

Innovations in collecting siblings' survival histories

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Outline

- ▶ Background on siblings' survival histories
- ▶ Study design
- ▶ Adding and testing new SSH questions.
 - ▶ A detailed example: HIV/AIDS mortality
 - ▶ Other questions

Background on siblings' survival histories

Siblings' survival histories

Frequently collected in DHS, and increasingly in MICS.

Requires obtaining a list of the maternal siblings of a respondent.

- ▶ Then ask short questions about each sibling (sex, vital status, age)
- ▶ Allows calculating death rates directly.

MM12	LIST THE BROTHERS AND SISTERS ACCORDING TO THE ORDER NUMBER IN MM10. ASK MM13 TO MM24 FOR ONE BROTHER OR SISTER BEFORE ASKING ABOUT THE NEXT BROTHER OR SISTER. IF THERE ARE MORE THAN 12 BROTHERS AND SISTERS, USE AN ADDITIONAL QUESTIONNAIRE.	(01)	(02)	(03)	(04)	(05)	(06)
MM13	NAME OF BROTHER OR SISTER.						
MM14	Is (NAME) male or female?	MALE 1 FEMALE ... 2	MALE 1 FEMALE ... 2	MALE 1 FEMALE ... 2	MALE 1 FEMALE ... 2	MALE 1 FEMALE ... 2	MALE 1 FEMALE ... 2
MM15	Is (NAME) still alive?	YES 1 NO 2 GO TO MM17 DK 8 GO TO (02)	YES 1 NO 2 GO TO MM17 DK 8 GO TO (03)	YES 1 NO 2 GO TO MM17 DK 8 GO TO (04)	YES 1 NO 2 GO TO MM17 DK 8 GO TO (05)	YES 1 NO 2 GO TO MM17 DK 8 GO TO (06)	YES 1 NO 2 GO TO MM17 DK 8 GO TO (07)
MM16	How old is (NAME)?	<input type="text"/> <input type="text"/> GO TO (02)	<input type="text"/> <input type="text"/> GO TO (03)	<input type="text"/> <input type="text"/> GO TO (04)	<input type="text"/> <input type="text"/> GO TO (05)	<input type="text"/> <input type="text"/> GO TO (06)	<input type="text"/> <input type="text"/> GO TO (07)
MM17	How many years ago did (NAME) die?	<input type="text"/> <input type="text"/>	<input type="text"/> <input type="text"/>	<input type="text"/> <input type="text"/>	<input type="text"/> <input type="text"/>	<input type="text"/> <input type="text"/>	<input type="text"/> <input type="text"/>
MM18	How old was (NAME) when (he/she) died? IF DON'T KNOW, PROBE AND ASK ADDITIONAL QUESTIONS TO GET AN ESTIMATE.	<input type="text"/> <input type="text"/> IF MALE OR DIED BEFORE 12 YEARS OF AGE, GO TO MM23	<input type="text"/> <input type="text"/> IF MALE OR DIED BEFORE 12 YEARS OF AGE, GO TO MM23	<input type="text"/> <input type="text"/> IF MALE OR DIED BEFORE 12 YEARS OF AGE, GO TO MM23	<input type="text"/> <input type="text"/> IF MALE OR DIED BEFORE 12 YEARS OF AGE, GO TO MM23	<input type="text"/> <input type="text"/> IF MALE OR DIED BEFORE 12 YEARS OF AGE, GO TO MM23	<input type="text"/> <input type="text"/> IF MALE OR DIED BEFORE 12 YEARS OF AGE, GO TO MM23
MM19	Was (NAME) pregnant when she died?	YES 1 GO TO MM23 NO 2	YES 1 GO TO MM23 NO 2	YES 1 GO TO MM23 NO 2	YES 1 GO TO MM23 NO 2	YES 1 GO TO MM23 NO 2	YES 1 GO TO MM23 NO 2
MM20	Did (NAME) die during childbirth?	YES 1 GO TO (02) NO 2	YES 1 GO TO (03) NO 2	YES 1 GO TO (04) NO 2	YES 1 GO TO (05) NO 2	YES 1 GO TO (06) NO 2	YES 1 GO TO (07) NO 2
MM21	Did (NAME) die within two months after the end of a pregnancy or childbirth?	YES 1 NO 2 GO TO MM23	YES 1 NO 2 GO TO MM23	YES 1 NO 2 GO TO MM23	YES 1 NO 2 GO TO MM23	YES 1 NO 2 GO TO MM23	YES 1 NO 2 GO TO MM23
MM22	How many days after the end of the pregnancy or childbirth did (NAME) die?	<input type="text"/> <input type="text"/>	<input type="text"/> <input type="text"/>	<input type="text"/> <input type="text"/>	<input type="text"/> <input type="text"/>	<input type="text"/> <input type="text"/>	<input type="text"/> <input type="text"/>
MM23	Was (NAME)'s death due to an act of violence?	YES 1 GO TO (02) NO 2	YES 1 GO TO (03) NO 2	YES 1 GO TO (04) NO 2	YES 1 GO TO (05) NO 2	YES 1 GO TO (06) NO 2	YES 1 GO TO (07) NO 2
MM24	Was (NAME)'s death due to an accident?	YES 1 NO 2 GO TO (02)	YES 1 NO 2 GO TO (03)	YES 1 NO 2 GO TO (04)	YES 1 NO 2 GO TO (05)	YES 1 NO 2 GO TO (06)	YES 1 NO 2 GO TO (07)

