High mortality despite good care-seeking behaviour: a community study of childhood deaths in Guinea-Bissau

M. Sodemann,1 M.S. Jakobsen,1 K. Mølbak,2 I.C. Alvarenga Jr.,3 & P. Aaby4

The care-seeking behaviour of mothers of 125 children deceased aged 1–30 months was investigated by verbal autopsy in an urban area of Guinea-Bissau. A total of 93% of the children were seen at a health centre or hospital during the 2 weeks before death. In a previous survey covering the period 1987–90 we found that 78% of the children who died had presented for consultation (8); despite this increase in care seeking, infant mortality had not decreased. Comparison of elapsed time from disease onset to first consultation between children who died and matched surviving controls indicated that the interval was shorter for children who died than for those who survived (odds ratio (OR) = 0.7; 95% confidence interval (CI): 0.5–0.99). Of the 125 terminally ill children, 56 were hospitalized. A total of 20 children died on the way to hospital or while waiting in the outpatient clinic. Lack of hospital beds resulted in 15 mothers being refused hospitalization for their child. Of hospitalized children, 42% were discharged as improved or recovered during the 30 days preceding death. These results reveal a need for improved hospital admission criteria, improved recognition of the symptoms of serious illness, better discharge criteria, and the implementation of quality assurance systems for health services.

Introduction

Many studies have reported a significant decrease in child mortality following general improvements in primary health care (PHC) (1,2). Such decreases are mainly the result of improvements in antenatal care and vaccination coverage; the effect of diarrhoeal disease programmes is less unequivocal. However, as vaccines and antenatal care cannot entirely eradicate the problem of excess childhood mortality in developing countries, better case management of severely ill children is clearly needed.

Improvements in the management of severely ill children are often based on audits of case histories with fatal outcomes (3). However, few studies in developing countries have investigated care-seeking behaviour prior to death in serious childhood illness in order to improve case management (4–6). Mortality surveys have found large variations in the proportion of children seen at a health facility before dying (7–10). It is important to explain why mortality remains high among under-5-year-olds in settings with easy access to health care facilities. For example, in a rural area of the Gambia, where 80% of children were fully immunized and PHC programmes had been active for 10 years, infant mortality was still 120 per 1000 live births in 1990 (11). In the Bandim suburb of Bissau, Guinea-Bissau, we previously reported that the infant mortality was 94 per 1000 and under-5-year-old mortality 215 per 1000, despite the presence of two health centres, a mother-and-child health clinic and an outpatient clinic (8).

We conducted the present study on patterns of care-seeking behaviour prior to a child’s death to investigate child mortality on the basis of the mother’s experience. The aim was to obtain individual case histories that could be used to improve patient management in primary health care programmes and thereby lower childhood mortality in developing countries.

Subjects and methods

Study area

The study was carried out in the suburbs Bandim 1 and Bandim 2 of the capital Bissau, Guinea-Bissau. The population of approximately 25000 persons

1 Department of Epidemiology and Social Medicine, University of Aarhus, Hoegh-Guldbergsqade 10, DK-8000 Aarhus C, Denmark; and Danish Epidemiology Science Centre, Statens Seruminstitut, Copenhagen, Denmark. Requests for reprints should be sent to Dr Sodemann at the former address.
2 Danish Epidemiology Science Centre, Statens Seruminstitut, Copenhagen, Denmark.
3 Ministry of Health, Bandim, Bissau, Guinea-Bissau.
4 Danish Epidemiology Science Centre, Statens Seruminstitut, Copenhagen, Denmark; and Projecto de Saúde, Bandim, Bissau, Guinea-Bissau.
Reprint No. 5771
is served by two local health centres (with senior nurses consulting), one mother-and-child health clinic (with physicians consulting) as well as an outpatient clinic at the paediatric ward of the national hospital (with hospital paediatricians consulting). All inhabitants live within 1 km of a health centre and within 3 km of the mother-and-child health clinic and outpatient clinic. Apart from a small one-time charge levied for a child’s vaccination chart, no fees were charged at health facilities in Bissau during the study period. Since 1979, the area has had a demographic and health surveillance system that covers the following: registration of all pregnancies and births; and for children less than 3 years of age, routine collection, by means of 3-monthly visits to all houses, of information on vaccinations, infections, nutritional status, migrations, and deaths. Morbidity and care seeking are monitored by weekly household interviews. Traditional remedies for severe diseases are not generally the first treatment choice.

