J HEALTH POPUL NUTR 2002 Jun;20(2):148-155
ISSN 1606-0997 $ 5.00+0.20

Pathways to Infant Mortality in Urban Slums of Delhi, India: Implications for Improving the Quality of Community- and Hospital-based Programmes

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ABSTRACT

The study aimed at obtaining insights into the processes underlying infant deaths to help identify preventive interventions which may bring down infant mortality rates further. Verbal autopsies were performed on 162 deaths of liveborn infants that occurred in a birth cohort in two urban slums of Delhi, India, between February 1995 and August 1996. A structured verbal autopsy form was used for ascertaining the cause of death. The narratives of caretakers on seeking of care and treatment received for illness were reviewed to identify the actions and behaviours that might have contributed to death. Seeking of care was less common (57%) for illnesses that led to death in the first week of life than at later ages. The first-week deaths commonly (61%) occurred within 24 hours of recognition of illness which might have been too a short time for effective interventions by care providers. Only six of 45 neonates who had features of sepsis, pneumonia or meningitis, major congenital malformations, birth asphyxia, or prematurity were advised by primary care providers for hospitalization. Similarly, only 25 (41%) of 61 older infants who had severe malnutrition and sepsis or meningitis, diarrhoea or pneumonia, or other illnesses were referred to hospital. Parenteral antibiotics were prescribed less often than warranted. Only two of 16 neonates with serious bacterial infections and eight of 19 postneonates with features of sepsis or meningitis received parenteral antibiotics. Inappropriate healthcare practices were common among the practitioners of modern and indigenous systems of medicine and registered medical practitioners. Forty percent of the neonates and a little over half of the older infants, advised for hospitalization, were taken to hospital. Fifteen percent of the infants taken to hospital were refused admission. Of 21 hospitalized infants discharged alive, five (23%) died within 48 hours and 13 (62%) within a week of returning home. A major effort is required to improve skills of healthcare providers of the biomedical and indigenous systems of medicine in caring for neonates and infants. Development of home-based treatment regimens for young infants and objective criteria for their hospitalization and discharge should receive a high priority.

Key words: Infant mortality; Causes of death; Slums; Healthcare; India

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INTRODUCTION

Mortality rates among children aged less than five years in developing countries have declined over the past years consequent to improving socioeconomic conditions and child-survival programmes (1). Infant mortality has also declined in most settings; the challenge now is how to reduce the current rates further. One of the ways could

be to obtain greater insights into the processes underlying infant deaths, beginning from recognition of illness and its severity by the family, care-seeking practices, and the quality of care received when it is sought. This knowledge will help improve the impact of current health programmes.

We present results of an analysis of infant deaths in a birth cohort of 4,000 newborns enrolled in a multi-centre randomized controlled trial that evaluated the safety and benefits of vitamin A administration to mothers within four weeks of delivery and to their infants at each polio and DPT immunization (2). In this trial, infants were randomly allocated to receive vitamin A or placebo at three weeks of age and followed up at monthly intervals until their first birthday. The point and period prevalence of common childhood illnesses were ascertained, and deaths occurring during infancy were identified. There was a modest benefit of the intervention on vitamin A status at six months but without any impact on morbidity or mortality. As the surveillance for morbidity was largely passive, the study offered a unique opportunity for in-depth analysis of causes and underlying processes of deaths in depth.

MATERIALS AND METHODS

Study site

The study was conducted in two urban slums in Delhi, India, between February 1995 and August 1996. Residents here usually live in single-room hutments. About half of the families are nuclear. Four-fifths of women and two-fifths of men have never been to school. Malnutrition among children aged less than three years is widely prevalent. About 42% of them are stunted (height-for-age z-score ≤-2), and 17% are wasted (weight-for-height z-score ≤-2) at the age of 12 months (3,4). These children suffer from 6-8 episodes of diarrhoea and 1-2 episode(s) of acute lower respiratory infections per year (3,4).

