

Assessing the feasibility of a life history calendar to measure HIV risk and health in older South Africans

Enid Schatz, University of Missouri
Lucia Knight, University of Western Cape
Sanyu Mojola, Princeton University

Life history calendars capture patterns of behavior over time, uncovering transitions and trajectories. Little is known about older Africans' HIV testing and risk in the context of a mature HIV epidemic. Operationalizing a 'life course approach to HIV vulnerability' through a Testing & Risk History Calendar [TRHC], we collected pilot data in rural and urban South Africa on older persons' risk and HIV testing. We found that older adults were able to provide (1) reference points within a 10-year period to facilitate recall, (2) specifics about any and all HIV tests during that decade, and (3) details of living arrangements, relationships, health status, health care utilization including changes in each, over this period. When used on a larger scale, the TRHC could reveal the relationship between testing and risk, as well as helping to outline the timing of changes in health and relationships at older ages.

INTRODUCTION

Life history calendars have been used in a variety of contexts and populations to facilitate large-scale quantitative life course research, and more recently to add qualitative techniques to deepen what can be learned about the life course from this method (1–4). The purpose of life history calendars is to collect retrospective data in a number of domains through a fluid interview that facilitates recall by making use of personal and social/political landmarks or reference points (5,6). Life history calendars have been used to capture information on sexual relationships (7,8), health among middle aged and older adults (9–11), as well as important life transitions (4,8,12). This other research on sensitive topics suggests that the use of a life history calendar [LHC] can increase the scope and quality of data collected, and reduce social desirability bias (7), even for monthly intervals over an extended retrospective period. There is evidence that life history calendars produce high quality data across contexts, including in low and middle income countries (LMICs) (5,7,13).

Currently, there is limited data on HIV testing and its correlation to health status and relationships as individual's transition into older ages in HIV endemic African contexts. For the entirety of the HIV epidemic the focus of HIV data collection, interventions and programming has been on those aged 15-49 (14–17). Only recently has there been an increased interest in collecting data on and understanding the implications of HIV for populations outside this age range (18–21). However, the survey remains the primary form of data collection, and the questions, particularly about HIV testing and sexual behavior remain limited. In 2018, we pilot tested a life history calendar, the Testing & Risk History Calendar (TRHC) with 30 individuals aged 50-plus. The TRHC included domains related to HIV testing, relationships, health status and health care utilization in order to better understand these issues and their relationship to one another in an urban and rural context, to assess the feasibility of collecting this information in this format.

The standard means of learning about HIV counseling and testing is through cross-sectional survey data. In surveys, individuals are generally asked about whether they have ever tested for HIV and for the recency of the last test. The survey usually includes questions about sexual behavior and risk, but rarely with a compatible timeframe to be able to associate these risk behaviors with when people choose to test (8). Some qualitative studies have looked more in depth into testing norms, and barriers and facilitators of testing, the majority of these studies also focus on younger populations (22–25). While we laud the qualitative work, it cannot be scaled up to assess population level dynamics.

