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## Learning to Listen

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In this issue of *Pediatrics*, Lapidot et al<sup>1</sup> report the findings of modified verbal autopsies (VAs) conducted for infants from the ages of 4 days to 6 months who were brought in dead to the main teaching hospital in Lusaka, Zambia. Universal health coverage<sup>2</sup> and attaining the Sustainable Development Goals<sup>3</sup> can only be achieved if the causes of death are known and actions to intervene are monitored. Yet, 1 in 2 deaths in low- and middle-income settings goes unreported because few low- and middle-income countries have a fully functional civil registration and vital statistics system in which to register deaths.<sup>4</sup> These unregistered deaths occur in deprived communities in which health care is limited and poverty abounds. The investigators are based in Lusaka at the university teaching hospital, at which infants who have died out of a hospital are brought to have the deaths registered. The primary aim of the study is to identify the pathologic causes of death. Postmortems are performed after consent from the family. When obtaining permission and recording demographic details of a child, the interviewers ask the family some open-ended questions about the events leading up to the death. It is these narratives that Lapidot et al<sup>1</sup> report in this issue of *Pediatrics*.

The authors call the stories “modified verbal autopsies,” although a standardized and validated questionnaire was not used and the analyses were retrospectively planned. The free-text answers were physician-coded and analyzed for common patterns leading up to the deaths. A main finding was delay in care, categorized in 3 groups: (1) delays in the decision to seek help (54.8%); (2) delays in reaching care (24.6%), typically from problems at night when transport, lighting, and security are inadequate; and (3) delays in receiving adequate care (24%), when deaths occurred in a health unit, while waiting for referral or waiting to be seen. When there was delay in the decision to actively seek help, almost all of the children had had at least one danger sign, as defined in the Integrated Management of Childhood Illnesses.<sup>5</sup> A substantial number of children had been sent home after being assessed by a

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clinician for the present illness, and subsequent visits were delayed. A total of 18% of deaths were reported by the study team as sudden unexpected infant deaths. This may be the case, but, from the findings that some danger signs were unknown to families, it is likely that subtle signs of illness, particularly in a neonate, went unnoticed.

There are 2 parts to a more standard VA: the collection of information and the analysis. Information is collected from the closest member of the family to the deceased, who is approached soon after the death and no later than 1 year afterward. This information is coded by physicians (physician-certified VA) or, increasingly, by computer (computerized coding of VAs) and analyzed by algorithm.<sup>6</sup> The latter is less labor intensive, less costly, and more consistent than the physician-certified VA.

The World Health Organization has encouraged the use of VAs and developed a standardized questionnaire, which was last updated in 2016.<sup>7</sup> The causes of deaths can be classified according to the *International Classification of Diseases, 10th Revision*.<sup>8</sup> VAs are able to identify the causes of death on a community level but are less precise for individual diagnoses.<sup>9</sup>

Social autopsies (SAs) are less well standardized or validated overall than VAs but, nevertheless, involve carefully developed and piloted questions administered by trained interviewers. They address the social circumstances and treatment-seeking journeys surrounding a death, often revealing difficulties in the access to, cost of, and expectations of care, local interpretations of the symptoms and signs of illness, and dilemmas and negotiations around family members' attempts to seek assistance. SAs can give some insight beyond the biomedical illness into why a child may have died.<sup>10</sup>

One can pick holes in the research methodology of Lapidot et al,<sup>1</sup> including the lack of a standard interview tool, a comparator group, and any in-depth analyses. Nevertheless, the stories are raw and revealing. They were told shortly after a child's death and so may be incomplete and were likely shaped by the emotional context, but they do give insight into the events leading up to the death from the perspective of parents. They are powerful, both as a call to action and a prompt for further learning about the complex and multifaceted decision-making processes and care pathways that families undertake in contexts of vulnerability and constrained agency (ie, the ability to act).<sup>11</sup>

Reports from other communities are not dissimilar.<sup>12-15</sup> In a deprived urban area of Freetown, Sierra Leone, where SAs were undertaken by trained community field-workers, it was found that families felt that they knew the common causes of childhood death but their main concerns had been difficulties in accessing timely care.<sup>12-15</sup> A total of 12% of interviewees in the Freetown study had not thought that medical care was necessary, but 77%, almost always the mothers, had been to at least one provider during their child's illness. Nighttime security and lack of public transport made their journeys difficult. When giving feedback to the community, it was these stories and challenges that the community could really relate to.

Clear messages come through the stories shared by Lapidot et al<sup>1</sup> and in the wider literature: that some are unaware of danger signs of illness in infants, that transport at night is a

real problem, and that health facilities need a better system of triage to prioritize the most sick. Communication should be taken as seriously on discharge as on arrival to a health facility so that parents understand the door is open for a quick return to the facility if an infant is not improving.<sup>13,14</sup> Feedback and discussion with the community is essential for change; without their understanding, involvement, and inputs, improvements are likely to fail or falter. Some activities are amenable to rapid change in homes and facilities, others are deeper and more structural, related to resource constraints and gendered social norms and relations.

We hope that Lapidot et al<sup>1</sup> discuss their findings in a respectful and sensitive way with health providers and managers and, most important, with the communities that own them so that, together, they can codesign interventions that support positive change. This should be accompanied by advocacy with policy makers and social leaders for change in deeper, structural influences that contribute to tragedy for so many families. We can learn from listening, but action must follow to effect real change.

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## Abbreviations

SA	social autopsy
VA	verbal autopsy

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