This population is served by a pluralistic healthcare system that includes traditional and modern healthcare providers (5). The providers include physicians trained in the biomedical system of medicine (30%), in indigenous systems of medicine, primarily Ayurveda (20%), and registered medical practitioners or RMPs (30%). The government based on their work experience certifies the latter category, but they usually lack formal training. The remaining are either nurses or community health workers who have set up a practice. Within and around the study area, about 50 such healthcare providers attend to clients in small clinics or larger nursing homes; the latter also offer inpatient facilities. Outpatient services are provided by two clinics run by non-government organizations and one government clinic. Some families also visit faith healers who are usually based in places of worship. In this paper, we refer to public hospitals as source of care as those where medical care is government-sponsored and is provided almost free of charge to patients. On the other hand, patients seeking care from private sources need to make out-of-pocket expenses for care.

Enrollment of birth cohort and identification of deaths

Pregnancies and new births were identified through a door-to-door survey covering the entire community of 125,000 inhabitants, and pregnant women were followed up weekly until delivery. Infants were enrolled in the intervention trial at three weeks of age. Whenever an identified newborn did not turn up at the clinic for enrollment, a home-visit was made to identify the live/dead status. After the initial nine months of the study and until the 18th month, i.e. the end of enrollment, an informant-based system was used for identifying newborns or infants aged less than three weeks. During this period, deaths in the first three weeks of life were not ascertained.

Ascertainment of cause and the pathway to death

Female physicians, trained in ethnographic techniques, soon after the death but within 16 weeks, visited families of dead infants. They conducted verbal autopsies at home, using a semi-structured questionnaire developed and validated by the World Health Organization (WHO) to identify the medical causes of death (6-8). First, the narratives of the caretakers were recorded in the local language. During the narration, the caretakers were encouraged to describe, in details, the events in their own words pertaining to the illness and the circumstances that led to death. Following this, the structured component of the questionnaire for neonatal or postneonatal deaths was completed as appropriate. The questionnaire covered symptoms, signs, management of illness that led to death, and hospitalization details.

Three paediatricians independently reviewed the completed verbal autopsy forms to assign up to four causes of death using the definitions provided with the verbal autopsy instrument for guidance (6). Disagreements between paediatricians regarding the designated causes of death were discussed together to arrive at a consensus.

A paediatrician and a social scientist together reviewed the narratives to obtain an insight into the pathway to deaths. They focused on identifying points at which the death might have been averted, and the actions and behaviours that might have contributed to death. The inferences from this review were recorded in a structured format developed after a reiterative process involving several pilot evaluations.

Socioeconomic and other baseline data and weight measurements of infants were available from the main trial. Antecedent weight measurements closest to death were used for estimating the weight-for-age status.

For deaths in the first week of life, standard medical definitions were used. The recommendations of Integrated Management of Childhood Illness (IMCI), proposed by the WHO, were considered the standard against which healthcare received by the infants as reported by their mothers during verbal autopsies was assessed (9,10).

RESULTS

A total of 185 infant deaths were reported during the study period. The causes of death by age ascertained through verbal autopsies are given in Table 1. In the neonatal period, pneumonia, sepsis, or meningitis were considered to be a single category, but at later ages, pneumonia was treated as a distinct group from septicaemia or meningitis. Of the total 162 respondents, 85% were mothers of infants, and the remaining 15% were either fathers, grandparents, or an adult relative residing with the family at the time of fatal illness. The data presented pertain to 162 deaths of liveborn infants where verbal autopsies could be conducted. Fifty-seven (35%) of these infants died in the neonatal period. Forty-six percent who died were males. Two-thirds were born at home, and the remaining in hospitals or nursing homes. Of the hospital-born infants, 14 died before they could be sent home. The main contributory factors identified were premature birth (n=4), meconium aspiration (n=3), prolonged labour (n=2), congenital malformations (n=2), and 'very weak' baby (n=3).

