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Brought in dead cases to a tertiary referral pediatric Emergency Department: a prospective qualitative study

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Abstract

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

Setting: Tertiary Pediatric 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 was 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 post neonatal children. The most frequent symptom was breathing difficulty (n=80,80%). Common diagnoses included respiratory distress syndrome (n=21,38.2%), birth asphyxia (n=19,34.5%) 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 post neonatal children. Eighty-nine cases were referred from another health care facility, majority after first health care contact (n=77,86.5%). Progressive severity of illness (n=61,71%) and lack of expertise for acute care (n=35,39.3%) 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) minutes respectively. Respiratory support during transport included supplemental nasal oxygen (n=41,46%) and bag and tube ventilation (n=30,34%). Clinical deterioration was recognized in 62 children during transport, only

5 received CPR en-route. Ninety-five children underwent CPR at the referral center, 2 (2%) had return of spontaneous circulation (ROSC).

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

Introduction:

Low- and middle-income countries (LMIC) like India face unique challenges in the health care sector. Growing population and limited ability to expand health care resources puts the vulnerable age groups of neonates and young children at high risk for morbidity and mortality. Although global estimates of under-5 mortality have shown a substantial decline over the past two decades, the United Nations' Millennium Development Goal of reducing under-5 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 5 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, diarrhea 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 (DOA) 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 pre-hospital 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 recognize 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

Enrollment: 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. The study was approved by the Ethics Committee of the Institute.

Patient and public involvement (PPI): 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 semi-structured interviews. Although no specific relationship was established prior to conducting interviews, the participants were informed about the authors' professional background, objectives of the study and outlined about the nature of interview. Authors PK1, KN and JM were involved in field visits. Data collection began immediately after enrollment 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 child had become symptomatic at home to the point of presentation to ED was noted. The questionnaire also included elements described in WHO verbal autopsy standards.[12] The entire process of interview was completed in 20 – 30 minutes. In situations where obtaining complete information was not possible immediately, telephonic interview or home visit at a later point were arranged after parent's consent.

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 center. 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 was de-identified and kept strictly confidential.

Using the information obtained, a detailed timeline of events was generated for each patient; variables were grouped into pre-hospital determinants (social and disease related factors), health system based factors and referral factors.

Statistical analysis: Authors PK1 and KN compiled and analyzed the data. Descriptive statistics were used. Data are presented by compiling the possible contributory factors in all the cases. Categorical variables are mainly presented as proportions. Continuous variables are presented as mean and standard deviations (normally distributed data) or as median and interquartile range (non-parametric data). Statistical package for social sciences (SPSS) version 20.0 for Windows (SPSS, IBM, Chicago, IL, USA) 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, 55%) were neonates. Two thirds of all neonates (n=37, 67%) presented within first 3 days of life, majority (n=21, 38%) within first 24 hours. More than three fourths of enrolled neonates (n=43, 78%) were low birth weight (< 2.5kg); 12(28%) very low birth weight and 3 (7%) extremely low birth weight babies. Post neonatal infants (aged 29 days to 1 year) constituted (n=22, 22%) about a quarter of all enrolled cases. There was a slight male predominance with boys:girls ratio of 1.27:1. Among post neonatal children, more than two thirds (n=31, 69%) were undernourished with weight for age below 2 standard deviation 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 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, 80%), refusal to feed (n=17, 17%), and cyanosis (n=11, 11%). Other symptoms such as fever (21%), vomiting (12%) and loose stools (10%) were predominantly seen in post neonatal age. The median duration of symptoms was shorter in neonates as compared to post neonatal age group [1 (1-1) vs 3 (1-4) days]. The common diagnoses in neonates were respiratory distress syndrome (n=21, 38.2%), birth asphyxia (n=19, 34.5%), sepsis (n=11, 20%) and meconium aspiration syndrome (n=8, 14.5 %). In post neonatal 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]. Majority were referred after first health care contact (n=77, 86.5%), while 11 (12.4%) were referred after two health care contacts. One (1.1%) 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 out-patient services (93%), indoor admission wards (88%) and an emergency room (85%) were commonly available, level II or higher neonatal (29%) and pediatric (19%) 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 pediatricians (38%) or undergoing training in pediatrics (20%).

Pre-referral 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, 33.7%). Eight (9%) children received mechanical ventilation and one child received bubble CPAP. Antibiotics (47, 53%) were the most commonly administered drugs followed by vitamin K (19, 21.3%), steroids (7, 7.9%) and antiepileptics (6, 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, 39.3%). Financial constraints (n=6, 6.7%) and lack of specific treatment (n=5, 5.6%) were less common reasons [Table 3].

Transport:

Of the 100 children, a little over three fourth used ambulance (n=77, 77%) to commute from referring hospital or home. All except one of the ambulances used for transit (n=76, 98.7%) had provision for oxygen supply while less than half (n=32, 41.5%) 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, 63.6%). The distance travelled by the study subjects ranged from 0.3 km to 322 km with the median (IQR) of 80 (25-111.5) km. Correspondingly, the time taken to travel the distance ranged from 10 minutes to 540 minutes with the median (IQR) 120 (60-180) minutes. In 62% (n=62) cases, clinical deterioration was recognized during commute; majority were respiratory deterioration in the form of gasping or laboured breathing (n=58, 93.54%). Only 5 (8%) children received cardiopulmonary resuscitation during transport [Table 4]. Ninety-five children underwent cardiopulmonary resuscitation on

reaching the referral center, of which only 2 (2.1%) cases had return of spontaneous circulation (ROSC).

