

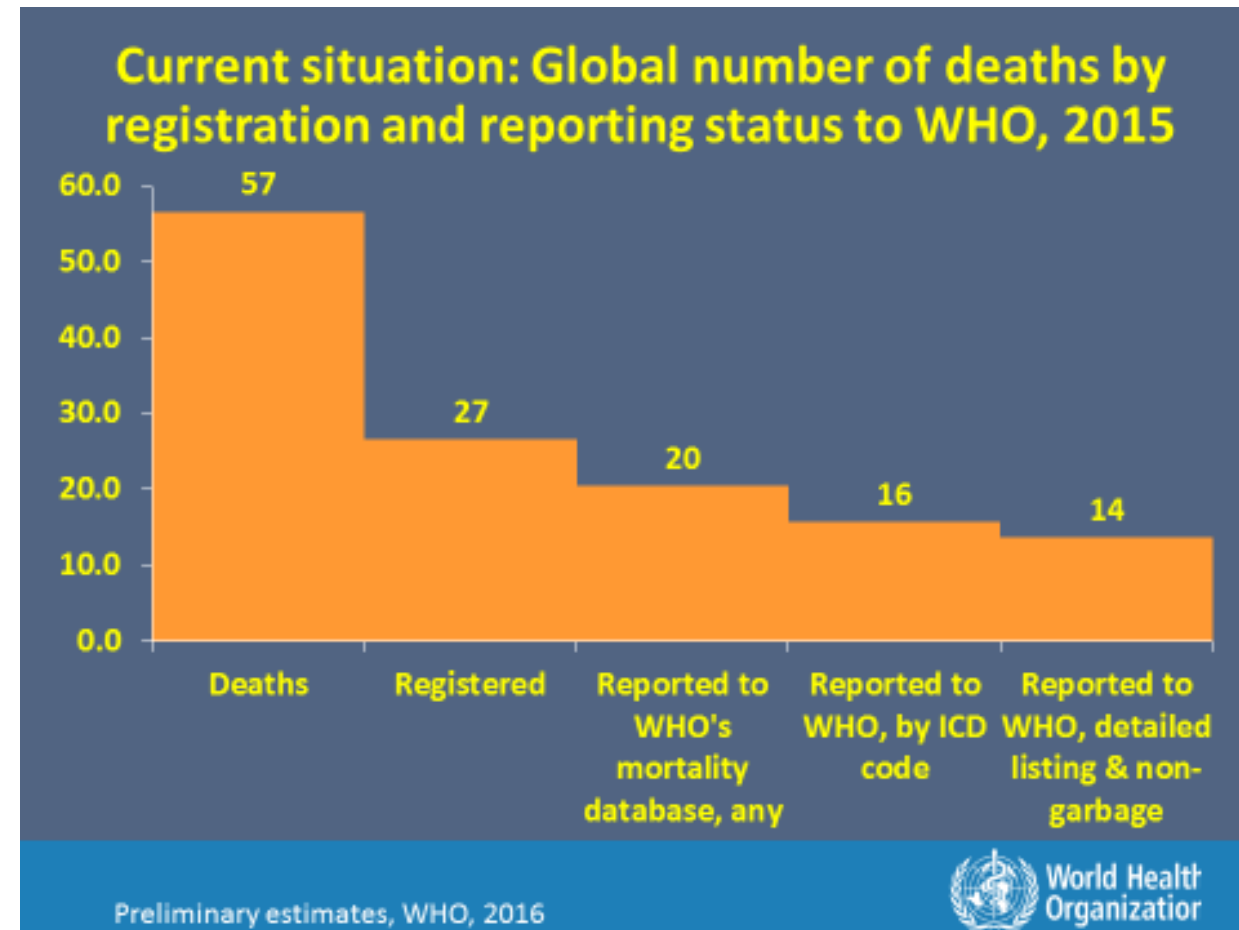


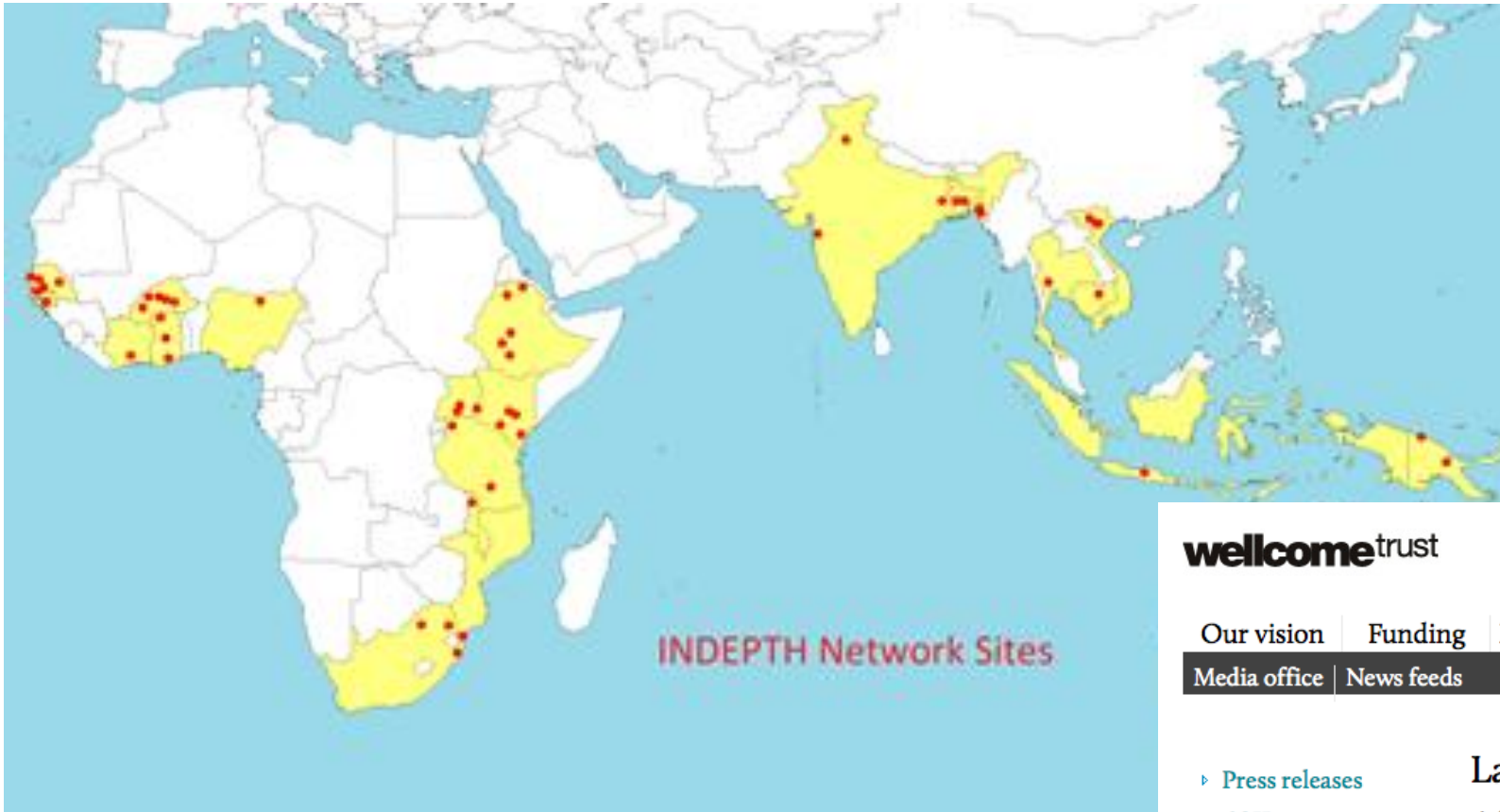
Verbal Autopsy with Participatory Action Research (VAPAR): Developing a people-centred health systems research methodology

