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Why do Families of Sick Newborns Accept Hospital Care? A Community-Based Cohort Study in Karachi, Pakistan

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Abstract

Objective—Sick young infants are at high risk of mortality in developing countries but families often decline hospital referral. Our objective was to identify the predictors of acceptance of referral for hospital care among families of severely ill newborns and infants <59 days old in three low-income communities of Karachi, Pakistan.

Study design—A cohort of 541 newborns and infants referred from home by community health workers doing household surveillance, and diagnosed with a serious illness at local community clinics between January 1 and December 31, 2007, was followed-up within 1 month of referral to the public hospital.

Results—Only 24% of families accepted hospital referral. Major reasons for refusal were financial difficulties (67%) and father/elder denying permission (65%). Religious/cultural beliefs were cited by 20% of families. Referral acceptance was higher with recognition of severity of the illness by mother (OR=12.7; 95% CI=4.6–35.2), family's ability to speak the dominant language at hospital (OR=2.0; 95% CI=1.3–3.1), presence of grunting in the infant (OR=3.3; 95% CI=1.2–9.0), and infant temperature <35.5°C (OR=4.1; 95% CI=2.3–7.4). No gender differential was observed.

Conclusion—Refusal of hospital referral for sick young infants is very common. Interventions that encourage appropriate care seeking, as well as community-based management of young infant illnesses when referral is not feasible are needed to improve neonatal survival in low-income countries.

Keywords

newborn health; care-seeking; Pakistan

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Conflict of Interest

All authors: No conflict of interest.

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INTRODUCTION

Of the 130 million babies born every year, approximately 4 million die in the first 4 weeks of life. Developing countries account for about 99% of these deaths, with South Asia accounting for almost half of these deaths.¹ The overwhelming majority of these deaths (75%) occur within the first week of life, with almost 50% occurring within the first 24 hours.¹ Three major causes, prematurity, complications related to birth, and infections, are responsible for more than 80% of neonatal mortality² and result in almost 50 million healthy life years lost (HeaLYs) due to neonatal deaths in the region.³ With approximately 5,000,000 births per year, and a neonatal mortality rate of 56 per 1000 live births⁴, Pakistan contributes nearly a quarter-million (7%) neonatal deaths, to the global burden of neonatal mortality.

There is a well-established association between not seeking care at all, or delays in seeking appropriate care, and the rate of child deaths in developing countries.⁵⁻¹⁰ There are many steps involved from the time the child falls ill at home until (s)he receives needed therapy at an appropriate health facility. Not only must the mother/care-giver of the child recognize the seriousness of the illness, she should be able to bring/take the child to the primary, and if necessary, tertiary care facility. Furthermore, the infrastructure necessary to manage and treat the child's illness successfully at each point of contact between the sick child and the health system must also be present.⁵

Many studies have looked at care-seeking behavior of families for themselves, and for their children. Socio-demographic characteristics which have been related to health-seeking behavior include gender and birth order of the child, ethnicity, parental, specifically mothers', education and employment, distance from the health facility, and the cost of care.¹¹⁻¹⁸ Maternal and newborn care-seeking history and practices which may affect health-seeking behavior include social support for the mother¹¹, use of private or alternative healthcare providers^{11, 13, 19, 20}, mother bringing child for care¹⁵, and recognition of the severity of child's illness by the mother/family.^{15, 20-22}

While there is much emphasis on evaluating the immediate causes of deaths in children, few studies have assessed the underlying determinants of care-seeking by families of newborns and young infants < 59 days old, the period in which neonatal and infant mortality is highest in developing countries. The majority of births in Pakistan occur at home, aided by traditional birth attendants or female family members. A community-based referral system that ensures and facilitates appropriate therapy for sick newborns is critical in reducing morbidity and mortality in this vulnerable population. However, little is known about the socio-demographic, behavioral, cultural and other factors that may compete with each other and influence a family's decision to seek care for their sick newborns.

Since July 2003, we have maintained research sites, established as part of the large multicenter Young Infant Clinical Signs Study²³, in several low-income areas in, and around, Karachi. These sites have a community-based, outreach program for newborn health, and maintain primary care clinics for the diagnosis and management of serious

illnesses in young infants, with transport to the major public-sector pediatric hospital available for those requiring referral.

