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Pathways of care-seeking during fatal infant illnesses in under-resourced South African settings

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Summary

The purpose of this study was to examine care-seeking during fatal infant illnesses in under-resourced South African settings to inform potential strategies for reducing infant mortality. We interviewed 22 caregivers of deceased infants in a rural community and 28 in an urban township. We also interviewed seven local leaders and 12 health providers to ascertain opinions about factors contributing to infant death.

Despite the availability of free public health services in these settings, many caregivers utilised multiple sources of care including allopathic, indigenous and home treatments. Urban caregivers reported up to eight points of care while rural caregivers reported up to four points of care. The specific pathways taken and combinations of care varied, but many caregivers used other types of care shortly after presenting at public services, indicating dissatisfaction with the care they received. Many infants died despite caregivers' considerable efforts, pointing to critical deficiencies in the system of care serving these families. Initiatives that aim to improve assessment, management and referral practices by both allopathic and traditional providers (for example, through training and improved collaboration), and caregiver recognition of infant danger signs may reduce the high rate of infant death in these settings.

Keywords

Infant mortality; Health care seeking behaviour; South Africa; Qualitative research

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1. Introduction

The relationship between care-seeking and infant and child health is well established, and suggests that analysis of care-seeking patterns is essential to identify avoidable morbidity and mortality. In South Africa, services are available from a free but heavily-burdened public sector, as well as from private traditional and allopathic providers.¹ Demand for these private providers by pregnant women and families with young children is considerable, in spite of the availability of free care, and even among those for whom user fees would seem to be an obstacle.^{2–4} In addition, many caregivers in South Africa use home remedies purchased from a variety of outlets, including independently operating pharmacies, ‘African chemists,’ ‘muti shops,’ ‘health shops,’ and informal street and local vendors.⁵

In recent years in South Africa, efforts have been made to increase the availability of public health services to improve child health, for example through clinic building programmes (particularly in underserved rural areas), implementation of Integrated Management of Childhood Illnesses (IMCI) and promotion of access to antiretroviral treatment. Within this context, timely care-seeking at appropriate and quality health services can play an important role in preventing infant morbidity and mortality. However hospital-based audits of child deaths suggest many sick children still present late in under-resourced areas.⁶ Determining the extent to which caregivers first try to manage infant illnesses in the home, and whether they access public facilities, private allopathic providers or traditional providers as a first point of care, will help identify priorities for improving quality of care and community health education.

2. Methods

2.1. Settings

We conducted this study in two sites in South Africa’s KwaZulu Natal province: Umzimkhulu, a rural area, and Umlazi, an urban township. The two sites differ with respect to their location, population density, infant mortality rate (IMR), and HIV prevalence (Table 1). The local public health infrastructure also differs: Umzimkhulu has 16 fixed clinics, two district hospitals that provide generalist services to inpatients and outpatients, one specialist hospital,⁷ and two mobile clinics. Umlazi has 17 fixed clinics and one regional hospital.⁸

Three types of traditional healers practice in the study sites: *Inyangas* – herbalists who draw upon their knowledge of *muti* (traditional medicines made of herbal or animal products) to heal patients; *Sangomas* – diviners who obtain guidance from their ancestors (through possession/channeling, throwing bones, and interpreting dreams) to detect illness or provide advice and who also heal with *muti*; and *Divine Healers* – practitioners who prevent or cure disease with spiritual intervention. While data are not available on the number of traditional healers operating in the study sites specifically, traditional healers are popular: approximately 70% of South Africans consult the estimated 200 000 traditional healers practicing throughout the country.⁵ Independently operating private doctors, known locally as general practitioners (GPs), are also popular: approximately 30% of uninsured South Africans (most of whom are poor) consult them for care.⁹

2.2. Data sources and sample

In partnership with a randomized cluster trial (‘Good Start’) in the study sites, we recruited mothers or caregivers who experienced an infant death during the preceding year. The Good Start Maternity and Neonatal Follow-up Study¹⁰ began in 2003 as a situation analysis that aimed to: determine factors influencing the utilization of and barriers to utilization of

maternal health services; determine levels of awareness of risk factors associated with poor maternal and perinatal health outcomes; and determine the health seeking behavior of both HIV positive and HIV negative pregnant women. During Good Start's first phase, field researchers recorded 70 encounters with families who reported that their infants had died. However, it was outside of the scope of the Good Start study to assess the circumstances surrounding these deaths. As a result, the current study was initiated in conjunction with phase 2 of Good Start, a cluster randomized trial on peer support to improve exclusive breastfeeding which began in 2005.¹¹

