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Circumstances of child deaths in Mali and Uganda: a community-based confidential enquiry

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Summary

Background Interventions to reduce child deaths in Africa have often underachieved, causing the Millennium Development Goal targets to be missed. We assessed whether a community enquiry into the circumstances of death could improve intervention effectiveness by identifying local avoidable factors and explaining implementation failures.

Methods Deaths of children younger than 5 years were ascertained by community informants in two districts in Mali (762 deaths) and three districts in Uganda (442 deaths) in 2011–15. Deaths were investigated by interviewing parents and health workers. Investigation findings were reviewed by a panel of local health-care workers and community representatives, who formulated recommendations to address avoidable factors and, subsequently, oversaw their implementation.

Findings At least one avoidable factor was identified in 97% (95% CI 96–98, 737 of 756) of deaths in children younger than 5 years in Mali and 95% (93–97, 389 of 409) in Uganda. Suboptimal newborn care was a factor in 76% (146 of 194) of neonatal deaths in Mali and 64% (134 of 194) in Uganda. The most frequent avoidable factor in postneonatal deaths was inadequate child protection (mainly child neglect) in Uganda (29%, 63 of 215) and malnutrition in Mali (22%, 124 of 562). 84% (618 of 736 in Mali, 328 of 391 in Uganda) of families had consulted a health-care provider for the fatal illness, but the quality of care was often inadequate. Even in official primary care clinics, danger signs were often missed (43% of cases in Mali [135 of 396], 39% in Uganda [30 of 78]), essential treatment was not given (39% in Mali [154 of 396], 35% in Uganda [27 of 78]), and patients who were seriously ill were not referred to a hospital in time (51% in Mali [202 of 396], 45% in Uganda [35 of 78]). Local recommendations focused on quality of care in health-care facilities and on community issues influencing treatment-seeking behaviour.

Interpretation Local investigation and review of circumstances of death of children in sub-Saharan Africa is likely to lead to more effective interventions than simple consideration of the biomedical causes of death. This approach discerned local public health priorities and implementable solutions to address the avoidable factors identified.

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Introduction

Almost 3 million deaths are estimated to have occurred in children younger than 5 years in sub-Saharan Africa in 2015, accounting for nearly half of all global child deaths.¹ The absolute number of deaths in sub-Saharan Africa is estimated to have fallen by only 24% since 1990.¹ Therefore, this rate of reduction needs to accelerate markedly to reach the Sustainable Development Goal of 25 or fewer under-5 deaths per 1000 livebirths by 2030.¹ When this study started, in 2011, under-5 mortality was estimated to be 95 deaths per 1000 livebirths in Mali and 90 per 1000 in Uganda.^{2,3}

Some have argued that the majority of these deaths could be prevented by increasing the coverage of a small number of simple, evidence-based interventions focused on biomedical causes of death.^{4–6} However, the effective implementation of these interventions is not straightforward—the effect on mortality is often disappointing, reflecting a local failure to deliver

interventions with adequate quality of care.^{7–9} A systematic review of trials¹⁰ of evidence-based interventions to improve health care in sub-Saharan Africa showed that the variation in outcomes between local centres is often greater than the overall estimate of effect. This variation makes it difficult to generalise about the likely effect of an intervention in a particular setting. Therefore, it is important to understand the barriers to implementation that cause local variations in effectiveness.^{11,12}

The research that we report here was done in Mali and Uganda, as part of the Human Resources for Primary Health Care in Africa programme, funded by the European Union. The two countries were selected as exemplars because they are both struggling to address high rates of child mortality, but have contrasting health-care systems (eg, health care in Uganda is nominally free at the point of delivery, whereas in Mali it is not) and diverse cultural norms (eg, in Mali the population is

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For the Human Resources for Primary Health Care in Africa programme see <http://www.huraprim.ugent.be/drupal/?q=home>

Research in context

Evidence before this study

We searched the databases MEDLINE, Embase, Global Health (CABI), Popline, CINAHL, and the Science Citation Index from their inception to July, 2014. We included studies of confidential enquiries and institutional reviews of maternal, perinatal, or child deaths that measured associated changes in mortality. We found one cluster-randomised trial of institutional maternal death reviews that reduced in-facility maternal mortality. We found several verbal or social autopsy studies that investigated causes of child death and identified some avoidable factors on the basis of closed questions, mainly about delay in the care process, but none had initiated local discussion of avoidable factors to identify solutions. We also found 13 uncontrolled observational assessments of changes in facility-based mortality rates associated with in-facility case reviews of maternal deaths, perinatal deaths, or both. We identified no studies that assessed the effect of community-based death reviews or of child death reviews in any setting.

Added value of this study

To the best of our knowledge, this study is the first community-based confidential enquiry into child deaths in Africa using open questions to construct a narrative on

circumstances of death and explicitly seeking to avoid attribution of blame. Local discussion of circumstances of deaths led to the formulation of practical recommendations to address avoidable factors, particularly failures in local delivery of preventive and acute care. These recommendations often focused on generic actions that were independent of the specific biomedical cause of death.

Implications of all the available evidence

Understanding the circumstances of child deaths is as important as understanding the biomedical cause of death for achieving the Sustainable Development Goal of reducing child mortality. Mortality reviews are known to be effective in addressing care failures in hospitals, but most child deaths occur outside hospitals. Our community-based confidential enquiry has led to recommendations on local remedial actions to address avoidable causes, but our observational study design provided only circumstantial evidence of its effect on mortality. A confidential enquiry is not cost-free and questions remain about the most cost-effective method of scaling up this type of intervention, particularly the frequency with which confidential enquiries need to be done in a local area and whether all deaths (or only a sample) need to be investigated.

predominantly Muslim, whereas in Uganda it is predominantly Christian). We hypothesised that the inadequate progress made in reducing under-5 mortality in both countries reflected local difficulties in implementing national policy initiatives, and that potential solutions might be best identified by local enquiries into the circumstances of death.