Despite provision of transport and a dedicated physician to provide free medical care at the referral hospital, 50% of families from our urban sites, and 70 – 90% of families from our semi-rural sites refuse hospital care for their sick young infants. Based on these observations, we designed a longitudinal cohort study to follow and observe the families of sick newborns as they made critical care-seeking decisions regarding the health of their child. The availability of population surveillance and primary healthcare infrastructure, along with removal of barriers of referral transport and cost of therapy, provided a unique setting in which to observe family decision-making about sick newborns in real-time. Our aim was to understand the care-seeking attitudes and practices regarding maternal and newborn health, and specifically to identify predictors of acceptance of referral for hospital care for sick young infants among these families.

METHODS

Study Setting

This study was conducted in three low-income areas of Karachi. Community A is an urban setting, with numerous tanneries providing the main source of employment for its residents. There is a charity hospital serving the population of Community A, but it has limited neonatal care facilities. Communities B and C are both peri-urban areas, situated 20 km outside of Karachi. The major income generating activities include fishing and livestock rearing. Community B has a 30-bed public-sector hospital, but does not admit patients overnight, and has no newborn care facility. Community C does not have any facilities with overnight admission services. The total combined population under surveillance in these three areas during the study period was about 80,000.

These research sites have active surveillance systems and primary health clinics providing free health care services that operate between 0900–1600 hours daily and maintain a clinical database of all young infants presenting to the center. Clinical information recorded includes illness history, prior treatment and therapy sought, full physical examination findings, diagnosis assigned, management given, and final patient outcome. A referral system, with free transportation to a major pediatric hospital, is also provided for any sick child who needs referral care.

Fieldwork

A maternal and newborn health surveillance network, conducted by local women trained as community health workers (CHWs), was in place in all three study sites prior to start of the study period. The study used the infrastructure put in place for the Young Infant Clinical Signs Study to identify clinical signs of illness that signal the need for urgent referral to hospital in infants 0–59 days old.²³ CHWs referred any infant with serious illness to the local primary healthcare clinic.

Young infants presenting with complaints at the primary health centers were examined by a physician. If an infant had an illness requiring urgent hospital referral, the family was

counseled, and offered transport to the major public-sector pediatric hospital, with a dedicated neonatal intensive care nursery. At the hospital all diagnostic tests, medications and related supplies are provided free of cost.

Families who refused referral were offered recruitment in a trial of clinic-based antibiotic therapy. If trial participation was refused, injectable or oral antibiotics were offered.

Study Participants

The mothers/care-providers of 541 consecutive newborns and infants < 59 days, who were diagnosed with a serious illness at the above mentioned clinics between January 1, 2007 and December 31 2007, were interviewed at home, within one month of the onset of serious illness requiring referral. Because of the comprehensive newborn surveillance at our study sites (multiple home visits by CHWs during the first 2 months of baby's life), we estimate that > 90% of all serious illness episodes in young infants in the study area were captured at the primary healthcare clinic. A pilot-tested, pre-coded questionnaire was used to collect information on demographic characteristics, socioeconomic factors, and behavioral attitudes towards care-seeking for pregnant women and children. These interviews were conducted by Aga Khan University staff, trained in community-based data collection procedures. Most of the staff members had also been working in the area clinics for at least six months.

Infants who (i) were not residents of the study areas, (ii) required immediate cardiopulmonary resuscitation, or (iii) whose parents did not provide informed consent were excluded from the study.

Variable derivation

Information on age, sex and ethnicity of the child, as well as literacy and occupations of parents, travel time to nearest tertiary healthcare facility, and maternal (antenatal, intra and postpartum) and newborn care history and practices was collected during home interviews. In addition, a father's concern for his family's health was also collected on a 5-point scale, with 1 indicating no concern and 5 indicating adequate concern, as perceived by the child's mother. Information on parity, and the clinical signs and symptoms each child presented with was obtained from the Young Infant Clinical Signs Study database.