Discussion

In this observational study in a tertiary referral public health care setting, we could discern several factors potentially influencing the BID status of children at presentation. Firstly, a significant proportion of our children belonged to a socially and economically deprived strata placing them at a disadvantaged position with respect to health seeking. Additionally, most parent's education level was till 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 post neonatal 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]

Secondly, the BID cohort 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 hospitalized 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 destabilization, were the most common reason for seeking care. Among the post neonatal children, the leading illness was pneumonia (24.4%), followed by congenital heart diseases (13.3%) and acute diarrheal disease (11.1%). Most neonates in our study had one or more known risk factors for increased mortality; one third (33%) were premature, nearly four fifth (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/ low birth weight, neonatal infections, birth asphyxia and birth trauma.[18] Pneumonia and diarrhea 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 health care systems especially in LMIC. [19, 20]

Thirdly, 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 in-patient wards. However, facilities for acute care beyond immediate stabilization were limited. The emergency rooms/wards were common for both adults and children and an organized 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 recognized for 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 stabilization. Missing the 'golden hour' at first health care 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, pre-referral 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 pre-referral 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 health care system. The average distance travelled, and time taken to travel by a patient to reach the referral center in our study was 80 km (IQR:25-111.5) and 2 hours respectively. Contrary to many other studies, the commonest mode of transportation in our study was ambulance (77%).[23-25] The increased use of ambulance could be attributed to more prevalent and free of cost national ambulance service (NAS) which is now operational in India. Majority of ambulances were equipped with oxygen and fewer with life support drugs and resuscitation equipments. Although a paramedic accompanied the patient in 63% cases, majority were ill equipped to recognize deterioration and stabilize 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 first of its kind to look at non-disease related determinants of brought in dead 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 enroll all

consecutive cases during the study period due to declined consent by some parents. Our study suffers from the inherent shortcomings of qualitative studies which includes subjectivity and limited generalizability.

Conclusions

Complications of prematurity, birth asphyxia, sepsis and pneumonia were the common etiologies in children brought in dead to tertiary care Emergency Department. 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.

What is already known?

Hospital based data have mainly focused on disease specific mortality in children. Complications of prematurity, diarrhea and pneumonia are the leading causes of neonatal and child deaths. Children who are brought in dead to a hospital in low middle income countries represent deaths due to complex interplay of disease related determinants with social and 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 pre-referral communication, poor documentation and inadequate transport services to address resuscitation needs were the common factors identified in children with decompensated referrals.

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Contributors: KN and PK1 were responsible for the conception of the work, with all authors contributing to the study design. PK1 collected the data and with KN completed the data analysis. MJ and PK2 critically reviewed the interpretation of data. PK1 and KN wrote the first draft and all authors revised it critically. All authors approved the final version.

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Ethics approval: The study was approved by Institute Ethics Committee, PGIMER, Chandigarh. Approval No. NK/2588/MD/2433-34

Data availability statement: No additional data available

Table 1: Study population characteristics

Characteristics	n=100 (%)
Age	
Median (IQR) in months	4 (2-5)
Neonates	55 (55)
0 ≤ 24 hours	21 (21)
>24 hours≤ 72 hours	16 (16)
> 3days ≤ 7 days	9 (9)
>7 days ≤ 28 days	9 (9)
Post neonatal age	45 (45)
>28 days≤ 1 Year	22 (22)
>1 Year ≤ 5 Years	14 (14)
>5 Years ≤12 Years	9 (9)
Sex	
Male	56(56)
Female	44(44)
Underweight	
Neonates: LBW (<2.5Kg)	45 (78)
Post neonatal children: Weight < 2SD	31(69)
Birth order	
1	46(46)
2	25(25)
3	22(22)
4	06(6)
5	01(1)
Immunization status	
Fully immunized	45(45)
Partial immunized	8(8)
Not immunized	47(47)
Background	
Rural	52 (52)
Urban	48 (48)
Religion	
Hindu	74 (74)
Muslim	8 (8)
Sikh	18 (18)
Socio economic status	
Upper middle class	10 (10)
Lower middle class	21 (21)
Upper lower class	33 (33)
Not known	36 (36)

Highest education of parents	
Graduate/ postgraduate	13 (13)
Intermediate	11 (11)
High school	20 (20)
Middle school	13 (13)
Primary school	5 (5)
Illiterate	2 (2)
Not known	36 (36)
Details of neonates (n=55)	
Place of delivery	
Hospital	49 (89)
Home	6 (11)
Mode of delivery	
Vaginal delivery	41 (74.5)
Emergency LSCS	11 (20)
Elective LSCS	3 (5.5)
Cried immediately after birth	
Yes	23 (42)
No	27 (49)
Weak cry	04 (7.3)
Not Known	01 (2)
Resuscitation at birth	
Yes	29 (52.7)
No	25 (45.5)
Not Known	1 (2)

