

Actual Versus Perceived HIV Testing Norms, and Personal HIV Testing Uptake: A Cross-Sectional, Population-Based Study in Rural Uganda

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Abstract HIV testing is an essential part of treatment and prevention. Using population-based data from 1664 adults across eight villages in rural Uganda, we assessed individuals' perception of the norm for HIV testing uptake in their village and compared it to the actual uptake norm. In addition, we examined how perception of the norm was associated with personal testing while adjusting for other factors. Although the majority of people had been tested for HIV across all villages, slightly more than half of men and women erroneously thought that the majority in their village had never been tested. They underestimated the prevalence of HIV testing uptake by 42 percentage points (s.d. = 17 percentage points), on average. Among men, perceiving that HIV testing was not normative was associated with never

testing for HIV (AOR = 2.6; 95% CI 1.7–4.0, $p < 0.001$). Results suggest an opportunity for interventions to emphasize the commonness of HIV testing uptake.

Resumen La prueba de VIH es una parte esencial en el tratamiento y prevención de la enfermedad. Utilizando una base de datos de 1664 adultos, representando la población de ocho aldeas de una zona rural de Uganda, examinamos cómo individuos percibían la norma de la realización de la prueba de VIH en su aldea y la comparamos con la norma actual. Además, examinamos cómo la percepción de la norma se asoció con la realización personal de la prueba, mientras ajustamos por otros factores. Aunque la mayoría de la gente en cada aldea se había realizado la prueba de VIH, más de la mitad de los hombres y de las mujeres pensaron erróneamente que la mayoría de la gente en su aldea nunca se realizó la prueba de VIH. Ellos subestimaron la prevalencia de la realización de la prueba de VIH en 42 puntos porcentuales (s.d. = 17 puntos porcentuales), en promedio. Entre los hombres, la percepción de que la realización de la prueba no era la normativa estuvo asociada con nunca haberse hecho la prueba del VIH (AOR = 2.6, 95% CI: 1.7–4.0; $p < 0.001$). Nuestros resultados sugieren una oportunidad en las intervenciones para enfatizar el carácter común de la realización de la prueba de VIH.

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Introduction

Early identification of persons with HIV is a critical component of “test and treat” strategies for addressing the HIV epidemic [1–3]. Although uptake of HIV testing has

increased in Sub-Saharan Africa, a recent review of data from the Demographic and Health Surveys showed that many people had never been tested [4]. HIV testing uptake is driven by a complex interplay of factors, including having ever been pregnant and routine antenatal screening for women [5–7]; economic expenses associated with health facility-based testing, including the costs of traveling to the clinic and waiting times [8]; scheduling difficulties or perceived lack of sufficient services [9, 10]; worries about confidentiality of services [10] or stigma [11–15]; perception that testing is only needed when symptoms are present [16]; having a partner who tested [17, 18]; and gender-unequal norms [10, 19]. Although community-based [20, 21] or home-based [22, 23] counseling and testing services and community-wide health campaigns may address some of these barriers, they are unlikely to achieve universal coverage of testing, thus requiring complementary approaches to increase HIV testing uptake [24]. The lack of more widespread testing contributes to major public health problems because, over the past decade, persons with HIV in Sub-Saharan Africa have consistently presented to care or initiated treatment at late stages of disease [25].

Theoretical Framework

Social norms—the attitudes and behaviors held by the majority of a population—represent potentially important, but understudied, drivers of HIV testing uptake. Behavioral norms are the subset of social norms that are the most common actions made by people within a specific population (they are also referred to as descriptive norms) [26]. Descriptive norms are both real—what most people in a given population *actually* do—and perceived—what an individual *perceives* most people in a given population to do [26]. Thus, social norms may be discussed and measured as the actual norm (i.e., the majority of a defined group engages in a certain behavior such that the actual prevalence of the behavior is more than 50%), which is a contextual factor, or as the perceived norm (i.e., the behavior an individual perceives to be present among more than half of the people in that group), which is an individual social psychological factor [26–28]. Differentiating between these two concepts of social norms—actual versus perceived—is important because the behaviors that an individual perceives to be normative in a given population may not actually be normative in that population. Indeed, a growing body of research has distinguished actual behavioral norms from perceived behavioral norms and found that misperception of behavioral norms is common [29–44]. These studies have shown that, on average, people in a given population consistently underestimate the prevalence or extent of positive behaviors in that

population, as well as often perceive positive behaviors to not be normative even when such behaviors are actually normative. Similarly, people in a given population consistently overestimate the prevalence or extent of problem behaviors in that population, on average, and often perceive problem behaviors to be normative even when such behaviors are actually not normative.