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Centre for Global Development
University of Aberdeen
14 November 2016

Rationale and Objectives

- Lack of information limits capacity of health system to respond to needs of those excluded, sustaining exclusion and maintaining health inequities.
- Health systems need reliable information. Better data and better action on and for health of excluded/marginalised groups
- *Improved ways to record deaths*
- *Method to connect communities + authorities to assess local situations, identify priorities*





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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.

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

Extending VA to record local circumstances: developing methods with stakeholders



July 2015

What is VA?

Verbal Autopsy (VA) is used to determine medical causes of death (CODs) for people who die outside health facilities or without registration. 2 step process (1) Interview on medical signs & symptoms and (2) Data interpreted to generate data on levels and CODs in populations

A social view of VA

VA gives information on people who do not connect to health systems. VA is therefore also an opportunity to examine social exclusion from health systems.

Rationale

The following account of a maternal death gives a rationale for extending VA to collect new data on local circumstances that can lead to exclusion from access to care:



A case of pregnancy-related death

- Woman gave birth at home 10am accompanied by her sister. After delivery she bled heavily + did not deliver placenta
- TBA called but could not deliver placenta. 2nd TBA + male healer called at 1pm. The healer+ TBA delivered the placenta manually. The woman continued to bleed
- Family called ambulance, it took 2 hours to arrive. During the journey, the patient continued to bleed, became weak and died before the facility was reached

Cause of death? Policy implications?

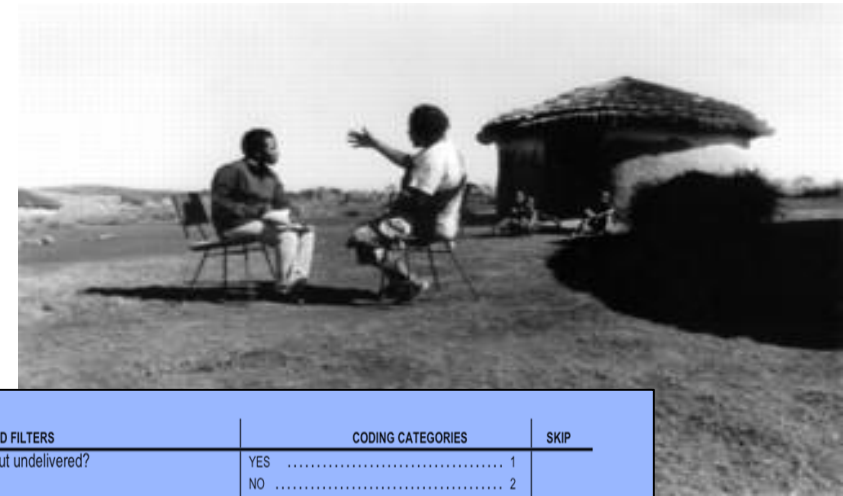
The COD in this example is obstetric hemorrhage. Organizing services with this information alone does not address use of traditional medicine or problems with emergency transport.

Could classification system be improved?

Aims

- Identify key local circumstances
- Develop system to record routinely
- Better information, better actions

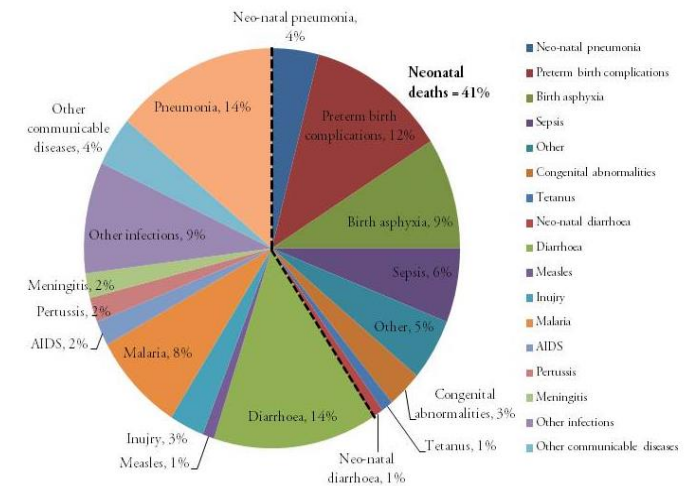
Phase 1 Verbal Autopsy (VA)



- VA established method to determine COD when deaths not certified/registered
- Standard interview on medical signs & symptoms
- Data interpreted to determine probable medical cause of death
- Disease burdens in populations

NO.	QUESTIONS AND FILTERS	CODING CATEGORIES	SKIP
805	Did she die during labor, but undelivered?	YES 1 NO 2 DONT KNOW 8	
806	Did she give birth recently?	YES 1 NO 2 DONT KNOW 8	→ 818 → 818
807	How many days after giving birth did she die?	DAYS <input type="text"/> <input type="text"/> DONT KNOW 9 8	
808	Was there excessive bleeding on the day labor started?	YES 1	
809	Was there excessive bleeding during baby?		
810	Was there excessive bleeding after c		
811	Did she have difficulty in delivering th		
812	Was she in labor for unusually long (
813	Was it a normal vaginal delivery?		

Global causes of child deaths



Pie chart derived from data in Black RE, Cousens S, Johnson HL et al. in "Global, regional, and national causes of child mortality in 2008: a systemic analysis," *The Lancet*, May 12, 2010.

VA Methods

- Widespread application
- Standardisation
- Scale up for health systems strengthening
- Interpret VA interviews reliably and consistently
- Automated models
- Mobile VA



Inter
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 as well as understand medical causes of death
- 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

Cause of death?



