Working with people: developing a people-centred action-oriented research method in South Africa

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Rationale, Objectives

- 3 in 4 deaths unreported cause
- Relationship between material and data poverty
- Health systems need reliable information
- Improved ways to record deaths
- Method to connect communities + authorities to assess local situations, identify priorities

Source: Boerma, 2016
Design, 3 Phases

1. Understand levels and medical causes of death and circumstances of mortality
2. Gain local knowledge on avoidable mortality and priorities for action
3. Combine in a process that connects routine data + local knowledge to the health system
Largest ever dataset on individual deaths in Africa and SE Asia reveals changing health

29 October 2014

An unprecedented insight into the changing health of people across Africa and Asia - including the fluctuating burdens of HIV, malaria and childhood mortality - is revealed today by the publication of the largest ever dataset of individual deaths recorded on the ground.
Phase 1  Verbal Autopsy (VA)

- Deaths outside hospitals and/or without proper registration
- Interview on medical signs & symptoms
- Interpreted to determine probable medical cause of death
- Disease burdens in unregistered populations

<table>
<thead>
<tr>
<th>NO</th>
<th>QUESTIONS AND FILTERS</th>
<th>CODING CATEGORIES</th>
<th>SKIP</th>
</tr>
</thead>
<tbody>
<tr>
<td>865</td>
<td>Did she die during labor, but unattended?</td>
<td>YES</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td></td>
<td>NO</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td></td>
<td>DONT KNOW</td>
<td>8</td>
</tr>
<tr>
<td>866</td>
<td>Did she give birth recently?</td>
<td>YES</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td></td>
<td>NO</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td></td>
<td>DONT KNOW</td>
<td>8</td>
</tr>
<tr>
<td>867</td>
<td>How many days after giving birth did she die?</td>
<td>DAYS</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td></td>
<td>DONT KNOW</td>
<td>8</td>
</tr>
<tr>
<td>868</td>
<td>Was there excessive bleeding on the day labor started?</td>
<td>YES</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td></td>
<td>DONT KNOW</td>
<td>8</td>
</tr>
<tr>
<td>869</td>
<td>Was there excessive bleeding during delivery of baby?</td>
<td>YES</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td></td>
<td>DONT KNOW</td>
<td>8</td>
</tr>
<tr>
<td>870</td>
<td>Was there excessive bleeding after delivery of baby?</td>
<td>YES</td>
<td>1</td>
</tr>
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<td></td>
<td>DONT KNOW</td>
<td>8</td>
</tr>
<tr>
<td>871</td>
<td>Did she have difficulty in delivering the baby?</td>
<td>YES</td>
<td>1</td>
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<td>DONT KNOW</td>
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<tr>
<td>872</td>
<td>Was she in labor for unusually long?</td>
<td>YES</td>
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<td>DONT KNOW</td>
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<tr>
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<td>Was it a normal vaginal delivery?</td>
<td>YES</td>
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</tr>
<tr>
<td></td>
<td></td>
<td>DONT KNOW</td>
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</tbody>
</table>

Global causes of child deaths

[Diagram showing global causes of child deaths]
VA Methods

• Widespread application
• Standardisation
• Scale up for health systems strengthening
• Interpret VA interviews reliably and consistently
• Automated models
• Mobile VA
Biosocial view of VA

• VA to determine medical causes of death for people who die outside health facilities or without registration
• VA about people who do not connect to health systems
• VA is an opportunity to examine social exclusion from health systems
• In the context of the methodological transition of VA, opportunity to do this routinely
Woman gave birth at home 10am accompanied by her sister. After delivery she haemorrhaged + suffered ruptured uterus retained placenta.

TBA was called but could not deliver placenta. A 2nd TBA + male traditional healer called at 1pm. The healer+ TBA delivered the placenta manually. The woman continued to bleed.