Misperceiving healthy behaviors as uncommon when they are actually normative or unhealthy behaviors as the most common when they are not actually normative in a given population, becomes problematic if, according to the classic sociological dictum, ‘what is perceived as real is real in its consequences’ [45]. To avoid social sanction, disapproval, or feeling like an outcast within a social group, individuals may rely on their (mis)perceptions of social norms as guidance in the process of shaping their own behaviors [46]. Indeed, decades of research dating back to classic studies in social psychology have demonstrated the strong tendency of people to conform to social norms [47–49]. Therefore, individuals are likely to conform to perceived behavioral norms (that is, what they thought was typical in their various reference groups) by acting in ways that match their perceptions. If their perceptions of what is normative behavior are inaccurate, then the individual may paradoxically be encouraged to engage in non-normative behaviors.

Previous work on social norms across diverse topics and populations has found that perceived behavioral norms among peers are often better predictors of personal behaviors than are the actual behavioral norms among peers (and also better predictors than other well-known risk factors) [34–36, 50, 51]. In addition, studies using longitudinal data on perceptions, actual norms, and personal behaviors to conduct cross-lagged analyses have provided causal evidence that perceptions of norms may determine personal behaviors [52–56]. Moreover, quasi-experiments and randomized controlled trials based on interventions that attempt to change perceived norms by communicating information about accurate norms have shown that changes in perception of norms led to changes in behavior [57–69]. Thus, finding evidence of these two phenomena (extensive misperception of actual behavioral norms coupled with a potentially strong influence of one’s perception of the norm on personal behaviors) would provide motivation to reduce misperceptions of what is normative behavior.

To our knowledge, no studies on HIV testing uptake behavior have compared the gap between actual HIV testing uptake norms and perceived HIV testing uptake norms among defined population groups. Apart from conceptually acknowledging the potential difference between these two constructs, comparing the gap requires measuring what most people in a specific population actually do (i.e., whether more than 50% of the population has been tested to then know whether uptake is actually normative)

while also measuring what individuals perceive most others to do in that population. Given the additional effort required, few studies typically design their data collection to capture both actual and perceived norms. However, a study of men in a South African township found that men overestimated the prevalence and approval of three HIV-related risk behaviors (having multiple sexual partners, drinking before sex, and meeting a partner in a shebeen) and underestimated the prevalence and approval of a protective behavior (condom use) among men in their community [70]. In addition, a recent study asking young men in urban Tanzania about HIV testing uptake by their closest friend found that many of the identified friends had been tested for HIV even though a majority of men believed that their closest friend had never been tested for HIV [71].

Only a few studies have investigated the relationship between personal HIV testing and perception of HIV testing uptake as normative [12, 17, 72–74]. Thus, assessing whether a gap exists between perceived and actual HIV testing uptake norms, and whether perception predicts personal HIV testing uptake, motivated this study. Critically, if substantial numbers of people believe uptake is not normative in places where HIV testing is normative (or if they tend to underestimate the prevalence of HIV testing uptake even in places where it might not be normative), and if perception is associated with HIV testing behavior, then efforts to increase uptake of HIV testing might be hampered.

The Current Study

We undertook a cross-sectional, population-based study in southwestern rural Uganda to (a) quantify the prevalence of people who misperceived the HIV testing uptake norm and also assess the extent to which they underestimated the prevalence of uptake, and (b) determine how perception of the norm was associated with personal testing uptake. According to a Demographic and Health Survey conducted in Uganda in 2011, the majority of men aged 15–54 years and women aged 15–49 years in rural areas have previously been tested for HIV (53 and 74%, respectively) [75]. Given that HIV testing is normative in the country and prior research has found that the prevalence of healthy behaviors tends to be underestimated, we hypothesized that many people across all villages would erroneously perceive that HIV testing uptake was not normative in their village (i.e., people would perceive that 50% or less had been tested even though the majority (>50%) had actually been tested in their village). Moreover, we thought that most people who misperceived the norm would also substantially underestimate the prevalence of people in their village who had ever received an HIV test. In addition, we hypothesized that people who thought HIV testing uptake was not normative

in their village would be at greater risk for never having been tested for HIV as compared to people who perceived testing to be normative. However, we thought that the relationship between perception and HIV testing uptake would be much stronger for men than for women. For men, HIV testing uptake is likely more about making a deliberate choice whereas, for most women who have had or are planning to have multiple children, free HIV testing is a routine part of antenatal care in Uganda.