Data Analysis

We imported the data into Statistical Analysis Software (SAS), version 9.2, for statistical analysis. Median (range) was calculated for continuous variables. Frequency and percentage was computed for categorical variables. Associations between the primary outcome (i.e., acceptance of referral to tertiary care facility) and each of the demographic and socioeconomic factors, and care-seeking history/practices for pregnant women and children, as well as individual clinical signs and symptoms were examined by way of odds ratios (OR). The variables collected during home interviews and those obtained from the Young Infant Clinical Signs Study database were pre-sorted and grouped into one of three clusters of variables mentioned above. A multivariate model was fitted using stepwise selection. All variables considered to be significantly associated with the study outcome at the univariate level ($p < 0.05$) were included. Demographic variables were entered first, followed by socio-

economic factors, maternal and newborn care-seeking history and practices, and clinical indicators, respectively. Mortality rates were calculated for those who accepted referral and for those who did not.

Ethics

The study was approved by the Ethical Review Committee of AKU. Informed consent was obtained verbally from the mother or care-provider of each child. The data collectors were fluent in all languages spoken in the study sites, and ensured that the mother/care-provider fully understood the benefits and risks associated with the study. No breaches of confidentiality occurred.

RESULTS

During the study period, 541 newborns and infants < 59 days old were sick enough to require referral to the tertiary care hospital, and were eligible for inclusion in the study. Of these, families of 41 children had either moved away from the area or refused to participate, and were considered lost to follow-up. Thus, 500 children are included in the analysis.

The study population was socioeconomically homogenous. Only 15 mothers were salaried employees. Among the fathers, the most common occupation was that of fisherman (36.3%), followed by factory-worker (17.1%), and laborer (14.7%). Parental literacy rates were also low, with higher education (high school or beyond), being even more uncommon. Only 6 (1.2%) mothers reported having finished high school, of whom 3 (0.6%) had attended college. Among the fathers, 18 (3.6%) reported having finished high school, including 6 (1.2%) who had attended college. Other household characteristics are summarized in Table 1.

The clinical profile of the children in our cohort is presented in Table 2. The most common presenting symptoms were fast breathing (60.2%), followed by prolonged capillary refill (50.1%) and poor suck (47.3%).

Hospital referral for the sick young infant was accepted by 24.2% of the families. Children for whom referral was accepted were more likely to present with weight < 2 kg ($p < 0.001$), body temperature < 35.5 °C ($p < 0.001$) and poor sucking ($p < 0.01$).

The most frequently mentioned reasons for refusing to accept referral included financial difficulty due to non-medical costs related to hospital admission (66.7%), father and/or family-elders not giving permission (65.4%), and lack of adequate facilities for attendants at hospital (44.9%). One in five (21.4%) families who refused referral also cited religious and cultural beliefs for doing so (Table 3).

Overall, 69.4% of study participants believed that home delivery is safe for the mother and newborn. Sixty-three percent reported that they had planned to have a traditional birth attendant (TBA) deliver the baby, and 59.5% were convinced that TBAs could handle all obstetric emergencies. Sixty percent of the respondents were not convinced about the benefits of receiving antenatal care (ANC), and only 43.8% of reported receiving ANC

during their last pregnancy. These families were also less likely to accept hospital referral for their sick young infants, but this association was not significant.

The strongest socio-demographic indicators, and maternal and newborn care-seeking history and practices, which predicted the acceptance of referral for the sick infant, were the recognition of the child's illness by the mother, followed by ethnicity other than Sindhi, maternal literacy and husband/father's concern for his family's health (Table 1). Gender of the child was not associated with the decision. Families where mothers reported having made the decision to accept the referral, as opposed to fathers or family-elders, were twice as likely to have accepted. Acceptance of referral was also more likely if the child was hypothermic, grunted, or weighed < 2.0 kg. If the child suffered from the more common clinical signs, such as fast breathing, families were less likely to accept referral (Table 2).

Table 4 presents the results of the stepwise multivariate regression analysis. Among the demographic indicators, being able to speak the dominant language spoken at the hospital was significantly associated with acceptance of referral for the sick infant ($p < 0.01$). Among the maternal and newborn care-seeking history and practices, recognition of child's illness by the mother ($p < 0.01$) was associated with acceptance of hospital referral. Among the clinical indicators, poor suck ($p = 0.03$), and body temperature < 35.5 °C ($p = 0.02$) were significantly associated with acceptance of hospital referral for the sick newborn.