Care-seeking practices

Seeking of care was less common (57%) for those infants who died during the first week of life, whereas care was sought for most of the infants who died in the 8-28-day and postneonatal periods. Seeking of care was delayed, i.e. interval between onset of symptoms and seeking of care was ≥72 hours in 25% and 22% of deaths occurred between 8 and 28 days and in the postneonatal period respectively (Table 2).

The most probable reason for the lower prevalence of care-seeking for infants who died in the first week was the rapid evolution of illness in the first week of life; 61% of the deaths in this period occurred within 24 hours of recognizing the illness by the mother as against 12% between eight and 28 days and 15% of those in the postneonatal period (Table 2). After seven days of age, the duration between reported onset of symptoms and death was ≥7 days in 52% and ≥14 days in 33% of the cases.

Among the first-week deaths, 'refusal to feed', 'very small baby' and 'cold to touch' were the most frequently-quoted reasons for seeking care. Cough, fever, fast breathing, and diarrhoea were rarely cited. The reasons for seeking care for infants who died between 8 and 28 days were diarrhoea, excessive crying, 'very weak child', refusal to feed, fever, difficult breathing, and vomiting; cough was not reported. In the postneonatal period, diarrhoea, respiratory symptoms, fever, vomiting or 'very weak child' were expectedly the common reasons for seeking care.

Table 1. Causes of death by age-at-death among 162 infant deaths

Cause of death	Age of children who died		
	0-7 day(s)	8-28 days	29-365 days
Pneumonia, sepsis, or meningitis	7	9	-
Congenital malformations	6	-	-
Birth asphyxia	11	-	-
Prematurity	9	-	-
Diarrhoea	-	5	35
Meningitis or sepsis	-	-	19
Pneumonia	-	-	17
Diarrhoea and pneumonia	-	-	18
Others	7	3	16

The age of infants did not influence the type of first care provider visited during the illness that led to death, or prematurity (n=12). Of these, only four (11%) were advised for hospitalization. Of those who died between

Table 2. Timing of care-seeking after onset of first symptom of illness as reported by caretakers

Care-seeking	Age at death		
	≤7 days (n=26)*	8-28 days (n=17)	29-365 days (n=105)
Care sought, no. (%)	15 (57.6)	16 (94)	91 (86.6)
Interval between onset of illness and time of seeking care (hours)			
≤24	13	8	56
25-48	1	4	8
49-72	-	-	7
≥72	1	4	20
Care not sought, no. (%)	11 (42.3)	1 (5.8)	14 (13.3)

* 14 hospital-born infants were excluded as they died in the hospital before discharge

Table 3. Treatment received by infants, aged 29-365 days, who sought care for illness that led to death

Advice	Sepsis or meningitis (n=19)	Diarrhoea (n=33)	Pneumonia (n=15)	Diarrhoea and pneumonia (n=16)	Others (n=8)
Injections	8	8	5	3	3
Oral drugs	14	28	10	13	4
Oral rehydration solutions	2	19	-	3	-
Home fluids	-	-	-	1	-
Intravenus fluids	2	7	3	2	2
Referral to hospital	7	13	5	6	2
Proportion severely malnourished: sepsis or meningitis–10/19, diarrhoea–25/33, pneumonia–12/15, diarrhoea and pneumonia–12/16, others–2/8					

hospital versus outpatient care. The registered medical practitioners and providers trained in the indigenous systems of medicine (54%) were consulted more often than biomedically-trained physicians (38%). Private sources of care were preferred (71%) despite their higher expense. About half (44%) of the families visited a single provider, a quarter visited two, and the remaining visited three or more during the illness that lead to death. Care was more commonly sought from a provider practising within the slum (62%). The age of infants at the time of the illness that led to death did not influence this decision; 19% of the neonates and 18% of the older infants were directly taken to hospital.