Methods

Study Population

The study targeted all adults (aged 18 years or older) whose main household was located within one parish containing eight villages in rural southwestern Uganda. (A parish is a governmentally defined geographic area (Level 2) that typically encompasses multiple villages (which are Level 1)). Using a census enumeration (which was conducted in early 2011 and then continuously updated from that point forward), the study team searched for all 1939 potential participants across the 716 households present in the parish from October 2011 to August 2012. By the end of the data collection period, there were 1669 eligible people who had been found and interviewed. Among the remaining 270 people, 16 refused, 62 could not be contacted (because the person was away from the parish during every attempted contact), 192 became ineligible as 166 had moved their primary residence to outside the parish, 11 were consistently too incapacitated/sick to participate, and 15 had died. Thus, after excluding the ineligible participants, the overall response rate was 96% (1669 out of 1747), with little variation in response rates across villages. The final analytical sample consisted of 1664 participants after excluding five people who did not provide HIV testing history. The number of participants ranged from 145 to 263 across villages.

Procedures

Ethical approval for all study procedures was obtained from the Committee on Human Subjects Research, Harvard University and the Institutional Review Committee, Mbarara University of Science and Technology. We also received study clearance from the Uganda National Council for Science and Technology and the Research Secretariat in the Office of the President. All participants provided written informed consent, either with a signature or, if there were cultural literacy reasons why a signature was not appropriate, a thumbprint. Interview materials were translated from English into Runyankore (the local language), back-translated, and pilot-tested to ensure

accuracy and consistent word choice. The process was iterative to ensure linguistic equivalence. Trained local research assistants conducted one-on-one hour-long structured interviews with eligible participants, typically at a participant's place of residence.

Measures

Personal HIV Testing Uptake and the Actual Norm

Participants reported whether they had ever had an HIV/AIDS test (yes/no). Using those responses, we calculated the prevalence of ever having been tested in each village. If more than 50% of adults in the village reported having previously tested for HIV, then we defined uptake of HIV testing as “normative” in the village (i.e., the actual behavioral norm was to have been tested if the majority had done it).

Perceived Norm for HIV Testing Uptake

Participants were asked to estimate the percentage of people (0–100) in their village who had ever been tested for HIV using the following prompt and question: “I would like to know how many people in your cell [village] you think have been tested for HIV/AIDS. I am going to give you an example to help you think about this question. If there were 100 people in your cell [village], how many of them do you think would have been tested for HIV/AIDS?” The individual's estimate was used to measure the individual's perception of whether HIV testing uptake was normative in his or her village. If an individual provided an estimate that was greater than 50%, then the individual thought that the majority of people would have been tested and therefore perceived HIV testing uptake as normative in his or her village. If an estimate was within 0–50%, then the individual thought that the majority of people had not been tested, and therefore perceived that HIV testing uptake was not normative in his or her village. Individuals who were not able to provide an estimate (despite prompting for his or her best estimate) were labeled as not knowing their own perception of the HIV testing uptake norm. We also created more refined categories of perception to indicate individuals who thought it was a) ‘highly normative to not get tested’ (i.e., they had estimated 0–24% had not been tested), ‘moderately normative to not get tested’ (i.e., they had estimated 25–49% had not been tested), ‘perceived equality between testing and not testing’ (i.e., they had estimated 50% testing prevalence), ‘moderately normative to get tested’ (i.e., they had estimated 51–75% had been tested) and ‘highly normative to get tested’ (i.e., they had estimated 76–100% had been tested).

Accuracy of Perceived Norm and Extent of Prevalence Underestimation

Participants were labeled as having misperceived the HIV testing uptake norm (i.e., having an inaccurate perception) if what they perceived to be the behavioral norm in their village was not the actual behavioral norm in their village. Among people who misperceived the norm, we also calculated the extent to which they underestimated the prevalence of HIV testing uptake in their village (given that the actual behavioral norm in their village was to have been tested as was verified in this study). We did this by subtracting their estimated prevalence of uptake in the village from the actual prevalence of self-reported uptake in their village and reported an individual's extent of underestimation in terms of the percentage point difference.

Other Explanatory Variables

Information on gender, age, whether the participant had children, education, household wealth, whether the participant had a main partner who had been tested for HIV, and having stigmatizing beliefs about AIDS were included because prior studies and reports have identified patterns of HIV testing uptake according to these factors [4, 12, 17, 76–79]. Moreover, some of these variables (e.g., partner's testing status and AIDS-related stigma) could have also theoretically been associated with perception.

