



## CARESEEKING FOR ILLNESS IN YOUNG INFANTS IN AN URBAN SLUM IN INDIA

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**Abstract**—Illness in infants in the first two months of life can take a precipitous life-threatening course, and requires timely and appropriate medical assessment and management. We conducted a focused ethnographic study of illness in young infants and associated careseeking practices in an urban slum in New Delhi, India, in order to identify the constraints in securing effective care for severe illness in this age group. The findings suggest that maternal recognition of illness is not a limiting factor in the use of health care services for sick young infants in this setting. Mothers respond to a number of important signs of illness, including changes in the young infant's sleeping or feeding behavior, and they are usually prompt in seeking care outside the home. They are not able, however, to discriminate among the many sources of health care available in this setting, and give preference to local unqualified private practitioners. Most practitioners, including qualified medical practitioners, display critical failures in the assessment and management of sick young infants. The continuity and effectiveness of care is further compromised by the caretakers' expectations of rapid cure, which result in discontinued treatment courses and frequent changes in practitioners, and by their reluctance to seek hospital care. The implications of these findings for the design of programs to reduce young infant mortality are discussed. In particular, the feasibility and acceptability of hospital referrals according to current program guidelines are called into question. © 1998 Elsevier Science Ltd. All rights reserved

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### INTRODUCTION

This paper presents the results of a study to assess mothers' perceptions of illness in their young infants and to investigate associated treatment practices, including careseeking outside the home and acceptance of referrals by health providers. The impetus for the study was provided by the recognition that a substantial proportion of childhood deaths occurs in the first two months of life, and that this proportion is growing as gains are made in reducing mortality in older age-groups†. Deaths that occur during the first week after birth are largely influenced by events during pregnancy and delivery. Thereafter, infectious diseases become predominant as causes of death (Bartlett and Paz de Bocaletti, 1991; Khan *et al.*, 1993; Bhan and Bahl, 1996). Unfortunately, the management of illness in young infants continues to pose major clinical challenges. Conditions such as acute lower respiratory

tract infections, septicemia, diarrhoea and severe malnutrition, may present with atypical or masked signs, can all take a precipitous life-threatening course, and require careful assessment and aggressive treatment. In order to address the particular diagnostic and management challenges posed in this age-group, WHO and UNICEF have developed guidelines to assist first-level facility health workers in the assessment, classification and treatment of illness in young infants from one week to two months of age (WHO, 1995a), which form part of an effort to strengthen and rationalize clinical services for the 'sick child' (WHO, 1995b). These guidelines describe procedures for dealing with common conditions, and recommend urgent referral to hospital if the young infant presents 'danger signs' suggestive of serious bacterial infection, severe diarrhoea-associated dehydration, or severe persistent diarrhoea (Table 1).

The use of this approach requires, first of all, that caretakers recognize and correctly interpret the signs of illness in their young infant, and seek timely and appropriate medical care. It also requires that the medical practitioners consulted, provide the necessary advice and treatment, including referral to hospital if indicated. Finally, it requires that the caretakers accept the advice and treatment provided. We are not aware of any studies that have examined this entire sequence of careseeking for

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†In 1990, India had 16% of the world's population and accounted for 19% of all deaths (World Bank, 1994). An estimated 2.5 million infant deaths occur every year in the country and infant mortality rates remain high in most areas. More than half of infant deaths occur in the first two months after birth (Jain and Visaria, 1988; Bhargava *et al.*, 1991)

Table 1. Indications for urgent referral of young infants (age one week up to two months) to hospital, according to the guidelines of WHO/UNICEF on the management of childhood illness

**Possible serious bacterial infection**

Any one of the following signs

- fever or low body temperature
- convulsions
- fast breathing
- severe chest indrawing
- nasal flaring
- grunting
- bulging fontanelle
- pus draining from ear
- umbilical redness extending to the skin
- many or severe skin pustules
- lethargic or unconscious
- less than normal movement
- not able to feed, or no attachment at all, or no sucking at all

**Severe diarrhoea-associated dehydration**

Any two of the following signs

- lethargic or unconscious
- sunken eyes
- skin pinch goes back very slowly

**Severe persistent diarrhoea**

diarrhoea lasting 14 days or more

Source: WHO, 1995a.

young infant illnesses. Studies of careseeking in older children indicate that caretakers often have difficulty in identifying serious conditions such as diarrhoea-associated dehydration or pneumonia,

and that, if they do, they do not always appreciate the severity of the child's condition (Nichter, 1988; Tupasi *et al.*, 1989; Gove and Pelto, 1994; Herman *et al.*, 1994). Care may not be sought at all, may be sought after a delay or may be sought from untrained health providers. These problems are likely to be compounded in young infants, because the recognition of a severe illness is more difficult in this age-group, even for trained physicians. Other possible causes of delay in seeking care for young infants include the common practice of seclusion of mothers and newborns in the home for up to 40 days after delivery (Bang *et al.*, 1993), and a preference for traditional sources of health care for young infants (Bhattacharyya, 1993; Sutrisna *et al.*, 1993; Gove and Pelto, 1994; Kresno *et al.*, 1994; Herman *et al.*, 1994). Yet, because of the rapid course of infectious diseases in the first two months of life, even a small delay in initiating appropriate treatment can result in the illness becoming so severe that the infant cannot be saved. There is evidence that young infants even are more likely than older children to die at home, without having had any contact with a trained health practitioner\*. In this study our focus was on assessing maternal recognition and interpretation of illness in young infants, and on identifying constraints to the adequate provision of care for the illness.