Table 2: Common symptoms and referral diagnosis

Clinical details	Study population (100) n (%)	Neonates (55) n (%)	Post neonatal group (45) n (%)	Duration of symptoms Median (IQR)
Symptoms				
Breathing difficulty	80 (80)	50 (91)	30 (66.6)	1(1-2) days
Fever	21 (21)	0	21 (46.6)	3 (3-6) days
Refusal of feed	17 (17)	10 (18)	7 (15.5)	2 (1-3) days
Vomiting	12 (12)	1 (2)	11 (24.4)	2(1-6.5) days
Cyanosis	11 (11)	6 (11)	5 (11)	1.0(1-3) days
Loose stools	10 (10)	0	10 (18)	2.5(1-6) days
Seizures	5(5)	1 (2)	4 (9)	2.5(1.5-4) days
Jaundice	3(3)	2 (3.6)	1 (2)	3(2-3) days
Cough	7(7)	0	7 (15.5)	4.0(3-6) days
Lethargy	4(4)	0	4 (9)	2.5(1.5-3.5) days
Referral diagnosis				
Respiratory Distress Syndrome	21	21 (38)		
Birth asphyxia	19	19 (34.5)		
Prematurity	18	18 (32.7)		
Meconium Aspiration Syndrome	8	8 (14.5)		
Neonatal jaundice	3	3 (5.45)		
Pneumonia	17	3 (5.4)	14 (31)	
Congenital heart disease	12	6 (11)	6 (13)	
Sepsis	14	11 (20)	3 (6.6)	
Shock	5	3 (5.5)	2 (4.4)	
Acute diarrhea			5 (11)	
Snake envenomation			3 (6.6)	
Seizure			2 (4.4)	

Table 3. Details of referral hospitals, pre-referral management and referral process

Referral details	
Type of referral(n=100)	
Government hospitals	65 (65)
Private hospitals	24 (24)
Came directly from Home	11 (11)
Facility available at referring hospital (n=41)	
OPD	38 (92.6)
In patient ward	36 (87.8)
Emergency Unit	35 (85.4)
Neonatal Ward	30 (73)
NICU	12 (29.3)
PICU	08 (19.5)
Biochemistry/Hematology	35 (85.4)
Xray	33 (80.5)
USG	32 (78)
CT scan	09 (22)
MRI	03 (7)
Ambulance	29 (70.7)
Bed strength (n=41)	
≤ 10	10 (24.5)
11-20	18 (44)
21-50	8 (20)
>50	2 (5)
Not estimated	3 (7.3)
Physician qualification (n=88)	
MBBS	35 (39.7)
MD Internal medicine	1 (1)
Others (Unqualified)	1 (1)
Pediatrician (MD / DCH)	32 (36.5)
MD/DNB trainee	18 (20.4)
Neonatologist (DM)	1 (1)
Respiratory support (n=89)	
Oxygen by Nasal prongs	41 (46)
Continuous positive airway pressure	1 (1)
Bag & tube ventilation	30 (33.7)
Mechanical ventilation	8 (9)
Oxygen driven nebulization	5 (5.6)
Not known	1 (1)
No support	8 (9)
Circulatory support	
Intravenous fluid	59 (66.3)
Vasoactive/inotropic agent infusion	21 (23.6)
Not known	9 (10)

Drugs	
Antibiotics	47 (53)
Vitamin K	19 (21)
Caffeine	3 (3.4)
Calcium gluconate	3 (3.4)
Sodium bicarbonate	1 (1)
Steroids	7 (8)
Antiepileptics	6 (6.7)
Blood transfusion	3 (3.4)
Referral Document	
Present with adequate information	28 (31.4)
Present without adequate information	61 (71)
Referral note not present	0
Reason for referral	
Severity of illness	61 (71)
Need for expertise	35 (39)
Failure of treatment	5 (5.6)
Non-availability of physician	2 (2)
Financial constraints	6 (6.7)
Duration between decision and actual referral	
<2 hours	76 (85.3)
2-4 hours	13 (14.6)
4-6 hours	1 (1)
>6 hours	2 (2)

Table 4. Details of transport

Transport	**n=100** (%)
Type of transport	
Ambulance	77 (77)
Car	10 (10)
Taxi	07 (7)
Bus	1 (1)
Auto rickshaw	3 (3)
Scooter/bike	1 (1)
Walk	1 (1)
Facilities in ambulance vehicle (n=77)	
Oxygen	76 (98.7)
Resuscitation drugs and equipment	32 (41.5)
Multiparameter monitor	08 (10)
Doctor/paramedical staff	49 (63.6)
Deterioration noted during transit (n=100)	
Yes	62 (62)
No	12 (12)
Could not recognise	26 (26)
Signs of deterioration (n=100)	
Gasping	58 (58)
Fall in BP	1 (1)
Worsening of sensorium	1 (1)
Cyanosis	1 (1)
Vomiting	1 (1)
Intervention done during deterioration (n=100)	
None	35 (35)
Increased flow of O2	18 (18)
IV fluids given	1 (1)
Bag and mask ventilation started	2 (2)
CPR	5 (5)
Suction	1 (1)
Perceived delay during transit (n=100)	
No delay	53 (53)
Poor roads	15 (15)
Heavy traffic	29 (29)
Arranging funds	4 (4)
Use of public transportation	1 (1)
Difficulty in finding transportation	5 (5)
Stopped at other facility	3 (3)
Unfamiliarity with the route	7 (7)
Distance travelled to reach referral centre (in km)	
Median (IQR)	80 (25-111.5)
Time taken to reach referral centre (in minutes)	
Median (IQR)	120(60-180)

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Brought in dead cases to a tertiary referral pediatric Emergency Department in India: a prospective qualitative study

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Abstract

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

Setting: Tertiary Pediatric 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 was 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 post neonatal 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 post neonatal children. Eighty-nine cases were referred from another health care facility, majority after first health care 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) minutes respectively. Respiratory support during transport included supplemental nasal oxygen (n=41,46%) and bag and tube ventilation (n=30,34%). Clinical deterioration was recognized in 62 children during transport, only 5 received

CPR en-route. Ninety-five children underwent CPR at the referral center, 2 had return of spontaneous circulation (ROSC).