Main partner data were linked in this population-based dataset (if the main partner was part of the targeted population, which was usually the case). Therefore, information on marital status and self-reported HIV testing uptake was used to create a ‘partner's testing uptake’ variable with the following four categories: (a) participant was married/cohabiting and partner self-reported as having been tested, (b) participant was married/cohabiting and partner self-reported as never having been tested, (c) participant was married/cohabiting and partner testing history was unknown (because the partner was not an eligible participant and therefore information on his or her testing status was not available), and (d) participant was single. Only one respondent had missing marital status information for this variable.

Based on prior research, we measured endorsement of AIDS-related stigma using nine items (representing a broad range of stigma beliefs) with a four-point response scale (strongly disagree, disagree, agree, and strongly agree) [80]. We reverse coded one item and then re-coded all items so that responses to all questions were coded in the same direction where 1 = having the fewest stigmatizing beliefs about AIDS (i.e., disagreeing with statements endorsing AIDS-related stigma) and 4 = having the most amount of stigmatizing beliefs about AIDS (i.e., agreeing

with statements endorsing AIDS-related stigma). We then calculated the mean response across eight items (dropping one entirely uncorrelated item) as long as no more than three items were missing responses across the eight items. (Only 9 participants had more than 3 missing items). The mean was set equal to missing otherwise. Cronbach's alpha was 0.79.

Age (16 missing responses) was categorized as (a) less than 30 years old, (b) 40–49 years, (c) 50–59 years, (d) 60–69 years, and (e) 70 years or older. Having any children (50 missing responses) was a binary measure. Education (32 missing responses) was categorized as having completed (a) none, (b) primary school, (c) secondary school, or (d) postgraduate studies. To measure household wealth, we created a household asset index, by conducting a principal components analysis on 26 separate variables representing household assets and housing characteristics (no missing data). We retained the first principal component to define the wealth index and then split it into quintiles [81].

Statistical Analysis

We first provide descriptive statistics of the population, and the prevalence of HIV testing uptake across subgroups as well as the percentage of people in each perception category. We then estimate the log-odds of a participant never having been tested for HIV as a function of the participant's perception of the village uptake norm, adjusting for AIDS-related stigma, partner's HIV testing uptake, and several individual socio-economic factors. To do so, we use a multivariable multilevel logistic regression model that accounts for the clustering of observations at the household level. Dummy variables are included for the eight villages. Because HIV testing is incorporated into routine antenatal care for women, all regression models are fitted to the data for men and women separately. All significance tests are conservative as almost the entire population was represented in the data.

We use categories of perception in the regression model as the main explanatory factor (instead of the continuous measure of estimated prevalence) because, in this study, we are substantively interested in the role of social norms. Specifically, we are interested in the relationship between perceiving a behavior as normative and personal behavior, and, subsequently whether there is a difference in the associated risk of the outcome between perceiving a slight majority to engage in the behavior and perceiving a large majority to do it. Such categories of perception carry substantively more cognitive meaning for the individual than single 1 point increases in estimated uptake prevalence.

Results

The characteristics of the men and women who participated in this study are presented in Table 1. More than 60% were less than 40 years old. Almost two-thirds of men and 82% of women had children, and 60% of men and 73% of women had completed primary school or less.

Prevalence of HIV Testing Uptake and Its Normativity

Overall, 503 (67%) men and 713 (78%) women reported having been tested for HIV, with the majority of people having been tested across most socio-demographic subgroups (Table 1). The village-level uptake of HIV testing ranged from 64 to 79% (57–75% of men and 69–85% of women across villages), indicating that HIV testing was normative for adults in all eight villages.

Misperception of the Norm for HIV Testing Uptake

Only 273 (36%) men and 282 (31%) women accurately perceived that HIV testing uptake was normative in their village. In contrast, slightly more than half of participants ($n = 853$) believed that HIV testing uptake was not normative in their village (despite it being so). This misperception was pervasive across the population as about half of people in most sociodemographic subcategories erroneously perceived that HIV testing uptake was not normative in their village (Table 2). Likewise, 45–59% of people in each village misperceived the norm (44–62% of men and 46–58% of women across villages). The number of people not accurately perceiving the norm rose to about two-thirds of participants across each of the sociodemographic subcategories and villages when including the 256 participants (15%) who did not know their own perception of the HIV testing uptake norm in their village. Supplemental Table 1 shows the distribution of perceived norm accuracy using the more refined categories of perception. For example, 116 men (15%) and 195 women (21%) erroneously thought that never testing was highly normative as per their very low estimation of their village's uptake prevalence (i.e., they estimated less than 25% uptake in their village).