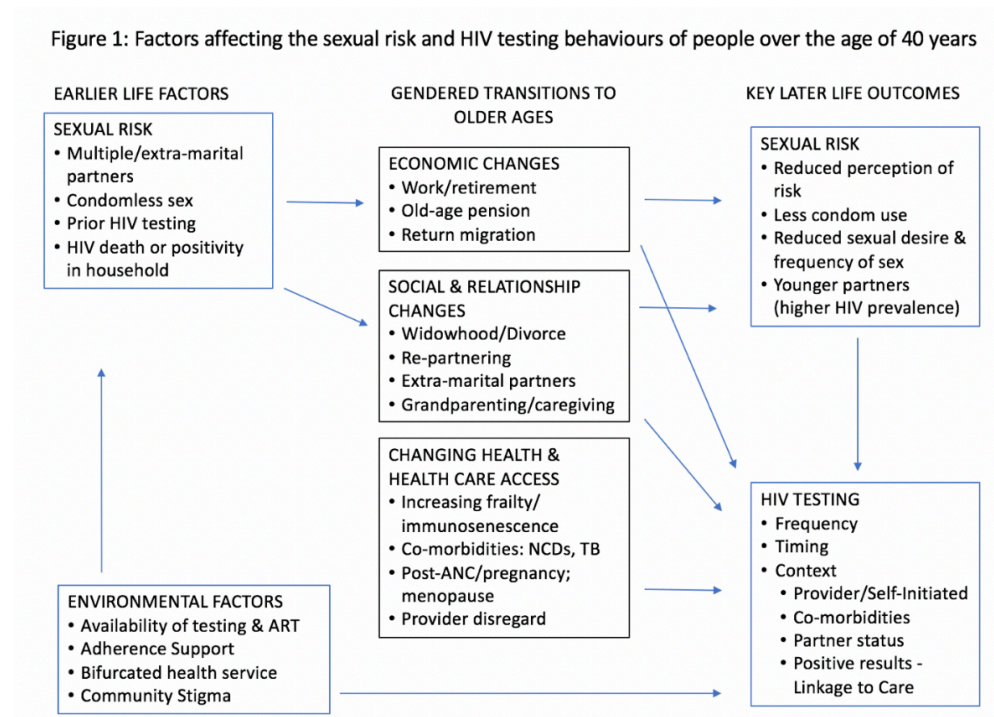
There are a number of potential biases related to current means of collecting testing data. First, surveys introduce the potential telescoping of recency of last test to be within the last 12 months, making it appear that more individuals tested within the year than actually did (26). In addition, there is some evidence that recall error can be a challenge in survey data, particularly for older persons due to the ways that memory works (10,27,28). Second, there is some evidence that HIV negative adults over report prior testing (26), and that men often over-report sexual partnerships, while women under-report them due to social desirability bias (7,8). Third, cross-sectional surveys limit the ability to identify associations and prevent building causal models between potential risk factors and HIV testing behavior (29). Current data collection on HIV counseling and testing also includes very little data on the social context surrounding testing decisions, nor do they capture the potential importance of sexual and marital histories or the role of personal health and wellness (8).

The majority of studies on barriers to and motivations for testing focus on those in reproductive ages, particularly documenting younger adults' and pregnant women's experiences (30,31). Not only are older persons less likely to have been tested for HIV, talk to their partners about HIV (19), and correctly identify transmission vectors (32); they also know less about ART (33). The few studies that provide information on risk behaviors show that older persons often continue risky sexual behaviors (34–37), or become exposed to risk due to relationship and residence changes related to aging (18). In recent survey data from rural South Africa, two-thirds of respondents 40-plus reported multiple life-time partners. Among the 57% reporting sex in the last two years, 75% reported never using a condom (37). Despite having sexual partners in high prevalence age groups (38–40), engaging with new partners in older ages due to widowhood and divorce (38,41), and continued risk of sexual violence (42,43); older persons do not perceive that risk reduction messages are for them (44). New data are needed to support and direct efforts to create interventions that are targeted to the needs of older persons. Further, sub-Saharan Africa has an emerging NCD epidemic, for which older South Africans are particularly at risk (45,46). Thus, there is a need to understand links between risk, health and testing over time.

CONCEPTUAL FRAMEWORK

Using a 'life course approach to HIV vulnerability' (3), we aim to explicitly understand risk trajectories that matter for HIV testing as individuals transition into old/older ages in the context of a mature HIV epidemic (18,47,48). Thus, the Testing & Risk History Calendar was

designed to reflect the conceptual framework outlined in Figure 1 built from reviewing the literature and pilot work by Knight and Schatz.



