 3 days of life, majority (n=21, 38%) within the first 24 hours. More than three-fourths of enrolled neonates (n=43, 78%) were of low birth weight (LBW; <2.5 kg); 12 (28%) very LBW and 3 (7%) extremely LBW babies. Postneonatal infants (aged 29 days to 1 year) constituted (n=22) about a quarter of all enrolled cases. There was a slight male predominance with boys to girls ratio of 1.27:1. Among postneonatal children, more than two-thirds (n=31, 69%) were undernourished with weight for age below 2 SD of mean for the age according to WHO growth standards. Haryana (n=41) and Punjab (n=38) were the two neighbouring states that accounted for the largest share (79%) of enrolled cases. The proportion of patients coming from rural background (n=52) and urban areas (n=48) were almost equal. The distribution of religion in the study cohort to a certain extent is reflective of the distribution in the community as most cases were Hindus (n=74), followed by Sikhs (n=18) and Muslims (n=8). Information regarding socioeconomic status and education of parents could not be ascertained in 36 cases due to inadequate information and parents' preference to not disclose. Among the rest (n=64), about half belonged to upper lower class (n=33, 51%) and a third to lower middle class (n=21, 33%) (table 1).

Disease-related factors

Clinical symptoms and referral diagnoses are presented in table 2. The most frequently reported symptoms common to all age groups were breathing difficulty (n=80), refusal to feed (n=17) and cyanosis (n=11). Other symptoms such as fever (n=21), vomiting (n=12) and loose stools (n=10) were predominantly seen in postneonatal age. The median duration of symptoms was shorter in neonates as compared with postneonatal age group (1 (1–1) vs 3 (1–4) days). The common diagnoses in neonates were respiratory distress syndrome (n=21, 38%), birth asphyxia (n=19, 35%), sepsis (n=11, 20%) and meconium aspiration syndrome (n=8, 15 %). In postneonatal age group, pneumonia (n=11, 25%) was the most frequent illness, followed by congenital heart disease (n=6, 13%) and acute gastroenteritis (n=5, 11%).

Health system-based factors

Out of 100 cases, 89 were referred from another health-care facility and 11 reached directly from home (table 3).

Table 1	Study population characteristics
Characteristics	**n=100**
Age	
Median (IQR), months	4 (2–5)
Neonates	55
0 to ≤24 hours	21
>24 to ≤72 hours	16
>3 to ≤7 days	9
>7 to ≤28 days	9
Postneonatal age	45
>28 days to ≤1 year	22
>1 to ≤5 years	14
>5 to ≤12 years	9
Sex	
Male	56
Female	44
Underweight	
Neonates: LBW (<2.5 kg)	43 (78%)
Postneonatal children: weight <2 SD	31 (69%)
Birth order	
1	46
2	25
3	22
4	6
5	1
Immunisation status	
Fully immunised	45
Partially immunised	8
Not immunised	47
Background	
Rural	52
Urban	48
Religion	
Hindu	74
Muslim	8
Sikh	18
Socioeconomic status	
Upper middle class	10
Lower middle class	21
Upper lower class	33
Not known	36
Highest education of parents	
Graduate/postgraduate	13
Intermediate	11
High school	20
Middle school	13
Primary school	5
	Continued

Table 1 Continued	
Characteristics	**n=100**
Illiterate	2
Not known	36
Details of neonates	**n=55 (%)**
Place of delivery	
Hospital	49 (89)
Home	6 (11)
Mode of delivery	
Vaginal delivery	41 (75)
Emergency LSCS	11 (20)
Elective LSCS	3 (5)
Cried immediately after birth	
Yes	23 (42)
No	27 (49)
Weak cry	4 (7)
Not known	1 (2)
Resuscitation at birth	
Yes	29 (52)
No	25 (46)
Not known	1 (2)

LBW, low birth weight; LSCS, lower segment caesarean section.