The 853 participants who misperceived the norm and provided a numeric estimate of the HIV testing uptake prevalence in their village underestimated the actual prevalence by an average of 42 percentage points (s.d. = 17 percentage points). These people, on average, only thought that 32% of people in their village had ever been tested. Among men who misperceived the norm, the average amount of underestimation across the villages ranged from 32 percentage points (s.d. = 15 percentage

Table 1 Sociodemographic characteristics of men and women aged 18 years or older across eight villages in rural Southwestern Uganda and the prevalence of HIV testing uptake

Respondent characteristics	Men (N = 752)			Women (N = 912)		
	N	% ^a	% ever having been tested for HIV	N	% ^a	% ever having been tested for HIV
Total	752	100	66.9	912	100	78.2
Age						
Less than 30 years	315	41.9	64.4	377	41.3	82.5
30–39 years	158	21.0	69.0	171	18.8	89.5
40–49 years	131	17.4	77.9	135	14.8	86.7
50–59 years	64	8.5	73.4	70	7.7	75.7
60–69 years	37	4.9	56.8	60	6.6	70.0
70 years or more	40	5.3	37.5	90	9.9	33.3
Had children						
No	248	33.0	59.7	150	16.5	64.7
Yes	470	62.5	70.0	746	81.8	81.4
Education						
None	66	8.8	53.0	208	22.8	67.3
Primary school	387	51.5	66.4	459	50.3	82.6
Secondary school	201	26.7	66.2	202	22.2	78.7
Postgraduate studies	72	9.6	80.6	37	4.1	83.8
Household asset quintile						
Lowest	110	14.6	69.1	163	17.9	75.5
2nd	140	18.6	64.3	176	19.3	84.7
3rd	147	19.6	62.6	179	19.6	80.5
4th	174	23.1	66.7	206	22.6	73.3
Highest	181	24.1	71.3	188	20.6	77.7
Partner's HIV testing history						
Partner tested	363	48.3	75.8	312	34.2	90.4
Partner not tested	58	7.7	50.0	117	12.8	75.2
Partner's uptake unknown	36	4.8	77.8	73	8.0	84.9
No partner	295	39.2	58.0	410	45.0	68.5
Village						
1	106	14.1	62	123	13.5	79
2	124	16.5	71	139	15.2	75
3	96	12.8	75	112	12.3	81
4	95	12.6	57	117	12.8	69
5	65	8.6	68	88	9.7	85
6	101	13.4	63	136	14.9	81
7	62	8.2	65	83	9.1	70
8	103	13.7	73	114	12.5	85

^a Column percentages within category may not add to 100% due to small amount of missing data (6% for men overall and 3% for women overall)

points) to 45 percentage points (s.d. = 15 percentage points), and, among women who misperceived the norm, the average amount of underestimation across the villages ranged from 29 percentage points (s.d. = 15 percentage points) to 53 percentage points (s.d. = 18 percentage points).

Predictors of Personal HIV Testing Uptake

A simple bivariate association showed that among men who perceived uptake as normative, 81% had been tested. In contrast, among men who thought uptake was not normative, 63% had been tested. Regression analyses found

Table 2 Men and women's accuracy of their perception of the norm for HIV testing uptake in their village across sociodemographic characteristics and eight villages in rural Southwestern Uganda

Respondent characteristics	Men			Women		
	Accurate Perception: % who thought that HIV testing uptake was normative	Erroneous Perception: % who thought that HIV testing uptake was not normative	Did Not Know Own Perception: % who insisted on not knowing anything about the level of HIV testing uptake	Accurate Perception: % who thought that HIV testing uptake was normative	Erroneous Perception: % who thought that HIV testing uptake was not normative	Did Not Know Own Perception: % who insisted on not knowing anything about the level of HIV testing uptake
Total	36	51	13	31	51	18
Age						
Less than 30 years	38	54	9	32	58	10
30–39 years	34	58	8	34	57	9
40–49 years	40	52	8	42	45	13
50–59 years	33	47	20	26	51	23
60–69 years	46	32	22	22	38	40
70 years or more	20	25	55	13	31	56
Had children						
No	34	57	9	30	55	15
Yes	37	48	15	31	51	18
Education						
None	24	41	35	24	40	36
Primary school	38	51	11	32	54	14
Secondary school	36	55	9	37	53	10
Postgraduate studies	36	54	10	24	73	3
Household asset quintile						
Lowest	42	44	14	23	54	23
2nd	36	50	14	28	56	16
3rd	37	50	13	31	52	17
4th	34	54	12	36	47	17
Highest	34	55	11	36	48	16
Partner's HIV testing history						
Partner tested	39	52	9	37	54	10
Partner not tested	34	40	26	27	55	18
Partner's uptake unknown	36	47	17	29	55	16
No partner	34	53	13	28	48	24
Village						
1	28	54	18	28	53	19
2	44	46	10	37	55	8
3	49	44	7	36	46	18
4	26	51	23	19	46	35
5	37	62	1	34	58	8
6	30	51	19	26	51	23
7	39	53	8	34	54	12
8	38	54	8	35	48	17