The family called an ambulance but it took 2 hours to arrive. During the journey to hospital, the patient continued to bleed, became weak and died before the facility was reached.
Could classification systems be improved?
Social Autopsy - A method to examine barriers to health care, risky behaviours and missed opportunities for health interventions 

Karin Källander, PhD, MSc 

Improving data improving health: Verbal Autopsy for health systems strengthening 

17th October 2016
# New VA indicators: ‘Circumstances of Mortality’

<table>
<thead>
<tr>
<th>Structure</th>
<th>Theme</th>
<th>VA Question/Indicator</th>
</tr>
</thead>
<tbody>
<tr>
<td>Recognition</td>
<td>Were there any <strong>doubts</strong> about whether care was needed?</td>
<td></td>
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<tr>
<td></td>
<td>Was <strong>traditional medicine</strong> used?</td>
<td></td>
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<tr>
<td>Access</td>
<td>Did anyone use a <strong>telephone</strong>/cell phone to call for help?</td>
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<tr>
<td></td>
<td>Did (s)he use <strong>motorised transport</strong> to get to the hospital/facility?</td>
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<tr>
<td></td>
<td>Did (s)he <strong>travel to a hospital/facility</strong>?</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Does it take &gt;2 <strong>hours</strong> to get to the nearest hospital/facility?</td>
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<td></td>
<td>Did the total <strong>cost of care</strong> prohibit other household payments?</td>
<td></td>
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<tr>
<td>Quality</td>
<td>Were there problems during <strong>admission</strong>?</td>
<td></td>
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<tr>
<td></td>
<td>Were there problems with the way (s)he was <strong>treated</strong> in the hospital/facility?</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Were there problems with getting <strong>medications</strong>, tests or treatments?</td>
<td></td>
</tr>
</tbody>
</table>
• Problems with access
  • Not calling for help
  • Not going to facility
  • Overall costs (incl. travel, transport, meds, food etc.)
• Traditional medicine
• Lower/no problems with quality (for those going to facilities)
• Varied by COD
Phase 2 VA + PAR

- Participatory action research (PAR) process to elicit local knowledge on the causes of mortality and priorities for action
- PAR seeks to overcome conventional subject-object distinctions to shift power towards those affected to know, problematize, understand, act and transform
• 3 village based discussion groups
• 8 weeks - series of meetings
• 2 conditions selected on the basis of high prevalence and community and health authorities priorities
Subjective perspectives elicited and systematised into collective accounts
• Photovoice, visual method
• Directly representative of people’s perspectives
• Images of physical environment as an input to the discussions
Housing, unemployment
Unclean water
Unsafe environments

Perceived neglect
Quality of Care

• Poor quality care
  • Long waiting times, overcrowded clinics
  • Delays in treatments, lack of medications
  • Lack of confidentiality

• Blame + negativity towards nurses despite lack of autonomy
Priorities for Action

- Reduce unemployment
- Provide clean water
- Expand clinics
- Improve accountability and responsiveness of staff
- Engage with communities for health education
Phase 3 Health Systems Appraisal

• Provincial stakeholders - interpret data, identify actions, critique method
  • *Flexible waiting times in clinics*
  • *Re-organisation of ambulance services*
  • *Health education and information*
  • *Multi-level inter-sectoral collaboration in policy and planning*

• Continuum of action - no/low cost to more substantial
• Beyond the clinic - connecting actors at different levels
• Robust, innovative partnerships approach, acceptable and relevant for use in health systems
Outputs + Next Steps

- **HSR method**: based on core standards, contextually relevant Pioloted suitable for application in other sites
  - New ways to understand deaths in VA
  - PAR with communities
  - Embedded in health system

- **Co-produced evidence**: practical knowledge built from multiple perspectives (services users, providers) + embedded in local policy context. Promotes capacity building + evidence-based advocacy

- **Knowledge partnerships**: Planning for extending into an ongoing process of reflection and action
Whose voices count?

“Global Health community needs to reflect on whom it is seeking to serve

• promote involvement of marginalized people

• reflect on how benefits distributed

• work with introspection and humility

(Sheikh et al 2016)
Further information


Worldwide, 65% of deaths go uncounted – here’s how to change that http://tinyurl.com/j4hk98e

When communities help authorities tally births and deaths, health care equalises http://tinyurl.com/zn25272

Engaging with communities can help tackle poverty linked health problems http://tinyurl.com/zh89dag
Acknowledgements

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