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

Introduction:

Low- and middle-income countries (LMIC) like India face unique challenges in the health care sector. Growing population and limited ability to expand health care resources puts the vulnerable age groups of neonates and young children at high risk for morbidity and mortality. Although global estimates of under-5 mortality have shown a substantial decline over the past two decades, the United Nations' Millennium Development Goal of reducing under-5 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 5 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, diarrhea 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 (DOA) 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 pre-hospital 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 recognize 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

Enrollment: 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. The study was approved by the Ethics Committee of the Institute.

Patient and public involvement (PPI): 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 semi-structured 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 outlined about the nature of interview. Authors PK1, KN and JM were involved in field visits. Data collection began immediately after enrollment 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 child had become symptomatic at home to the point of presentation to ED was noted. A predesigned semi structured questionnaire was used to record the information (Supplementary file). The questionnaire also included elements described in WHO verbal autopsy standards.[12] The entire process of interview was completed in 20 – 30 minutes. In situations where obtaining complete information was not possible immediately, telephonic interview or home visit at a later point were arranged after parent's consent.

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 center. 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 was de-identified 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, i) pre-hospital determinants (social and disease related factors), ii) health system based factors and iii) referral factors.

During enrollment, we observed that a significant proportion of BID cases were neonates. Data saturation was planned to be achieved based on sizeable representation of post neonatal children and non-emergence of new referring hospitals. 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 analyzed the data. Majority of the data were arranged in prefigured deductive codes derived from the semi structured 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 standard deviations (normally distributed data) or as median and interquartile range (non-parametric data). Statistical package for social sciences (SPSS) version 20.0 for Windows (SPSS, IBM, Chicago, IL, USA) 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 first 3 days of life, majority (n=21, 38%) within first 24 hours. More than three fourths of enrolled neonates (n=43, 78%) were low birth weight (< 2.5kg); 12(28%) very low birth weight and 3 (7%) extremely low birth weight babies. Post neonatal 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:girls ratio of 1.27:1. Among post neonatal children, more than two thirds (n=31, 69%) were undernourished with weight for age below 2 standard deviation 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 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 post neonatal age. The median duration of symptoms was shorter in neonates as compared to post neonatal 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 post neonatal 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]. Majority were referred after first health care contact (n=77, 87%), while 11 (12%) were referred after two health care 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 out-patient services (93%), indoor admission wards (88%) and an emergency room (85%) were commonly available, level II or higher neonatal (29%) and pediatric (19%) 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 pediatricians (38%) or undergoing training in pediatrics (20%).

Pre-referral 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 CPAP. 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 lack of specific treatment (n=5, 6%) were less common reasons [Table 3].

Transport:

Of the 100 children, a little over three fourth 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 km to 322 km with the median (IQR) of 80 (25-111.5) km. Correspondingly, the time taken to travel the distance ranged from 10 minutes to 540 minutes with the median (IQR) 120 (60-180) minutes. In 62 cases, clinical deterioration was recognized during commute; majority were respiratory deterioration in the form of gasping or laboured breathing (n=58, 94%). Only 5 (8%) children received cardiopulmonary resuscitation during transport [Table 4]. Ninety-five children underwent cardiopulmonary resuscitation on reaching the referral center, of which only 2 cases had return of spontaneous circulation (ROSC).

Discussion

In this observational study in a tertiary referral public health care setting, we could discern several factors potentially influencing the BID status of children at presentation. Firstly, a significant proportion of our children belonged to a socially and economically deprived strata placing them at a disadvantaged position with respect to health seeking. Additionally, most parent's education level was till 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 post neonatal 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]

Secondly, the BID cohort 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 hospitalized 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 destabilization, were the most common reason for seeking care. Among the post neonatal children, the leading illness was pneumonia (24%), followed by congenital heart diseases (13%) and acute diarrheal disease (11%). Most neonates in our study had one or more known risk factors for increased mortality; one third (33%) were premature, nearly four fifth (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/ low birth weight, neonatal infections, birth asphyxia and birth trauma.[18] Pneumonia and diarrhea 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 health care systems especially in LMIC. [19, 20]

Thirdly, 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 in-patient wards. However, facilities for acute care beyond immediate stabilization were limited. The emergency rooms/wards were common for both adults and children and an organized 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 recognized for 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 stabilization. Missing the 'golden hour' at first health care 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, pre-referral 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 pre-referral 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 health care system. The average distance travelled, and time taken to travel by a patient to reach the referral center in our study was 80 km (IQR:25-111.5) and 2 hours respectively. Contrary to many other studies, the commonest mode of transportation in our study was ambulance (77%). [23-25] The increased use of ambulance could be attributed to more prevalent and free of cost national ambulance service (NAS) which is now operational in India. Majority of ambulances were equipped with oxygen and fewer with life support drugs and resuscitation equipments. Although a paramedic accompanied the patient in 63% cases, majority were ill equipped to recognize deterioration and stabilize 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 first of its kind to look at non-disease related determinants of brought in dead 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 enroll all consecutive cases during the study period due to declined consent by some parents. Our data predominantly reflect information generated from apriori themes. This study suffers from the inherent shortcomings of qualitative studies which includes subjectivity and limited generalizability.

Conclusions

Complications of prematurity, birth asphyxia, sepsis and pneumonia were the common etiologies in children brought in dead to tertiary care Emergency Department. 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.

What is already known?