Study population

The cohort followed in the present study consisted of all 1347 children born in Bandim 1 or 2 between 1 May 1992, and 30 April 1993. Deaths were ascertained by means of the routine surveillance system. Two additional rounds of data collection were carried out in 1993 and 1994; furthermore, a census of the entire population was performed in 1994. Verbal autopsies were conducted by two of the authors (MS & ICA) and a specially trained Guinean midwife. Interviews were carried out from July 1992 to November 1994, by which time the youngest children in the study cohort were 18 months of age and the oldest children 30 months of age. Median time from death to interview was 7 months (25–75th percentile: 6–9 months). The immediate cause of death was determined by combining information from the verbal autopsy, the morbidity survey, and a register of hospital diagnoses. Morbidity information was considered valid if the child had been followed up until death, and hospital diagnoses were considered valid when the child had been hospitalized for more than 24 hours. Hospital records were available for 43 of 56 hospitalized children (76.8%). A probable cause was determined for 93% of all deaths. In this study, “hospitalization” was defined as hospitalization at any time during the 30 days preceding death, regardless of subsequent discharge from hospital. Households with deaths were divided into two socioeconomic status groups: group 1 (50 mothers) consisted of households with two or more of the following: corrugated iron roof, television, inside toilet, and electricity; group 2 (75 mothers) consisted of households with less than two of these characteristics. Socioeconomic information was obtained from the health surveillance system.

Statistical methods

Sample means were compared with the Student’s t-test for normally distributed data, but the Kruskall–Wallis test was used when sample variances were significantly different. In bivariate analyses, background factors were controlled for by means of a Mantel–Haentzel stratified analysis of two-by-two tables. A nested case–control study was carried out by matching a control to each fatal case. The control was chosen from among children in the study population participating in a weekly morbidity survey, age-matched (±1 month), had experienced an episode of disease within the same month as the fatal case, was seen at a health centre or a hospital, but survived at least 3 months following the episode. Time to consultation was measured as the number of days between the onset of illness and the first consultation. The odds ratio was calculated as the ratio of discordant pairs, and 95% confidence intervals (CI) were calculated with Miettinen’s test-based approach (12).

Results

Childhood mortality in the study group

All deaths of live-born children (248/1347) were investigated by verbal autopsies with the mother, or the nearest relative if the mother was absent. The circumstances, timing, and location of each contact with health care personnel during the fatal illness were recorded during the interviews. The proportion of stillbirths was 55 per 1000 births, perinatal mortality was 81 per 1000 births, and infant mortality 91 per 1000 live births. However, only post-neonatal deaths (125/1347) were included in this analysis.

Of the 125 such cases, 114 had verifiable information on care seeking. Of these, 106 children (93%) were seen by a health professional during the 14 days preceding death. Of the eight others, two died on the way to consultation, three died suddenly and unexpectedly, and three from diseases ascribed to traditional ceremonial causes. Compared with our previous mortality survey in the same city, the behaviour reported here represents a significant reduction in the risk of not being brought to a health facility (risk ratio = 0.3; 95% CI: 0.2–0.7) (8). Moreover, 33 (26.4%) of the deaths occurred in hospital, whereas in the previous survey 45% of deaths occurred in hospital. A total of 23 children (18.4% of deaths) died
### Table 1: Cause of death and pattern of care seeking