Siblings' survival histories

- ▶ SSH constitute the main source of data on adult and maternal mortality in countries with limited CRVS systems.
- ▶ Methodological research on estimation of mortality rates from SSH.
 - ▶ How to address sample selection biases?
 - ▶ How to address reporting errors?

Siblings' survival histories and the SDGs

- ▶ SSH have major limitations in times of SDGs:
 - ▶ Only provide data on all-cause and pregnancy-related mortality
 - ▶ Seldom allow exploring mortality differentials between sub-groups or locations
 - ▶ Very sparse data above age 50 in most settings
 - ▶ No data on death registration

Study design

Study settings

- ▶ Multi-country project supported by NICHD (R01HD088516) and NIAID (R21AI127286)
 - ▶ Senegal (pilot study)
 - ▶ Malawi
 - ▶ Guinea-Bissau
 - ▶ Bangladesh
 - ▶ Uganda

Specific aims

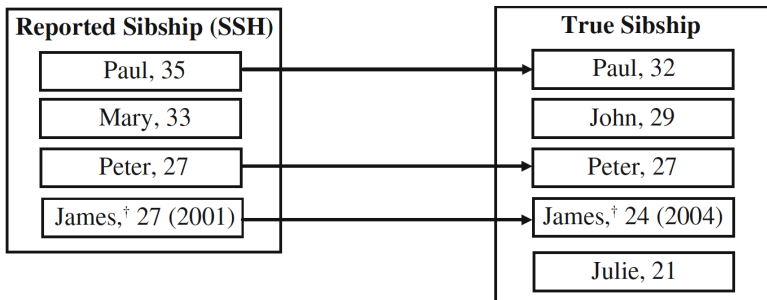
- ▶ First aim is to validate SSH data on all-cause and pregnancy-related mortality
- ▶ Second aim is to devise new statistical models that account for reporting errors (in collaboration with L. Alkema and B. Masquelier).
- ▶ **Third aim is to test additional questions and new modalities of data collection**

Validation studies of SSH data

- ▶ Main sample varying from 1,000 (Malawi) to 2,500 respondents (Bangladesh).
 - ▶ Data from Health and Demographic Surveillance System as sampling frame and reference.
 - ▶ Oversample families with adult death(s) among siblings in recent past to guarantee sufficient statistical power.
 - ▶ Migrant tracking to avoid “closeness” bias.
- ▶ Supplemental samples added to test new questions and modalities.

Records linkages

Record linkages at the sibling level for detailed validation.



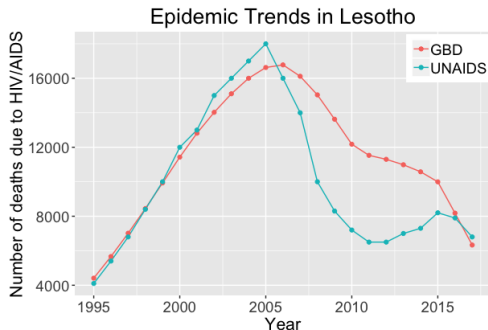
Measuring HIV/AIDS mortality

Context

Objective of "zero AIDS-related deaths by 2030".

But in most LMICs, very limited data on HIV/AIDS as cause of death

- ▶ Partial and selective data from CRVS and HMIS
- ▶ Robust data in clinical cohorts and HDSS



New questions on HIV/AIDS

- ▶ SSH are main source of data on all-cause and maternal mortality in LMICs, but no questions on HIV/AIDS mortality. Why?
 - ▶ Limited knowledge about HIV status would yield a lot of missing data.
 - ▶ Stigma would lead to refusals to answer questions about HIV status of siblings and/or misreporting.
 - ▶ Takes too long to ask additional questions
- ▶ Recent developments in HIV prevention and treatment have eroded these concerns.