Implications for policy and planning?

*Could
classification
systems be
improved?*

Social Autopsy



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 strengthened
17th October 2016

REVIEW

Open Access

Social autopsy for maternal and child deaths: a comprehensive literature review to examine the concept and the development of the method

Henry D Kalter^{1*}, Rene Salgado², Marzio Babile³, Alain K Koffi¹ and Robert E Black¹

Abstract

"Social autopsy" refers to an interview process aimed at identifying social, behavioral, and health systems contributors to maternal and child deaths. It is often combined with a verbal autopsy interview to establish the biological cause of death. Two complementary purposes of social autopsy include providing population-level data to health care programmers and policymakers to utilize in developing more effective strategies for delivering maternal and child health care technologies, and increasing awareness of maternal and child death as preventable problems in order to empower communities to participate and engage health programs to increase their responsiveness and accountability.

Through a comprehensive review of the literature, this paper examines the concept and development of social autopsy, focusing on the contributions of the Pathway Analysis format for child deaths and the Maternal and Perinatal Death Inquiry and Response program in India to social autopsy's success in meeting key objectives. The Pathway Analysis social autopsy format, based on the Pathway to Survival model designed to support the Integrated Management of Childhood Illness approach, was developed from 1995 to 2001 and has been utilized in studies in Asia, Africa, and Latin America. Adoption of the Pathway model has enriched the data gathered on care seeking for child illnesses and supported the development of demand- and supply-side interventions. The instrument has recently been updated to improve the assessment of neonatal deaths and is soon to be utilized in large-scale population-representative verbal/social autopsy studies in several African countries. Maternal death audit, starting with confidential inquiries into maternal deaths in Britain more than 50 years ago, is a long-accepted strategy for reducing maternal mortality. More recently, maternal social autopsy studies that supported health programming have been conducted in several developing countries. From 2005 to 2009, 10 high-mortality states in India conducted community-based maternal verbal/social autopsies with participatory data sharing with communities and health programs that resulted in the implementation of numerous data-driven maternal health interventions.

Social autopsy is a powerful tool with the demonstrated ability to raise awareness, provide evidence in the form of actionable data and increase motivation at all levels to take appropriate and effective actions. Further development of the methodology along with standardized instruments and supporting tools are needed to promote its wide-scale adoption and use.

Introduction and background

In developing country settings with inadequate vital registration systems and where many deaths occur at home, verbal autopsy is the investigative method most often used to determine the prevailing biological causes of death. Health policymakers and programmers require

these data to identify health priorities, allocate sparse resources, and evaluate the impact of health programs. Social autopsy consists of questions on modifiable social, cultural, and health system factors that contribute to the same deaths investigated by verbal autopsy. Because social autopsy studies are often conducted without a control group of survivors, it is important that the factors included be based on interventions of proven efficacy. Health care programmers and policymakers need these data to identify strategies for increasing health-

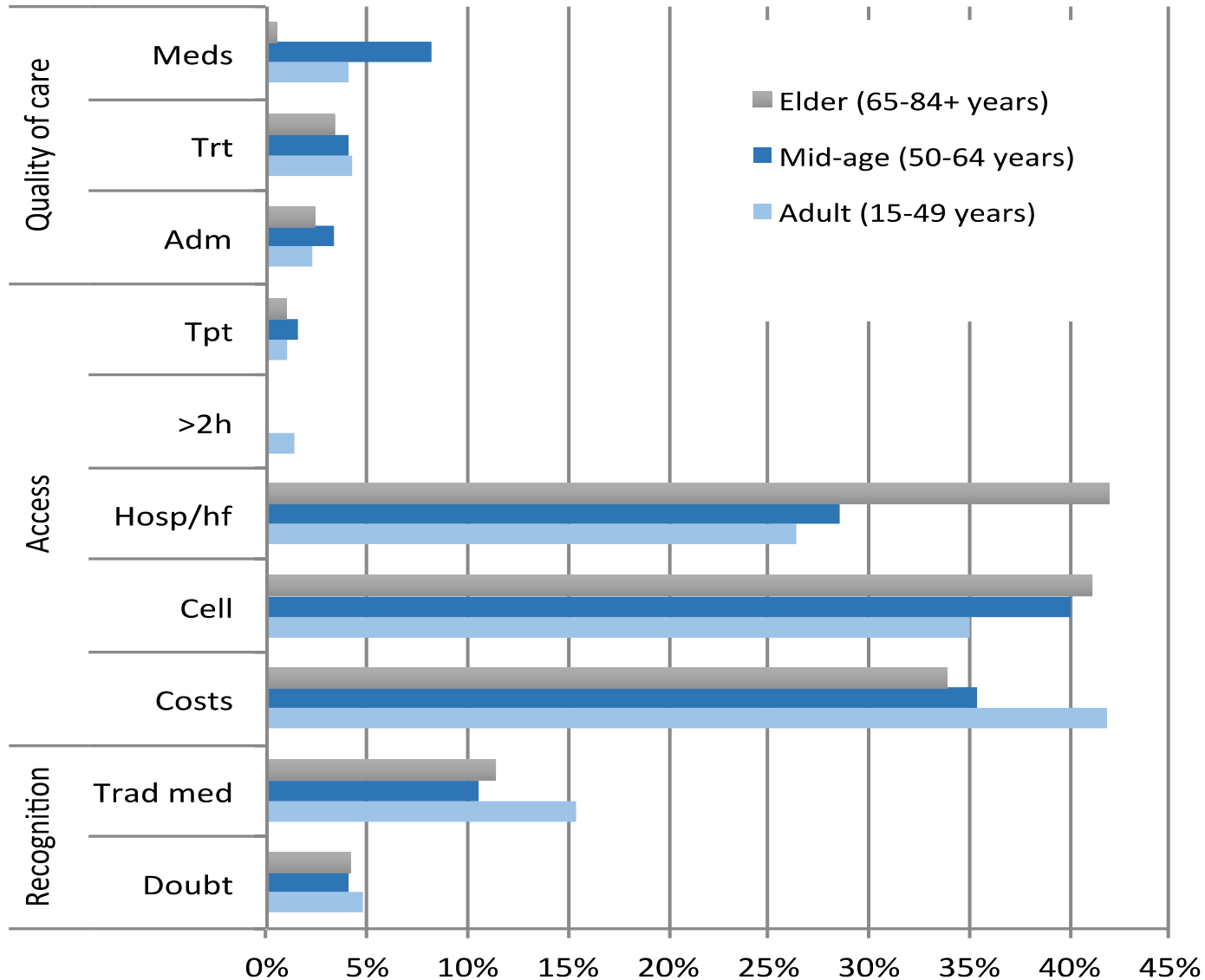
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New VA indicators: 'Circumstances of Mortality'