<table>
<thead>
<tr>
<th></th>
<th>Median duration of illness (days)</th>
<th>Median days to first consultation</th>
<th>No. of children, by place of first consultation:</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>Health centre</td>
<td>Outpatient clinic</td>
</tr>
<tr>
<td>Acute diarrhoea</td>
<td>7 (3–22)</td>
<td>2 (2–4.5)</td>
<td>13 (56.5)</td>
</tr>
<tr>
<td>Fever</td>
<td>4 (3–25)</td>
<td>2 (1–5)</td>
<td>10 (31.3)</td>
</tr>
<tr>
<td>Pneumonia</td>
<td>10 (5–30)</td>
<td>3 (1–5)</td>
<td>9 (56.3)</td>
</tr>
<tr>
<td>Malaria</td>
<td>8 (2–20)</td>
<td>3 (2–5)</td>
<td>3 (50.0)</td>
</tr>
<tr>
<td>Other*</td>
<td>7 (2–30)</td>
<td>1.5 (0–15)</td>
<td>4 (11.4)</td>
</tr>
<tr>
<td>Chronic diarrhoea</td>
<td>30 (25–60)</td>
<td>14.5 (1–46)</td>
<td>8 (66.7)</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td></td>
<td></td>
<td>47</td>
</tr>
</tbody>
</table>

* Figures in parentheses are the 25th–75th percentiles.

* Figures in parentheses are percentages.

* Mother-and-child health clinic or regional hospitals in the interior.

* Malnutrition ($n = 5$), measles ($n = 8$), congenital diseases ($n = 8$), sudden death ($n = 3$), unknown ($n = 11$).
at home after being discharged from hospital. No information on the location of death was available for seven children.

**Time to consultation**

To determine whether mothers delayed consultation in fatal cases, we performed a nested case–control study. It was possible to match a surviving control for 93 cases. Equal delay occurred in 9 of the matched pairs. In 35 matched pairs, the case exhibited the longest delay and in 49, the control. Cases were more likely to have a shorter delay than controls, with an odds ratio of 0.70 (95% CI: 0.50–0.99).

**First consultation and hospitalization**

The place of first consultation according to cause of death is shown in Table 1. The median time from onset of symptoms to first consultation was independent of child's age, ethnic group, mother’s education, socioeconomic status, and cause of death.

Of the 47 children first seeking care at a health centre, only 23 (49%) were admitted to hospital and, of these, 20 only after the mother sought consultation more than once. Of the 38 children first seeking care at the outpatient clinic at the paediatric ward, 22 (58%) were admitted to hospital. Immediate hospitalization was more likely among children presenting at the outpatient clinic first than for children presenting at the health centre (risk ratio = 5.0, 95% CI: 2.0–12.5). Children taken to a health centre survived longer (median, 8 days; 25–75th percentile: 2–24 days) following first consultation than children initially taken to the paediatric ward (median, 2 days; 25–75th percentile: 0–8 days; \( P = 0.01 \)). No difference in survival time after first consultation was found between children hospitalized immediately (\( n = 18 \)) and others (\( n = 20; P = 0.8 \)). After controlling for mother’s education, socioeconomic status, and child’s age, there were no differences in place of first contact with the health system. However, children with diarrhoea were more likely to contact a health centre first. Of those children surviving at least 2 days from first consultation without hospitalization, 39 (84.8%) later reattended a health facility.

**Hospitalization: reasons for refusal or discharge**

Of the 114 deaths for which we have information, 103 children (90.3%) presented at hospital one or more times during their terminal illness. Of these, 10 children died on the way to hospital and 10 while waiting for treatment in the outpatient clinic (Table 2). Of the remaining 83 children, 56 (67.4%) were admitted either at the first visit (\( n = 22 \)) or at a subsequent visit; of those admitted, 18 children died the day of admission. For the 61 children not admitted at first consultation, 15 of the mothers stated they were turned away from the outpatient clinic having been informed that their child should be hospitalized, but that there were insufficient beds. Refusal of admission did not depend on mother’s education, socioeconomic status, or child’s age (\( P = 0.9 \)). Elapsed time since disease onset (>14 days) increased the risk of refusal (risk ratio, 2.4; 95% CI: 0.9–6.6).