Of the 500 newborns and young infants included in the study, 30 (6.1%) died within the month following the serious illness requiring referral. Of these, families of 18 children had accepted referral, for a mortality rate of 14.9% in that group. The mortality rate for children, whose families refused referral to the major government-run pediatric hospital, and received out-patient therapy, was 3.2% (12 deaths). Of these, over 90% received daily injectable antibiotics at the clinics. Causes of death were ascertained through verbal autopsies. The major cause of death was sepsis ($n=21$; 70% of deaths). Other causes of death included birth asphyxiation ($n = 4$, 13%), congenital syphilis ($n = 1$, 3%) and pneumonia ($n = 1$, 3%). Cause of death could not be determined for 3 (10%) infants. The cause of death by referral group is presented in Table 5. There were no significant differences between the two groups.

DISCUSSION

More than 75% of poor families included in our study refused hospital referral for their sick young infants. Two-thirds of these families cited financial reasons, even when medical care is free and transport to referral hospital was provided. Recognition of the severity of the child's illness and the ability to speak the dominant language at the referral hospital are strong predictors of acceptance of hospital referral for the sick infant. The clinical signs most predictive of acceptance of referral were body temperature < 35.5°C and poor sucking.

The continuum of newborn care involves the interaction of many disparate components. Socio-demographic and behavioral and cultural structure of a newborn's family, as well as the availability of healthcare infrastructure must interact almost serendipitously to ensure that a sick young infant receives appropriate and timely therapy.

Of the socio-demographic indicators, and maternal and newborn care-seeking history/practices included in the analysis, the recognition of the child's illness by the mother had the biggest impact on the outcome. This finding is consistent with Baqui et al ¹², Kamat ²¹, and Taffa and Chepngeno ²², and suggests families who correctly perceive the severity of the child's illness are more likely to seek qualified care. This is a vital link in the continuum of newborn care, and might constitute an avenue for interventions aimed at encouraging health-seeking behavior: educate the family to better recognize severe illnesses among their newborns.

A husband/father's concern for the health of his family was also related to acceptance of referral. This is another vital link in the continuum of newborn care by ensuring that the husband/father gives permission for the infant to be taken to the health facility without delay. This finding is also consistent with accepted behavioral norms in Pakistan, where the husband makes most of the important decisions as head of the household.

Maternal autonomy promotes health-seeking behavior for sick children.^{16–18} We observed a similar trend, even though the prevalence of maternal autonomy (mothers who were educated, employed, or made the decision about acceptance of referral) was very low. Furthermore, mothers rarely participated in birth preparedness, including the decision of place of delivery. This is another possible avenue of interventions aimed at improving care-seeking for sick young infants. Over the last several years, large scale, randomized trials have demonstrated that maternal and neonatal health outcomes can be dramatically improved with the help of a few simple, low-cost community-participatory programs aimed at women of reproductive age.^{24, 25}

There was no gender differential among those young infants for whom referral was accepted. This finding is contrary to that of Baqui et al ¹² and Willis et al.²⁶ The fact that more male newborns with serious illness (56%) presented at the primary healthcare clinic may be related to the observation that boys are biologically predisposed for worse survival through the neonatal period, compared to girls.^{27, 28}

The more prevalent clinical signs and symptoms, such as fast breathing, fever, and infant being restless and irritable, were associated with refusal of referral to tertiary care facility. This may be because the family is not recognizing the gravity of the child's illness. This is consistent with the finding of studies done in other developing countries, indicating that if the severity of the child's illness is underestimated, families are less likely to seek qualified care.^{15, 21, 22, 29, 30}

Even though the families participating in this study were offered free transportation to the hospital, and assured of no-cost medical care, two-thirds of those who refused to accept referral still cited financial difficulty as their main reason for refusal. Families report having to spend a substantial amount of money on non-medical costs, as well as suffering considerable physical discomfort at the hospital. Typically at least three people (the mother, an older female relative, and a male relative) accompany the sick child to the hospital. Facilities for these attendants to stay at the hospital are limited or non-existent. The family has to spend money on food and a place to stay near the hospital, with the male relative

often sleeping outside on the street. The male relative also has to take time off from work, which results in loss of income. Hostels near the referral hospitals, where attendants can stay are needed but not practical, given the resource constraints in countries with high neonatal mortality.