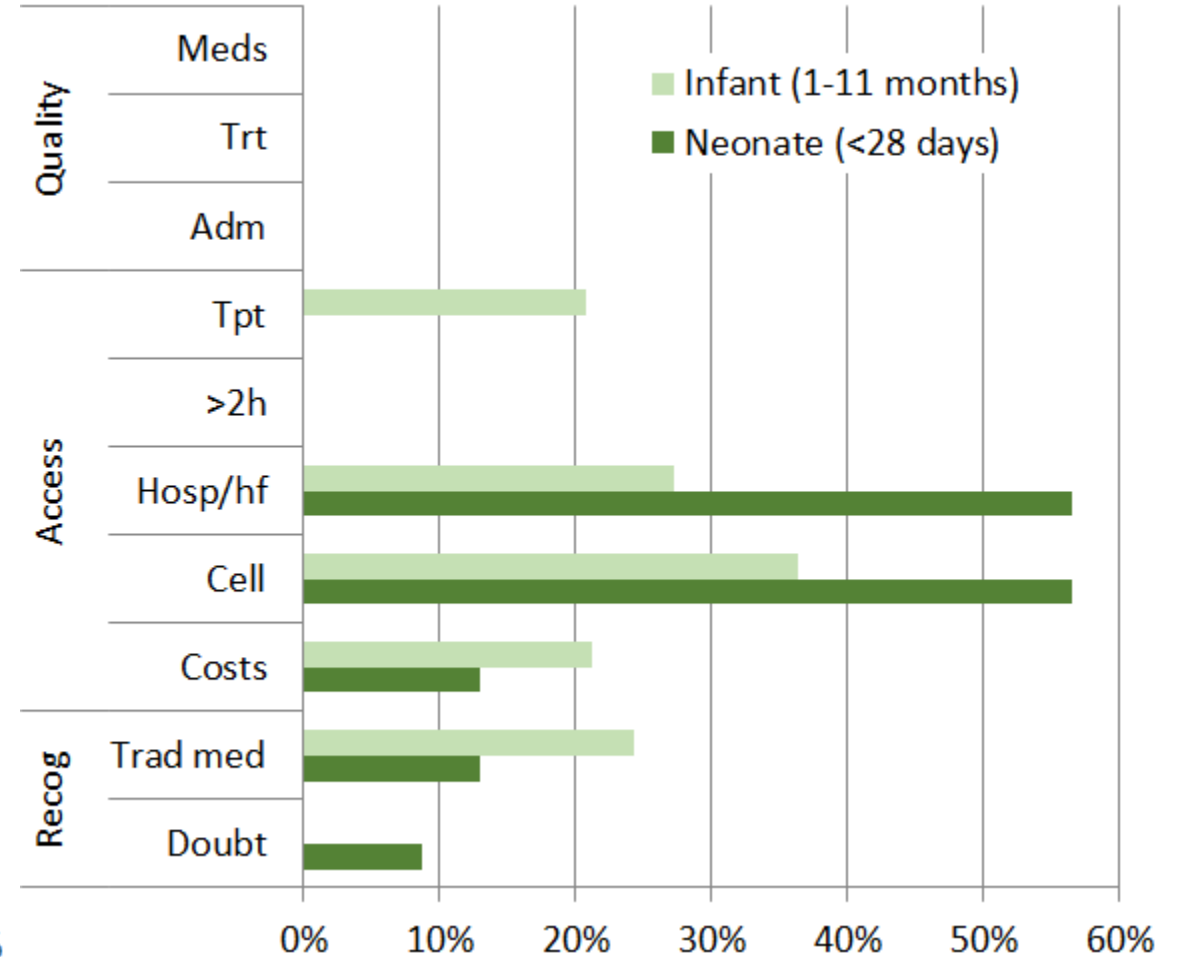
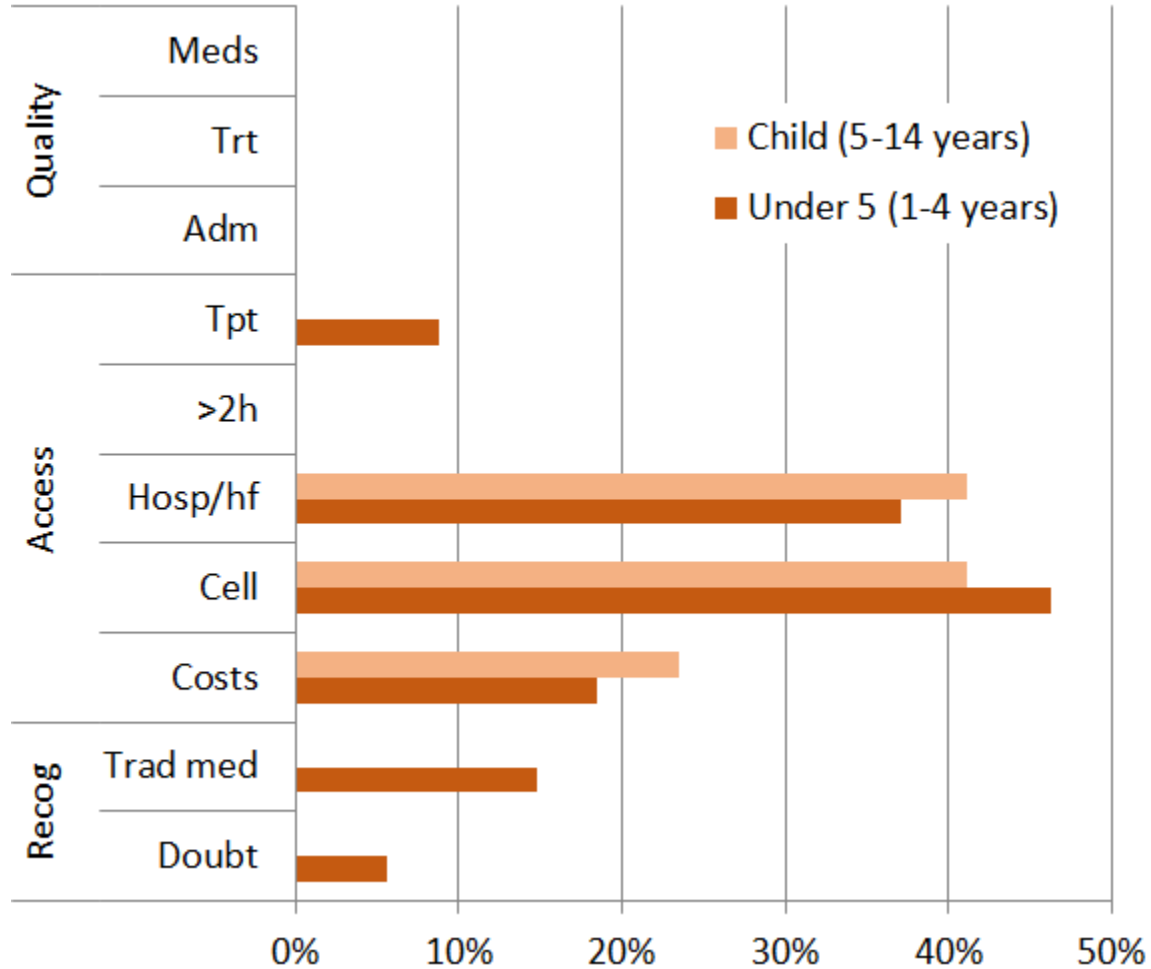
Structure	Theme	VA Question/Indicator
↓ Care Pathway Home To Hospital ↓	Recognition	Were there any doubts about whether care was needed?
		Was traditional medicine used?
	Access	Did anyone use a telephone /cell phone to call for help?
		Did (s)he use motorised transport to get to the hospital/facility?
		Did (s)he travel to a hospital/facility ?
		Does it take >2 hours to get to the nearest hospital/facility?
		Did the total cost of care prohibit other household payments?
	Quality	Were there problems during admission ?
		Were there problems with the way (s)he was treated in the hospital/facility?
		Were there problems with getting medications , tests or treatments?