Of the 56 children admitted to hospital, 23 (41.7%) were discharged before death, with the risk of discharge being independent of socioeconomic status (\( P = 0.44 \)) and child’s age (\( P = 0.35 \)). Of these, 9 children were discharged as “cured”, 10 as “improved” or “recuperating”, 1 was discharged by the mother, and 2 had no status information at discharge.

**Case histories**

Six representative case histories depicting the management problems of severe childhood illness in the study area are shown in Table 3.

**Discussion**

Despite a high percentage of children with fatal illness obtaining treatment from a health professional, infant mortality in the study suburban area of Guinea-Bissau has continued to be high; (1987–90, 94 per 1000; 1992–93, 91 per 1000). The proportion of children who later die after presenting for consultation both at health centres and hospitals has increased significantly since our previous mortality survey (8).

Among physicians and other health care workers in developing countries, a common explanation for high childhood mortality is that, as mothers are believed to be incapable of caring for a severely ill child, children are brought to care too late. Moreover, they do not recognize severe symptoms and may seek traditional care first. However, the present study indicates that mothers sought care sooner in cases of fatal illness than in other cases.

Conceivably, seriously ill children would have a better chance of survival if they were treated at the outpatient paediatric ward than at a health centre. The ratio of mothers choosing a health centre as site of first consultation to mothers choosing the paediatric ward was the same, regardless of mother’s education, socioeconomic status, child’s age, and ethnic group. Moreover, the chance of being admitted im-
Table 2: Place of first consultation and subsequent care seeking

<table>
<thead>
<tr>
<th>Place</th>
<th>Hospitalized:</th>
<th></th>
<th>Not hospitalized:</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Direct</td>
<td>After one or more consultations</td>
<td>Total hospitalized*</td>
<td>Died at home(c)</td>
</tr>
<tr>
<td>Health centre</td>
<td>3</td>
<td>20</td>
<td>23 (11)</td>
<td>19 (11)</td>
</tr>
<tr>
<td>Outpatient clinic</td>
<td>18</td>
<td>4</td>
<td>22 (6)</td>
<td>7 (6)</td>
</tr>
<tr>
<td>Mother-and-child health clinic</td>
<td>0</td>
<td>2</td>
<td>2 (1)</td>
<td>2 (1)</td>
</tr>
<tr>
<td>Hospital or health clinic in the interior</td>
<td>1</td>
<td>4</td>
<td>5 (2)</td>
<td>3 (2)</td>
</tr>
<tr>
<td>No information on place</td>
<td>—</td>
<td>—</td>
<td>4 (3)</td>
<td>—</td>
</tr>
<tr>
<td>No consultation</td>
<td>—</td>
<td>—</td>
<td>—</td>
<td>6</td>
</tr>
<tr>
<td>No information on consultations</td>
<td>—</td>
<td>—</td>
<td>—</td>
<td>4</td>
</tr>
<tr>
<td>Total</td>
<td>22</td>
<td>30</td>
<td>56 (23)</td>
<td>41 (20)</td>
</tr>
</tbody>
</table>

* Figures in parentheses are number of children subsequently discharged who died outside hospital.
\(c\) Figures in parentheses are number of children dying at home after one or more reconsultations.
mediately to the paediatric ward of the hospital was remarkably lower for children presenting initially at a health centre than for children presenting initially at the outpatient paediatric ward. It is therefore possible that health centres retard needed hospitalization. As health centers were visited more frequently than in our previous mortality survey, this could have serious implications.