## RESEARCH SETTING AND METHODS

The study was conducted in a slum settlement in New Delhi, which accommodates about 60,000 persons who have emigrated to the capital from various parts of India over the past two decades†. The slum covers an area of about four square kilometers within a larger urban complex, and is very dense, comprising a tortuous network of narrow, winding lanes lined with open drains and flanked by mud and brick dwellings. All households are served by illegal electrical connections, but few have access to private water supplies or latrines. Most people draw their water from communal hand pumps, and use public latrines or, in the case of children, defecate in the open. The majority of households consist of nuclear families, although close ties are kept with family members from the 'village' of origin. Women tend to be fully occupied with child care and household chores. A few women also work outside the home, as laborers or domestic servants. Men are primarily unskilled workers (e.g. laborers) or skilled workers (e.g. carpenters or cobblers) on daily wages‡.

The slum inhabitants have access to a wide range of health services, a common situation in an urban setting of this kind and a reflection of the prevalent pluralistic health system§. Within the slum or in its immediate vicinity, over 25 private practitioners attend to clients in small consulting rooms, or in larger clinics or nursing homes. Health services are

\*A study of deaths in children under five years of age conducted in rural Indonesia found that only 36% of all children who died had sought care from a doctor, nurse or midwife in the private or public sector, even though the majority of households had close access to a government health post. A full 46% of deaths occurred among infants in the first two months of life, of which only 21% had sought medical care (Sutrisna *et al.*, 1993).

†The slum is fairly well established and was legalized in the early 1990s, so residents are entitled to municipal facilities such as water, sanitation and schools, and can hold land rights.

‡Daily wages are in the order of 25–75 rupees (US\$0.70–2.10) for men and less for women.

§The formal health system in India brings together people with medical degrees (MBBS) or other degrees in allopathic medicine, and practitioners of Indian medical systems who have received training in recognized medical schools, leading to degrees in Ayurvedic medicine (such as the BAMS) and in Unani Medicine (such as the BUMS). Many of these practitioners of Indian medical systems have also been trained in and exposed to allopathic medicine, and practice a form of integrated medicine, either in government institutions or in the private sector (Liebeskind, 1995; Shankar and Manohar, 1995). Then, there is a large informal sector comprising a multitude of unqualified, largely self-trained private practitioners who are generally known as registered medical practitioners (RMPs), even though such registration should nowadays only be conferred to persons who have undergone some kind of formal training (Rohde and Viswanathan, 1995). RMPs tend to have an 'eclectic' approach to medical practice (Nichter, 1978). Finally, at the community level, there are folk healers and other persons who perform preventive and therapeutic rituals for specific problems and illnesses (Lambert, 1996).

Table 2. Socio-demographic characteristics of 37 mothers of young infants

Age	range 17–38 years median 25 years
Education	84% have no schooling and are illiterate
Length of residence in slum settlement	50% less than 6 years 80% less than 10 years
State of origin	predominantly Rajasthan (43%) and Uttar Pradesh (32%)
Religion	95% Hindu 5% Muslim
Employment	all home makers at the time of interview
Parity	range 1–8 median 3

also provided by two nongovernmental organizations (which operate in the slum itself) and in a government dispensary (situated at about three kilometers from the slum). Finally, a large number of folk healers regularly provide services in times of illness\*.

The study was conducted between July and December 1996. Discussions were held with the staff from the nongovernmental organizations serving the community, and with staff from a research team involved in a vitamin A supplementation trial among infants in this and adjoining slum communities. In-depth interviews were conducted with a purposive sample of key informants identified through community contacts, including five traditional birth attendants (*dāīs*), none of whom had received any formal training, and six mothers, who were generally considered to be knowledgeable about child health issues. In-depth interviews were also conducted with 37 mothers of young infants (between one week and two months of age). Mother–infant pairs were identified through conversations with slum inhabitants in the lanes, or with the help of community-based informants, such as key informants and field workers from the nongovernmental organizations. Repeated visits were made to some particularly responsive key informants and mothers. Structured procedures were used in most interviews with key informants and mothers, including free listing of common illnesses of young infants in the community, a sorting exercise to link signs and symptoms to specific illnesses, and an illness severity rating task. Narratives of illness episodes were sought from mothers who complained of a recent or current illness in their young

infant. Nine episodes of illness were followed prospectively through repeated household visits. In addition, interviews using a semistructured open-ended schedule were conducted with 22 private practitioners and one medical officer from the local government dispensary, and in-depth interviews were conducted with three folk healers, all selected among popular sources of care for illness in young infants in the community. In the course of visits to these practitioners, unstructured observations were conducted of more than 60 consultations (27 of them for illness in young infants) conducted by 16 practitioners. Finally, four hospitals and three nursing homes which serve the area were visited, to interview key health providers and investigate admission procedures. Approaches to data collection and analysis were guided by those used in the focused ethnographic studies on acute respiratory infections developed by the World Health Organization (Gove and Pelto, 1994).