Transitions occur as individuals move out of work, antenatal care and routine testing, experience menopause, changing sexual and marital relationships, deteriorating health profiles, and decreasing perceptions of HIV risk (16,18,49). While perception of risk declines, HIV vulnerability and risk trajectories vary as people age, due to changes in behavior, protective strategies and the environments in which people live (18). Due to the intersection of age and gender, the changes in risk and health occur at different times and in different ways for men and women (18,50). Household and larger structural factors (work, finances, partner/household dynamics) impact the experience of aging and vulnerability to HIV risk (18). The health care environment, including the availability, accessibility and acceptability of HIV testing and care are crucial factors related to persons' HIV testing behavior, and engagement in the HIV care cascade.

Testing & Risk History Calendar

In 2017, we developed a Testing and Risk History Calendar to understand when and why older persons do or do not test, and how HIV testing is related to histories of health and risk. We specifically developed the TRHC for the South African context and population. The TRHC, as a life history calendar, facilitates the collection of retrospective, complex, time-specific data, reflecting our life course approach (1,7,51). The TRHC, modifying the Relationship History Calendar used with youth in Kenya (7), provides time-bound and time-varying data on HIV testing, sexual risk and health at monthly intervals over a 10-year retrospective period for individuals aged 50-plus, i.e., those in and transitioning to older ages.

The TRHC is formatted as a fold-out grid (1,3,7). [See Figure 2]. Months, our unit of time, are listed across the top of the grid. Life domains (socio-demographic details and HIV testing, relationships, and health status) are noted down the left side of the page and extend in rows representing timelines across the months of the 10-year reference period. Each month of an ongoing relationship is marked with a letter/line indicating relationship type, and letters/lines for the frequency of sex and condom use consistency over the course of the relationship, and partner characteristics (age, residence, HIV status, etc.). The domains reflect the types of risk that have been correlated with older persons' HIV acquisition and testing in the limited work available (24,37,52). The field research staff filled in the matrix cells with information given by the respondent. The TRHC's detailed information enables us to create time-bound and time-varying measures (across the 10-year period) for these domains to develop and assess the later-life risk trajectories and covariates that lead (or do not lead) to HIV testing.

Figure 2. TRHC Sample

TESTING & RISK HISTORY CALENDAR

N.B: The following is a truncated SAMPLE FILLED IN version of the Testing & Risk History Calendar instrument. The full TRHC instrument will start in June 2009 and ends in Dec 2019 (start and end month will be adjusted by month of interview to ensure a full 10 years of data) Questions T2-T16 will be asked for the first test and each other test appearing on the TRHC (e.g., first test + all tests in previous 10 years)

		RESPONDENT ID																																				Male <input checked="" type="checkbox"/> Female	
		2010												2011												2012													
YEAR		2010												2011												2012													
MONTH		J	F	M	A	M	Jn	Jl	A	S	O	N	D	J	F	M	A	M	Jn	Jl	A	S	O	N	D	J	F	M	A	M	Jn	Jl	A	S	O	N	D		
1	Birthdate																																						
M	MAR																																						
1	Respondent Age																																						
Y	1951																																						
	Reference points	World Cup																								Marikana													
		+																								+													
2	Location	K												K EC												EC K												K	
3	Urban/Rural	U												U R												R U												U	
4	Housing type	I												I F												F F												F	
5	Marital Status	M												M W																								W	
6	Economic Activity	Domestic worker																																					
		EI												EI NL																								NL	
7	Pension/Grants																																					OA	
8	HIV Test*	XN																								XY													
9	Partner initials																																						
XM																																							
10	P age at rel. start	14																																				E	
35		SH																																				SH	
11	P Birthdate	SI												SI NL																								NL	
M	Jan																																						
17	Pension/Grant																																						
18	Type of Relationship	M																								M													
Y	1947																																						
19	Main Reason	M																								M													
12	P educ level																																						
S6		AM												AM N																								N	
22	Frequency of Sex																																						
23	Contraception	N																								N													
13	YR rel. start																																						
1982		N																								N													
24	Condom Use																																						
25	P Pregnancy (male R)																																						
26	P HIV Test													XY																									
21	Reason for end																																						
Died		M																								M													