Circumstances of mortality

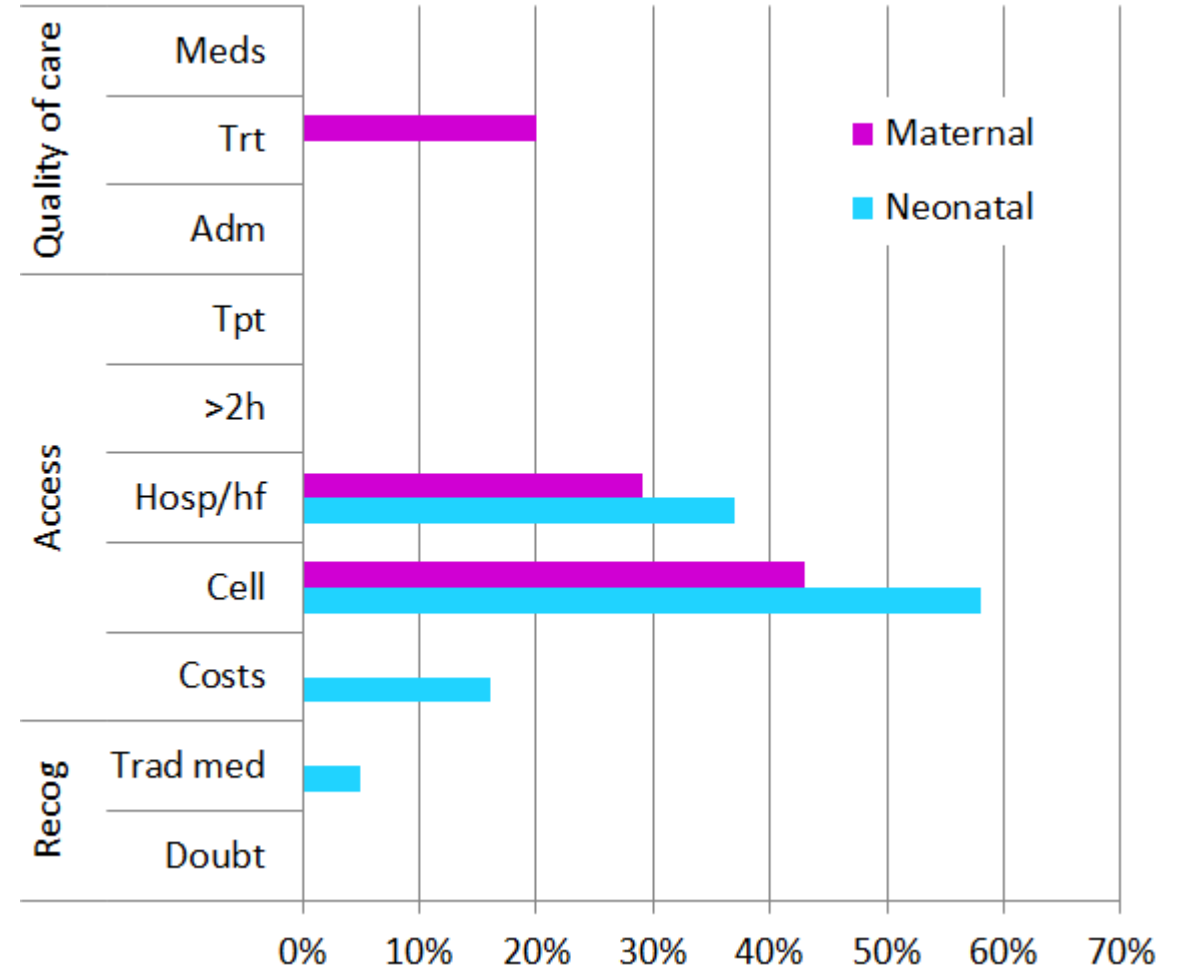
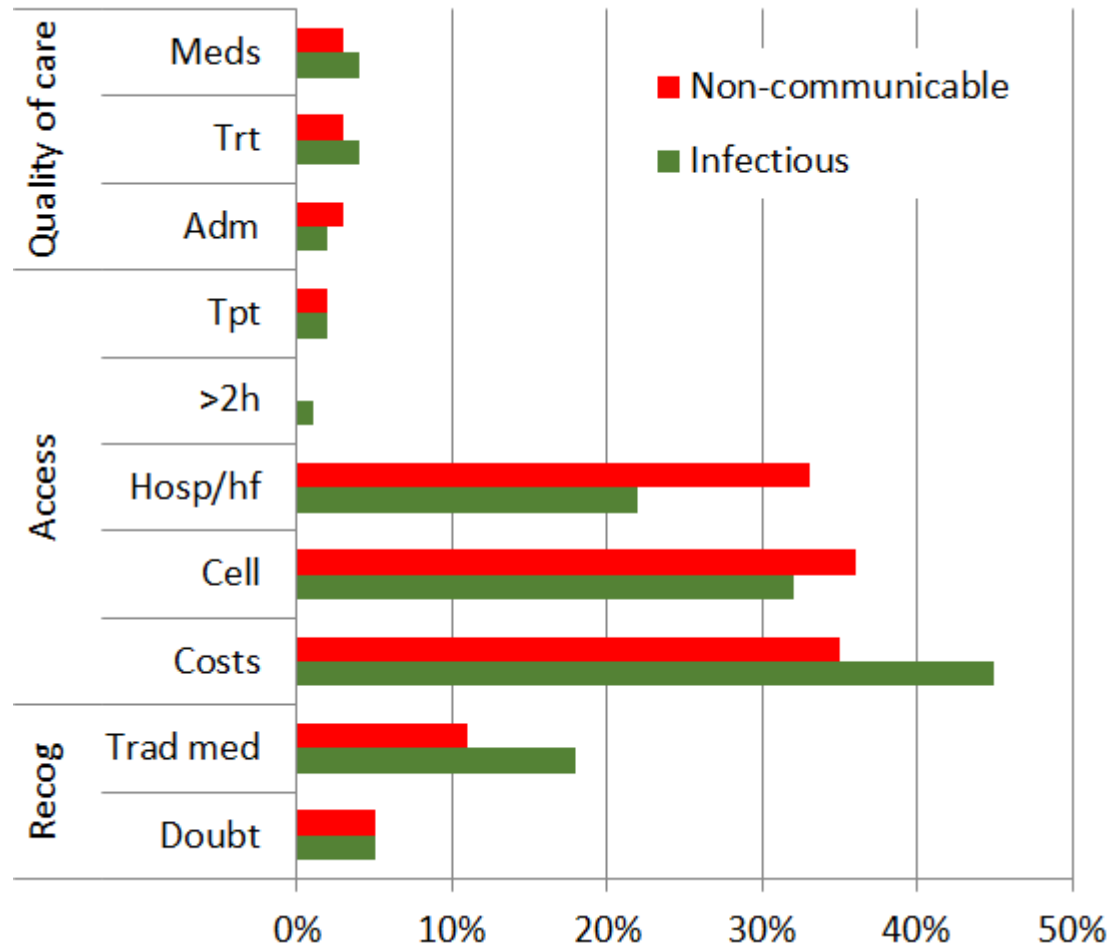