#### BIRTHING PRACTICES AND NEWBORN CARE

The socio-demographic characteristics of the 37 mothers of young infants whom we interviewed are listed in Table 2. The majority of these women had received some form of antenatal care in local clinics run by nongovernmental organizations or in a hospital. However, only five (14%) had opted for an institutional delivery, primarily because they had experienced complications in earlier deliveries. The rest had preferred a home delivery, which they considered to be 'more convenient'. The home deliveries, described to us, took place with the assistance of a *dāī*, and with limited contact with another health provider†. Medical care around the time of delivery was less valued than social support, which enabled the mothers to rest and recover, and ensured that their newborns received the attention that they required. In most cases, support was provided by the *dāī* and female family members, who helped with newborn care and with household chores in early days or occasionally weeks after delivery. During this period, mothers rest as much as they can. However, they move freely in and out of the home, and young infants are readily taken out of the home if this is thought to be necessary. We were unable to identify a specific time period

\*Most healers play some religious role in the community, in the form of regular service in a Hindu temple or shrine, or in a mosque (Lambert, 1992).

†A local private practitioner was frequently called to the home by family members to give a *sūā* (injection), probably of oxytocin, if labor was not progressing well or 'taking too long'. In some cases, practitioners were also called in immediately after the delivery to give a *sūā* (this time of tetanus toxoid) to the mother and baby. This was done even if the mother had been immunized during pregnancy, 'for extra precaution'. The role of these practitioners at the time of delivery was limited to the administration of injections, and they were not consulted on other issues.

after delivery during which mothers are expected to take special precautions for themselves or their infants. Nonetheless, mothers expressed concern about the health of their babies and indicated that children are most vulnerable during the first few months of their life. Experience with young infant deaths is common in this community. Nine (24%) of the 37 mothers had lost a previous child. Of the 15 previous child deaths that were described to us by these nine mothers, all but one had occurred during infancy and more than half had occurred during the first two months of life.

#### RECOGNITION AND INTERPRETATION OF ILLNESS IN YOUNG INFANTS

Cultural models of illness in young infants that emerged in the course of the study are described in Table 3. Recognition of illness is based on the identification of a constellation of signs, such as a change in the frequency, consistency, color or smell of infant's stools, in the case of *dast* (diarrhoea) or a change in the infant's body temperature and behavior, in the case of *bukhār* (fever), and an interpretation of the circumstances and course of the illness. It is important to note that the illness 'types' described to us by our respondents are not rigidly and categorically defined. They include an assortment of illnesses, illness signs and even etiologies, some of which may be combined with others, such as *bukhār* with *khānsī* (cough), or develop into others, so an episode of *khānsī* can lead to *pasī chalti hain* (labored breathing). Illnesses tended to be frequently re-assessed and re-interpreted over

their entire course (Gould, 1965; Chand and Bhattacharyya, 1994; McNee *et al.*, 1995), and we found that they were not always satisfactorily labelled as a specific illness 'type' even after the episode was resolved. Furthermore, the attribution of cause tended to be tentative, at least until the illness was firmly identified. Most illness in young infants was ascribed to a disruption in the necessary equilibrium between heat and cold, and bodily humors (Lambert, 1992), affecting the mother-infant dyad\*.

In practice, therefore, it was not so much the identification of a specific illness 'type' that determined initial careseeking outside the home, but the presence of a sign that caused concern, such as fever, which can be associated with several illnesses, or a change in the young infant's behavior. Mothers paid close attention to changes in their baby's sleeping and feeding patterns. As explained by one mother: 'we know something is wrong if the baby cries a lot more than usual'. This causes anxiety and aggravation and leads to sleepless nights for the whole family. Others worried when the baby didn't suckle well ('*dūdh nahīn pīta*'). These behavioral changes were the most common triggers for a visit to a health provider who was expected to check the infant for the presence of fever and other problems.