The three key life domains include: Relationships & Sexual Risk, Health Status & Health Care Utilization, and HIV Testing. (1) *Relationships & Sexual Risk*: For each relationship over the past 10 years, relationship dimensions and sexual behaviors specific to that partnership were recorded. This section allowed for the reporting of formal partnerships, multiple concurrent partners, long and short term partnerships, casual sex, and all instances of sexual risk. (2) *Health Status & Health Care Utilization*: This section captured non-communicable diseases,

acute and infectious health events, and both routine and acute engagement with the health care system. This domain allows us to track the timing of illness, diagnosis, and care; and the ways that engagement with the health system corresponds to HIV testing. (3) *HIV Testing*: In addition to placing on the calendar each instance in the last 10-years that individuals tested for HIV, there was a set of survey questions about each test.

The HIV testing survey questions include, for each of the 4 most recent tests, where the test occurred, motivation and reason for testing, health status, relationship status, as well as if they received results/what they were, disclosed result, were linked to HIV care, and if so timing of ART initiation and adherence. In addition, the TRHC includes background sociodemographic information over the 10 year period (age, residence, education, marital status, employment, and social grant status).

PILOT

In 2018, we piloted the TRHC with 18 individuals in an urban site and 12 in a rural site. The urban site is situated on the outskirts of the city of Cape Town. It is an area of mixed formal and informal housing and characterized by a largely black African population. The community has high levels of unemployment and for those with work this is often in the informal sector and therefore widespread low socio-economic status. The community is serviced by a number of primary public health facilities. Many of the older people within this urban community maintain links with and intermittently travel back and forth between rural areas within the Eastern Cape (another province within the country) which is where they or their families originally migrated from. The rural site is situated in the northeast of South Africa. It is characterized by low levels of employment and high levels of migration – particularly among young men and women – to more urban areas to look for work. In recent years, infrastructure projects have brought more paved roads to the area, as well as an increasing number of services (major grocery and department store chains, etc). The site has a wide wealth distribution, but the majority of people in the area live in poverty, dependent upon social grants and irregular remittances for household income.

The study aimed to purposively sample older men and women (50 years and older) to reflect a range of ages, and also a significant proportion who were HIV-positive and had therefore experienced HIV-testing. In the urban site previous qualitative research experience showed that it was not always easy to find older people living with HIV especially those who were over 65 years of age and male. To overcome these challenges snowball sampling was used with key informants within the community providing introductions to older people and respondents were selected to ensure the sampling criteria were met and all demographic groups included. In the rural site, the fieldwork happened alongside another study which was conducting community focus group interviews with individuals aged 40-49, 50-59 and 60-plus. The interviewer who conducted the TRHC interviews recruited respondents who were interested but did not fit the age-group for a particular village, or others who he met while in the area who met the age description. In the rural area, there was good age and gender distribution but only one of the respondents disclosed as being HIV-positive.

The interviews were conducted by trained research assistants. The pilot interview process was focused on assessing the usability and feasibility of the calendar method for collecting the required data from older people. Unlike the standard collection of quantitative data using a questionnaire the TRHC interviews were less structured and the process was guided by the identification of reference points and discussions about key topics. The flexible nature of the interview allowed for points to be added to any section of the calendar at any time as they were recalled by the respondent. In many cases discussion about one aspect, for example illness within a certain period, may trigger a memory about another issue that was occurring at the same time, for example risk.

Each interview took about 2 hours allowing respondents to specify up to four partners and four health conditions.

- In the final paper we will be able to include this additional information from the pilot data that is currently being cleaned and entered: The average number of relationships specified by women in the previous 10 years was X (range x-x) and by men was Y range (y-y). The average number of health conditions reported on by women in the previous 10 years was X (range x-x) and by men was Y range (y-y).