- Problems with access
 - Not calling for help
 - Not going to facility
 - Overall costs (incl. travel, transport, meds, food etc.)
- Traditional medicine
- Lower/no problems with quality (for those going to facilities)
- Varied by age/COD

Circumstances by age groups



Circumstances by medical causes



Transport and communications barriers

- Mpumalanga operates 12 ambulances for obstetric emergencies and a toll-free helpline for emergency services
- 43% maternal deaths did not make call
- 29% did not travel to a facility
- Informing decision making for IFC to seek care in obstetric emergencies may be beneficial
- Extending transport interventions may be a further priority locally

RESEARCH

Open Access



Moving from medical to health systems classifications of deaths: extending verbal autopsy to collect information on the circumstances of mortality

Lucia D'Ambruso^{1,2,3*}, Kathleen Kahn^{2,3,5}, Ryan G. Wager^{2,3}, Rhian Twine³, Barry Spies⁴, Maria van der Merwe⁴, F. Xavier Gómez-Olivé^{3,5}, Stephen Tollman^{2,3,5} and Peter Byass^{1,2,3}

Abstract

Background: Verbal autopsy (VA) is a health surveillance technique used in low and middle-income countries to establish medical causes of death (CODs) for people who die outside hospitals and/or without registration. By virtue of the deaths it investigates, VA is also an opportunity to examine social exclusion from access to health systems. The aims were to develop a system to collect and interpret information on social and health systems determinants of deaths investigated in VA.

Methods: A short set of questions on care pathways, circumstances and events at and around the time of death were developed and integrated into the WHO 2012 short form VA (SF-VA). Data were subsequently analysed from two census rounds in the Agincourt Health and Socio-Demographic Surveillance Site (HDSS), South Africa in 2012 and 2013 where the SF-VA had been applied. InterVA and descriptive analysis were used to calculate cause-specific mortality fractions (CSMFs), and to examine responses to the new indicators and whether and how they varied by medical CODs and age/sex sub-groups.

Results: One thousand two hundred forty-nine deaths were recorded in the Agincourt HDSS censuses in 2012–13 of which 1,196 (96 %) had complete VA data. Infectious and non-communicable conditions accounted for the majority of deaths (47 % and 39 % respectively) with smaller proportions attributed to external, neonatal and maternal causes (5 %, 2 % and 1 % respectively). 5 % of deaths were of indeterminable cause. The new indicators revealed multiple problems with access to care at the time of death: 39 % of deaths did not call for help, 36 % found care unaffordable overall, and 33 % did not go to a facility. These problems were reported consistently across age and sex sub-groups. Acute conditions and younger age groups had fewer problems with overall costs but more with not calling for help or going to a facility. An illustrative health systems interpretation suggests extending and promoting existing provisions for transport and financial access in this setting.

Conclusions: Supplementing VA with questions on the circumstances of mortality provides complementary information to CSMFs relevant for health planning. Further contextualisation of the method and results are underway with health systems stakeholders to develop the interpretation sequence as part of a health policy and systems research approach.

Keywords: Verbal autopsy, Social determinants, Health systems, Civil registration and vital statistics, Health surveillance, South Africa

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Financial barriers

- No patient required to meet all costs if excessive financial burden
- Subsidised care for people with disabilities, recipients of social grants, unemployed
- Despite provisions, prohibitive costs reported consistently >30%
- May be linked to indirect costs (transport, food, meds) in combination with direct
- NHI major commitment to equitable access
- PHC Re-engineering to formalise and expand roles of CHWs through WBOTs

RESEARCH

Open Access



Moving from medical to health systems classifications of deaths: extending verbal autopsy to collect information on the circumstances of mortality