Good Start researchers recruited mothers residing in the cluster randomized trial study areas between September 2005 and December 2007, when they were at least seven months pregnant or within one week of giving birth.¹¹ They then conducted routine home visits to assess the health of the mother and infant during which they identified families that experienced an infant death. Following an explanation of the purpose of this study, they asked the infant's caregiver to participate in an additional interview regarding the child's health care and last illness. The final sample included 22 caregivers in Umzimkhulu and 28 in Umlazi. All participants were mothers of deceased infants except for two grandmothers who were their infants' primary caregivers. For the purposes of this report both mothers and grandmothers are further referred to as caregivers. Infants' ages at death ranged from a few minutes to 43 weeks. Caregivers were not interviewed sooner than one month and not longer than one year following the death.

We also purposively sampled key informants (community leaders and health providers) who were knowledgeable about health issues relating to local women and children. Eleven key informants in Umzimkhulu included two community health workers, two traditional healers, one village chief, two village headmen, two community members, and two public sector nurses (one hospital-based and one clinic-based). Eight key informants in Umlazi included three traditional healers, two local government officials, and three public sector nurses (two hospital-based and one clinic-based).

2.3. Data collection

Between December 2006 and November 2007, we interviewed caregivers with a pre-tested and locally adapted instrument. Caregivers reported background information about their families, households and distance to services. They described their pregnancy and antenatal care (mothers only), labor and delivery care (mothers only), and the infant's illness that led to death (all caregivers). Our interview also included a series of semi-structured questions to confirm the sequence of events and reasons specific actions were taken. Bilingual field researchers conducted the interviews in Xhosa and Zulu and translated the data into English.

We conducted key informant interviews in March 2007 to document assessments of local health care accessibility and quality. Most interviews were conducted in English; in some cases (three in Umzimkhulu, one in Umlazi) an interpreter assisted with translation.

2.4. Data analysis

Kleinman¹² views the health care system as a cultural system that integrates all health-related components of a society (popular, professional, and folk). Consistent with that approach, our analytic framework incorporates public health clinics and hospitals, GPs, traditional healers, and home remedies and treatments.

We entered, cleaned and managed qualitative data using NVivo 7.0. The Framework Analysis method guided qualitative data analysis (QSR International, Cambridge, MA, USA) and we explored themes and patterns emerging during analysis in subsequent

interviews.¹³ In addition, a local Study Advisory Group provided critical assessments of themes emerging during analysis and conclusions drawn.

3. Results

3.1. Care-seeking pathways

The pathways caregivers took during their infants' final illnesses were often pluralistic, drawing on a variety of allopathic and indigenous treatments.

3.1.1. Public health services—Most mothers in both settings used public services for antenatal care and for delivery. All mothers attended antenatal care at least once during their pregnancy, and all but one in Umzimkhulu attended public clinics or hospitals. Most mothers (18/21 in Umzimkhulu and 25/27 in Umlazi) gave birth in a public hospital. Several of these women (8/21 in Umzimkhulu, 5/27 in Umlazi) reported that their babies died shortly after birth prior to discharge or on their way home from the hospital.

Caregivers of infants whose final illness began at home described the steps they took to treat their child. In Umlazi, 22 of 25 caregivers whose children first became sick at home took the infant to a public clinic or hospital at some point (16 as a first point of care). In Umzimkhulu, seven of 12 women whose children first became sick at home eventually took the infant to a public hospital, although none reported this as the first point of care. No Umzimkhulu caregivers took their child to a public clinic for treatment at any point during the final illness.

3.1.2. Traditional healers—Key informants in both sites reported that traditional healers are widely available, accessible, and desirable to families (Box 1). This is in spite of the fact that local healers charge both consultation fees (between 50–300 South African Rands (ZAR), or approximately US\$7–40 in 2010) and treatment fees, which vary considerably depending on the treatment prescribed.

