What Counselors Tell Low-Risk Clients About HIV Test Performance

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Abstract: In 1998, Gigerenzer *et al.* studied how heterosexual men with low-risk behavior were counseled about the accuracy of HIV test results. Most professional counselors conveyed the illusions that false positives do not occur and that a positive HIV test result means that the client is certainly infected. To help improve counseling quality, the authors provided feedback to all counseling centers in Germany. Sixteen years later we assessed whether HIV counseling in Germany has improved by replicating the original study with an expanded sample of 32 randomly selected counseling centers across the country. Since the original research, the positive predictive value (PPV) of HIV testing for a



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low-risk client has improved from about 50% to 96%. Hence, among every 26 low-risk clients who test positive, we can expect that one is actually not infected. Whereas test performance has improved over the last 16 years, counseling has not. About half of professional counselors communicated the illusion of certainty for sensitivity (15 of 30), specificity (16 of 30), and the PPV (18 of 30). Only one of the 30 counselors could correctly state the PPV. In what follows, we explain how to improve counselors' and clients' understanding of the PPV by representing the information in terms of natural frequencies rather than conditional probabilities. Doing so has been shown to improve the quality of counseling in different medical settings and may enhance future HIV counseling as well.

Keywords: HIV/AIDS, HIV counseling, HIV testing, natural frequencies, risk communication, risk literacy, numeracy, transparent information.

1. INTRODUCTION

In 1998, Gigerenzer and colleagues investigated in an undercover study how a heterosexual man with low-risk behavior (e.g., monogamous, no intravenous drug abuse) was counseled about the HIV test [1]. Using a convenience sample of 20 health centers, the researchers analyzed what information the 20 counselors communicated during pretest counseling sessions and whether they conveyed it in a way the client could (easily) understand. The majority of counselors communicated *illusions of certainty*: that false positives do not occur (13 of 19 counselors; one refused to answer the client's questions) or that a positive (reactive) test result most certainly indicates HIV infection (10 of 18 counselors; two refused to answer).

The *illusion of certainty* refers to the belief that an event, such as a positive test, is absolutely certain although it is not. For instance, in a representative survey, 63% of 1,000 German citizens over 18 believed that an HIV test result is absolutely certain [2]. Even the World Health Organization wrote in its current fact sheet that "A confirmed positive result from the second test method means that the individual is infected with HIV" [3]. But in fact, the test is not certain [4,5]. The statement fosters the illusion of certainty in people's minds. Confusing false-positive results with true positives can have severe consequences, including psychological distress and even suicide [6, 7].

Given that most counselors in Gigerenzer et al.'s study provided the illusion of certainty, the researchers forwarded the results to all counseling centers in Germany and also provided guidelines about how to better understand and communicate the performance of HIV tests. Sixteen years after the original study was conducted, we assessed whether counseling has improved.

1.1. The HIV Test Procedure

The HIV test procedure typically involves two individual tests. The first test, the ELISA, is an antibody detection test with high sensitivity [8]. If the ELISA is negative, the procedure stops and the client is notified. If the result is positive, the procedure continues with the Western Blot, a virus-specific "confirmatory" test with high specificity [8]. If the Western Blot is also positive, the client will receive notification of positive HIV status. There are variations in this procedure, as it is not standardized. If the first ELISA test is positive, a second ELISA from a different manufacturer may be used and only if both are positive the Western Blot is ordered. Often, the test procedure is repeated on a second blood sample. The inconsistency in the test procedure is also reflected in the counselors' descriptions of the test procedure to the client in our study (see *Appendices A-D*).

Two possible errors can occur in the HIV test procedure. The first occurs when a client who is infected is notified that he or she is not infected (i.e., HIV-negative). This error is called a *false-negative* result and the rate of this error (the miss rate) is the complement of the sensitivity of the test procedure. Sensitivity is the probability that the test correctly

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identifies those who are HIV-positive. To illustrate, imagine an HIV test with a sensitivity of 97%. Of 100 people infected with HIV, the test will identify 97 as being positive. It will miss the remaining three infected people, who will be wrongly told that they are HIV-negative (i.e., receive a false-negative result). The second error occurs when a client who is *not* infected is notified that he is infected (i.e., is HIV-positive). This error is called a *false-positive* result and the rate of this error is the complement of the specificity of the test procedure. The specificity is the probability that the test identifies somebody as HIV-negative (i.e., as not infected) if the patient is indeed not infected.

The currently estimated sensitivity of the combined procedure of the two tests on HIV is about 99.7% [8]. Estimates for the specificity range between 98.5% and up to 99.9996% [8-10]. Note that estimates for the sensitivity have been fairly unchanged since 1998, when Gigerenzer *et al.* undertook their study [1], but those for specificity have improved, depending on the kind of test.

1.2. Communicating Test Statistics

What does it mean when a client tests positive? The answer depends on three factors: the prevalence of HIV in the client's risk group, as well as the sensitivity and specificity of the test procedure (i.e., ELISA and Western Blot combined). Consider a prevalence of 0.01%, a sensitivity of 99.7% and a specificity of 99.9996%. Fig. (1), left side, shows one way to calculate the positive predictive value; hence, the probability that a client is truly infected after receiving a positive test result. The answer is 96%. In other words, among 26 clients who test positive, we expect that 25 are infected and one is not.