Majority were referred after the first healthcare contact (n=77, 87%), while 11 (12%) were referred after two healthcare contacts. One child, however, had four health facility visits before being referred. The median (IQR) duration of stay in referring hospital was noted to be 3 (1–20.5) hours. A total of 41 referring hospitals were identified that served as the last contact point for the 89 referred cases. Most (n=26, 63%) hospitals had a bed strength of less than 20. While outpatient services (93%), indoor admission wards (88%) and an emergency room (85%) were commonly available, level II or higher neonatal (29%) and paediatric (20%) acute care facilities were less prevalent. About a third (n=12, 30%) of all referring hospitals did not have ambulance services for referral. Of 88 referring physicians interviewed in our study, a little more than half (n=51, 58%) were either qualified paediatricians (38%) or undergoing training in paediatrics (20%).

Prereferral management and referral process
Respiratory support was commonly provided by supplemental oxygen through nasal prongs (n=41, 46%) or bag and tube ventilation (n=30, 34%). Eight (9%) children received mechanical ventilation and one child received bubble continuous positive airway pressure. Antibiotics (n=47, 53%) were the most commonly administered drugs followed by vitamin K (n=19, 21%), steroids (n=7, 8%) and antiepileptics (6, 7%). Inotropic/vasopressor support was provided in 21 (24%) children through a peripheral venous access. The common reasons for

referral were progressive severity of illness (n=61, 71%) and lack of expertise for acute care at referring hospital (n=35, 40%). Financial constraints (n=6, 7%) and failure of treatment (n=5, 6%) were less common reasons (table 3).

Transport
Of the 100 children, a little over three-fourths used ambulance (n=77) to commute from referring hospital or home. All except one of the ambulances used for transit (n=76, 99%) had provision for oxygen supply while less than half (n=32, 42%) were equipped with resuscitation drugs and equipment. A healthcare provider (doctor or paramedic) accompanying a sick child was noted in a little less than two-third of cases (n=49, 64%). The distance travelled by the study subjects ranged from 0.3 to 322 km with the median (IQR) of 80 (25–111.5) km. Correspondingly, the time taken to travel the distance ranged from 10 to 540 min with the median (IQR) 120 (60–180) min. In 62 cases, clinical deterioration was recognised during commute; majority were respiratory deterioration in the form of gasping or laboured breathing (n=58, 94%). Only 5 (8%) children received CPR during transport (table 4). Ninety-five children underwent CPR on reaching the referral centre, of which only two cases had return of spontaneous circulation.

DISCUSSION
In this observational study in a tertiary referral public healthcare setting, we could discern several factors potentially influencing the BID status of children at presentation. First, a significant proportion of our children belonged to a socially and economically deprived stratum placing them at a disadvantaged position with respect to health seeking. Additionally, most of parents' education level was until high school or lower. Education level and socioeconomic status are closely interlinked. The level of education is an important determinant of the total income and the health perception of the family. Expectedly a reciprocal relationship has been reported between per capita income and under-five mortality.[13] A study from Bangladesh observed an increasing trend of neonatal and postneonatal mortality with lower educational qualification of the father.[14] Biswas et al showed that in urban slums of Kolkata the morbidity episode/child/year increased as the per capita income decreased.[15]

Second, the BID cohorts were very young; about half were neonates and another quarter were infants under 1 year of age. This age distribution mirrors the trend reported from LMIC where neonates and young infants form a significant proportion of hospitalised children.[16] In a study from southern India, infants comprised 69% of total patients presenting to ED with 33% being within 2 months of age.[17] We observed that respiratory ailments of high acuity leading to rapid destabilisation were the most common reason for seeking care. Among the postneonatal children, the leading illness was pneumonia

Table 2 Common symptoms and referral diagnosis

Clinical details	Study population (100) n	Neonates (55) n (%)	Postneonatal group (45) n (%)	Duration of symptoms in days Median (IQR)
Symptoms				
Breathing difficulty	80	50 (91)	30 (67)	1 (1–2)
Fever	21	0	21 (47)	3 (3–6)
Refusal of feed	17	10 (18)	7 (16)	2 (1–3)
Vomiting	12	1 (2)	11 (24)	2 (1–6.5)
Cyanosis	11	6 (11)	5 (11)	1.0 (1–3)
Loose stools	10	0	10 (18)	2.5 (1–6)
Seizures	5	1 (2)	4 (9)	2.5 (1.5–4)
Jaundice	3	2 (4)	1 (2)	3 (2–3)
Cough	7	0	7 (16)	4 (3–6)
Lethargy	4	0	4 (9)	2.5 (1.5–3.5)
Referral diagnosis				
Respiratory distress syndrome	21	21 (38)		
Birth asphyxia	19	19 (35)		
Prematurity	18	18 (33)		
Meconium aspiration syndrome	8	8 (15)		
Neonatal jaundice	3	3 (5)		
Pneumonia	17	3 (5)	14 (31)	
Congenital heart disease	12	6 (11)	6 (13)	
Sepsis	14	11 (20)	3 (7)	
Shock	5	3 (5)	2 (4)	
Acute diarrhoea			5 (11)	
Snake envenomation			3 (7)	
Seizure			2 (4)	