Quality of healthcare

The healthcare providers grossly under-estimated the need for hospitalization. At least in 36 of 41 infant deaths in the first week, the verbal autopsy suggested a clear need for hospitalization for features suggestive of sepsis, pneumonia, or meningitis (n=7), congenital malformations (n=7), birth asphyxia (n=10), or 8 and 28 days, only two of nine infants with features of pneumonia, sepsis, or meningitis were advised for hospitalization. A similar pattern for hospital referral was seen in older infants (Table 3). Sixty-one (67%) of these infants were severely malnourished (weight-for-age <60% of National Center of Health Statistics median) at that age and had features suggestive of sepsis or meningitis, diarrhoea, pneumonia, or other illnesses. Of these, only 25 (41%) were referred to hospital.

The treatment prescribed was inadequate in other aspects as well. Parenteral antibiotic therapy was given less often than warranted. For instance, only two of the 16 neonates, who fulfilled the IMCI criteria for serious bacterial infections, such as sepsis, pneumonia, or meningitis, received injections prior to death. Also, only eight of the 19 infants who died in the postneonatal period with features of sepsis or meningitis were given parenteral antibiotics.

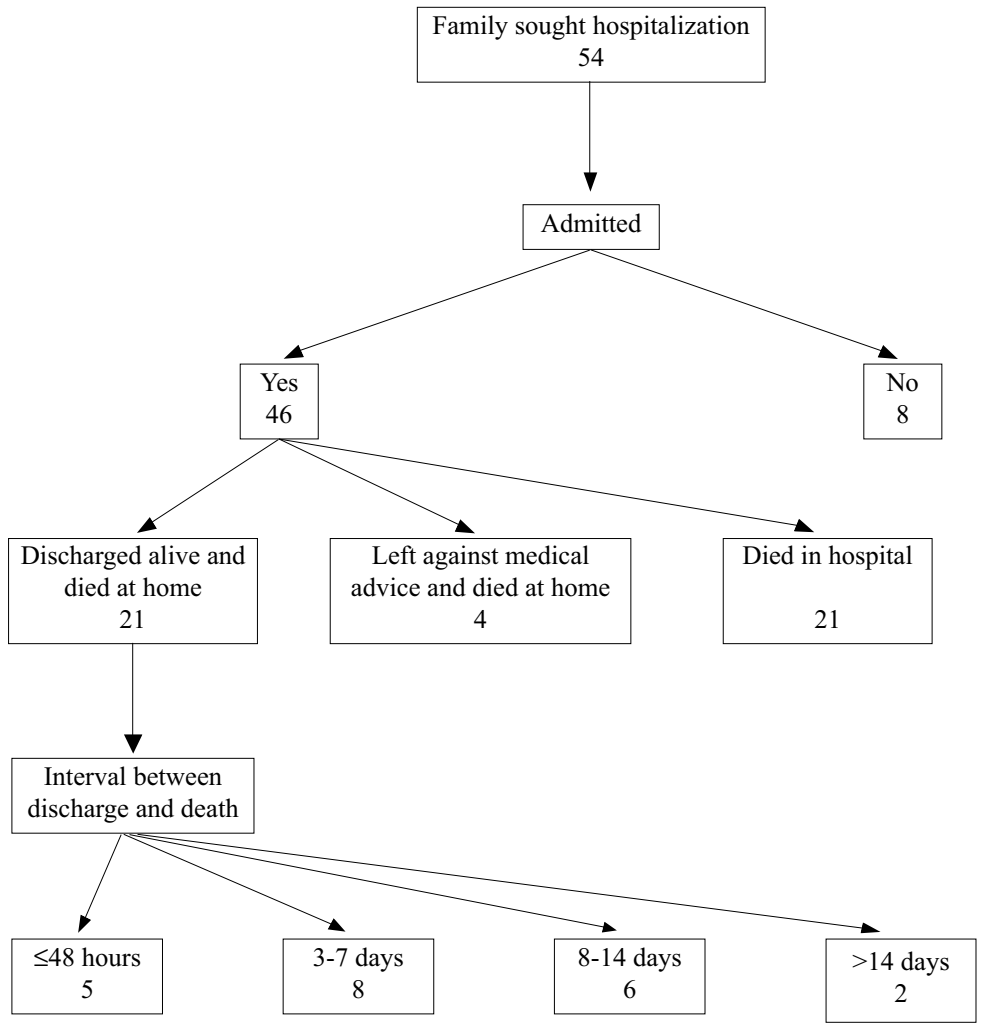
Twenty-seven (48%) of 56 infants who had diarrhoea as a single or one of the multiple illnesses were prescribed