that perception had a statistically significant association with HIV testing uptake after adjusting for several other explanatory variables (Table 3). Men who perceived uptake as not normative were 2.6 times more likely (95% CI 1.7–4.0, $p < 0.001$) to never have been tested for HIV compared to men who perceived uptake to be normative in

their village; similarly, men who did not know their own perception about the HIV testing uptake norm in their village were 4.0 times more likely (95% CI 2.2–7.4, $p < 0.001$) to never have been tested. Higher endorsement of AIDS-related stigma (AOR = 1.5; 95% CI 1.0–2.1, $p = 0.028$), having a partner who had not been tested

(AOR = 2.3, 95% CI 1.2–4.6, $p = 0.019$), and being single (AOR = 2.1, 95% CI 1.1–3.8, $p = 0.019$) also predicted never having been tested among men.

When using the perceived norm variable with more refined categories, the likelihood of testing did not differ between men who thought that HIV testing was ‘moderately normative’ and men who thought that HIV testing uptake was ‘highly normative’ in their village (Supplemental Table 2). However, men who perceived equality between uptake as normative and not normative (i.e., they estimated 50% uptake prevalence), and, separately, men who perceived that not getting tested was moderately normative (i.e., they estimated 25–49% uptake prevalence), were both more than two times more likely to never have been tested for HIV compared to men who perceived testing to be ‘highly normative’ (AOR = 2.4, 95% CI 1.3–4.6, $p = 0.009$, and AOR = 2.1, 95% CI 1.1–4.1, $p = 0.026$, respectively). Furthermore, men who perceived that not getting tested was highly normative (i.e., they estimated 0–24% uptake prevalence,) and, separately, men who did not know their own perception (i.e., they were not able to provide an estimate of the uptake prevalence) were about 4 times more likely to

never have been tested (AOR = 4.2, 95% CI 2.2–8.3, $p < 0.001$, and AOR = 4.2, 95% CI 2.2–8.7, $p < 0.001$, respectively).

Results differed for women. A simple bivariate association showed that among women who perceived uptake as normative, 85% had been tested, and among women who perceived uptake as not normative, 83% had been tested. The lack of association between perceived norm for HIV testing uptake and personally being tested was further demonstrated by the regression analyses. However, women who did not know their own perception about the HIV testing uptake norm in their village were almost three times more likely to never have been tested (AOR = 2.9, 95% CI 1.6–5.1, $p < 0.001$) compared to women who perceived HIV testing uptake to be normative in their village (Table 3). For women, other statistically significant factors associated with never having been tested included having a partner who had not been tested (AOR = 2.2; 95% CI 1.1–4.3, $p = 0.019$), and not having any children (AOR = 3.9; 95% CI 2.1–7.5, $p < 0.001$). Results using the more refined perceived norm variable were comparable (Supplemental Table 2).

Table 3 Multilevel logistic regression odds-ratios for never having been tested for HIV among men and women (aged 18 years or older) in eight villages in rural Southwestern Uganda

	Men (n = 707)			Women (n = 883)				
	AOR	95% CI	p value	AOR	95% CI	p-value		
Perceived norm for HIV testing uptake in village								
Did not know own perception (i.e., no estimate of uptake)	4.0***	2.2	7.4	<0.001	2.9***	1.6	5.1	<0.001
Perceived testing as not normative (i.e., estimated 0-50% uptake)	2.6***	1.7	4.0	<0.001	1.1	0.7	1.7	0.722
Perceived testing as normative (i.e., estimated > 50% uptake) [REF]	1.0	–	–	–	1.0	–	–	–
Aids-related stigma (unit change from mean)	1.5*	1.0	2.1	0.028	0.9	0.6	1.2	0.415
Partner’s HIV testing history								
No partner	2.1*	1.1	3.8	0.019	1.7	1.0	2.9	0.051
Partner’s uptake unknown	1.0	0.4	2.6	0.918	1.0	0.4	2.4	0.944
Partner not tested	2.3*	1.2	4.6	0.019	2.2*	1.1	4.3	0.019
Partner has tested [REF]	1.0	–	–	–	1.0	–	–	–
Had children								
No	1.6	0.8	3.2	0.163	3.9***	2.1	7.5	<0.001
Yes [REF]	1.0	–	–	–	1.0	–	–	–