Institutional death audits are already a government aspiration in Uganda, and in Mali, the QUARITE trial¹³ showed that maternal death reviews in hospitals were effective in reducing hospital maternal mortality rates. However, most deaths of children younger than 5 years in sub-Saharan Africa occur in the community, outside health-care institutions.^{14–19} Therefore, we undertook a community-based audit of the circumstances of death in under-5s to identify avoidable factors and local solutions.

Methods

Study design

We undertook a community-based investigation of child deaths in Mali and Uganda, with use of local community informants to ascertain deaths, and applied a blame-avoiding confidential enquiry method²⁰ to encourage the active involvement of local health-care workers in their review. In these two countries, we purposefully sought contrasting study areas, both urban and rural. In Uganda, we selected three areas: one encompassing three rural subcounties of the Mbarara district; the urban parish of Kibuli (much

of which consists of a so-called slum) in Kampala, the capital city; and the very remote rural subcounty of Kayonza (Kanungu district, adjoining the rainforest). In Mali, we selected two contrasting areas in terms of ethnic groups, climate, geography, epidemiology, and access to health-care services: one encompassing two subdistricts of Kolokani district, about 140 km north of the capital, and another comprising three subdistricts of Sikasso district, about 380 km southeast of the capital. Overall, we included five subcounties in Uganda (covering an estimated population of 244 921) and five subdistricts in Mali (covering an estimated population of 76 140).

Ethical approval was obtained from the Oxford Tropical Research Ethics Committee (OXTREC 28-11 and 37-11), the institutional ethics review committee of the Mbarara University of Science and Technology (MUIRC 01/07-02), the Ugandan National Council for Science and Technology (HS 1255), and the ethics committee of the Institut National de Recherche en Santé Publique in Mali (05-11). We explained the study to participating communities, families of the deceased, and health workers, and sought written consent to interview those involved in the care of the child during the fatal illness.

The enquiry was introduced in phases. We started investigations in the first sites (two subcounties in Mbarara district, Uganda, one subdistrict of Sikasso district and two subdistricts of Kolokani district, Mali) in August–October, 2011. We started enquiries in the other sites in 2012–13. In three sites, we investigated deaths

that occurred over a 3-year period, while in the remaining sites, we investigated deaths that occurred over a 2-year period. Data collection was completed in all sites by 2015.

Ascertainment and investigation of deaths

Deaths were ascertained by volunteer informants in each village of the study areas, recruited through the existing networks of Village Health Teams in Uganda²¹ and so-called relais (volunteers who serve as a link between health-care facilities and the communities) in Mali. The informants were asked to report all deaths in children younger than 5 years as soon as possible by mobile phone to an employed fieldworker at the subdistrict level (six in Mali, ten in Uganda). The informants reported the date of death, name, sex, age, and location of residence of the deceased child. In return, they received a small payment to compensate for the cost of their telephone call and the time involved in introducing the fieldworker to the family. We used several measures to ensure that all reports were valid and that no deaths were missed, including re-investigating a random sample, cross-checking with other sources of information where available, and doing so-called snowball sampling by asking families of children who died about other recent child deaths in the village.

The fieldworkers were responsible for investigating circumstances of the deaths, from initial illness through to death, first by interviewing the family to ascertain the sequence of events and their help-seeking behaviour. Local informants introduced the fieldworkers to the families, who were given a small sum of money as a condolence payment, in accord with local custom. The interview was recorded by use of written field notes and the completion of a structured questionnaire modified from that used in the QUARITE trial to investigate maternal deaths.¹³ The modifications included translation into local languages (taking account of local terms to describe different illnesses), addition of local piloting with community feedback, and a change in the focus of the questionnaire from maternal to child deaths. The fieldworkers then attempted to find and interview all the health-care workers who had been involved in the antemortem care of the child (including traditional healers and staff at private shops or clinics) and, with their help, to obtain information from the medical records of any official health-care facilities to which the child had been taken.

Identification and discussion of avoidable factors

At the completion of the investigation, all the available information was collated by the fieldworker and presented in each district as a formal report to a multidisciplinary panel of local health-care workers, who had been trained in the no-blame confidential enquiry method. Confidentiality was maintained by use of anonymised information—neither the patients, their families, nor the health-care workers were named.

The mean number of panel attendees at each district panel meeting ranged from eight to 15 and consisted primarily of local doctors, nurses, health-care assistants, and usually at least one community representative (village health team members in Uganda, local traditional health practitioners in Mali). Study fieldworkers and local study investigators also attended. The chair of the meeting was usually a local paediatrician (or another senior doctor, if no local paediatrician was available). The frequency of meetings was decided locally—in most sites, it was roughly once per month, for half a day (to discuss about three or four cases) or a whole day (to discuss about eight or ten cases). In one of the sites, there was a weekly 1 h meeting to discuss one or two cases.

The panels were asked to ascertain the most likely cause of death, identify avoidable factors, and make recommendations to prevent similar deaths in the future. Avoidable factors were classified as probable if there was reasonable certainty about the cause of death and the patient had not received an intervention known to prevent that cause of death (eg, a child died of malaria and was not sleeping under a bednet). Factors were classified as possible if there was substantial uncertainty about the cause of death, whether the child had received an intervention that could have prevented one of the suspected causes of death, or both. When considering issues of child protection, in the absence of any agreed global definition, panels made decisions on the basis of what was considered negligent or abusive behaviour by local standards. Selected cases were also discussed at the community level (in whole-village meetings in Mali and in meetings of village health teams in Uganda), in

	Mali (n=762)		Uganda (n=442)	
	Number, % (95% CI)	WHO estimate for Mali ²²	Number, % (95% CI)	WHO estimate for Uganda ²²
Neonatal deaths	198, 26% (23–29)	33%	210, 48% (43–52)	35%
Prematurity	44, 6%	10%	36, 8%	10%
Neonatal asphyxia	39, 5%	9%	67, 15%	10%
Neonatal infection	96, 13%	10%	49, 11%	9%
Other/unspecified	19	..	58	..
Postneonatal deaths	564, 74% (70–78)	67%	232, 53% (48–57)	65%
Postneonatal Infections	443, 58% (55–62)	46%	159, 36% (32–41)	42%
Malaria	326, 43%	24%	71, 16%	7%
Acute respiratory	36, 5%	11%	35, 8%	14%
Diarrhoeal	35, 5%	9%	18, 4%	8%
Other/unspecified	46	..	35	..
Other postneonatal deaths	121, 16% (14–19)	21%	73, 17% (13–20)	33%
Severe acute malnutrition	97, 13%	Not reported	16, 4%	Not reported
Accidents and injuries	2, 0.3%	4%	21, 5%	7%
Other non-infectious diseases	20, 3%	Not reported	20, 5%	Not reported
Cause not established by panel	2	..	16	..