New questions on HIV/AIDS

For each reported death at ages 15 and older:

- ▶ Was [INSERT NAME OF THE DECEASED] ever tested for HIV?
- ▶ What were [INSERT NAME OF THE DECEASED]'s latest test results?
- ▶ *if not reported as HIV-positive*: How likely do you think it is that [INSERT NAME OF THE DECEASED] was infected with HIV?

New questions on HIV/AIDS

- ▶ Not a diagnostic of the cause of death, e.g., using ICD codes.
- ▶ But, in combination with data on HIV prevalence among the survivors, data would allow estimating relative risk of death associated with HIV infection.
- ▶ As we move towards “zero AIDS-related deaths”, ratio should go to 1.

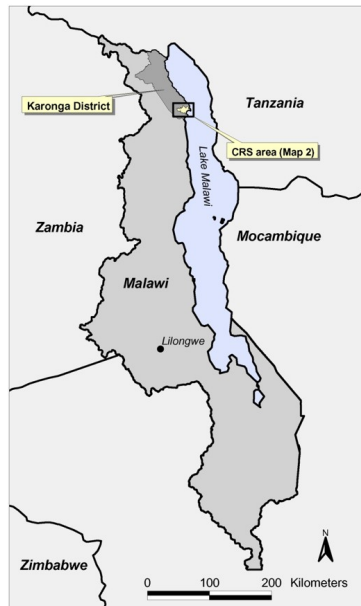
Validation study:

Worked in Karonga HDSS in Malawi.

Sampled deaths for which we had pre-mortem records of HIV status, then interviewed surviving sibling of the deceased.

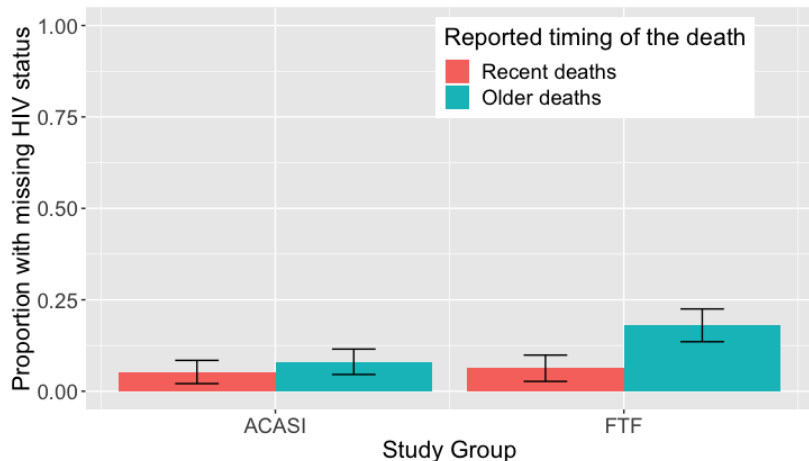
Randomized trial of ACASI vs. face-to-face interviewing (n=535).

- ▶ Primary outcomes: sensitivity/specificity
- ▶ Secondary outcome: time needed to collect data



Results

Limited extent of missing data, particularly for the deaths that occurred in a recent “reference” period.



Results of the validation of SSH data

Sensitivity: proportion of deaths to person with HIV according to HDSS, also reported as such during the survey.

Sensitivity	Overall	ACASI	FTF	p-value
Reference data	0.90 (0.84, 0.94)	0.90	0.90	0.93
Imputed data	0.75 (0.67, 0.83)	0.77	0.74	0.55

No interaction with timing of the death, but when both groups are pooled, more recent deaths appear better reported.