Hospital based data have mainly focused on disease specific mortality in children. Complications of prematurity, diarrhea and pneumonia are the leading causes of neonatal and child deaths. Children who are brought in dead to a hospital in low middle income countries represent deaths due to complex interplay of disease related determinants with social and 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 pre-referral communication, poor documentation and inadequate transport services to address resuscitation needs were the common factors identified in children with decompensated referrals.

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Contributors: KN and PK1 were responsible for the conception of the work, with all authors contributing to the study design. PK1 collected the data and with KN completed the data analysis.

MJ and PK2 critically reviewed the interpretation of data. PK1 and KN wrote the first draft and all authors revised it critically. All authors approved the final version.

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Data availability statement: No additional data available

Table 1: Study population characteristics

Characteristics	n=100
Age	
Median (IQR) in months	4 (2-5)
Neonates	55
0 ≤ 24 hours	21
>24 hours≤ 72 hours	16
> 3days ≤ 7 days	9
>7 days ≤ 28 days	9
Post neonatal age	45
>28 days≤ 1 Year	22
>1 Year ≤ 5 Years	14
>5 Years ≤12 Years	9
Sex	
Male	56
Female	44
Underweight	
Neonates: LBW (<2.5Kg)	45 (78%)
Post neonatal children: Weight < 2SD	31 (69%)
Birth order	
1	46
2	25
3	22
4	6
5	1
Immunization status	
Fully immunized	45
Partial immunized	8
Not immunized	47
Background	
Rural	52
Urban	48
Religion	
Hindu	74
Muslim	8
Sikh	18
Socio economic 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
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)

Table 2: Common symptoms and referral diagnosis

Clinical details	Study population (100) n	Neonates (55) n (%)	Post neonatal 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 diarrhea			5 (11)	
Snake envenomation			3 (7)	
Seizure			2 (4)	

Table 3. Details of referral hospitals, pre-referral 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)
In patient ward	36 (88)
Emergency Unit	35 (85)
Neonatal Ward	30 (73)
NICU	12 (29)
PICU	08 (20)
Biochemistry/Hematology	35 (85)
Xray	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)
Pediatrician (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 & tube ventilation	30 (34)
Mechanical ventilation	8 (9)
Oxygen driven nebulization	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)
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)

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 O2	18
IV 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 (in km)	
Median (IQR)	80 (25-111.5)
Time taken to reach referral centre (in minutes)	
Median (IQR)	120 (60-180)

Brought in dead cases to a tertiary referral pediatric Emergency Department in India: a prospective qualitative study

Date: …. /….. /…… Time: … : … hours

Interviewer:

Main respondent's relationship to the child: Language of the interview:

Educational status of the respondent:

Are there other people present at the interview? If yes, their relationship:

Enrol No. CR No.

Address: _____

_____

Mobile No. _____

- Age: years month days hours
- Date of birth- ___/____/____Time of birth: : hrs
- Sex: Male Female
- Order of birth:

1	2	3	4	5

- Religion:

  Hindu /Muslim / Sikh / Christian/Others

- Socioeconomic status: (modified Kuppuswamy scale)

  Education of head of family: (score) Highest education of parents:

  Occupation of head of family: (score)

  Monthly income of family: (score)

- Does the family have a BPL (Below Poverty Line) card: Yes / No
- Immunization status: (as per National Immunization Schedule)

  ……

  Fully immunized / Partial / Unimmunized

- Weight: Kg Grams

Birth details (Neonates)

Born to G……P…….

Gestation…… Weeks (on time / early / late / don't know)

Place of delivery: Home ☐ Hospital ☐

Type of Hospital

Nursing home / PHC ☐

- Pediatrician availability ☐

District hospital/Multispecialty hospital ☐

State medical college / PGIMER ☐

Delivery attended by

Untrained Dai / Trained Dai / Nurse / Obstetrician / Others

Mode of Delivery

Vaginal Delivery: Normal
Instrumental delivery

LSCS: Elective
Emergency

How much time did the labour and delivery take?.....

Were you informed about drugs to induce labour?.....

Cried immediately after birth: Yes/Weak /No/Don't Know

Able to suckle after birth: Normal/Weak/No/Don't Know

Apgar score (from referral note): 1 minute…… 5 minute…… 10 minute……

Any Resuscitation: Yes/No Description /details if available……

……..

- **Description of illness** (open ended, unprompted)

Prompt: was there anything else?

What was the length of time the child was ill? ……..

- **Disease related Symptoms during illness**

During the illness, did she/he have

Refusal to feed	Yes/No/Don't Know	duration
Fever	Yes/No/Don't Know	duration
Loose stools	Yes/No/Don't Know	duration
Vomiting	Yes/No/Don't Know	duration
Fast breathing	Yes/No/Don't Know	duration
Cough	Yes/No/Don't Know	duration
Chest indrawing	Yes/No/Don't Know	duration
Noisy breathing	Yes/No/Don't Know	duration
Seizures	Yes/No/Don't Know	duration
Bulging fontanelle	Yes/No/Don't Know	duration
Altered consciousness	Yes/No/Don't Know	duration
Malformation	Yes/No/Don't Know	
Complicated delivery	Yes/No/Don't Know	
Born early	Yes/No/Don't Know	
Very small at birth	Yes/No/Don't Know	
any other symptoms		
Specify		duration

Referred case : ☐ Discontinued care at other hospital: ☐ Came from home ☐

Total number of contacts with health care systems /health care providers since the onset of illness and details:

Names and addresses of the referring hospitals:

……

Date & time of admission: Date & time of referral: Duration of stay:

……

Date & time of admission: Date & time of referral: Duration of stay:

……

Date & time of admission: Date & time of referral: Duration of stay:

Treatment received at the referring facility: (Narrative)

……..……

……..……

……..……

Pre-referral communication: Yes /No Referral note: Yes / No

Referral diagnosis: *Information from parents:* *From Referral note:*

Referral information: Complete / Incomplete – Details mentioned:

(Referral document checklist)

- HR: /min Not Mentioned ☐
- RR: /min Not Mentioned ☐
- BP: ...../..... mmHg Not Mentioned ☐
- If hypotensive whether fluid bolus: Yes / No Inotropes Yes / No
- If in respiratory distress/failure whether on: Supplemental O_2 / CPAP / PPV_ BMV/IMV
- SpO2 %
- Consciousness / GCS E V M Not Mentioned ☐
- Pupil: size reaction Not Mentioned ☐
- Blood glucose Not Mentioned ☐
- Any other important finding
- Treatment given: Not Mentioned ☐

  Drugs: Blood components:

- Reason for referral to PGIMER?

……

Severity of illness

Need for critical care expertise

Failure of treatment

Nonavailability of doctors

Financial constraints

Others (specify)…….

- Duration between first communication on decision of referral and actual referral time:

Immediately (within 2 hrs)

Some delay (within 2-4 hrs)

Great delay (within 4-6 hrs)

Severe delay (>6 hrs)

Reason for delay.....

……

- Mode of transport used to reach PGIMER (Tick the appropriate)

Hospital referral services /Ambulance

Own Vehicle

Car / Scooter / Bike / Others

Private hire

Taxi / Auto rickshaw

Public transport system

Bus / Train

- If by ambulance whether it was equipped with

a. Oxygen Y/N

b. Multiparameter monitor Y/N

c. Resuscitation equipment / drugs Y/N

d. Accompanied by a doctor or para-medical staff: Y/N

- Any deterioration noted during transport: Y/N

If yes, describe…….

a. Worsening of sensorium/loss of consciousness
b. Seizure
c. Gasping/Worsening of breathing
d. Fall in blood pressure / loss of pulse
e. Fall in oxygen saturation
f. Tachycardia / Bradycardia

If yes what was done to treat? Describe the intervention

……..

……..

(Oxygen, Fluids, Drugs, Bag ventilation, Chest compression)

- Travel distance: (From the point of referral to PGIMER) in Kms
  ……..……
- Time taken to reach PGIMER from the point of referral (Time of start to arrival time in ED) ……
- Perceived delay in transport?
- If yes, reasons
  ……
  ……

Triage details at PGIMER

Date & Time of admission:

Physiological Categorization:

Cardiorespiratory failure

Cardiorespiratory arrest

CPR

ROSC

Final diagnosis

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Brought in dead cases to a tertiary referral pediatric Emergency Department in India: a prospective qualitative study

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Abstract

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

Setting: Tertiary Pediatric 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 was 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 post neonatal 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 post neonatal children. Eighty-nine cases were referred from another health care facility, majority after first health care 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) minutes respectively. Respiratory support during transport included supplemental nasal oxygen (n=41,46%) and bag and tube ventilation (n=30,34%). Clinical deterioration was recognized in 62 children during transport, only 5 received

CPR en-route. Ninety-five children underwent CPR at the referral center, 2 had return of spontaneous circulation (ROSC).

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

Introduction:

Low- and middle-income countries (LMIC) like India face unique challenges in the health care sector. Growing population and limited ability to expand health care resources puts the vulnerable age groups of neonates and young children at high risk for morbidity and mortality. Although global estimates of under-5 mortality have shown a substantial decline over the past two decades, the United Nations' Millennium Development Goal of reducing under-5 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 5 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, diarrhea 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 (DOA) 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 pre-hospital 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 recognize 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

Enrollment: 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. The study was approved by the Ethics Committee of the Institute.

Patient and public involvement (PPI): 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 semi-structured 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 outlined about the nature of interview. Authors PK1, KN and JM were involved in field visits. Data collection began immediately after enrollment 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 child had become symptomatic at home to the point of presentation to ED was noted. A predesigned semi structured questionnaire was used to record the information (Supplementary file). The questionnaire also included elements described in WHO verbal autopsy standards.[12] The entire process of interview was completed in 20 – 30 minutes. In situations where obtaining complete information was not possible immediately, telephonic interview or home visit at a later point were 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 center. 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 was de-identified 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, i) pre-hospital determinants (social and disease related factors), ii) health system based factors and iii) referral factors.

During enrollment, we observed that a significant proportion of BID cases were neonates. Data saturation was planned to be achieved based on sizeable representation of post neonatal 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 analyzed the data. Majority of the data were arranged in prefigured deductive codes derived from the semi structured 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 standard deviations (normally distributed data) or as median and interquartile range (non-parametric data). Statistical package for social sciences (SPSS) version 20.0 for Windows (SPSS, IBM, Chicago, IL, USA) 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 first 3 days of life, majority (n=21, 38%) within first 24 hours. More than three fourths of enrolled neonates (n=43, 78%) were low birth weight (< 2.5kg); 12(28%) very low birth weight and 3 (7%) extremely low birth weight babies. Post neonatal 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:girls ratio of 1.27:1. Among post neonatal children, more than two thirds (n=31, 69%) were undernourished with weight for age below 2 standard deviation 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 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 post neonatal age. The median duration of symptoms was shorter in neonates as compared to post neonatal 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 post neonatal 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]. Majority were referred after first health care contact (n=77, 87%), while 11 (12%) were referred after two health care 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 out-patient services (93%), indoor admission wards (88%) and an emergency room (85%) were commonly available, level II or higher neonatal (29%) and pediatric (19%) 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 pediatricians (38%) or undergoing training in pediatrics (20%).