Estimates were obtained using a multilevel logistic regression model that accounted for clustering of observations at the household level and included categorical or dummy variables for age, education, household wealth quintiles, and village

* $p < 0.05$; *** $p < 0.001$

Discussion

In this study, only one-third of the adult population in an HIV-endemic area believed HIV testing uptake to be normative in their village despite nearly three-quarters of people in each village having been tested for HIV. The findings of pervasive misperception were true for both men and women. Furthermore, at least half of people across most socio-demographic categories and villages erroneously thought that the majority of people in their village had not been tested for HIV. Moreover, the people who misperceived the norm substantially underestimated the prevalence of HIV testing uptake (by more than 40 percentage points, on average). (Notably, the prevalence of self-reported HIV testing uptake in this study was similar to the rates found in a 2011 Demographic and Health Survey conducted in Uganda [75].) Similar findings on the discrepancy between actual and perceived behavioral norms have been reported in research on alcohol and other drug use, sexual risk behaviors, intimate partner violence, bullying, seat belt use and unhealthy food and beverage consumption [29–32, 34, 35, 51, 62, 70, 82–85]. In particular, these results were comparable to the prevalence of misperception regarding other HIV-related risk behaviors among men in a South African township [70].

We also found that perceiving HIV testing uptake as anything less than normative (i.e., estimating the prevalence of testing as 50% or less) in one's village was a strong risk factor for never having been tested among men. In contrast, individuals who perceived HIV testing to be highly normative in their village (i.e., they estimated more than 75% uptake) were no different in terms of personal HIV testing uptake as compared to individuals who perceived HIV testing to be moderately normative in their village (i.e., those people who estimated 51–74% uptake). Moreover, not being able to provide a perception of the HIV testing uptake norm had a strong negative association with personal testing uptake among both men and women. Our findings are consistent with results from other studies of the relevance of perceived behavioral norms to various personal health-related behaviors [31, 32, 34, 53, 57, 59, 70, 86, 87]. As expected, perception of the HIV testing uptake norm may be slightly less important for women as a motivation for getting tested because in having or expecting to have children, testing may just be accepted as a part of routine antenatal care in Uganda. This observation would be consistent with the finding that women who reported no children were much less likely to have ever been tested for HIV, which is similar to results among South African women [78]. Overall, our findings are also consistent with initial findings from the Project Accept study (HPTN 043), which conducted a community-based

HIV counseling and testing intervention where activities were purposely not concealed, perhaps increasing perceived normativity of testing [88]. The intervention resulted in a large increase in HIV testing and HIV detection across 32 communities in Tanzania, Zimbabwe, and Thailand. Thus, our findings underscore the need to engage both men and women in HIV prevention programming in Sub-Saharan Africa [77, 89–91], particularly as it relates to perceptions.

There are several factors that may lead to pervasive misperception of the norm for HIV testing uptake [31]. For example, a lack of conversation about what is actually common in a population or in a friend group may lead people to think that the visible non-behavior is most common. In addition, normative behaviors that are positive simply do not receive attention in the media the way that negative outcomes and risky behaviors do. Thus, it may seem like more people are engaged in the risky behavior (e.g., not testing) than in the healthy behavior. Taken together, the results of our study suggest that there is an opportunity for public health interventions to increase awareness of the commonness of HIV testing uptake. Interventions could disseminate information on true behavioral norms regarding HIV testing uptake in specific populations, for example, through community-wide media such as billboards or radio messages. Sending true population-wide SMS text-messages like 'Most people in this parish have been tested for HIV in the past' or 'Most men and women and friends in your village have been tested for HIV at least once' might also be effective [92, 93]. Trained local leaders could also provide information on true community norms in village meetings. Alternatively, they could do so in one-on-one conversations. Similarly, health workers could provide personalized normative feedback to men when they go to clinics for reasons unrelated to HIV.

These types of interventions may correct erroneous perceptions while reinforcing the perceptions of individuals who had correctly perceived the norm. In turn, such outcomes may help increase actual testing uptake behavior among men (and among women who did not have a perception of the uptake prevalence, or, perhaps, women before they have children). For example, having more information on true norms may directly encourage an individual who has not yet been tested to conform to the normative behavior and decide to be tested. In addition, it may encourage people in the community who had already been tested, but who perhaps thought that testing was not normative, to become more vocal about being tested and thus encourage others to get tested. Furthermore, social norms interventions that change perceptions may increase the impact of other HIV testing uptake interventions by creating a more informed population with which to work.