oral rehydration solutions (ORS). Prescription for ORS was particularly low for children with diarrhoea and pneumonia (18%) compared to those with diarrhoea alone (57%, p=0.004). Caretakers of only two of the 56 infants recalled having received instructions to increase the use of home-available fluids. None of seven neonates with watery diarrhoea and only six of 25 older infants with diarrhoea and severe malnutrition were given injectable antibiotics. Three of these neonates and 11 postneonates were referred to hospital. These inappropriate practices were nearly equally common in physicians of the modern system of medicine and other providers (data not shown).

Compliance with advised treatment

All caretakers reported full compliance with the prescribed oral drugs, injectables, and ORS. Four (40%) of 10 neonates and 18 (54%) of 33 older infants advised for hospitalization were taken to hospital. Common reasons for not complying with advice for hospitalization were the lack of perception that the child was gravely ill, perceived improvement in the condition of child, inability to leave the home because of other siblings, economic reasons, reluctance because of unpleasant past experiences, and advice against doing so by other family members.

Fig. Outcome of infants who sought hospital care for illness that led to death



*Excludes 14 hospital-born infants who died shortly after birth in the hospital

Outcome of infants who sought hospital care

Families of 54 infants went to hospital to seek admission of their children. Eight (15%) were not admitted because the physician felt that the children would die anyway (n=4) or the children did not require hospitalization (n=3), and because of a strike of workers (n=1). Almost half of 46 infants hospitalized died in the hospital, and four were brought home against medical advice. A notable finding was that five (23%) of 21 infants discharged alive died within 48 hours and 13 (62%) within a week of returning home. This suggests that the infants were discharged prematurely and that follow-up advice was either communicated poorly or not complied with.

DISCUSSION

Analysis of the pathway from illness to death in infants residing in an urban slum revealed major lacunae in care-seeking behaviour and care provided to the sick infants that might have significantly contributed to their deaths. The majority of deaths occurred in infants aged less than four months and those who were malnourished.

Care-seeking rates were low for illnesses occurring during the first week of life. The illnesses in these infants were unique to this age group linked as they are to the birth process and evolved rapidly. Death often occurred within a day or so of the onset. In settings where the majority of babies are delivered at home, improved case management by physicians as a strategy to reduce deaths during day 0 to 7 is less likely to be successful. Promoting institutional deliveries and measures to reduce prematurity and low birth-weight must be accorded a higher priority. Further research is needed to explore whether delayed recognition of illness during the perinatal period contributed to deaths occurring within a short period of onset of symptoms.

Seeking of care was common after the first week, but in a significant proportion, only after an avoidable delay. At this age, over half of the deaths occurred after seven or more days of onset of symptoms, suggesting potential for prevention through appropriate and timely case management. It is notable that the major causes of death between seven and 30 days of age are similar to those between one and 11 months, and these deaths can be prevented by careful implementation of currently-recommended algorithms for integrated assessment and care (9,10).

A substantial proportion of infants who died had multiple illnesses and nutritional problems. Notable is the lack of appreciation of the additional care required by ill infants who also have associated malnutrition. The healthcare providers of all systems lacked skills for adequate comprehensive care of such infants. Training programmes for healthcare providers in developing countries with a focus on a comprehensive, integrated assessment and treatment of sick infants are clearly required. The development of generic concept of IMCI by the WHO is a step in this direction (9).