Pre-referral 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 CPAP. 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 lack of specific treatment (n=5, 6%) were less common reasons [Table 3].

Transport:

Of the 100 children, a little over three fourth 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 km to 322 km with the median (IQR) of 80 (25-111.5) km. Correspondingly, the time taken to travel the distance ranged from 10 minutes to 540 minutes with the median (IQR) 120 (60-180) minutes. In 62 cases, clinical deterioration was recognized during commute; majority were respiratory deterioration in the form of gasping or laboured breathing (n=58, 94%). Only 5 (8%) children received cardiopulmonary resuscitation during transport [Table 4]. Ninety-five children underwent cardiopulmonary resuscitation on reaching the referral center, of which only 2 cases had return of spontaneous circulation (ROSC).

Discussion

In this observational study in a tertiary referral public health care setting, we could discern several factors potentially influencing the BID status of children at presentation. Firstly, a significant proportion of our children belonged to a socially and economically deprived strata placing them at a disadvantaged position with respect to health seeking. Additionally, most parent's education level was till 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 post neonatal 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]

Secondly, the BID cohort 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 hospitalized 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 destabilization, were the most common reason for seeking care. Among the post neonatal children, the leading illness was pneumonia (24%), followed by congenital heart diseases (13%) and acute diarrheal disease (11%). Most neonates in our study had one or more known risk factors for increased mortality; one third (33%) were premature, nearly four fifth (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/ low birth weight, neonatal infections, birth asphyxia and birth trauma.[18] Pneumonia and diarrhea 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 health care systems especially in LMIC. [19, 20]

Thirdly, 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 in-patient wards. However, facilities for acute care beyond immediate stabilization were limited. The emergency rooms/wards

were common for both adults and children and an organized 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 recognized for 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 stabilization. Missing the 'golden hour' at first health care 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, pre-referral 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 pre-referral 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 health care system. The average distance travelled, and time taken to travel by a patient to reach the referral center in our study was 80 km (IQR:25-111.5) and 2 hours respectively. Contrary to many other studies, the commonest mode of transportation in our study was ambulance (77%). [23-25] The increased use of ambulance could be attributed to more prevalent and free of cost national ambulance service (NAS)

which is now operational in India. Majority of ambulances were equipped with oxygen and fewer with life support drugs and resuscitation equipments. Although a paramedic accompanied the patient in 63% cases, majority were ill equipped to recognize deterioration and stabilize 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 first of its kind to look at non-disease related determinants of brought in dead 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 enroll all consecutive cases during the study period due to declined consent by some parents. Our data predominantly reflect information generated from apriori themes. This study suffers from the inherent shortcomings of qualitative studies which includes subjectivity and limited generalizability.

Conclusions

Complications of prematurity, birth asphyxia, sepsis and pneumonia were the common etiologies in children brought in dead to tertiary care Emergency Department. 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.

What is already known?

Hospital based data have mainly focused on disease specific mortality in children. Complications of prematurity, diarrhea and pneumonia are the leading causes of neonatal and child deaths.

Children who are brought in dead to a hospital in low middle income countries represent deaths due to complex interplay of disease related determinants with social and 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 pre-referral communication, poor documentation and inadequate transport services to address resuscitation needs were the common factors identified in children with decompensated referrals.

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Table 1: Study population characteristics

Characteristics	n=100
Age	
Median (IQR) in months	4 (2-5)
Neonates	55
0 ≤ 24 hours	21
>24 hours≤ 72 hours	16
> 3days ≤ 7 days	9
>7 days ≤ 28 days	9
Post neonatal age	45
>28 days≤ 1 Year	22
>1 Year ≤ 5 Years	14
>5 Years ≤12 Years	9
Sex	
Male	56
Female	44
Underweight	
Neonates: LBW (<2.5Kg)	45 (78%)
Post neonatal children: Weight < 2SD	31 (69%)
Birth order	
1	46
2	25
3	22
4	6
5	1
Immunization status	
Fully immunized	45
Partial immunized	8
Not immunized	47
Background	
Rural	52
Urban	48
Religion	
Hindu	74
Muslim	8
Sikh	18
Socio economic 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
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)

Table 2: Common symptoms and referral diagnosis

Clinical details	Study population (100) n	Neonates (55) n (%)	Post neonatal 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 diarrhea			5 (11)	
Snake envenomation			3 (7)	
Seizure			2 (4)	

Table 3. Details of referral hospitals, pre-referral 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)
In patient ward	36 (88)
Emergency Unit	35 (85)
Neonatal Ward	30 (73)
NICU	12 (29)
PICU	08 (20)
Biochemistry/Hematology	35 (85)
Xray	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)
Pediatrician (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 & tube ventilation	30 (34)
Mechanical ventilation	8 (9)
Oxygen driven nebulization	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)
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)

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 O2	18
IV 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 (in km)	
Median (IQR)	80 (25-111.5)
Time taken to reach referral centre (in minutes)	
Median (IQR)	120 (60-180)

Brought in dead cases to a tertiary referral pediatric Emergency Department in India: a prospective qualitative study

Date: …. /….. /…… Time: … : … hours

Interviewer:

Main respondent's relationship to the child: Language of the interview:

Educational status of the respondent:

Are there other people present at the interview? If yes, their relationship:

Enrol No. CR No.