Apart from five children dying suddenly at home or on the way to their first consultation, only five children were not presented for consultation at hospital, which is a marked decrease from our previous survey. However, it is significant that so few fatally ill children were admitted to hospital, even from among those who first presented at the outpatient paediatric ward. In many cases, the reason was a shortage of beds. There were nine terminally ill children admitted by a paediatrician at the outpatient clinic 48 hours prior to death without being admitted. The risk of refusal of admission after consultation at the outpatient paediatric ward was higher if symptoms had a duration of more than 14 days, indicating that chronic illness was less likely to be seen as requiring hospitalization. This is significant, as the two most common chronic illnesses, persistent diarrhoea and malnutrition, both have a very high mortality (8). Since children not returning for a second consultation died rapidly (median survival, 1 day) mothers' lack of knowledge does not explain why children were not hospitalized. Children not hospitalized after a first visit to the outpatient paediatric clinic died as rapidly as those who were; it is therefore unlikely that refusal of admission was based exclusively on clinical criteria. Hospitalization was not influenced by socioeconomic status, mother's education, child's age, or ethnic group. However, verbal autopsies suggested that hospitalization was obtained more easily if a mother knew a staff member in the outpatient clinic.

A considerable proportion of children died waiting for consultation at the outpatient clinic or laboratory. Some of these deaths could probably have been avoided by means of a revision of clinic procedures and by training health personnel to recognize children requiring immediate care.

A major problem is the high proportion of children dying at home after discharge from hospital. In light of discharge status, this could not have been caused by mothers fleecing the hospital with dying children. No sociocultural factors were related to risk of discharge, suggesting that inadequate recognition by medical staff of the potential consequences of illness or nosocomial infections may have been responsible. If so, this problem has been aggravated since our previous mortality survey, since a larger proportion of hospitalized children later die at home. The number of beds in the paediatric ward remained constant between the two surveys. Hence, demand for limited bed space may have contributed to some premature discharges. Hospital beds can be occupied for long periods of time by chronically ill children suffering from malnutrition, persistent diarrhoea, complications resulting from cerebral malaria, or tetanus. A clearer distinction between acute and long-term illness in terms of management and the need for care, as well as a more strict set of rules for admission and discharge could potentially lower demand for bed space.

The present mortality survey consists of case histories with a fatal outcome. Since medical consultations for terminally ill children represent only a small fraction of all consultations for sick children, this survey may be biased as an evaluation of the adequacy of health system procedures. However, the present study does point to a number of specific problems in case management. Previous studies ana-
lysing care-seeking behaviour have focused particularly on traditional beliefs and practices that prevent mothers from seeking proper medical care (5, 6, 9). However, our experience suggests that it may be equally important to examine the quality of the medical care provided. This is supported by a Mexican study using verbal autopsies in a similar way. In an area where no household was farther than 30 minutes from a health facility, 60% of the deaths in children occurred at home and 80% of these children had received qualified medical care within 3 days of death (4).

For dealing with problems associated with severely ill children WHO/UNICEF recommends "integrated management of the sick child", which combines the principles learnt over the past 15 years in disease-specific health programmes into a unified approach to managing childhood illness (13). This initiative focuses on improvements in health-worker performance and changing family behaviour in relation to sick children. Training courses for the inpatient case management of sick children have also been developed.

The present analysis clearly supports the need for such initiatives. Surveys analysing fatal cases can be a valuable tool, and can serve as a cost-effective means for health care workers to identify areas for improvements in the case management of severely ill children. Improving the management of such children may be as important for decreasing childhood mortality as vaccination and antenatal care programmes have been, especially in countries with poorly educated and badly paid health care workers. Inadequate supplies, physical facilities, and equipment may also contribute to the persistence of high childhood mortality in Bissau. Such constraints emphasize improved health system management as a means of better using available resources.