Box 1

Selected key informant comments on the popularity of traditional healers

We as black people, we also believe in cultural things, something like 'ubuthakathi' [bewitchment]. So when the baby is sick, maybe the child is crying a lot and, you know, you're giving the baby food, and the baby doesn't want to eat and he just keeps on crying and you do everything that you can and then you say, 'Oh this child has something else.' That happens a lot here. People report those conditions. (*Community Health Worker, Umzimkhulu*)

I have worked in this department for about 10 years. We have had mothers wanting to take the child from here, wanting us to disconnect oxygen; she wants to take the child away because the traditional healer told them that the child is possessed by the dead people [ancestors]. So the dead people are sitting on them. Their spirits are with them. So they perform a sort of a ceremony to cleanse them. You'll find that the parent doesn't want to stay in the hospital believing that you are delaying the child. So they demand us to remove the child from the oxygen so that they will go to the healer to perform the ceremony, and then come back with the child. Usually you try and convince the mother and say that they baby might die before she reaches the main gate. So, usually we try and calm them down. Sometimes, you find, you can convince them. Some do listen to us, some just don't. (*Hospital Nurse, Umlazi*)

In this study, four of 25 caregivers in Umlazi and five of 12 caregivers in Umzimkhulu whose infants became sick at home took their infants to a traditional healer during the child's final illness. For these children, healers prescribed various treatments including infant inhalation/ingestion of burning herbs, infant consumption of tablets, or 'isihlambezi' – special water for drinking or bathing by mothers during pregnancy to facilitate labor and delivery. Caregivers who consulted traditional healers said they associated the child's symptoms with pathogenic agents or events occurring outside the body such as 'evil spirits.'

3.1.3. General practitioners—Key informants stated that few local families seek treatment from GPs because of high consultation fees. In this sample, seven of 25 in Umlazi and five of 12 caregivers in Umzimkhulu consulted GPs. Among these caregivers, only six (four in Umlazi, two in Umzimkhulu) went there first for treatment, while the others went there only after they perceived that their child's first treatment did not help. Box 2 presents the account of one Umlazi caregiver.

Box 2

18 year old Umlazi mother's account of her infant's final illness

My son started his illness one week after immunization. He had a temperature so I took him to the clinic and was given panado syrup which did not help. I then took him to a GP who also gave panado which did nothing. I took him to a second GP who gave him a lot of medication (panado, multivitamins, and for cough) but that did not help. I then took him to hospital where he was examined and given panado syrup and nose drops but was never admitted. Two weeks later we went back to the clinic where I was told that he was being allergic to vaccination and he is still going to develop fits and die. I was given a referral to go to the hospital.

He did start having fits. In hospital they admitted him and then tested his fluids because the doctor was suspecting meningitis. The baby stayed in hospital between two and three weeks and then he suddenly developed a reddish rash on his whole body. The nurses wanted to change the drip from his arm to his head but I refused and ended up taking him back home with me. We stayed home for two weeks and then the fits started again so I took him to another hospital, where he was admitted in ICU and died after five days.

3.1.4. Home remedies—Treatment with home remedies – both over-the-counter and traditional medicines – was common and was provided either to protect the child from, or to cure, illness. Eleven of 12 caregivers in Umzimkhulu and 10 of 25 in Umlazi whose children's final illnesses first began at home tried a home remedy (18 as a first point of care). Several (eight in Umzimkhulu and eight in Umlazi) gave oral rehydration therapy or an over-the counter medication as a first treatment, in some cases (four in Umzimkhulu) in conjunction with a traditional remedy. Two (Umzimkhulu only) provided traditional *muti* alone as a first treatment.

In Umzimkhulu, informants said families give infants enemas to cleanse the child's gut, a practice called 'isiqoni,' or to reduce high temperature. In addition, a community health worker in Umzimkhulu said, '*In the case of HIV positive mothers if they opted not to give breast milk, when they get home, members of the family say they must also practice 'sprouting,' where they put herbs in a syringe and put it in the baby's anus.*' Another Umzimkhulu informant, a clinic nurse, said, '*Mothers will put Vicks VapoRub or toothpaste up the baby's anus because they think it will cure diarrhea.*'

Key informants working in public facilities also reported that many local caregivers know how to – and do – give home treatments that are recommended by allopathic providers (e.g., oral rehydration sachets or home rehydration mixtures of water, salt and sugar).