Table 1: Primary cause of death of children younger than 5 years as determined by district review panels in Mali and Uganda

	Mali (n=194)		Uganda (n=194)	
	Number, % (95% CI)	Estimate including possible cases*	Number, % (95% CI)	Estimate including possible cases*
Inadequate antenatal care	76, 39% (33–46)	69%	31, 16% (12–22)	46%
Mother did not attend antenatal care	26, 13%	20%	8, 4%	7%
Mother attended antenatal care at least once but did not receive essential intervention	41, 21%	48%	17, 8%	32%
No plan or referral made for high-risk pregnancy	16, 8%	23%	10, 5%	19%
Failure to screen for and treat maternal infection	25, 13%	30%	3, 1%	8%
Failure to manage HIV or malaria risk	10, 5%	7%	3, 1%	5%
Failure to measure fundal height and refer it when abnormal	15, 8%	12%	4, 2%	5%
Inadequate management of delivery	76, 39% (33–46)	65%	77, 37% (30–43)	58%
Assisted delivery not referred to an appropriate health-care facility when essential	53, 27%	37%	35, 17%	23%
Inadequate management of delivery in hospital	10, 5%	7%	25, 12%	16%
Mother delivered without assistance	22, 11%	18%	23, 11%	17%
Inadequate neonatal care	146, 75% (69–81)	94%	134, 64% (57–70)	83%
No adequate resuscitation	35, 18%	27%	58, 28%	38%
Application of potentially unclean substances to the cord	37, 19%	20%	6, 3%	3%
Failure to keep the baby warm	4, 2%	4%	27, 13%	17%
No vitamin K injection given	6, 3%	4%	12, 6%	8%
Failure to recognise or act on symptoms or signs of serious illness	99, 51%	59%	84, 40%	44%
Inadequate routine monitoring while in health-care facility	8, 4%	6%	21, 10%	11%
No routine postbirth examination (baby-check)	65, 34%	37%	47, 22%	27%
Baby with feeding difficulties not recognised or managed appropriately	29, 15%	18%	30, 14%	16%
Inadequate child protection	11, 6% (3–10)	6%	19, 9% (6–14)	9%
Inadequate use of family planning	22, 11% (8–17)	23%	37, 18% (13–23)	27%

Column headings show total number of neonatal deaths for which information on avoidable factors was available. Information on avoidable factors was not available for five neonates in Mali and 16 in Uganda. Totals might not sum because children might have been exposed to more than one avoidable factor. The other failures of antenatal care were no screening for gestational diabetes, no anti-D vaccination, failure to prevent delivery after 42 weeks, insecticide-treated nets not used, no folic acid, inadequate management of antenatal bleeding, and failure to detect or refer high blood pressure. The other failures during delivery were inadequate monitoring of labour or fetal heart, no treatment of fever during delivery, and cord not tied properly. The other failures of neonatal care were antiretrovirals not given to baby of mother seropositive for HIV, premature discharge, and no follow-up. *Upper estimate achieved by including cases where the review panel categorised a factor as possibly contributing to death (the main estimates include only factors categorised as probable).

Table 2: Main avoidable factors that could have prevented illnesses resulting in neonatal deaths

which community members were encouraged to agree and implement solutions to address any of the community-related issues identified. Those responsible for local health-care facilities participated in the panels that formulated the recommendations related to health-care quality and, because local panels often involved the individuals directly responsible for providing care, the meetings themselves functioned as a form of local continuing professional education.

Sample size and statistical analysis

Sample size was based on what was feasible to achieve with the available time and resources—we estimated that the teams could investigate and review about 100 deaths per year per site. All the statistical analysis was descriptive: confidence intervals are reported where appropriate, on the basis of the standard error of a proportion. The main analysis included all factors considered by the review panels to be definitely or probably related to the death;

more than one contributory factor was frequently identified. When appropriate, the effect of including both possible and probable factors was additionally reported. For deaths for which the information retrieved was incomplete, the scarcity of data was either reported as an outcome or the case was excluded from the relevant analysis, as deemed appropriate. Under-5 mortality rates were calculated by dividing the reported number of deaths per year by the number of births per year ($\times 1000$), estimated from government statistics on the birth rates and populations of the study areas. National-level data on child mortality were obtained from the WHO Global Health Observatory.²²

Confidence intervals for the number of deaths and mortality were calculated by assumption of a Poisson distribution.²³ We calculated the change in under-5 mortality between years 1 and 2 (appendix), with confidence intervals calculated by the method of Ederer and Mantel.²⁴