A key step in improving case management should be the establishment of an effective triage system that singles out seriously ill children as soon as they come to a health facility and ensures that appropriate action is taken. More formal criteria for admission, referral, and discharge are also needed, accompanied by clinical and system-management training of staff. Finally, measures should be taken to assure the quality of services provided by health care workers, e.g. by medical audit or the use of epidemiological methods such as those used here. These findings could be extended to the health services of other developing countries; however, important differences may exist depending on available resources, personnel, and payment systems. Hence, additional studies investigating the case management of severe illness at the primary health care and hospital levels in other countries are warranted.

Acknowledgements

We are indebted to Angelina Da Silva and Queba Djana for assistance during interviews and identification of mothers. This study was supported by the Science and Technology for Development Programme of the European Community (contract No. TS3-CT92-0060) and by the Danish Council for Development Research (grant No. 104.DAN8/535).

Résumé

Une mortalité élevée malgré la recherche de soins appropriés: résultats d'une enquête communautaire sur les décès d'enfants en Guinée-Bissau

Bien que de nombreuses études aient fait état d'un déclin significatif de la mortalité infantile à la suite d'améliorations générales des soins de santé primaires, la vaccination et les soins prénataux ne peuvent supprimer à eux seuls la surmortalité infantile dans les pays en développement. Une prise en charge plus efficace des enfants gravement malades est donc nécessaire. Rares sont les études qui ont été faites dans les pays en développement sur la recherche de soins appropriés comme moyen d’améliorer la prise en charge des enfants gravement malades. La présente enquête sur la demande de soins avant le décès a été conduite pour analyser le problème de la mortalité infantile en fonction de l’attitude de la mère. Il s’agissait de recueillir des antécédents médicaux individuels en vue d’améliorer la prise en charge des cas dans le cadre de programmes de soins de santé primaires et ainsi, de réduire la mortalité infantile dans les pays en développement.

La demande de soins par les mères de 125 enfants décédés entre 1 et 30 mois a été étudiée au moyen d’autopsies verbales dans une zone urbaine de Guinée-Bissau. Tous les habitants sont à moins de 3 km d’un centre de santé. Au total, 93% des enfants avaient été reçus dans un centre de santé ou un hôpital dans les deux semaines ayant précédé leur décès. Notre précédente enquête, sur la période 1987–1990, avait montré que 78% des mères des enfants décédés les avaient montrées en consultation; toutefois, malgré cette augmentation de la demande de soins, la mortalité infantile n’a pas baissé. Si l’on compare le temps écoulé entre l’apparition de la maladie et la première consultation pour les enfants décédés et des témoins survivants appariés, il apparaît que cet intervalle avait été plus court pour les enfants qui sont décédés que pour ceux qui ont survécu (odds ratio = 0,7; intervalle de
confiance à 95% = 0,5–0,99). Sur les 125 enfants qui étaient en phase terminale, 56 ont été hospitalisés. Vingt sont décédés lors du transport à l’hôpital ou en attendant d’être vus en consultation dans un dispensaire. Faute de lits disponibles, 15 mômes se sont vu refuser l’hospitalisation de leur enfant. Sur les enfants hospitalisés, 42% ont été déclarés en meilleure santé ou guéris et renvoyés chez eux dans les 30 jours ayant précédé leur décès. Ces résultats montrent qu’il est nécessaire d’améliorer les critères d’hospitalisation, la reconnaissance des symptômes des maladies graves et les critères de sortie et de mettre en œuvre des systèmes d’assurance de la qualité des services de santé.

La solution préconisée par l’OMS et l’UNICEF pour le traitement des enfants gravement malades est la “prise en charge intégrée de l’enfant malade” qui associe les principes acquis depuis 15 ans dans le cadre de programmes de lutte contre des maladies déterminées en une approche uniforme et cohérente de la prise en charge des maladies de l’enfance. La présente étude montre très clairement que de telles initiatives sont nécessaires. Les enquêtes sur les cas mortels peuvent être un instrument précieux et fournir aux agents de santé un moyen d’un bon rapport coût/efficacité de déterminer les domaines dans lesquels des améliorations doivent être apportées à la prise en charge des enfants gravement malades.

References