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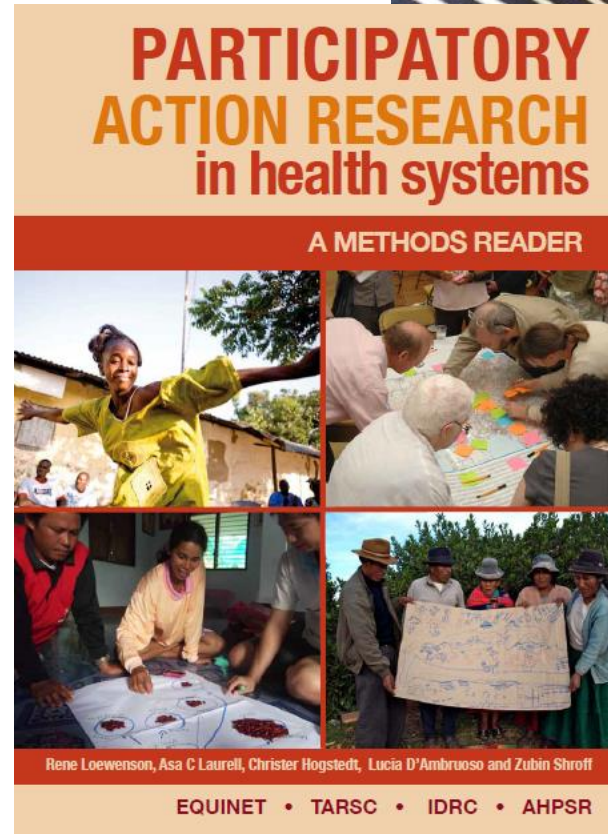
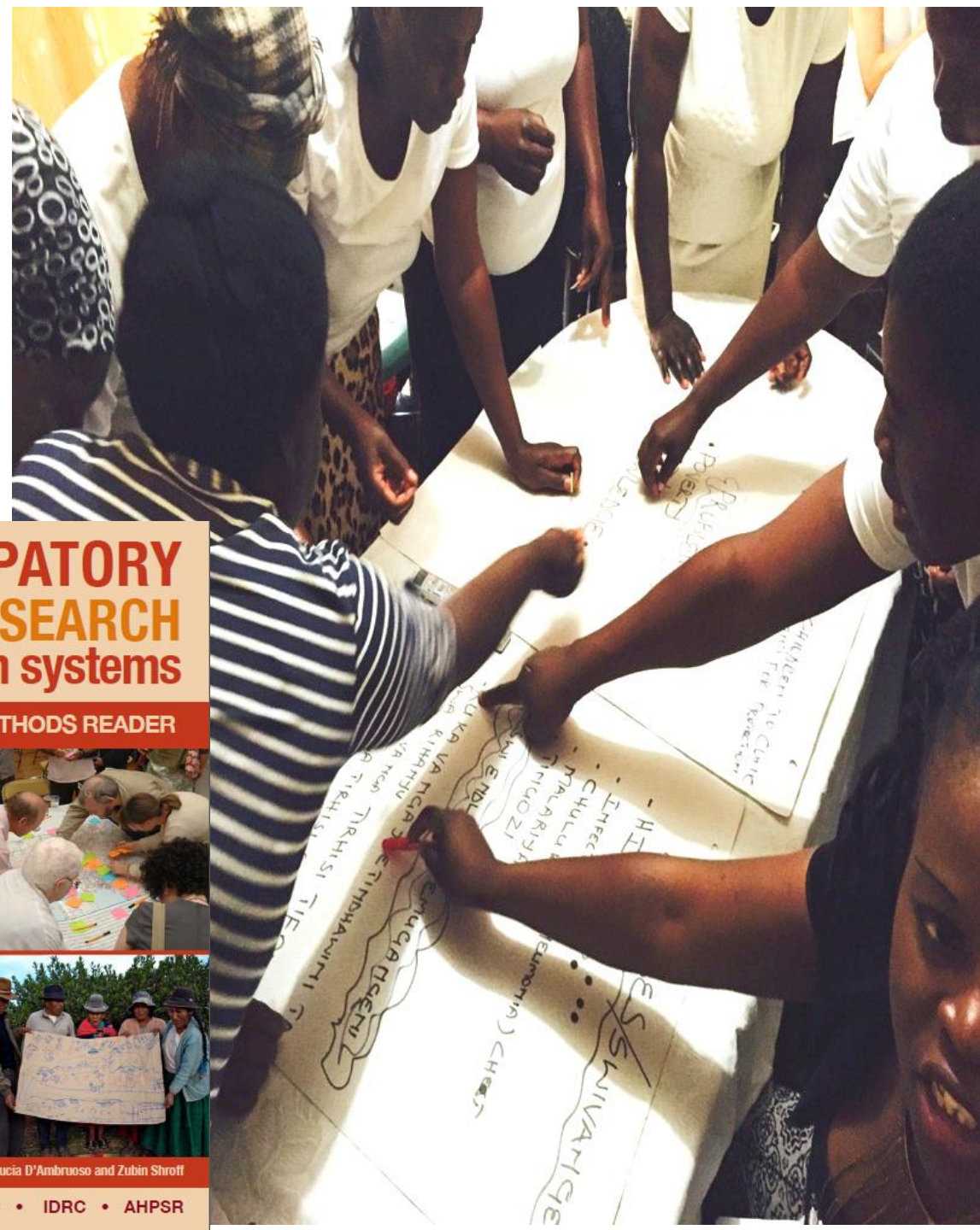
²Umeå Centre for Global Health Research, Umeå University, Umeå, Sweden

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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
- 6 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



Inadequate housing



"...the cold was coming in the house until my child had pneumonia"



Unemployment and widespread poverty

*“how would I buy the milk?
...the father of my child is not working”*

“... she doesn't have money to travel to the clinic...so the child might be unlucky and die”



Shortages of clean water

*“...if you look
carefully at this place
there are cars
collecting water,*

*...this place is dirty
even our livestock
drinks water there,
people drink water
there”*

“...people are suffering because of water, we go to streams to dig ... the water we get is not right”



11/11/2015 08:43

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Unsafe environments

"...That child drowned while there are people in the house"



*“...Another thing is negligence...
a child has diarrhea
and the parent say
it’s nothing and it will pass.*

*when the child is too weak
is when they try hospital
...it’s already [too] late”*

**Perceived
negligence**



Quality of Care

- **Poor quality care**
 - Long waiting times, overcrowded clinics
 - Lack of staff
 - Delays in treatments, lack of medications
 - Confidentiality breaches
- **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 and promotion