See Online for appendix

	Mali (n=562)		Uganda (n=215)	
	Number, % (95% CI)	Estimate including possible cases*	Number, % (95% CI)	Estimate including possible cases*
Malnutrition	124, 22% (19–26)	30%	29, 14% (10–19)	26%
Environmental issues	31, 6% (4–8)	20%	17, 8% (5–12)	11%
Child given potentially contaminated or untreated drinking water	29, 5%	20%	9, 4%	7%
No access to latrine	7, 1%	2%	0, 0%	1%
Domestic (unsafe house, fire, or cooking facilities)	2, 0.4%	0.4%	6, 3%	3%
External (no pavement, open drain, or unfenced pond)	0, 0%	0%	2, 1%	1%
Inadequate child protection	49, 9% (7–11)	9%	63, 29% (24–36)	29%
Parental neglect	37, 7%	7%	44, 21%	21%
Physical abuse (beating or poisoning)	5, 1%	1%	6, 3%	3%
Inadequate supervision	2, 0.4%	0.4%	6, 3%	3%
Harmful procedure (eg, toothbud extraction, scarification, circumcision)	5, 1%	1%	7, 3%	3%
Inadequate use of family planning	65, 12% (9–15)	18%	30, 14% (10–19)	27%
No bednet and child died from malaria	23, 4% (3–6)	6%	19, 9% (6–13)	14%
Incomplete or no vaccination	32, 6% (4–8)	20%	10, 5% (3–8)	20%
No antenatal HIV screening or prevention of mother-to-child transmission	5, 1% (0–2)	3%	2, 1% (0–3)	7%

Column headings show total number of postneonatal deaths for which information on avoidable factors was available. Information on avoidable factors was not available for one child in Mali and 17 in Uganda. Totals might not sum because children might have been exposed to more than one avoidable factor. Inadequate use of family planning was assigned as an avoidable cause by review panels if the investigation reported that the child was unwanted, the circumstances into which the child was born meant that they had little chance of survival, or a subsequent pregnancy severely prejudiced the child's survival. *Upper estimate achieved by including cases where the review panel categorised a factor as possibly contributing to death (the main estimates include only factors categorised as probable).

Table 3: Missed opportunities to prevent the illnesses resulting in postneonatal death

Role of the funding source

The funder of the study had no role in study design, data collection, data analysis, data interpretation, or writing of the report. The corresponding author had full access to all the data in the study and had final responsibility for the decision to submit for publication.

Results

We ascertained 762 deaths at age younger than 5 years in Mali and 442 in Uganda. Although panels postulated a cause for almost all deaths, they were certain of the cause in only 13% of deaths in Mali (99 of 749, excluding cases with missing data) and 15% in Uganda (64 of 415, excluding cases with missing data). Furthermore, more than one medical cause was identified for 19% of deaths in Mali (143 of 762) and 17% (73 of 442) in Uganda. The primary causes of death were broadly consistent with those reported in published national data, but there were some important differences between the judgments made by the community review panels and the 2015 national mortality data reported by WHO²⁵ (table 1). For example, severe acute malnutrition, which is not included in WHO national data, was cited as the primary cause of 13% (95% CI 10–15) of deaths by the review panels in Mali. The proportion of deaths occurring in the neonatal period was substantially greater than predicted by WHO data in Uganda and lower in Mali (table 1).

Panels identified avoidable factors more easily than precise causes of death. In only six cases in Mali (1%) and

33 in Uganda (8%) was it impossible to obtain any information on avoidable factors. Of the remaining cases (756 in Mali, 409 in Uganda), at least one avoidable factor was identified in 97% (95% CI 96–98, 737 of 756) in Mali and 95% (93–97, 389 of 409) in Uganda. These factors fell broadly into two categories: missed opportunities for prevention and problems in the treatment-seeking pathway.

Inadequate neonatal care was a factor in 76% of neonatal deaths in Mali and 64% in Uganda (table 2). The issue observed most frequently in both countries was the failure of birth attendants or parents to act on symptoms or signs suggestive of serious illness (eg, low birthweight or breathing difficulties). However, the need for neonatal care often resulted from inadequate management of delivery, antenatal care, or both (table 2). In Mali, 39% of neonatal deaths were classified as probably preventable by effective antenatal care, and this proportion rose to 69% if cases classified as possible were included. In both Mali and Uganda, the problem was not only insufficient attendance at antenatal clinics, but also the inadequate quality of antenatal care provided (an avoidable factor for 21% of neonatal deaths in Mali and 8% in Uganda).

The main opportunities to prevent fatal postneonatal illnesses are reported in table 3. In Uganda, the avoidable factor most frequently identified was inadequate child protection, mainly child neglect. In Mali, malnutrition was the most important avoidable factor. Inadequate use of family planning was cited by panels as a fairly frequent

	Primary care clinics		Private community providers		Traditional healers	
	Mali (n=396, 52%)	Uganda (n=78, 18%)	Mali (n=163, 21%)	Uganda (n=134, 30%)	Mali (n=117, 15%)	Uganda (n=67, 15%)
Clinical diagnosis						
Danger signs not recognised	136 (43%, 38–48)	30 (39%, 28–50)	95 (58%, 51–66)	76 (57%, 48–65)	71 (61%, 52–69)	31 (46%, 35–58)
Not examined adequately	52 (13%, 10–17)	11 (14%, 8–24)	40 (25%, 19–32)	39 (29%, 22–37)	Not assessable	Not assessable
Clinical treatment						
Essential treatment not given	154 (39%, 34–44)	27 (35%, 25–46)	74 (45%, 38–53)	47 (35%, 28–44)	Not assessable	Not assessable
Harmful treatment given	12 (3%, 2–5)	1 (1%, 0–7)	3 (2%, 1–5)	9 (7%, 4–12)	2 (2%, 1–6)	22 (33%, 23–45)
Onward referral and safety-netting						
No onward referral when essential	202 (51%, 46–56)	35 (45%, 34–56)	112 (69%, 61–75)	94 (70%, 62–77)	99 (85%, 77–90)	45 (67%, 55–77)
No safety-netting or follow-up	47 (12%, 9–15)	7 (9%, 4–17)	22 (14%, 9–20)	20 (15%, 10–22)	Not assessable	Not assessable

Column headings show number of children seen. Table data are number of patients (% 95% CI). Each child might have been seen at more than one type of facility before death and exposed to more than one quality of care failure. Private community providers were usually simple offstreet shops (usually only one room but occasionally with one or two beds) staffed by a single individual who might or might not have received any formal health-care training.