The majority of the population in the study area spoke Sindhi (50%), and was less likely to accept referral compared to those whose dominant language was not Sindhi. Few doctors at tertiary care hospitals in the city are able to speak Sindhi; most are Urdu-speaking. This may add to a family's discomfort at the hospital and contribute to their distrust of hospital care.

One in five families included in the study cited religious and cultural reasons for refusing to accept hospital care. Belief in supernatural causes of illness, especially for pregnant women and neonates, have been identified as a barrier to appropriate healthcare seeking in developing countries.³¹⁻³³ Confining the mother and baby to their home immediately after delivery^{31, 33}, and seeking care from traditional/faith healers before seeking qualified care^{32, 33}, are the main cultural/religious reasons which lead to delayed care-seeking in South Asia.

The mortality rate among children whose families accepted referral was more than 4 times that of children whose families did not accept referral. This merits discussion. We were unable to conduct a full analysis of the determinants of mortality due to sample size limitations (30 deaths recorded in the study). Several reasons may explain the differential in mortality rates among the two groups. Children for whom referral was accepted were sicker and of lower weight compared to those whose families refused referral. Children whose families refused referral were not left untreated and received daily home visits by CHWs, who brought them to the local clinics for injectable antibiotic therapy if needed. It may also be that children who went to the hospital did not receive appropriate or timely treatment for their illness. This also strengthens the case for developing protocols for appropriate management of severely ill children within their communities. The evidence-base for community management of neonatal sepsis is being established.³⁴

Our multidisciplinary study provides unique insight into a family's decision-making process to seek care for their newborn. Demographic indicators, maternal and newborn care-seeking history and practices, and clinical signs of severe illness are independently associated with acceptance of hospital referral for young infants. Behavioral interventions that encourage care-seeking, as well as community-based management of newborn and young infant illnesses are needed to improve child survival in low-income countries.

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Table 1
Socio-demographic profile and maternal and newborn care-seeking history and practices of families with sick newborns and infants in semi-urban Pakistan

	Total (n = 500)	Accepted referral (n = 121)	Declined referral (n = 379)	OR (95% CI)	p
Demographic information					
Infant age					0.19
0 – 6 days (%)	50.9	44.6	52.9	Ref.	
7 – 27 days (%)	30.1	36.4	28.0	1.5 (1.0 – 2.4)	
28 – 59 days (%)	19.0	19.0	19.1	1.2 (0.7 – 2.1)	
Male child (%)	56.3	55.8	56.5	1.0 (0.6 – 1.5)	0.90
Mother's median age at marriage (years)	18	18	18	1.0 (1.0 – 1.1)	0.62
Mother's median age at time of enrollment (years)	26	25	26	1.0 (0.9 – 1.0)	0.38
Main language spoken at home					<0.01
Sindhi (%)	50.2	37.2	54.3	Ref.	
Urdu and others (%)	49.8	62.8	45.6	2.0 (1.3 – 3.1)	
Parity					0.2
1 – 3 (%)	54.3	63.3	48.5	1.6 (1.1 – 2.5)	
> 3 (%)	45.7	36.7	51.5	Ref.	
Socio-economic information					
Mother is literate (%)	15.4	22.3	13.2	1.9 (1.1 – 3.2)	0.02
Mother works for a wage (%)	3.0	3.3	2.9	1.1 (0.4 – 3.7)	0.82
Father is literate (%)	34.0	36.4	33.2	1.1 (0.7 – 1.8)	0.53
Father works for a wage (%)	95.4	94.2	95.8	0.7 (0.3 – 1.8)	0.48
Travel time to nearest tertiary healthcare facility					0.30
Less than 11 minutes (%)	19.8	15.0	21.2	Ref.	
11 – 30 minutes (%)	38.5	39.2	38.3	1.4 (0.8 – 2.7)	0.55
Greater than 30 minutes (%)	41.7	45.8	40.4	1.6 (0.9 – 2.9)	0.19
Maternal and newborn care-seeking history/practices					
Husband is concerned for family's health (%)	86.4	91.7	84.7	2.0 (1.0 – 4.1)	0.05
Preferred healthcare provider is private (%)	91.0	90.9	91.0	1.0 (0.5 – 2.0)	0.97
Previous neonatal deaths (%)	12.6	9.1	13.7	0.6 (0.3 – 1.2)	0.18