TELESCOPING AND RECALL ERROR

In both contexts, older persons were able to recall and place on the TRHC when they had tested for HIV, the timing of sexual and romantic relationships, and information related to their health conditions. They were able to specify which components of each changed over time and which were static, e.g. changes in condom use and the frequency of sex over the course of a relationship.

In order to facilitate recall and reduce telescoping, we included three public reference points in the pilot TRHC (i.e., June/July 2010-World Cup, August 2012-Marikana Massacre, December 2013-Mandela's death), which were printed on the TRHC. The field research staff/respondents then added salient personal reference points to the TRHC at the beginning of the interview. These included the birth of grandchildren, the death of family members, an adult child getting a job or new car, moving and retirement. The interviewers were also encouraged to move back and forth between domains to check on the timing of events, including HIV tests. For example, if a woman's husband had passed away and she had said she had already reported that she tested in the month following his death. The interviewer would say, "You said your husband died in March of 2015, and you also said you had an HIV test in April of 2015. Was your HIV in the month after your husband died?" If the respondent answered yes, the date would remain the same in the calendar, if the respondent corrected the date to the same month or to two months later, the interviewer could then correct the date on the calendar. Having both personal and cultural/political/social landmarks as well as the ability to look at the timing of events across life domains helped individuals to anchor critical events (sexual behavior, HIV testing) more accurately in time and reduce the likelihood of telescoping behaviors (3).

Telescoping results in more reports of testing within the last 12 months, making it appear more individuals tested within the year when really they did test but in the more distal past (26). By contextualizing questions about life events, recall improves and there is a reduction in the likelihood of reporting events as more recent than they actually are (3,7).

- In the final PAA paper we will report the percent/number of TRHC respondents who reported testing in the last year, and/or who reported testing in the last year and additional times in the previous 9 years. We will then compare it to the reported testing in the previous year in Agincourt (data analyzed in Schatz et al. 2017). This comparison will be done with caution since the TRHC is not representative, but more as an illustrative comparison.

SOCIAL DESIRABILITY

There are a number of ways that social desirability might affect our understanding from survey data older persons' propensity to test for HIV and their risk from sexual relationships. Even older persons know from media and health campaigns that everyone is 'supposed to' test for HIV. In qualitative work from the rural site, Schatz and colleagues found that in fact older persons are more likely to claim that people their age should be testing, than actually are testing (24). Social desirability bias has been found to increase reporting of HIV by adults who are HIV-negative (27).

Social desirability bias is also a suggested root cause of men over-reporting sexual partners and women under-reporting them. While a validation study is needed to ensure the veracity of the information in the TRHC, the TRHC data seems as good if not better than recent survey data in reporting relationships. The flexibility of LHC interviews allows for interviewer-respondent collaboration, building rapport (1,7) and embedding sensitive questions in a broader history of respondents' lives. These features reduce social desirability bias (3), particularly related to reports of sexual behavior (7).

- For the PAA data we will have this information checked and more formally reported: Men on average had 1-2 partners, rarely concurrent, with only one reporting three partners, whereas in other data from the same/similar context men on average report X partners in the last 2 year (suggesting that over 10 it would be at least the same if not more); compare with Houle et al. 2017. Women on the other hand mostly reported zero partners, other than husbands who were still living, in the past 10 years. Our interviewers asked women if they had a man who they used as "roll-on", or that they were "keeping for the future", but still women were reluctant to share information about non-marital partners. It is unclear if this is because women really are stopping sex, and not finding new partners, or if they remain reluctant to report sexual activity that is outside of normative behavior.