3.1.5. No care—Only two caregivers of the total 37 across both sites whose infants' first became sick at home provided neither home treatment nor outside care prior to their infants' death; both infants were in Umzimkhulu and both died shortly after birth at home. During interviews with key informants, it was suggested that some families may not provide any care if caregivers identified some signs of illness as normal and expected infant conditions. A hospital matron in Umzimkhulu said such thinking with respect to diarrhea, weight loss and marasmus is common: *'They think it is not an illness that needs to be taken care of and there are some [education] needs around that.'*

3.2. Complexity of care-seeking pathways

Figures 1 and 2 illustrate the complexity of care-seeking pathways taken: back and forth within public health services and between public services and other types of care. In Umzimkhulu, respondents accessed up to four points of care, most often starting at home. Eight respondents only consulted a public hospital, but this was only true for women whose infant died in the hospital shortly after delivery or whose newborn died on the way home following discharge. In Umlazi, respondents accessed up to eight points of care, most often starting with public health services (seven to clinics and nine to hospitals). For three of these caregivers, the hospital was the only point of care because the child died shortly after delivery in the hospital.

No participants consulted a traditional healer as a first point of care, although nine of the 37 across both sites whose infants' first became sick at home consulted healers following treatment at home or at allopathic services.

Only one caregiver in Umzimkhulu was referred to the hospital from another source (a GP), and in Umlazi, five caregivers were referred to the hospital: two by GPs, two by clinics, and one by a district level hospital to a regional hospital). One other Umlazi caregiver was referred to an HIV clinic by the hospital.

4. Discussion

All but two caregivers in this study sought help from at least one and up to eight types of care for their infants during the final illness. Public health services, particularly hospitals, were the most widely utilized source in both sites, however many caregivers reported using other types of care after presenting at public services, indicating that they felt the need for additional assistance. It is notable that in Umzimkhulu no caregivers whose child became sick at home accessed a public hospital as their first point of care and none of these caregivers accessed a public clinic *at any point* along their care-seeking pathway. This perhaps reflects caregivers' assessment of poor quality of care at clinics (as was found previously in the same settings),¹⁴ or, as has been found elsewhere, that women select private providers or care at hospitals if they consider the child's illness to be severe.¹⁵

Eighteen of the 37 caregivers whose child's final illnesses first began at home reported giving home remedies before seeking other services which may have exacerbated some infants' illnesses. Studies in other settings have linked inappropriate home treatments and remedies with increased mortality.¹⁶ A study in Chad,¹⁷ for example, concluded that self-medication led many otherwise easily treatable problems to 'spiral out of control' (p 229).

In addition, traditional healers, while never a first point of care, were consulted in both sites, perhaps unsurprising given that they are reportedly popular, and given that many families report having had negative experiences with other local health services. Traditional healers' methods of curing and explanatory models of illness differ substantially from those of western medical services. For example, the counseling and explanations provided by allopathic providers in low-resource settings may be minimal or non-existent. In contrast, traditional healers often offer an explanation for the occurrence of misfortune (and how to respond to it). A caregiver may therefore go to a traditional healer for an explanation of the illness or, if a caregiver's explanatory model of illness incorporates externalizing causes¹⁸ (e.g., evil spirits), the traditional healer may be a preferred point of care.

The finding that GPs, while rarely the first point of care, were consulted by caregivers in these settings confirms other research findings that even families with limited financial resources seek care from private health services that they trust.^{2,9}

4.1. Implications for programs and policies

South Africa has a relatively good public health infrastructure compared to many African countries¹⁹ and provides free primary health services. Yet caregivers continue to seek care from other sources when faced with a severely ill child, including from those that charge for services. In some cases, other sources are consulted as a first point of care, perhaps reflecting caregivers' discontent with the quality of care offered by public facilities. Indeed, the fact that several infants in this study died shortly after being seen at public clinics or discharged from hospitals (including 11 neonates that died either before discharge after a hospital birth or on their way home after discharge) suggests fundamental deficiencies in the services offered, particularly with respect to assessment, discharge and referral protocols. Indeed, a 2009 study of IMCI implementation in KwaZulu Natal and another province found that only 18% of observed health workers who were trained in IMCI assessed all the main symptoms in every child, and less than half (46.8%) of severely ill children who required urgent referral to hospital were identified.²⁰ Similarly, a 2010 evaluation of the implementation and integration of the prevention of mother to child transmission of HIV (PMTCT) programme in two similar districts in KwaZulu Natal found that while there is high coverage of PMTCT interventions during pregnancy and delivery, the follow-up of mothers and infants is very poor and often done by lay counselors.²¹