For example, informed individuals may be more likely to use mobile or community-based HIV voluntary counseling and testing sites, positively respond to community liaisons building support for couples-based testing as part of antenatal care, engage in community programs that promote HIV-related communication, or accept new technologies and messaging systems to encourage adherence to testing appointments [18, 73, 94–97].

Interpretation of our findings is subject to several limitations. First, the cross-sectional design precludes our ability to make definitive causal claims. It is possible that personal uptake behavior may have some impact on one's perception of the uptake norm. Previous norms research on other behaviors, however, has provided extensive evidence of behavior change as the subsequent outcome of change in perceptions of norms [52–69]. Thus, although the relationship between perceived HIV testing uptake norms and personal HIV testing uptake may be bi-directional to some degree, theory and prior similar research on norms suggest that perception of the HIV testing uptake norm is likely to have a substantial causal effect on personal HIV testing uptake behavior.

Second, the data are self-reported and therefore are subject to the challenges inherent to all studies based on self-reported data. The testing rates and actual norms presented in this study, however, were similar to those found in a national 2011 study [75]. Furthermore, even in South Africa where the prevalence of HIV is much higher, the majority of men and women have been tested at least once [98]. Thus, we have no reason to believe that the actual uptake norms reported in this study are much different from what could be objectively measured. Moreover, even if people had lied, the power of social desirability bias could have worked in either direction for reporting of personal HIV testing uptake. Some people may have wanted to say they had personally been tested even if they hadn't as they perhaps thought that being tested would be the right thing to say. At the same time, others might not want to say they had been personally tested due to perceived stigma associated with testing. Finally, even if as many as one-fifth of people in this study had lied about uptake, the majority of people would still have been tested.

Third, our measure of one's perception of the actual HIV testing uptake norm was fairly general. Questions with a more proximal reference frame (e.g., inquiring about "men" or "young women" or "people within your age and gender group" in your village instead of simply "people" in your village) could have potentially shown misperception of the norm to still exist, but perhaps at a less extreme level [31]. Although the potential association of close peer perceived norms with personal attitudes or behavior may be stronger than the association with more distal perceived peer norms, the extent of misperception, and thus the

possible extent of change (correction) in the perceived norm would likely be less [31]. In contrast, even though the distal peer norm may be less influential, there is likely to be massive misperception, thus allowing more potential change to occur in the perceived norm, and ultimately, perhaps, in behavior. Fourth, our data were derived from a population-based survey conducted in rural Uganda. The findings may not generalize to settings where HIV is non-endemic or urban settings. However, the consistency between our findings and findings of other perceived norms studies conducted in different settings suggests that the existence of misperceptions and the association between perceived norms and behavior may be generalizable.

Finally, other unmeasured confounding factors could have influenced the results. For example, perceiving one's partner to have been tested may influence both perception of the village uptake norm and one's likelihood to be tested. In addition, it is certainly possible that people who perceive themselves to be at low risk for contracting HIV may not get tested and may also think that most people haven't been tested. It is likely, however, that at least some people who are at high risk have not been tested. Moreover, waiting for individuals to become high risk (or for them to recognize that they are at high risk) so that they will be motivated to get tested is not the healthiest pathway to HIV prevention.

Conclusions

In this cross-sectional, population-based study conducted in rural Uganda, we report two main findings: First, the majority of participants misperceived HIV testing uptake as not normative in their village when it actually was normative. Moreover, these participants vastly underestimated the prevalence of HIV testing uptake in their village. Second, people who thought HIV testing uptake was not normative (despite it being so) and people who were not able to provide their perception of the uptake prevalence were much more likely to never have been tested for HIV. The estimated associations were statistically significant, large in magnitude, and robust. Our findings suggest that interventions to correct misperceived norms of HIV testing uptake may advance HIV prevention and treatment in Sub-Saharan Africa.

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Compliance with Ethical Standards

Conflict of interest Jessica M Perkins declares that she has no conflict of interest. Viola N Nyakato declares that she has no conflict of interest. Bernard Kakuhikire declares that he has no conflict of interest. Pamela K. Mbabazi declares that she has no conflict of interest. Alexander C. Tsai declares that he has no conflict of interest. S. V. Subramanian declares that he has no conflict of interest. Nicholas A. Christakis declares that he has no conflict of interest. David R. Bangsberg declares that he has no conflict of interest.

Ethical Approval All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards.

Informed Consent Informed consent was obtained from all individual participants included in the study.

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