Nevertheless, a few conditions seemed to be readily recognized and, because they are considered to be serious and potentially life-threatening, were also common 'triggers for action'. In particular, *dast*, *bukhār*, *pasī chalti hain* and *sukhā* (wasting) were given salience in narratives of illnesses and deaths†. The severity of *dast* is related to the frequency of the stools. Mothers were not concerned if the young infant passed one or two watery stools in a day, as the stools of young infants who are exclusively breastfed are often frequent and runny. They worried, however, if the stools were more frequent, if there were other signs such as vomiting or fever, or if the episode did not resolve after 2–3 days. *Bukhār* is considered to be serious in young infants, and steps were usually rapidly taken to seek confirmation from a health provider that the young infant had got an elevated temperature, and to determine and treat its underlying causes. The primary concern is that '*dimāg me bukhār chadta hai*' ('the fever can go to the brain'), and cause brain damage. *Pasī chalti hain* (literally: 'the ribs move') is recognized as a serious illness among young infants, which requires the immediate attention of a health provider. Respondents would explain (usually by placing their hands on both sides of their lower rib cage and demonstrating a breathing problem, or by pointing to their infant's lower ribs) how the baby's lower rib cage heaves up and down because she has to struggle to take her breaths. Sometimes, they also explained how the skin between the ribs and the area just below the rib cage become indrawn‡. People's focus seemed to be

\*Most acute respiratory conditions and some diarrheas are attributed to the exposure of the infant or the mother to cold air or wind, or to a sudden change in temperature, as might occur if the infant is left to sleep in a draught, or if the mother breastfeeds after sleeping under a fan, handling cold water, or working out in the sun and getting sweaty. The mother's diet is also important, and eating the 'wrong' kinds of foods and thereby disrupting the body's humoral balance is thought to lead to loose stools or vomiting in the young infant. In addition the mother can transmit an illness if she breastfeeds when she herself is ill. This is the only concept of contagion that we identified. No one seemed to have any notion that illnesses such as coughs and colds and diarrhoea can be spread from person-to-person otherwise than through breastfeeding.

†It is significant that these illness 'types' reflect the major causes of death documented among young infants in this setting, that is, diarrhoea, acute lower respiratory infections, and septicemia without diarrhoea or acute lower respiratory infection, as well as the contribution of severe malnutrition to early infant mortality (Bhan and Bahl, 1996).

‡Interestingly, *pasī chalti hain* has been identified in ethnographic studies of acute respiratory infections, conducted in different parts of Pakistan (see Kundi *et al.*, 1993, for a detailed description of the illness), but not in other parts of India, such as Maharashtra (Chand and Bhattacharyya, 1994) and West Bengal (Bhattacharyya, 1993).

Table 3. Conceptual models of illnesses in young infants<sup>a</sup>

Illness name	<i>Dast, taṭī</i> (diarrhoea, stools)	<i>Bukhar</i> (fever)	<i>Zukām, sarā</i> (cold)	<i>Khānsā</i> (cough)	<i>Pash chalti hain, numonia</i> (labored breathing)	<i>Sukhā</i> (wasting)	<i>Nazar</i> <sup>b</sup> (evil eye)
Signs	change in frequency, consistency, color, or smell of stools	body feels hot or cold, infant may cry excessively or feed poorly	discharge of phlegm from the nose, sneezing, sometimes fever or diarrhoea	cough, sometimes breathing problems, may be associated with fever or excessive crying	heaving of lower rib cage, difficult breathing	wasting, visible ribs, loose skin	night terrors, excessive crying, inability to feed, convulsions, may be associated with persistent diarrhoea or <i>sukhā</i>
Causes	humoral imbalance, or inappropriate foods eaten by the mother	may be a sign of another illness, or may be due to environmental heat	exposure of mother or infant to cold air or wind, or a sudden change in temperature	exposure of mother or infant to cold air of wind, or a sudden change in temperature, or 'cold' or sour foods eaten by the mother	exposure of mother or infant to cold temperatures	persistent diarrhoea, inadequate feeding, or <i>nazar</i>	envious glances, spells, or exposure to evil spirits
Consequences	can lead to <i>kamzor</i> (weakness), <i>sukhā</i> , or <i>pām ki kam</i> (dehydration)	may lead to brain damage	may progress to <i>khānsā</i>	can lead to <i>pash chalti hain</i>	can lead to death	can lead to death	can lead to death
Treatment	medical care is sought if many stools are passed in a day, if vomiting or fever are present, or if the episode persists	can be managed with syrups provided by health provider, but will persist until the cause is removed	massages, hot dry poultices, sun baths, home-made mixtures given by mouth	massages, home-made mixtures given by mouth, medical care is sought if associated with fever or difficult breathing	urgent medical care	underlying cause must be removed	specific rituals to be performed by a healer, use of protective amulets

<sup>a</sup>In order of frequency of mention in the free-lists.<sup>b</sup>Mentioned in the illness and death narratives, but not in the free-lists.

on labored breathing, rather than on fast breathing (which WHO and UNICEF have identified as a cardinal sign of pneumonia). It is possible that fast breathing is not recognized as such, but labelled instead as 'difficult breathing' as has been found in other settings (Gove and Pelto, 1994; Kresno *et al.*, 1994). *Sūkḥā* (literally: 'dried up') is a wasting illness, which was dreaded by our respondents and recognized to be a common cause of death among young infants in the community. An infant who has *sūkḥā* is thin, her ribs are visible and her skin is loose. *Sūkḥā* is thought to be a consequence of persistent diarrhoea, or inadequate feeding. *Sūkḥā* is also commonly believed to be caused by the evil eye (*nazar*) or spirits.