Private sources of care are increasingly being preferred when seeking care for infants in many developing countries. These care providers are usually excluded from training under the national programmes, and this trend requires to be reversed if appropriate case management is to become a reality for most sick infants. Practitioners of alternative systems of medicine should be integrated into the health system and trained adequately. Providers with no formal medical training should either be included for training under national programmes, or, if such an approach is inconsistent with the national policy, must be actively discouraged from practice.

It is currently recommended that all infants aged less than two months with features of possible serious bacterial infections be promptly hospitalized (9). Our findings and those of earlier studies suggest that families in developing countries often find advice for hospitalization difficult to comply with because of unpleasant past experiences of the family (11-13). Major reasons reported were long-waiting time, complex admission and investigation procedures, overcrowding of hospital beds, lack of empathy by doctors, and rude behaviour of paramedical staff. Care of other siblings also makes hospitalization a difficult choice for some mothers.

This difficult problem may be solved by according more emphasis during pre-service and in-service training to developing good communication skills, simplifying hospital procedures to make the system more user-friendly, and creating opportunities for one-to-one interactions between medical personnel and caretakers. For those who deliberately decide against hospitalization, even when offered, care close to home in their own community is the only available option. Clinical trials are required to evolve optimal regimens for home and community-based treatment of such sick young infants, and one of the challenges here relates to ethical issues. For conducting such trials, one would need to randomize

sick infants requiring hospital care by current recommendations to receive parenteral antibiotics and supportive care in a hospital or as outpatient care at clinics close to their homes; the risks involved in the latter would perhaps be considered ethically questionable at least in some settings. The designs that evaluate outcome only among infants whose parents refuse hospitalizations and are, therefore, given outpatient treatment may provide useful information but are limited by the fact that an appropriate control group for comparison is not available. A recent study in India demonstrated the efficacy of home-based oral co-trimoxazole and twice-daily intramuscular injections of gentamicin in the management of young infants with possible serious bacterial infections (14). It has been shown that aminoglycosides administered as a single dose are as effective as multiple doses (15,16). A combination of oral antibiotics with a single daily aminoglycoside injection and other regimens should be evaluated for efficacy and safety for outpatient-based treatment of sick young infants in developing countries.

Denial of hospital admission to those seeking it and premature discharge of admitted patients significantly contributed to death. There is an urgent need to objectivize criteria for hospital admission by training physicians in standardized case-management protocols (9) that would include specific danger signs that merit hospital care and recognize very young age and severe malnutrition as high-risk factors among sick infants. A recent assessment of quality of care in hospitals among developing countries also identified problems with assessment of cases, selection of appropriate treatments, and premature discharge as common findings in non-teaching hospitals (17). Another contributing factor is non-functioning primary and secondary referral facilities, which make tertiary hospitals overcrowded. Improvements in health systems are required to make primary and secondary-level inpatient facilities better used.

This study had some limitations. The findings emanate from a single setting. The relevance of some observations may vary in other cultures but issues relating to skills of health workers are widely relevant. Although the usual sources of care continued to be used during the main study, some influence of the study team on seeking of care is likely. Also, since the information on seeking of care was retrospective, there may have been bias on account of recall.

In conclusion, to reduce infant mortality further in developing countries, a major effort at improving skills of healthcare providers within and outside the public sector is required. Regimens for care of such infants that are applicable in hospitals and for home treatment require to be standardized. Greater urgency must be imparted to our efforts to improve foetal and postnatal growth and nutrition, as antecedent malnutrition is a key determinant of infant mortality.

ACKNOWLEDGEMENTS

We are grateful to the Department of Child and Adolescent Health and Development, World Health Organization, for funding this study, and the Norwegian Universities' Committee for Development and Research (NUFU) and the Advanced Centre for Diarrheal Disease, Indian Council of Medical Research, for core support to our unit.

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