Table 4: Main avoidable factors in the primary care management of the illness causing death

avoidable factor in Mali and Uganda, reflecting the risk to a child of having a mother who was unmarried or who already had more children than she could support. An absence of bednets was an issue in some deaths caused by malaria, but not in the majority—only 23 (7%) of 326 children in Mali who had died from malaria were reported as not sleeping under a net (19 [27%] of 71 in Uganda). Inadequate vaccination was an uncommon avoidable factor in both countries.

The majority of deaths of children younger than 5 years occurred outside an official (government recognised) health-care facility in both Mali (77%, 95% CI 74–80; 583 of 755, excluding cases with missing data) and Uganda (67%, 62–71; 279 of 417, excluding cases with missing data). However, most families had sought help from a health-care provider (official or unofficial) before the child's death—84% in Mali (618 of 736) and 84% in Uganda (328 of 391), excluding cases in which treatment-seeking was not relevant or that had missing data. The provider was usually a public hospital or primary care clinic, although 97 (25%) of 391 families in Uganda and 149 (20%) of 736 in Mali had only consulted an unofficial provider (a traditional healer or private provider of medicines in the community, usually an off-street shop staffed by someone without formal qualifications, but sometimes a small private clinic with a nurse or health-care assistant and one or two beds). Delays in consulting that, in the opinion of the review panel, were sufficient to have contributed to death were common, irrespective of which type of provider was chosen first (377 [64%] of 588 in Mali, 167 [53%] of 318 in Uganda; further details on place of death and health-seeking behaviour are given in the appendix).

Table 4 reports the number of children seen by community health-care providers and the quality of care issues contributing to deaths. Traditional healers in Mali and Uganda frequently failed to recognise danger signs in the child and advise urgent attendance at a primary care clinic or hospital. Harmful treatment was

uncommon in Mali, but in Uganda, almost a third of the children seen by traditional informal health-care providers (which included tooth extractors and traditional healers) were given a harmful treatment, such as removal of tooth buds, often with no aseptic precautions. Informal private community providers also frequently failed to recognise danger signs of serious illness in children and failed to refer them when essential. Essential treatment was not given by the private providers in almost half of the cases in Mali and a third of cases in Uganda.

The official primary care clinics had fewer quality of care issues, although, in both countries, danger signs were still missed in about four of ten children, and about one in seven children were not examined adequately. Consequently, more than a third of children did not receive an essential medicine, and about half of the children were not referred to a hospital when essential. Even when review panels thought that urgent onward referral had not been essential, the failure to follow-up or to safety-net (to advise carers on how to recognise and respond to deterioration of the child's health) was frequently cited as having contributed to death. Some children were taken directly to a hospital (or, in Uganda, to a Health Centre IV, which offers hospital services), while others were referred by primary care practitioners. Quality-of-care failures in these hospital facilities were less frequent than in primary care, but record keeping was poor and failure to give essential treatment was cited as an avoidable factor in relation to the deaths of about half of the children seen in both countries (further details of hospital care issues in the appendix).

The panel gives examples of the clinical diagnosis, treatment, and follow-up failures, and highlights three other underlying issues sometimes identified by review panels as contributing to inadequate quality of care. The first is corruption—seeking an under-the-counter payment for treatment was reported to review panels in some facilities and might reflect inadequate or unpaid wages (we could not explore this issue formally).

Panel: Clinical examples of quality of care issues contributing to death

Clinical diagnosis

- Danger signs not recognised: baby born at 7 months of gestation in a private community clinic; the health-care worker took no action to assess or manage the health of the baby, despite obvious breathing difficulties, and the baby died after 5 h (Uganda)
- Not examined adequately: 9-month-old child presented to a primary care clinic with profuse diarrhoea and fever; the nurse measured temperature but did not otherwise examine or assess hydration status (Mali)
- Essential investigation not done: 5-month-old child, with mother seropositive for HIV, admitted to hospital with fever and weight loss, and was discharged after 1 month; died 1 week after discharge, but was never tested for HIV (Uganda)

Clinical treatment

- Essential treatment not given: 1-year-old child presented to a primary care clinic with diarrhoea, vomiting, weight loss, dehydration, and fever; primary diagnosis was almost certainly acute gastroenteritis with dehydration; he was treated with antimalarials and antibiotics, but not given fluids (Mali)
- Harmful treatment given: 1-week-old baby with vomiting taken by mother to a tooth extractor who extracted her toothbuds; the baby then developed fever and died of sepsis after 5 days (Uganda)
- Inadequate monitoring: baby boy, born in hospital by caesarean section, seemingly healthy at birth; no monitoring of the baby was done on the postnatal ward, and he was found dead on the third day (Uganda)

Onward referral and safety-net precautions

- No onward referral when essential: gravida 6 woman, went to deliver in official primary health centre; because labour not progressing after 12 h, the family wanted to take her to a hospital but primary care centre staff did not let them, saying she would deliver there; the baby was born after 23 h of labour, was pale, cyanosed, did not cry, and had a cephalohaematoma; the baby died after 20 min of probable birth asphyxia, although nurse tried to resuscitate (Mali)
- No safety-netting or follow-up: baby boy born in hospital and was well at first, but temperature recorded to be 37.8°C; no further observations were done and he was discharged the next day; over the next 12 h the child became more irritable, feverish, and short of breath; he died 1 day later (Uganda)

Other issues

- Corruption: 3-year-old child admitted to hospital with fever and convulsions; according to the parents, the doctors wanted to sell them medicines from their pockets; when the father refused to pay, the doctors refused to help (Mali)
- Inadequate senior clinician review: 1-year-old child admitted to referral hospital with fever, cough, and respiratory distress; he was in hospital for 3 days before death and was managed only by an intern, with no senior review of the diagnosis or treatment (Uganda)
- Insufficient clinical skills: newborn baby died 35 min after birth after severe birth asphyxia; history of obstructed labour with four unsuccessful attempts to assist delivery—initially with vacuum extraction (three attempts) and then forceps; finally, a more experienced doctor delivered the baby with vacuum extraction (Uganda)

The second is an absence of senior review—it was frequently reported in review meetings that children with high mortality risk had been managed in hospital facilities by very junior staff, with no senior support or oversight. This factor overlaps with the third issue— inadequate clinical skills.