*Nazar* was frequently reported by respondents both as an illness, and as a cause of other illnesses among young infants. It was not mentioned in the free listing exercises, but emerged in narratives of previous (but not current) illnesses, as well as in death narratives. *Nazar* was usually associated with prolonged or serious illnesses, such as persistent diarrhoea and *sūkḥā*. It was identified through the presence of signs such as excessive crying (especially when the infant seemed frightened and could not be consoled), inability to feed, or convulsions. It was frequently a cause given for illnesses that couldn't otherwise be explained, and that did not respond to medications. In this way, illnesses that led to young infant deaths despite resort to multiple medical therapies were, post hoc, attributed to *nazar*. As stated by Mull and Mull (1988), with reference to their research on childhood diarrhoea in Pakistan, "such folk diseases are often the attributions of last resort, not immediately thought of as causes when diarrhoea first occurs but diagnosed in intractable cases — the very cases that are likely to prove fatal". *Nazar* is caused by glances of envious persons such as childless women, spells cast by ill-intentioned persons, or exposure to roaming spirits\*. Everyone does not believe in *nazar*, however. Some of our respondents, particularly the more educated ones, felt that beliefs and practices related to *nazar* were old-fashioned, and upbraided their neighbors for holding to them.

\*The majority of newborns in the community have pieces of black thread or cloth wrapped around their wrists, sometimes impregnated with strong-smelling spices or incense, which are intended to ward off evil spirits. The forehead of some young infants is smeared with kohl, and others are decked with amulets (or *tāviz*), containing a piece of paper on which words from the Quran or a *mantra* (sacred formula) have been written by a holy man, or another sacred substance. *Tāviz* are used by Muslims and Hindus.

†This is not surprising, as most practitioners favor *masāla* (mixed) medicine (Nichter, 1989)

#### PATTERNS OF CARESEEKING

Mothers in this community are not oblivious to signs of illness in their young infants, and are not passive in finding ways to seek care for them, despite the hardship and deprivation that threaten all other aspects of their lives. The analysis of illness narratives indicates a high level of use of available health services. Mothers generally took prompt action in seeking advice for any problem in their young infant that they judged to be more than a temporary nuisance, especially if it led to a change in the young infant's behavior or breast milk intake. They also sought advice if they were uncertain about the infant's condition. As expressed by one mother: 'We seek care if the problem is above our heads'. Home-based remedies were rarely used, except in the case of *zūkām* (akin to the common cold), and of *khānsī* (cough) which led to a number of treatments, mostly designed to warm up the baby, such as whole body massages with mustard oil and garlic, hot dry poultices and sun baths, or the administration of small amounts of home-made mixtures prepared with spices and a little breast-milk. Home-available or pharmacy-purchased drugs were not given to a young infant without a prior consultation with a health provider. Careseeking was usually very prompt, once it was felt to be necessary. Often, a young infant who developed a fever at night would be taken to a practitioner the next morning, and one who developed a fever in the course of the day would be taken to a practitioner that very evening. In a few instances, nonetheless, delays did set in, usually because the mother was unable to make arrangements for the care of her other children, or because she felt she should wait for her husband to come home to help out with advice or cash. Usually, however, women would turn to their neighbors in such instances for support with child care or for small cash loans.

Unfortunately, the source of care selected was often problematic. Most community members were unable to distinguish between qualified and unqualified practitioners and between the different systems of medicine†. They expressed confidence in the local private practitioners, all of whom they all called *daktar* ('doctors'), regardless of their actual training and experience. They asserted that: 'They are doctors, because they know about medicines', and commented that: 'good doctors' are the ones who give 'good medicines', that is, the ones that effect a quick cure. In general, the choice of a health care provider for a sick young infant was initially determined by three factors: convenience, courtesy and cost. These factors favored the unqualified practitioners or RMPs (see 7), who are more accessible in all ways. Caretakers tended to consult them for support in making a diagnosis (e.g. of fever) and to obtain medications (e.g. paracetamol or antibiotic syrups). Some caretakers, however, were will-

ing to go further afield and to pay a bit more for the services of a more 'up market' private practitioner, or one who was felt to have more experience in treating children's diseases — usually (but not necessarily) a qualified one. Such practitioners were consulted in cases of severe or prolonged illness. Free services, as provided in government institutions, are not valued and are associated with nuisances such as long travel and waiting times, and the shortage of drugs. Finally, recourse to a folk healer was common, particularly in the case of prolonged or unusual illnesses, such as *sūkhā*, in the presence of signs such as persistent, strident crying or convulsions, or in case of concern about the cause and prognosis of a particular illness. The healer seems to play a key diagnostic role (Lambert, 1996), by performing certain rituals\*, or by verifying the young infant's astrological status, in order to find an 'explanation' for the illness, or at least, to ascertain whether a spiritual cause can be identified. Healers and other respondents assured us that their intervention should lead to a rapid improvement in the infant's condition in the case of *nazar* or other illnesses associated with bad luck or spirits. Otherwise, the infant is considered to have a natural illness (*bīmāri*) and is redirected towards a medical practitioner (Lambert, 1996). Folk remedies, however, may usefully complement the biomedical treatment of illnesses (Gould, 1965; Nichter, 1978; Lambert, 1996). As explained to us by a Muslim healer: 'they strengthen each other'. So, the attribution of an illness to *nazar* does not preclude the use of other treatments that might be available.