(24%), followed by congenital heart disease (13%) and acute diarrhoeal disease (11%). Most neonates in our study had one or more known risk factors for increased mortality; one-third (33%) were premature, nearly four-fifths (78%) were LBW and more than half (53%) required resuscitation at birth possibly for birth asphyxia. These findings in both the age groups are largely in concordance with published literature although the frequencies differ slightly. In a nationally representative mortality survey, the common causes of neonatal death were attributed to prematurity/LBW, neonatal infections, birth asphyxia and birth trauma.[18] Pneumonia and diarrhoea continue to be the leading causes of mortality in children aged 1–59 months.[1] Not surprisingly, a significant proportion of congenital heart diseases were noted among our BID cases. Improved diagnostics, early detection of lesions and better newborn survival are some of the possible reasons for this increased incidence. As the rate of child mortality due to preventable diseases declines, congenital heart defects are predicted to cause a significant burden on healthcare systems especially in LMIC.[19 20]

Third, the type of healthcare facility, presence of a trained physician and availability of resources were important determinants for decision and timing of referral. Most children in our study were referred from public sector hospitals with facilities for inpatient wards. However, facilities for acute care beyond immediate stabilisation were limited. The emergency rooms/wards were common for both adults and children and an organised triage system was notably deficient despite some having staff assigned for this purpose. There was a wide variation in level of staff training and clinical decision-making. A hospital-based study in 2001 showed that inadequate staff training, inefficient triage, inappropriate emergency management, lack of standard case management guidelines and limited resources were the barriers in reducing child mortality at district and teaching hospitals in less developed countries.[21] Nearly two decades later, these factors continue to remain relevant in absence of sustainable large-scale interventions.

Among all the factors observed in our study, we believe that the weakest link was related to the execution of the referral process. Two main reasons recognised for

Table 3 Details of referral hospitals, prereferral management and referral process

Referral details	n (%)
Type of referral (n=100)	
Government hospitals	65
Private hospitals	24
Came directly from home	11
Facility available at referring hospital (n=41)	
OPD	38 (93)
Inpatient ward	36 (88)
Emergency unit	35 (85)
Neonatal ward	30 (73)
NICU	12 (29)
PICU	08 (20)
Biochemistry/haematology	35 (85)
X-ray	33 (81)
USG	32 (78)
CT scan	09 (22)
MRI	03 (7)
Ambulance	29 (71)
Bed strength (n=41)	
<10	10 (25)
11–20	18 (44)
21–50	8 (20)
>50	2 (5)
Not estimated	3 (7)
Physician qualification (n=88)	
MBBS	35 (40)
MD internal medicine	1 (1)
Others (unqualified)	1 (1)
Paediatrician (MD/DCH)	32 (37)
MD/DNB trainee	18 (20)
Neonatologist (DM)	1 (1)
Respiratory support (n=89)	
Oxygen by nasal prongs	41 (46)
Continuous positive airway pressure	1 (1)
Bag and tube ventilation	30 (34)
Mechanical ventilation	8 (9)
Oxygen-driven nebulisation	5 (6)
Not known	1 (1)
No support	8 (9)
Circulatory support (n=89)	
Intravenous fluid	59 (66)
Vasoactive/inotropic agent infusion	21 (24)
Not known	9 (10)
Drugs (n=89)	
Antibiotics	47 (53)
	Continued