Table 5 shows examples of the recommendations made by local panels to address avoidable factors and how they were implemented. Many recommendations involved community health education and improving treatment-seeking behaviour—these approaches were discussed in village meetings and, in some cases, led to specific actions, such as the establishment of a loan fund by villagers in Mali to facilitate emergency access to health care. Unfortunately, not all recommendations could be sustainably implemented. For example, the panels suggested that village health teams should keep a register of high-risk families, with child protection concerns, and visit them regularly to offer support. However, the families were expecting financial support from the teams, which we did not have the resources to provide, so this approach had to be discontinued.

There were also many recommendations for actions to improve quality of care in health-care facilities. Several actions were simple and very practical (eg, transfer of staff to understaffed health centres, setting up a mobile phone calling circle to solve a staff communication problem). Many actions involved refresher training for local staff or introduction of clinical algorithms or guidelines. The participation of health-care workers in the confidential enquiry meetings, and the open discussion of the circumstances leading to care failures, appeared itself to be an important educational intervention. For example, the management of patients with severe malaria greatly improved in participating health centres in Mali, because this was discussed at almost every case review meeting (which the meeting chair took as an opportunity to remind health-care workers of local treatment recommendations). Only one local panel (in Kanungu subdistrict) formally audited the implementation of recommendations (an extract of their audit spreadsheet is included in the appendix), but many issues were recurrent and panels necessarily discussed implementation issues when another death occurred.

	Examples of recommendations	Evidence of implementation
Patient factors		
Delay or absence of treatment-seeking	Organisation of a village fund to provide loans to enable rapid treatment-seeking in an emergency; community health education on danger signs; involvement of religious leaders in community health education	Loan fund established in two villages, managed by the villagers (Sikasso district, Mali); discussions held with villagers and village health-care workers on the recognition of danger signs and when to seek treatment (all sites); curriculum developed for training religious leaders, which was endorsed by the Ministry of Health (Kampala, Uganda)
Poor quality of maternity and neonatal care		
High-risk mother in labour not referred to hospital	Training of traditional birth attendants to recognise and refer women with danger signs	Training sessions held with traditional birth attendants (Kolokani and Sikasso districts, Mali)
Inadequate management of delivery	Continuing professional development for health-care workers on emergency obstetric care	Workers in primary care facilities participated in a standardised course on emergency obstetric care, with their knowledge improving in a before-and-after assessment (Mbarara and Kanungu districts, Uganda)
Inadequate neonatal resuscitation	Refresher training of primary care staff; development and use of a new sheet to record and document neonatal resuscitation	Neonatal resuscitation courses were held for primary care staff (all sites); a sheet was designed to record Apgar scores and to prompt and document actions taken in neonatal resuscitation, with an audit showing that it was being used (Bwindi Community Hospital, Kanungu district, Uganda)
Poor quality health care		
Government health centre has no nurses or midwives	District Health Officer should transfer staff from another health centre to the understaffed one	Staff were transferred to understaffed primary health centres (Sikasso district, Mali and Mbarara district, Uganda)
Private clinic is staffed only by unqualified staff	District Health Officer should supervise private clinics and ensure they comply with regulations	The District Health Team closed unlicensed health-care facilities and improved regulation of those available (Kampala, Uganda)
Inadequate physical examination	Height and weight should be measured and the z-score calculated for all children	Health centres started to systematically record height and weight for all children seen (Sikasso district, Mali)
Danger signs not recognised	Training for traditional healers to recognise and refer children with severe malaria; update on integrated management of childhood illness for health-care workers	Training sessions organised (all sites in Mali); continuing professional development sessions for health-care workers in primary care (all sites)
Essential treatment not given	New guideline for treatment of respiratory distress in premature babies, with use of locally available resources; for severe malaria, prereferral treatment should include intramuscular artemether and sublingual sugar	A new guideline was developed, including the use of aminophylline and doses of medicines, and posted on the wall of the neonatal room, with an audit showing that it was being followed (Bwindi Community Hospital, Kanungu District, Uganda); over the course of the confidential enquiry, inadequate prereferral treatment became much less frequent in the cases reviewed (all sites in Mali)
Other issues		
Inadequate child protection	Village health teams should keep a register of high-risk families and follow them more closely	The register was piloted, but discontinued because families were expecting financial assistance, which could not be provided (Kampala, Uganda)
Inadequate use of family planning	Refresher training for health-care workers on family planning	A family planning course was developed and piloted, with more than 55 health-care workers trained (Kanungu district, Uganda)
Inadequate communication between staff	Introduction of an internal telephone system to facilitate communication between paediatric nurses and doctors and the labour ward	A mobile phone network was created with initial funding from the study budget, which the hospital director pledged to continue from his own budget; this network enabled nurses and interns to contact the on-call consultant more easily, and also enabled the delivery suite to contact the doctor on call for paediatrics (Mbarara Regional Referral Hospital, Uganda)

Table 5: Examples of local solutions identified by review panels to address avoidable factors contributing to deaths in children

Under-5 mortality in the study areas was reduced during the study period, by 18% in Mali and 27% in Uganda, significantly more than predicted by national trends (appendix). This change is consistent with the actions taken being effective, because we could not explain it by a reduction in the effectiveness of ascertainment or other contaminating factors. However, the observational method of this study means that we cannot exclude the possibility that the mortality reduction in the study areas could have been attributed to unidentified bias.

Discussion

In this study, we found that the illnesses or circumstances leading to most of the deaths in children younger than 5 years could have been prevented. However, there was seldom a single disease-specific avoidable cause, which might explain why disease-specific interventions are sometimes less successful than anticipated. Poor

neonatal care was the most important factor in neonatal deaths, but this finding partly reflected inadequate antenatal care, such as failure to detect and treat infections (which were the most common factor precipitating premature births) and to appropriately manage high-risk deliveries. The most frequently mentioned preventive measures that could have averted postneonatal deaths were tackling malnutrition in Mali and child protection in Uganda. Most families sought help when a child became ill, but the quality of care provided was frequently inadequate. Failure to recognise danger signs, to examine the patient adequately, to give essential treatment, and to monitor or to safety-net effectively was endemic. Improving the quality of primary care delivery appears to be a very necessary, but neglected, step in reducing child mortality.