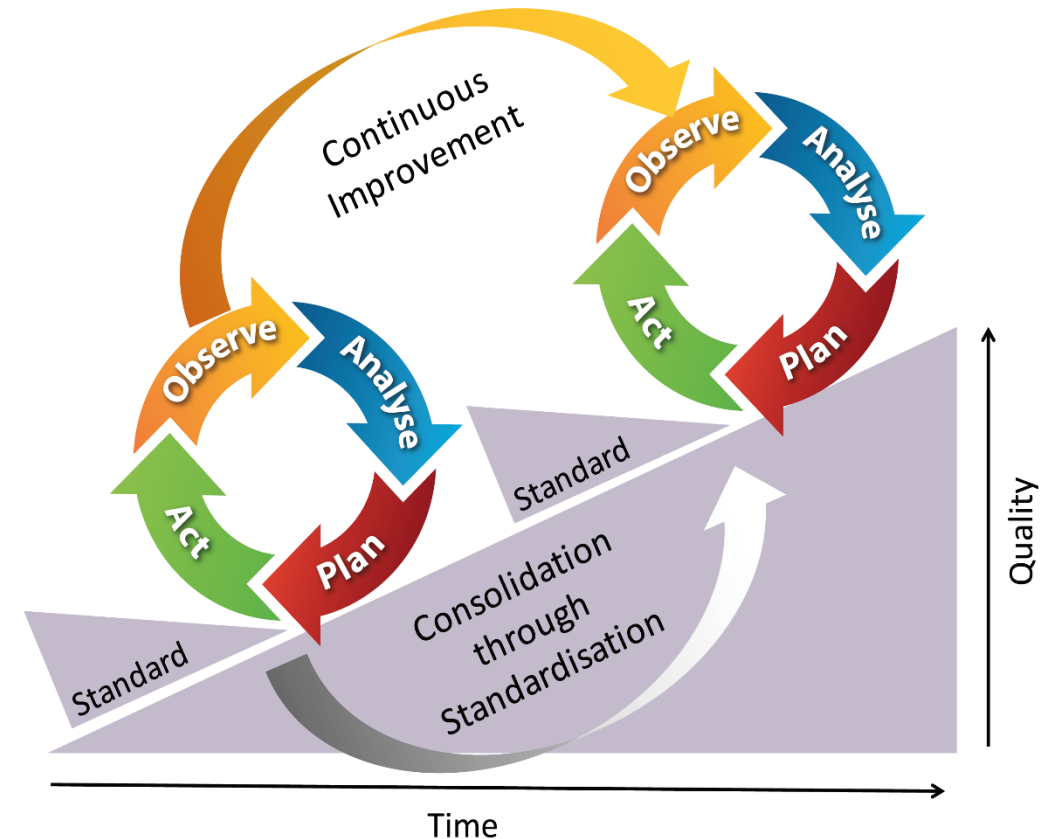
Phase 3 Health Systems Appraisal

- 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
 - 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. Extending what has been achieved into a process for action will add a crucial link expanding understanding of how change in health systems occurs and how, by which means, for whom, for whose purposes, and on the role of evidence in the process



Further information

D'Ambruso, L. et al (2016). 'Moving from medical to health systems classifications of deaths: extending verbal autopsy to collect information on the circumstances of mortality'. *Global Health Res Policy*, 1:2.

Hullur, N. et al (2016). 'Community perspectives on HIV, violence and health surveillance in rural South Africa: a participatory pilot study'. *J Global Health*, 6:010406.

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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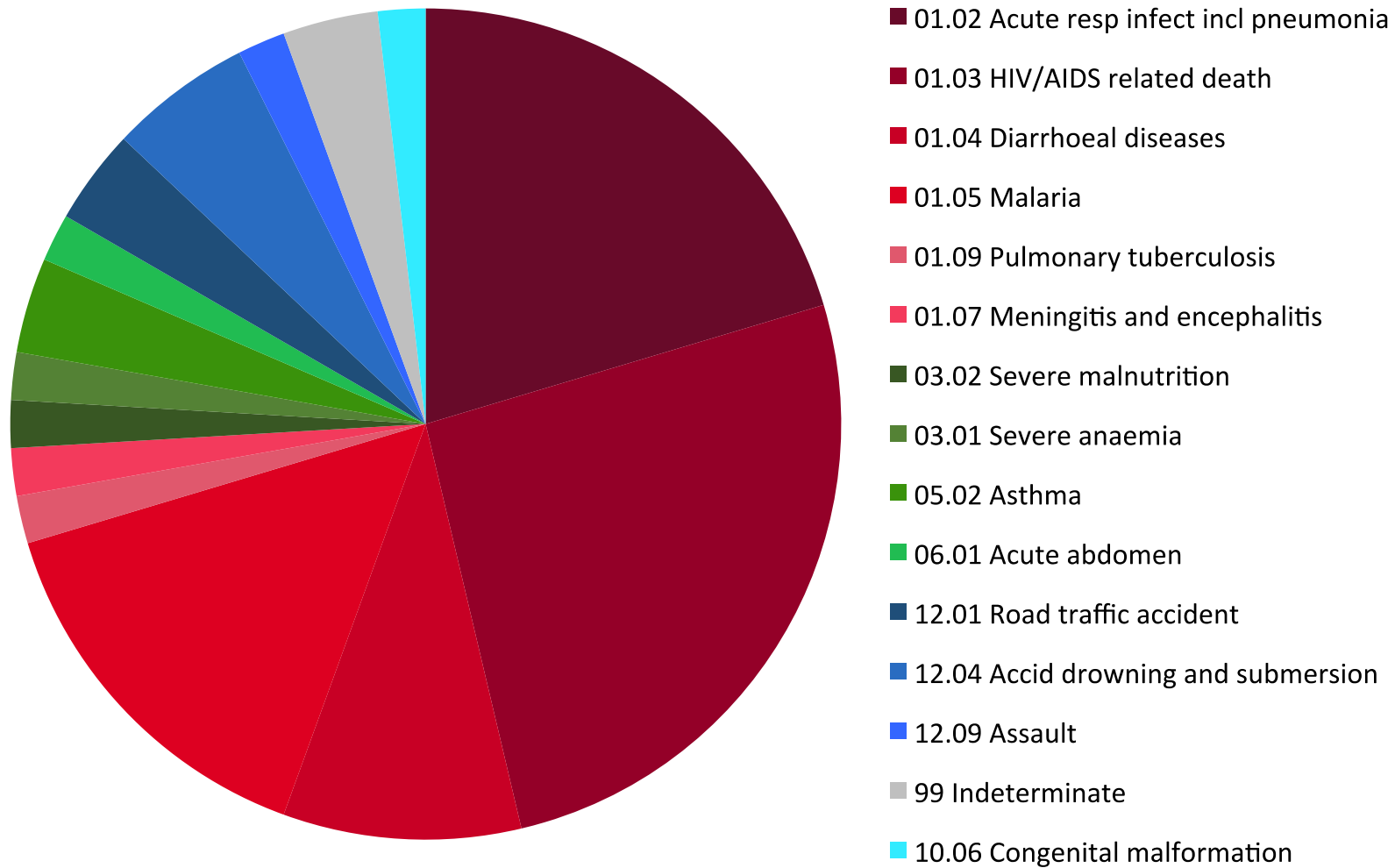
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Thank you

Phase 1 – VA data Under-5 deaths (n=54)



Phase 1 – VA data all deaths (n=1,196)

(a) neonate (<28 d), n=23



(b) infant (1-11 m), n=33



(c) under 5 (1-4 y), n=54



(d) child (5-14 y), n=17



(e) adult (15-49 y), n=537



(f) midage (50-64 y), n=172



(g) elder (65-84+ y), n=360



(h) total, n=1,196