Table 3 Continued

Referral details	n (%)
Vitamin K	19 (21)
Caffeine	3 (3)
Calcium gluconate	3 (3)
Sodium bicarbonate	1 (1)
Steroids	7 (8)
Antiepileptics	6 (7)
Blood transfusion	3 (3)
Referral document (n=89)	
Present with adequate information	28 (31)
Present without adequate information	61 (71)
Referral note not present	0
Reason for referral (n=89)	
Severity of illness	61 (71)
Need for expertise	35 (39)
Failure of treatment	5 (6)
Non-availability of physician	2 (2)
Financial constraints	6 (7)
Duration between decision and actual referral (n=89)	
<2 hours	73 (82)
2–4 hours	13 (15)
4–6 hours	1 (1)
>6 hours	2 (2)

NICU, neonatal intensive care unit; OPD, outpatient department; PICU, paediatric intensive care unit; USG, ultrasonography.

referral to higher level of care included progressive severity of illness and need for acute care expertise. However, despite recognition, many referrals seemed to have been made in haste without aiming for stabilisation. Missing the 'golden hour' at first healthcare contact and further transport in a decompensated state explains the increased number of children presenting to tertiary care in cardiac arrest.[22] More than two-thirds (71%) of the referrals were accompanied by inadequately written referral notes. Several domains with respect to referral diagnosis, prereferral vital signs, essential investigations and treatment provided were missing. Similar findings were reported by a study from north India where crucial details on referral document and prereferral communication were absent.[23]

Referral is an ongoing process and transport forms an integral part of this chain. Unfortunately, this area is one of the least addressed in the present healthcare system. The average distance travelled and the time taken to travel by a patient to reach the referral centre in our study were 80 km (IQR: 25–111.5) and 2 hours, respectively. Contrary to many other studies, the most common mode of transportation in our study was ambulance (77%).[23–25] The increased use of ambulance could

Table 4 Details of transport

Transport	n (%)
Type of transport (n=100)	
Ambulance	77
Car	10
Taxi	7
Bus	1
Auto rickshaw	3
Scooter/bike	1
Walk	1
Facilities in ambulance vehicle (n=77)	
Oxygen	76 (99)
Resuscitation drugs and equipment	32 (42)
Multiparameter monitor	08 (10)
Doctor/paramedical staff	49 (64)
Deterioration noted during transit (n=100)	
Yes	62
No	12
Could not recognise	26
Signs of deterioration (n=100)	
Gasping	58
Fall in BP	1
Worsening of sensorium	1
Cyanosis	1
Vomiting	1
Intervention done during deterioration (n=100)	
None	35
Increased flow of O_2	18
Intravenous fluids given	1
Bag and mask ventilation started	2
CPR	5
Suction	1
Perceived delay during transit (n=100)	
No delay	53
Poor roads	15
Heavy traffic	29
Arranging funds	4
Use of public transportation	1
Difficulty in finding transportation	5
Stopped at other facility	3
Unfamiliarity with the route	7
Distance travelled to reach referral centre (km)	
Median (IQR)	80 (25–111.5)
Time taken to reach referral centre (min)	
Median (IQR)	120 (60–180)

BP, blood pressure; CPR, cardiopulmonary resuscitation.

be attributed to more prevalent and free of cost national ambulance service which is now operational in India. Majority of ambulances were equipped with oxygen and fewer with life support drugs and resuscitation equipment. Although a paramedic accompanied the patient in 63% of cases, majority were ill equipped to recognise deterioration and stabilise them. These findings call for development of a robust interhospital transport system with joint efforts from both referring and referred hospitals and government agencies.

Our study has some important strengths. It is the first of its kind to look at non-disease-related determinants of BID status at a tertiary care level. We included a sizeable sample. Interview from parents and doctors with observational visits to referring hospital added predictive quality to the findings. However, a few limitations need mention. We could not enrol all consecutive cases during the study period due to declined consent by some parents. Our data predominantly reflect information generated from a priori themes. This study suffers from the inherent shortcomings of qualitative studies which include subjectivity and limited generalisability.

CONCLUSIONS

Complications of prematurity, birth asphyxia, sepsis and pneumonia were the common aetiologies in children brought in dead to tertiary care ED. Several social and system-related factors are associated with BID presentation. Streamlining the referral process and linking transport to hospital care are potential strategies to reduce decompensated referrals and thereby decrease child mortality.

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