Given that both GPs and traditional healers continue to play an important role in caring for sick infants, consideration must be given to how to improve their referral practices when presented with very sick children. This is particularly important because of the sub-standard and even harmful practices sometimes associated with care provided to children by private providers, both allopathic and traditional.²² The literature includes examples of successful coordination with traditional healers to improve referral practices,^{23,24} and suggests that recognition of referrals from these providers by staff at public hospitals may improve patient outcomes. Given the historically inclusive nature of traditional healers and their practices,²⁵ traditional healers in these settings may welcome the opportunity for better collaboration with allopathic providers.

Further, consideration should be given to how collaboration between traditional healers and public facilities might strengthen the quality of counseling offered to families about infant danger signs and when to seek care. Many traditional healers emphasize counseling, provide explanations and explain treatment options to their patients²⁶ while this is often a deficiency in care provided to families of young children by public providers in South Africa.²⁷ Indeed, the widespread reliance on home care during infants' final illnesses in this study demonstrates the need for education to improve caregivers' recognition of signs of illness severity and when to seek care. Problems relating to transport and long distances to facilities

also have been reported in the study settings,¹⁰ and are likely to influence the demand for home care treatments as well.

This is one of the first studies to describe care-seeking among caregivers whose infants died in impoverished South African areas and provides new information about the choices available to, and relied upon by, these families. Understanding the reasons caregivers choose different types of care as well as the ability of each type to respond effectively to an infant's health needs is critical to reducing the unacceptably high IMR in these settings, to preventing unnecessary treatment delays, and reducing pain and suffering among infants and their families. Identifying these factors will improve local planning efforts to target priority issues such as poor quality of care, initiatives to promote collaboration and referral systems across providers, and community health education.

4.2. Limitations

The study sample was small due to the qualitative, in-depth nature of each interview. In addition, it is possible that caregivers withheld certain information about the providers and treatments they utilized during their child's final illness, or about their inaction during that time. In an effort to minimize this and other sources of inaccuracies in the data, we made assurances during the informed consent process that there were no right or wrong answers, that responses would be anonymous and confidential and that the interview was not in any way intended to be judgmental. In addition, we trained the field researchers conducting the interviews to identify and respond to signs of distress in order to increase participant comfort and accuracy of reporting.

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Figure 1.

Sequence of care provided prior to infant death in Umzimkhulu (n=22) General practitioner: Private medical doctor; Home care: Over-the-counter medications available from a local chemist/pharmacy (e.g., electrolyte solutions, cough mixtures, panado syrup, gripe water) or home remedies (traditional, herbal); No care: Nothing was done in response to illness symptoms; Public hospital: Government hospital; Traditional healer: Sangoma (diviners), Inyanga (herbalists) or Divine (spiritual) healer.

Figure 2.

Sequence of care provided prior to infant death in Umlazi (n=28) General practitioner: Private medical doctor; Home care: Over-the-counter medications available from a local chemist/pharmacy (e.g., electrolyte solutions, cough mixtures, panado syrup, gripe water) or home remedies (traditional, herbal); No care: Nothing was done in response to illness symptoms; Public health: Government clinic or hospital; Traditional healer: Sangoma (diviners), Inyanga (herbalists) or Divine (spiritual) healer.

Table 1

Characteristics of study settings

Characteristic Site	Umzimkhulu	Umlazi
Location	Former Transkei 'Bantustan' area, KwaZulu Natal province	Township near Durban, KwaZulu Natal province
Population density	Rural (23 per km ²) ²⁶	Urban (1170 per km ²) ²⁷
Infant mortality rate	99 per 1000 ²⁸	60 per 1000 ²⁹
Antenatal prevalence of HIV (district level)	34.1% ³⁰	42.0% ³⁰