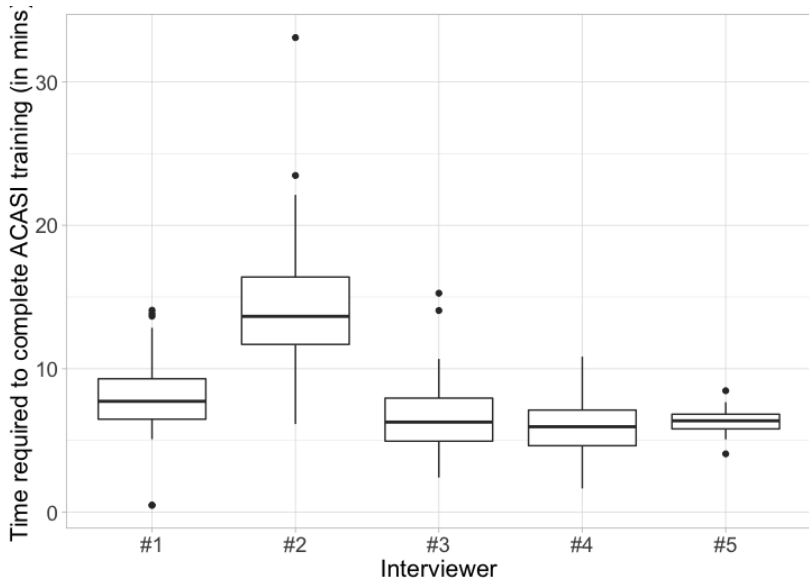
Results of the validation of SSH data

Specificity: proportion of deaths to person without HIV according to HDSS, also reported as such during the survey.

Specificity	Overall	ACASI	FTF	p-value
Reference data	0.94 (0.85, 0.97)	0.95	0.93	0.71
Imputed data	0.97 (0.94, 1.00)	0.97	0.97	0.85

Time required to collect data

It takes a long time to train respondents to use ACASI.



Time required to collect data

- ▶ Compare HIV questions to other questions about circumstances of the death that are currently asked.
- ▶ Time required per deceased adult sibling (in minutes):

	ACASI	FTF	p-value
External causes	0.44 (0.28, 0.75)	0.21 (0.15, 0.30)	<0.001
PR deaths	0.64 (0.39, 1.02)	0.24 (0.16, 0.41)	<0.001
HIV/AIDS	0.74 (0.45, 1.16)	0.40 (0.27, 0.70)	<0.001

Conclusions re: HIV/AIDS trial

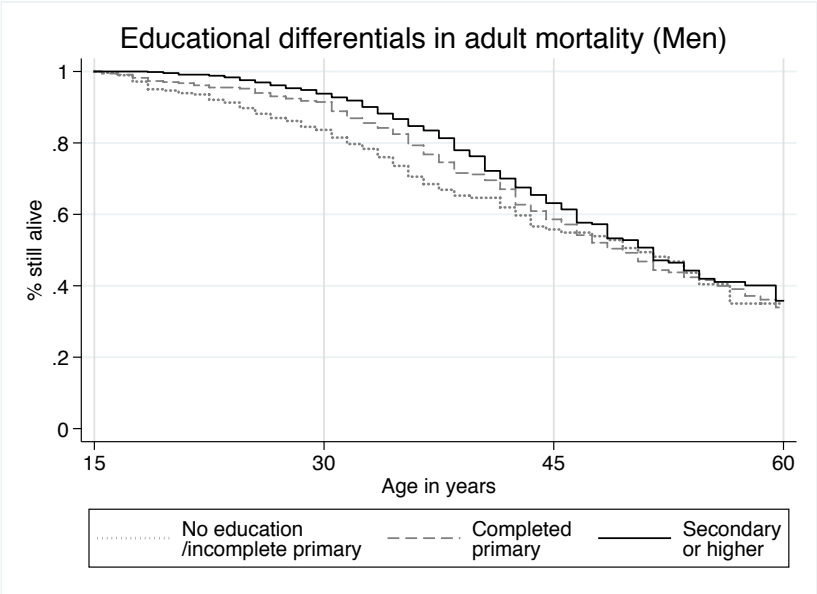
- ▶ 3 questions yield largely complete and accurate data on a highly prevalent risk factor/cause of death.
- ▶ Also take limited time to collect, so addition to current questionnaires feasible.
- ▶ Can be further improved, e.g., through training and probing.
- ▶ On the other hand, ACASI not worth the time investment.

Other additional questions

Indicative list of items currently being tested.

- ▶ Questions about smoking (observable risk behavior).
- ▶ Questions about educational levels of siblings, to enable measurement of adult mortality differentials.
- ▶ Questions about siblings' residence, to allow measuring sub-national variation in adult mortality.
- ▶ Questions about death registration coverage and reasons for registering/not registering a death.
- ▶ Questions about survival of parents to measure mortality above age 60.

Example: SES differentials



Conclusions

- ▶ Siblings' survival histories are an important but under-utilized tool in population-based research in LMICs.
- ▶ Adding a few questions about surviving and/or deceased siblings would improve monitoring of progress towards the SDGs and other global objectives.