Local low-cost solutions to address avoidable factors were implemented as a result of the enquiry. Although

the observed reduction in under-5 mortality is consistent with these local actions having an effect, the observational method means that this reduction is not reliable evidence of effect. However, this study does provide compelling evidence that few of the avoidable factors and local solutions identified by the local review panels would have been identified by consideration of the cause of death alone. This study also showed that reviews investigating the circumstances of death are a good way of identifying quality-of-care issues. However, promoting institutional death reviews is clearly insufficient—most deaths occurred in the community and much of the primary care was done by small or unofficial providers. Community-based ascertainment and investigation of deaths, using volunteer informants and confidential enquiry methods, proved to be a feasible and effective method for identifying avoidable factors and for engaging local communities and health-care workers in the discussion and resolution of these factors.

The main strength of this study was that the ascertainment was community-based and dependent largely on volunteer health workers from existing networks. Other studies have shown that it is possible to engage and retain community health volunteers in Uganda at a low cost, and achieve reductions in child mortality.²¹ The judgments on quality of care and potential remedial action were made by local care providers (rather than external agencies), and, therefore, approaches are more likely to be implemented and achievable with local resources. Another strength was the no-blame confidential enquiry method that not only encouraged the disclosure of errors, but also facilitated the active engagement of local health-care workers in the process. Although there was some local variation in how panel chairs enforced confidentiality in the meetings (for example, some health-care workers occasionally self-disclosed their involvement in a case and contributed extra information), the key principle of avoiding attribution of blame was achieved in most cases.

The main weakness of the study design was that it was a purely descriptive study. There is good evidence from trials for the effectiveness of institutional death audits in reducing maternal deaths¹³ and some before-and-after evidence in relation to perinatal deaths.²⁶ However, there is no evidence on the effect of community-based death audits. Although the cost of scaling up this approach would be less than the research costs incurred during this study (about £180 per death investigated), the main expenses (salaries and travel costs of fieldworkers to investigate deaths in the community) would still be incurred, unless volunteer workers could be trained to undertake this task. There is also an opportunity cost to involvement in reviews when there are few qualified health-care workers in a health-care facility.

Further research is needed to optimise the implementation model for community-based death reviews to

maximise their cost-effectiveness. For example, it would be cheaper to investigate and review only a sample of deaths. Because many of the same issues frequently recurred, the same recommendations were often repeated. Therefore, an effect similar to this study could probably be achieved by an intelligent sampling strategy for investigations to target areas or cases that are likely to yield new and important information. There could be a two-stage investigation, with a simple screening questionnaire for every death (which could be completed at a low cost by community health volunteers) that would be used to guide the selection of a sample of these deaths for a full investigation and review. There might also be better ways of engaging communities in the process of identifying and taking action on social issues—this seemed to work better in some sites than in others. Health policy and systems research might provide a complementary analytical framework to explore these issues.

A drawback of community-led ascertainment of deaths is that it is very difficult to assess completeness. We are soon hoping to be able to report on the results of a further study to quantify ascertainment using capture–recapture methods, but the assumption must be that our ascertainment was incomplete, because notifications were dependent on volunteer health workers. It is probable that health workers would have been more likely to identify a death if the parents of the child had tried to access health care than if no health care was sought. Therefore, we might have underestimated the proportion of deaths that occurred without any formal health-care seeking and, particularly, missed the stories of those children who died without the involvement of anyone outside the immediate family.

It is also important to recognise that cause of death was almost never verified by autopsy and seldom verified by results from hospital investigations (either because they had not been done or because the hospital records had been lost). The use of WHO verbal autopsy questionnaires²⁷ might have provided a validated way of assigning cause of death; providing panels with an assigned cause of death might have focused the discussion on circumstances of death and avoidable factors. Perhaps this approach should be considered as a future option, but the QUARITE method of enquiry has advantages. Its effectiveness has been proven in a randomised controlled trial and open questions facilitate the construction of a logical case narrative (and help to collect information that is unexpected and would not be collected by a standard questionnaire consisting only of closed questions).

The judgments concerning avoidable factors are likely to be more reliable than those concerning the cause of death, because they were based on multidisciplinary panel discussions of first-hand accounts of the fatal illness, whereas many patients had died without ever having any diagnostic investigations. Although it might have been expected that the predominance of health-care workers on the panels would increase the focus on medical care

issues, many recommendations were made to address social factors (such as improved uptake of preventive interventions, improved child protection measures, improved recognition of danger signs, improved treatment-seeking, and avoiding harmful behaviours) and these were discussed in many village meetings. However, it was not feasible to audit the implementation of these recommendations with the available resources. To do so would have required household surveys at several time-points in each study site.

Death review is a well-established mechanism for investigating avoidable causes of death in children in the UK,²⁰ which has previously been applied in sub-Saharan Africa. A systematic review of the literature showed reports of six studies in South Africa, one in Mozambique, and one in Tanzania, but all of them focused on perinatal deaths in hospital facilities (five of the eight studies were restricted to a single hospital).²⁸ For the first time, to our knowledge, we report findings of reviews of all deaths of children aged younger than 5 years in the study sites, including those who died outside of health-care facilities.

Although there has been considerable work investigating deaths by use of verbal and social autopsies,^{29,30} these studies were designed for a different purpose: to collect statistics on cause of death and on key indicators of access to care at a population level. The type of information collected is insufficient to assess problems with quality of care or to formulate recommendations on the basis of avoidable factors. Moreover, verbal and social autopsy studies are unlikely to identify unexpected avoidable factors that are not covered by the standard questionnaires. By contrast, this study uncovered evidence on unexpected factors, such as inadequate use of family planning and child protection issues.