At the same time, mothers tended to have unrealistic expectations of rapid cure. This led to a high rate of provider 'shopping' and 'switching', when the infant's condition did not improve within a day or so. In the absence of a treatment response, the parents questioned whether the provider had correctly identified the infant's problem and provided the appropriate treatment (an example of 'diagnosis by medications' as described by Nichter and

Vuckovic, 1994). They therefore interrupted the course of the treatment and sought the advice of another provider. The result is that resort to multiple, eclectic sources of care was very common, particularly in the case of a prolonged illness, despite the attendant high cost and inconvenience (McNee *et al.*, 1995; Lambert, 1996). As explained by Nichter (1978), with reference to his findings in rural south India: 'Doing the most for a sick family member (in the case of an extended illness) means taking him to as many healers and practitioners as possible'.

All the same, caretakers rarely sought care for their young infant at any distance from the slum. In particular, they are very reluctant to accept referrals to a hospital. Data from an earlier study conducted in this slum settlement and in a neighboring community by Bhandari *et al.* (1996) indicate that compliance with medical advice to take a sick young infant to hospital is poor†. Our community respondents explained the many difficulties that they face in taking young infants to hospital. Most women indicated that they require their husband's permission and support, as a trip to hospital is a significant and costly venture. They cannot go unaccompanied. As one mother explained: 'We are illiterate, we can't even read the bus number, how could we possibly go (to the hospital) on our own?' But: 'If my husband does not go to work for one or two days, then what will we eat, and how will we get treatments?' Many have other children, and need to make arrangements to leave them with neighbors or family members. A number of respondents expressed considerable anxiety about hospitals. The two government hospitals that serve the community seem to be particularly intimidating, as they are large and crowded, and difficult to negotiate for the uninitiated. One mother complained: 'We get into a lot of trouble if we go there. They tell you to go to this room and that room, and we always get lost...'. For all these reasons, many families do not follow through on referrals to hospital unless they feel that their child is critically ill. One mother said: 'We can get good treatment from the local doctors. Going to hospital causes a lot of difficulties'. This represents a major problem, as WHO/UNICEF recommend a low threshold for referral to hospital among infants of one week to two months of age (Table 1). For example, the presence of fever alone is considered to be a sufficient indication for urgent referral of a young infant to hospital, as it can signal a serious bacterial infection. The evidence from this community indicates that the majority of young infants will not be taken to hospital for a problem of this kind, despite medical advice (Bhandari *et al.*, 1996).

\*Common diagnostic and therapeutic procedures employed by these healers are *jhada* (sweeping), in which downwards sweeping movements are performed over the baby, or *phunk* (blowing), which is done on the baby's face or affected body part, while a *mantra* or prayer is recited (see Lambert, 1992, for a detailed account of such practices in Rajasthan). For suspected *nazar* incantations and burning of chili peppers and aromatic seeds may be conducted by healers or by family members. Healers might also provide a *tāviz* to hasten the infant's recovery and provide continued protection.

†In this study, 2007 infants aged 0–2 months were examined by a pediatrician in a community clinic setting. Hospital admission was advised for 273 (14%) of them, on the basis of the WHO/UNICEF guidelines for the management of illness in this age group. Only 66 (24%) followed this advice, despite assurance of free transportation and care in the government referral hospital.

### QUALITY OF CARE

Our interviews of the various health practitioners who serve the community, and our observations of their encounters with mother–infant pairs, provided us with some insights into their expectations and practices with respect to the management of sick young infants. These practitioners were not clearly differentiated, and tended to borrow key elements from the major systems of medicine (Nichter, 1978; Lambert, 1996). The knowledge base of many (but not all) of the unqualified practitioners was limited and to a large degree they shared the vocabulary and beliefs of their clients concerning disease transmission and management among young infants. The qualified practitioners, on the other hand, including those trained in Ayurvedic or Unani schools of medicine, had more accurate, though often patchy, knowledge of biomedicine. Unfortunately, as a result, they seemed to have greater difficulties communicating with their clients. They tended to be scathing about the ‘ignorant and demanding’ people of the slum, who, they complained, ‘won’t listen’ and ‘have unrealistic expectations’ about cure. The majority of practitioners, both unqualified and qualified, recognized that young infants are ‘fragile cases’, and indicated that they prefer to refer them to ‘specialists’ or to hospital, because they don’t want to take responsibility for any serious illnesses or deaths. They did not, however, seem to appreciate that young infants present with different problems and call for different management procedures than older infants. Furthermore, we identified alarming flaws in the practitioners’ assessment and management of sick young infants, among both the unqualified and the qualified practitioners of the various systems. On the surface, diagnostic and therapeutic approaches were very similar among the various types of practitioners. All wielded stethoscopes and other pieces of medical equipment. All collected very brief illness histories and conducted cursory examinations of the infant. Many practitioners took the infant’s temperature and pulse. Some performed a rapid (usually symbolic) auscultation of the infant’s chest. However, we observed very few practitioners conducting a full clinical examination of an infant and none counting a respiratory rate. Only one person (a pediatrician) was observed to weigh a young infant and provide specific advice regarding breastfeeding practices; most practitioners did not have scales. Finally, most practitioners relied on an array of allopathic and ayurvedic drugs, which all come nowadays in attractive, ‘modern’ packaging (Nichter and Vuckovic, 1994; Shankar and Manohar, 1995)\* and freely dispensed or prescribed short courses of paracetamol, antibiotic and antihis-