Address: _____

_____

Mobile No. _____

- Age: years month days hours
- Date of birth- ___/____/____Time of birth: : hrs
- Sex: Male Female
- Order of birth:

1	2	3	4	5

- Religion:

  Hindu /Muslim / Sikh / Christian/Others

- Socioeconomic status: (modified Kuppuswamy scale)

  Education of head of family: (score) Highest education of parents:

  Occupation of head of family: (score)

  Monthly income of family: (score)

- Does the family have a BPL (Below Poverty Line) card: Yes / No
- Immunization status: (as per National Immunization Schedule)

  ……

  Fully immunized / Partial / Unimmunized

- Weight: Kg Grams

Birth details (Neonates)

Born to G……P…….

Gestation…… Weeks (on time / early / late / don't know)

Place of delivery: Home ☐ Hospital ☐

Type of Hospital

Nursing home / PHC ☐

- Pediatrician availability ☐

District hospital/Multispecialty hospital ☐

State medical college / PGIMER ☐

Delivery attended by

Untrained Dai / Trained Dai / Nurse / Obstetrician / Others

Mode of Delivery

Vaginal Delivery: Normal
Instrumental delivery

LSCS: Elective
Emergency

How much time did the labour and delivery take?.....

Were you informed about drugs to induce labour?.....

Cried immediately after birth: Yes/Weak /No/Don't Know

Able to suckle after birth: Normal/Weak/No/Don't Know

Apgar score (from referral note): 1 minute…… 5 minute…… 10 minute……

Any Resuscitation: Yes/No Description /details if available……

……..

- **Description of illness** (open ended, unprompted)

Prompt: was there anything else?

What was the length of time the child was ill? ……..

- **Disease related Symptoms during illness**

During the illness, did she/he have

Refusal to feed	Yes/No/Don't Know	duration
Fever	Yes/No/Don't Know	duration
Loose stools	Yes/No/Don't Know	duration
Vomiting	Yes/No/Don't Know	duration
Fast breathing	Yes/No/Don't Know	duration
Cough	Yes/No/Don't Know	duration
Chest indrawing	Yes/No/Don't Know	duration
Noisy breathing	Yes/No/Don't Know	duration
Seizures	Yes/No/Don't Know	duration
Bulging fontanelle	Yes/No/Don't Know	duration
Altered consciousness	Yes/No/Don't Know	duration
Malformation	Yes/No/Don't Know	
Complicated delivery	Yes/No/Don't Know	
Born early	Yes/No/Don't Know	
Very small at birth	Yes/No/Don't Know	
any other symptoms		
Specify		duration

Referred case : ☐ Discontinued care at other hospital: ☐ Came from home ☐

Total number of contacts with health care systems /health care providers since the onset of illness and details:

Names and addresses of the referring hospitals:

……

Date & time of admission: Date & time of referral: Duration of stay:

……

Date & time of admission: Date & time of referral: Duration of stay:

……

Date & time of admission: Date & time of referral: Duration of stay:

Treatment received at the referring facility: (Narrative)

……..……

……..……

……..……

Pre-referral communication: Yes /No Referral note: Yes / No

Referral diagnosis: *Information from parents:* *From Referral note:*

Referral information: Complete / Incomplete – Details mentioned:

(Referral document checklist)

- HR: /min Not Mentioned ☐
- RR: /min Not Mentioned ☐
- BP: ...../..... mmHg Not Mentioned ☐
- If hypotensive whether fluid bolus: Yes / No Inotropes Yes / No
- If in respiratory distress/failure whether on: Supplemental O_2 / CPAP / PPV_ BMV/IMV
- SpO2 %
- Consciousness / GCS E V M Not Mentioned ☐
- Pupil: size reaction Not Mentioned ☐
- Blood glucose Not Mentioned ☐
- Any other important finding
- Treatment given: Not Mentioned ☐

  Drugs: Blood components:

- Reason for referral to PGIMER?

……

Severity of illness

Need for critical care expertise

Failure of treatment

Nonavailability of doctors

Financial constraints

Others (specify)…….

- Duration between first communication on decision of referral and actual referral time:

Immediately (within 2 hrs)

Some delay (within 2-4 hrs)

Great delay (within 4-6 hrs)

Severe delay (>6 hrs)

Reason for delay.....

……

- Mode of transport used to reach PGIMER (Tick the appropriate)

Hospital referral services /Ambulance

Own Vehicle

Car / Scooter / Bike / Others

Private hire

Taxi / Auto rickshaw

Public transport system

Bus / Train

- If by ambulance whether it was equipped with

a. Oxygen Y/N

b. Multiparameter monitor Y/N

c. Resuscitation equipment / drugs Y/N

d. Accompanied by a doctor or para-medical staff: Y/N

- Any deterioration noted during transport: Y/N

If yes, describe…….

a. Worsening of sensorium/loss of consciousness
b. Seizure
c. Gasping/Worsening of breathing
d. Fall in blood pressure / loss of pulse
e. Fall in oxygen saturation
f. Tachycardia / Bradycardia

If yes what was done to treat? Describe the intervention

……..

……..

(Oxygen, Fluids, Drugs, Bag ventilation, Chest compression)

- Travel distance: (From the point of referral to PGIMER) in Kms
  ……..……
- Time taken to reach PGIMER from the point of referral (Time of start to arrival time in ED) ……
- Perceived delay in transport?
- If yes, reasons
  ……
  ……

Triage details at PGIMER

Date & Time of admission:

Physiological Categorization:

Cardiorespiratory failure

Cardiorespiratory arrest

CPR

ROSC

Final diagnosis