The use of verbal autopsies to derive a single cause of death for each child also encourages a disease-specific focus for strategic planning in sub-Saharan Africa to reduce mortality in children younger than 5 years (eg, a focus on malaria).³¹ This planning often uses the Lives Saved Tool, which assesses public health priorities by applying international evidence about cost-effective interventions to national estimates of causes of death.^{32,33} For example, in Uganda, the top five priorities for the prevention of under-5 deaths established by this method were labour and delivery management, artemisinin combination therapies for malaria, oral rehydration solution, antenatal corticosteroids for preterm labour, and prevention of mother-to-child transmission of HIV.³⁴ In contrast, the top avoidable factors identified by our Ugandan review panels concerned newborn care, safe delivery and antenatal care to prevent fatal neonatal illness, child protection and family planning to prevent postneonatal deaths, and improved treatment-seeking and quality of care for neonatal and postneonatal illnesses.

Child protection issues were particularly important in Uganda, being associated with almost a third of

postneonatal deaths. No previous verbal and social autopsy studies have reported this problem in Africa and even in South Africa, which has a system for reviewing child deaths in hospitals, there is under-reporting of child abuse as a cause of death.³⁵ Most of the cases identified by the panels related to neglect: parents or guardians who did not adequately look after their children (provide adequate nutrition, supervision, or treatment) for several reasons, including the young age or unmarried status of the mother, need to work to survive, large size of the family, or disability of the mother (both physical and mental). Because neglect is a social construct, some part of the difference between Mali and Uganda might reflect different societal expectations. However, there were issues that were specific to Uganda. For example, in all the sites in the country, the belief that fever and diarrhoea in young children can be caused by a worm in the toothbud (called ebiino) led to tooth extraction by use of non-sterile implements, such as old razor blades or bicycle spokes. Identifying issues such as these, through active community involvement in death reviews, might be particularly important because there is evidence that bottom-up community-based interventions can be a very effective approach to dealing with child protection in an African context.³⁶

We found little published evidence about the quality of primary care delivered to children younger than 5 years in sub-Saharan Africa. High mortality rates in this age group strongly suggest primary care failure, but the 2008 WHO report³⁷ on primary care in the African region reported no systematic attempt to measure health-care quality in any country surveyed. Non-systematic qualitative evidence³⁸ suggested that continuing low primary care quality can be linked to staff shortages, inadequate training and support, and poor working conditions. The main published evidence on health-care quality seems to be from other death audits. These were all hospital-based, but the results related to obstetric care mirror our own findings. For example, an audit³⁹ of perinatal deaths in Uganda, in 2012, highlighted the failure of hospital staff to notice danger signs on partographs and to conduct timely caesarean sections to reduce high mortality risk. Similarly, the key health-care quality improvements that underpinned the mortality reduction in the QUARITE trial⁴⁰ in Mali were more careful assessment of risk and subsequent monitoring.

The key clinical issue identified across all health-care providers of primary care was a failure to recognise and act on the danger signs of serious illness. The panel discussions suggested that this failure was, in large part, due to insufficient training, feedback, and support for the staff at work, closely reflecting the anecdotal evidence of working conditions in primary care³⁸ and the barriers to achieving consistent health-care quality previously cited.^{10,11} However, even in the better staffed hospital facilities, the frequent disappearance of clinical records and inadequate clinical governance suggest that substantial improvement

is possible with better leadership and workplace culture,^{13,41} even within existing resource constraints. The importance of identifying and acting on danger signs is entirely consistent with WHO's integrated management of childhood illness strategy⁴² and maternal death surveillance and response strategy.^{43,44} The local panel meetings could offer an important opportunity to audit and improve the implementation of these strategies, providing primary health-care workers (both formal and informal) with feedback, education, and leadership.

Investigating the circumstances of death of children younger than 5 years in sub-Saharan Africa is as important as understanding the most common biomedical causes of death. This approach has the potential to improve implementation of evidence-based initiatives by identifying problems in leadership and health-care access and quality, which often underpin local underachievement of strategies to reduce under-5 mortality.^{11,12} This approach can also identify important public health priorities unrelated to specific diseases. Most child deaths were preventable by improving the local implementation of existing preventive and curative interventions. Local remedial actions were often identified to have the potential to improve implementation of these interventions, without additional use of resources.

Hospital perinatal death audits are already official policy in 11 sub-Saharan African countries.²⁶ Our results suggest that death audits restricted to hospitals will miss the majority of deaths in under-5s and will not identify most of the avoidable factors, because they relate to events that occurred in the community. Hospital-based audits also do not involve—and, therefore, do not audit and educate—the official and unofficial community-based health-care workers delivering primary care. Community-based death audits potentially offer a much-needed mechanism for clinical governance of primary care and a mechanism for supporting local education and facilitating change.

Our experience suggests that scaling up community-based death audits in any sub-Saharan African country would require leadership and attention to stages-of-change similar to those needed to sustain the Perinatal Problem Identification Programme in South African hospitals.⁴⁵ Careful thought also needs to be given to the best way to achieve full community involvement in the process, so that the social causes of child death can be better understood and addressed. Nevertheless, the ability to identify specific local problems in health-care quality, to suggest local public health priorities, and to recommend local solutions indicate that community-based death audits could be a key step forward in the implementation of WHO's integrated management of childhood illness strategy and the achievement of the Sustainable Development Goal for deaths in children younger than 5 years.

Contributors

MLW, AH, DM, EK, DD, CD, ED, JN, and JK collaborated in the conception and design of the confidential enquiry, including writing and

revising the protocol. MLW, EK, VM, FN, CD, ED, MT, PD, DBa, AT, DBe, SC, HF, RN, BM, and JN were involved in acquiring and interpreting the data. MLW, DM, AH, PD, VM, EK, and DBa were involved in analysing and interpreting the data. The manuscript was prepared by MLW, with the support of DM and AH. All authors contributed to revision of the manuscript and read and approved the final version.

Declaration of interests

We declare no competing interests.

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