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	Total (n = 500)	Accepted referral (n = 121)	Declined referral (n = 379)	OR (95% CI)	p
Baby was born at hospital or clinic (%)	37.2	42.1	35.6	1.3 (0.9 – 2.0)	0.20
Mother decided to accept referral (%)	2.6	4.1	2.1	2.0 (0.6 – 6.2)	0.24
Recognition of child's illness by mother (%)	76.3	96.7	69.8	12.7 (4.6 – 35.2)	<0.01
Aware that hospital care is important for sick infants (%)	92.0	93.4	91.5	1.3 (0.6 – 2.9)	0.51

Table 2

Clinical signs and symptoms of sick newborn and young infants in semi-urban Pakistan

	Prevalence of signs (n = 500)	Accepted referral (n = 121)	Declined referral (n = 379)	OR (95% CI)	p
Respiratory rate > 60/min (%)	60.2	50.0	63.5	0.6 (0.4 – 0.9)	<0.01
Prolonged capillary refill (%)	50.1	58.3	47.5	1.5 (1.0 – 2.3)	0.04
Restless and irritable (%)	50.1	43.3	52.4	0.7 (0.5 – 1.1)	0.09
Poor sucking (%)	47.3	59.7	43.3	1.9 (1.3 – 2.9)	<0.01
Temperature > 37.5 °C (%)	46.4	40.3	48.3	0.7 (0.5 – 1.1)	0.13
Excessive cry (%)	44.0	41.7	44.8	0.9 (0.6 – 1.3)	0.55
Chest indrawing (%)	38.4	32.8	40.2	0.7 (0.5 – 1.1)	0.15
Jaundice (%)	34.5	30.8	35.6	1.2 (0.8 – 1.9)	0.33
Lethargy (%)	19.8	29.2	16.9	2.0 (1.3 – 3.3)	<0.01
History of no cry at birth (%)	16.6	14.2	17.4	0.8 (0.4 – 1.4)	0.41
Weight < 2.0 kg (%)	15.4	26.7	11.9	2.7 (1.6 – 4.5)	<0.01
Temperature < 35.5 °C (%)	10.4	22.5	6.6	4.1 (2.3 – 7.4)	<0.01
Grunting (%)	3.2	6.7	2.1	3.3 (1.2 – 9.0)	0.02
Seizures/convulsions (%)	0.2	0.8	0.0	NA	NA

Table 3

Reasons given by families of sick newborns and young infants for refusing referral to the tertiary care facility in peri-urban Pakistan

	N = 379	%
Financial difficulties	253	66.7
Father/family elders did not give permission	248	65.4
Do not trust hospital care	217	57.3
Lack of adequate facilities for attendants at hospital	170	44.9
No one to look after children at home	166	43.8
Lack of support for the mother at hospital	154	40.6
Hospital is too far	137	36.1
Child did not seem so sick	112	29.6
Cultural belief of confinement for mother and child during postnatal period	61	16.1
Religious elders discouraged from seeking medical assistance	57	15.1

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Table 4

Results from stepwise multivariate regression analyses with demographic, socio-economic, maternal and newborn care-seeking history/practices, and clinical indicators as predictors of acceptance of referral for hospital care among families of sick newborns and infants in semi-urban Pakistan

	OR (95% CI)	p
Demographic indicators		
Main language spoken at home		
Sindhi	Ref.	
Urdu and others	2.2 (1.3 – 3.5)	<0.01
Maternal and newborn care-seeking history/practices		
Recognition of child's illness by mother	17.2 (6.0 – 49.4)	<0.01
Clinical indicators		
Breathing rate > 60	0.5 (0.3 – 0.9)	0.02
Poor sucking	1.8 (1.1 – 3.2)	0.03
Temperature < 35.5	2.4 (1.1 – 5.1)	0.02
Grunting	2.8 (0.9 – 9.3)	0.09

Table 5

Distribution of cause of death among sick newborns and young infants in peri-urban Pakistan

Cause of death	Accepted referral (<i>n</i> = 18)	Declined referral (<i>n</i> = 12)
Sepsis (%)	72.2	66.7
Birth asphyxia (%)	11.1	16.7
Pneumonia (%)	5.6	0
Congenital syphilis (%)	5.6	0
Not determined (%)	5.6	16.6

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