Social desirability bias, particularly in relation to sensitive questions related to sexual risk and health, plague survey data (7). However, the ability to use information from one domain to cross-check and resolve inconsistencies in other domains (55), is one means of reducing the

responses that are due to social desirability rather than actual events. The fluid form of the interview allowed the interviewers to ask participants about HIV testing both as part of the HIV Testing domain, and when 'risk' was mentioned in any other domain. They also could cross-check about relationships from the HIV testing questions – “were you in a relationship when you tested for HIV that time?” Or ask about HIV testing in relation to suspicion of a partner having other partners, or having passed away due to an illness (both questions that are part of the relationship domain).

CAUSAL INFERENCE

Despite the key importance of temporal order in order to assess causality, the majority of studies on HIV testing and risk do not have data at multiple points in time. Thus, cross-sectional surveys limit the ability to identify associations and prevent building causal models between potential risk factors and HIV testing behavior (27). While there is some legitimacy to the question of whether the timing of events in the TRHC is exactly as it occurred in real life, there is strong evidence from other settings and projects that the ordering is likely to be correct even if the exact timing is not (ADD CITES). For older persons, behavior and contexts over the previous 10 years are likely to shape their likelihood of testing both in the past and currently, particularly as they 'age out' of 'high risk age groups' but also out of routine testing.

The LHC captures more complex information than in a traditional survey (7,55). The innovative TRHC format captures not only the occurrence of an event, but also timing, duration, and sequence across domains capturing temporal order and thus allowing for causal inference (3,55). By having to situate events over time in relation to one another, each event can be anchored by whether it happened before or after another event, thus increasing the likelihood that the order is correct, even if the proximity in time or actual date are not exact (1,5,51,53). Thus the opportunity exists to assess the timing of HIV testing with other major life events (the beginning new relationships, the end of relationships, other health concerns, the death of a family member, etc.).

- For the PAA paper we will add some illustrative results from the TRHC pilot of how the timing of risk or relationship change was proximate and related in time to HIV testing.

CONTEXT

Current data collection on HIV counseling and testing includes very little on social context surrounding testing decisions, nor do they capture the dynamism of sexual relationships over time (7), or the potential importance of sexual and marital histories or personal health and wellness (8). The format of the TRHC interview was less structured and formal than a standard survey interview, but not as free form as a regular qualitative in-depth interview. Yet, because the interview is more open than a survey, in addition to collecting the information specifically requested in the calendar the interviewers found out other information that was important but not easily captured in the calendar format, but would have been lost altogether in the fielding of a standard survey.

- For the PAA paper we will add examples from the fieldnotes and margins of the calendar that highlight how the hybrid quality of the interview captures additional context necessary to build causal models and interpret statistical models developed from these data.

DISCUSSION

Since survey data are likely to be biased in the ways outlined above (27), we propose the need for a better way to capture HIV testing, personal circumstances and risk behaviors among older persons. For older persons, behavior and contexts over the previous 10-20 years are likely to shape their likelihood of testing both in the past and currently. Thus, it is essential to not just know their current sexual behavior, but also the history of (a) types of partnerships, (b) ages of partners, (c) extra-marital partnerships and infidelity, (d) safe and unsafe sexual behaviors. All of these may influence the decision to test or not to test. Older persons may view themselves as being at low risk currently because of discontinued or unknown unsafe behaviors, and thus they are not testing. Capturing, synthesizing and understanding the context, and correlates of testing behavior is particularly important for older persons as they 'age out' of 'high risk age-groups' but also out of routine testing, and have a longer lifetime of accumulated risk and history of testing.

- For the PAA paper we will connect the results (which we will add above) to the existing literature and discuss how this methodology will improve both the data collected and our understanding of this important topic.

While the literature on NCDs and older persons' engagement with the health system is growing, we know of no data that systematically connects the timing of health events with HIV testing to understand comorbidity in this context. Our work has the potential to add rigor by linking and understanding personal health and wellness. Adding data on the context of timing and coordination of health care access for HIV and comorbidities (i.e., TB, NCD) will uncover the connections between HIV testing, health and other life domains.

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