tamine syrups, and various ‘tonics’ for administration to young infants (Greenhalgh, 1987). In summary, practitioners followed very few of the procedures laid out by the WHO for the assessment, classification and treatment of the infant aged from one week to two months, and in particular, demonstrated their inability to deal with the widespread problems of low birth weight and severe malnutrition.

These unsystematic observations in no way constitute a thorough assessment of the quality of the care provided to young infants in this setting. They do, however, suggest that there are weaknesses across the board, and that even qualified and experienced physicians working at the primary level in urban communities may lack essential knowledge and skills with respect to the management of the major causes of illness and death in this age-group. Only a very small number of trained physicians (primarily pediatricians) provide quality services for young infants in these communities, but for various reasons these services are greatly underutilized by poor families, whether they stem from the private, governmental or voluntary sectors.

### CASE STUDIES

#### *Case one*

Saroj is the first born in a Hindu family. Her mother, Asha, had come to stay for a few months in her natal family in the settlement. Saroj was born at home, with the assistance of a *dai* and family members. When she was 10 days old she became ill. She cried excessively during the night and her body was hot. A day later, Asha and her mother took Saroj to consult a nearby RMP. He checked her temperature, confirmed that she had fever and provided some paracetamol syrup. Asha gave this to Saroj for three days, but the fever did not abate. So Asha took her to the government dispensary. The doctor there told her to continue with the same medicine. When Saroj still didn’t improve by the next day, Asha consulted a holy man (*maulānā*) in the nearby mosque. He gave her a *tāviz* and blew on the baby. After ‘half an hour’ the fever came down. Asha and her mother said that this means that the fever was probably due to *nazar*. However, Asha also had a fever after delivery, so they said that it might also have been a fever passed on through breastfeeding.

#### *Case two*

Sunil is the eighth born. His mother, Kamla, has lost three previous children due to *sūkḥā* (two aged between one and two months, the third aged about two years). He was born at home, ‘strong and healthy’. He started a fever on the evening of the sixth day. His mother explained that she had caught a cold, with fever, because she slept under the fan,

\*Only a few MBBS doctors stated that they exclusively prescribe allopathic drugs.



and that she passed it on to Sunil through her milk. He was upset, crying a lot, and wouldn't feed. The next morning his parents took him to Dr. A., a well-known RMP, whom they felt had a lot of experience. Dr. A. gave them two syrups. The next day his parents took him back for a follow-up visit and were reassured that his temperature was down. When the researchers visited the household for the first time a week later, Kamla expressed concern, because she felt that Sunil was getting thin, even though he was feeding well. She was given some breastfeeding advice and urged to take Sunil to the well baby clinic run by a local nongovernmental organization. Kamla did not visit the clinic. When Sunil was about three weeks old, he 'dried up' and developed *sūkha*. He also had loose stools, and was not feeding well. Within two days, Sunil's parents consulted another private practitioner, Dr. B. (an MBBS doctor), on the advice of a neighbor. Dr. B. prescribed some vitamin drops. The researchers made a repeat visit to the household that week. They noted that Sunil had visibly lost a lot of weight, and decided to take him and his parents to consult the physician (Dr. C.) from the vitamin A research project. On examination, Dr. C. found no signs of infection. However, Sunil's axillary temperature was low and he weighed 1.7 kg. Dr. C. referred him to hospital for further assessment of suspected septicemia. Sunil's parents were distressed, but hesitant. In the end, they agreed to go with the researchers to the government hospital. On arrival at the hospital, they received a very rough and rude reception by the medical staff in the triage area, but were allowed to move on to the pediatric ward. There, after an hour's wait, a physician conducted a thorough examination of Sunil. She explained that he couldn't be admitted because he was so weak. She gave advice on breastfeeding, and prescribed an ayurvedic tonic to be taken by Kamla. When the researchers visited the next day, they provided an oral antibiotic for Sunil's use (on Dr. C.'s recommendation). Three days later, on the researcher's next visit, Sunil's father expressed helplessness: 'We have seen all these doctors, and still he is not getting better. What are we to do now?'. The researchers took Sunil and his parents to consult Dr. D., a pediatrician in private practice nearby, who started him on intramuscular antibiotics, and subsequently recommended introducing bottle feeds, which Kamla did. Over the next four weeks, Sunil was taken back by his parents to Dr. D. seven times, and eventually he gained weight and became more active. All along, Sunil's parents expressed uncertainty about the causes of the ill-

ness. They didn't know why the other children had got *sūkha* and died either.

#### CONCLUSIONS AND PROGRAM IMPLICATIONS

The findings of this study suggest that maternal recognition of illness is not a limiting factor in the use of health care services for sick young infants in this setting. Mothers respond to a number of important cues in deciding whether their young infant is ill, and they are aware that illness in young infants can take a rapidly life-threatening course. Careseeking outside the home tends to be very prompt and, contrary to what has been found in other settings, is not constrained by cultural prescriptions that confine mothers and newborns to the home after delivery or by fatalistic interpretations of young infant illness (Bang *et al.*, 1993; Sutrisna *et al.*, 1993). There are, of course, important gaps in maternal knowledge about illness. For example, we found that mothers have a limited understanding about dehydration, and poor recognition of fast breathing as a marker of severe respiratory illness. The absence of the mothers' explicit references to these conditions does not mean, however, that diarrhoea-associated dehydration or pneumonia in young infants will not be brought to the attention of a health provider. Other 'triggers for action', such as changes in the infant's feeding or sleeping behavior, are more meaningful to mothers and easier for them to identify in this age-group, and may be more sensitive predictors of severe illness. In this study, we found that cultural beliefs about illness did not accurately predict the timing and the source of care\*. Even *nazar* may be treated simultaneously with pharmaceutical drugs and folk remedies, in what McNee *et al.* (1995) have called 'a pragmatic search for an effective cure'.

Caretakers rely on a wide and multiform range of health practitioners for the treatment of illness in young infants. The quality of care received, however, is very uneven. Unqualified health practitioners are popular, because they represent a cheap, acceptable and convenient source of care, but currently they are not competent to deal with any but the most simple problems affecting young infants. Qualified health practitioners are often consulted as well, especially in severe or prolonged cases. They are better prepared, yet many display critical failures in the assessment and in the management of sick young infants. This situation is aggravated by caretakers' expectations of rapid cure, which result in discontinued treatment courses and frequent changes in practitioners, and by their reluctance to seek hospital care. All of these factors pose serious threats to the continuity and effectiveness of care.

These results indicate that efforts to promote improved recognition of young infant illness and timely *initial* careseeking outside the home may not

\*See Evans and Lambert (1997) for a detailed discussion of this issue, with reference to the health seeking behavior of female sex workers in Calcutta.

be first priority in this setting. The most critical breakdowns in securing effective care and in ensuring the young infant's survival come later, and usually involve qualified health practitioners\*. Our sense is that the most significant constraints to care-seeking can be traced to deficiencies in the health system and to the poverty and marginalization of these slum communities. Parents do hold many misconceptions and biases, but in practice turn out to be concerned, thoughtful caregivers who have to make difficult choices using unequal resources in an adverse environment†.

In the short-term, the reduction of young infant mortality in urban areas in India, and probably most of south Asia, requires a more concerted effort to improve primary health care services in the private sector. An exclusive focus on the government sector is clearly insufficient, as it is greatly underutilized (World Bank, 1994). Clearly, the improvement of the quality of care in such a diverse and largely unregulated sector poses major challenges. However, some targeted training activities, initially aimed at qualified health practitioners, to improve their communication skills and to orient them in the use of standardized approaches for the assessment and management of sick young infants, could make a difference. Recommended approaches need to be adapted to local circumstances and acknowledge the reality that hospital referrals may not always be feasible or acceptable. The strict application of current program guidelines (which require, for instance, that all young infants with fever be referred urgently to hospital) might paradoxically lead to a further delay in initiating treatment. A number of authors (Bang *et al.*, 1993; Bhan and Bahl, 1996) have called for the evaluation of approaches that can be used for treating infections in early infancy at the community level. At the same time, greater emphasis needs to be placed on the prevention and management of low birth weight, which remains a major contributor to early infant deaths throughout south Asia (Nichter and Nichter, 1983), through the development of community-based early warning systems to identify and follow-up low birth weight infants, and the training of health providers in the necessary counselling and support skills (Nichter, 1985). Further research to develop practical approaches for the management of illness in the young infant with low weight is required.

\*In another study of diarrhoea-related mortality among children in a rural community close to Delhi, Bhan *et al.* (1986) found that 91% of 23 children who died had sought treatment from a trained practitioner.

†This is not to discount the probability of differential care, or even of selective neglect, of some young infants (especially female infants) in such communities (Bentley, 1982; Scheper-Hughes, 1984; Das Gupta, 1987; Levine, 1987), that we could not document in our short study.

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