As the calculations in Fig. (1) illustrate, deriving this answer is not easy to follow. Sensitivities and specificities are called *conditional probabilities* and using these to calculate the positive predictive value confuses many experts, as well as most laypeople [11-15]. An effective alternative is to translate conditional probabilities into *natural frequencies* [5, 16, 17]. Fig. (1), right side, shows how natural frequencies simplify the calculation of the positive predictive value. Note that the four values at the bottom of the right tree are natural frequencies, while the four values at the bottom of the left tree are conditional

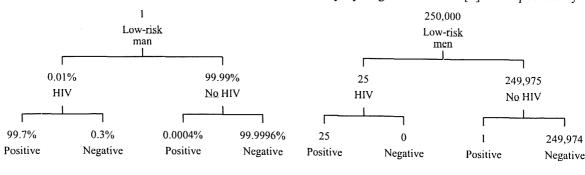
probabilities. The two values in the middle level of the tree are simple frequencies and simple probabilities, respectively. Thus, just as conditional probabilities refer to two events, natural frequencies are joint frequencies of two events, such as a positive test and disease [18]. Natural frequencies facilitate computation (and comprehension) because they are not normalized from the second to the third (bottom) level of the tree. In other words, the pairs of natural frequencies at the bottom level add up to the simple frequencies at the second level, which is not the case with conditional probabilities. Hence, calculating the positive predictive value on the basis of natural frequencies is much simpler (compare the two formulas underneath the two trees). Note that natural frequencies should not be confused with relative frequencies, which are normalized and numerically identical to conditional probabilities.

With the help of natural frequencies, physicians, medical students, judges, laypeople, and even 10-year-old children can understand the positive predictive value [5, 11, 16, 18]. As the studies with these groups demonstrate, the problem is not simply in people's minds, as has been claimed [20] but is a consequence of the way in which information is represented [21].

Using natural frequencies, a counselor can better understand and also transparently communicate the characteristics of an HIV test result: "Imagine 250,000 heterosexual men like you being tested. We expect that 25 have the virus and will test positive with virtual certainty. Of the other non-infected men, one will also test positive. This is the situation you are in if you test positive: The chance of having the virus is 25 out of 26, or 96%. "Put like this, the information is easily comprehensible and can be adjusted when prevalence or false-positive rates change. For instance, in a risk group where the prevalence is 1 in 1,000 (0.1%) instead of 1 in 10,000 (0.01%), the positive predictive value is 99.6% (Fig. 2, left); when the prevalence is 1 in 100,000 (0.001%), it is 71.4% (Fig. 2, right). Hence, the higher the prevalence, the higher the predictive value, and the lower the prevalence the lower the predictive value.

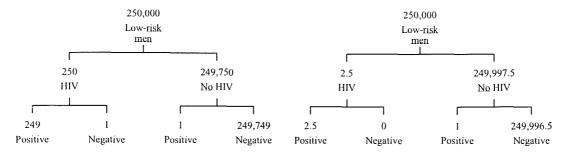
2. RESEARCH QUESTIONS

The general question is whether HIVcounseling for low-risk clients has improved in Germany since the original study by Gigerenzer et al. [1]. We specifically assessed the



p (HIV|Test positive) =
$$\frac{0.0001*0.997}{0.0001*0.997 + 0.9999*0.000004}$$
 p (HIV|Test positive) = $\frac{25}{25+1}$

Fig. (1). Calculation of the probability of an HIV infection given a positive test result (the positive predictive value, or PPV) based on the same information presented in conditional probabilities (left) and natural frequencies (right). Prevalence = 0.01%, sensitivity = 99.7%, specificity = 99.9996%. Both formulas are versions of Bayes' rule and result in the same PPV of about 96%.



p (HIV|Test positive) =
$$\frac{249}{249+1}$$
 p (HIV|Test positive) = $\frac{2.5}{2.5+1}$

Fig. (2). Calculation of the probability of an HIV infection given a positive test result (the positive predictive value, or PPV) with higher (0.1%) prevalence (left) or lower (0.001%) prevalence (right). In both cases: sensitivity = 99.7%, specificity = 99.9996%.

information counselors provided to the client (see below) on the following aspects:

- 1) What is the sensitivity of the HIV test?
- 2) What is the false-positive rate of the HIV test?
- 3) What is the prevalence of HIV among low-risk men in Germany?
- 4) What is the positive predictive value?

The third aspect concerns the prevalence of HIV in our client's risk group. This is important because being at high or low risk affects the positive predictive value, as noted before (see Fig. 2). In addition, we assessed the internal consistency of the information counselors provided, following up the observation by Gigerenzer *et al.* [1] that information was sometimes contradictory in the course of a counseling session.

3. METHOD

3.1. Sample

One limitation of the original study was that the sample of 20 centers was a convenience sample. We decided for a more representative approach and randomly drew two public health centers from each of the 16 German federal states (N=32). The sample included a broad spectrum of city sizes and population densities, ranging from about 10,000 to more than 3,000,000 citizens per city. Of the 32 counselors, 12 were physicians, 17 social workers, two social education workers, and one a nurse. As in the previous study, the sample consists of federal health centers, except in three cases where these centers had outsourced their counseling to the Deutsche AIDS-Hilfe (German Aids Aid, an institution focused on HIV prevention/counseling/testing). Whenever this was the case, the client visited the Deutsche AIDS-Hilfe for pre-test counseling instead. The Deutsche AIDS-Hilfe is also responsible for distributing brochures on HIV counseling to counselors at federal health centers.

3.2. Data Collection

In order to collect as realistic data as possible, one of us visited the 32 public health centers in 32 German cities as an

"undercover" client. The client presented himself as he was: a low-risk male, 26 years old, heterosexual, currently in a monogamous relationship and with no risky behavior such as intravenous drug abuse. Before these visits, the client was trained to use a structured interview guideline he memorized and covered the four research questions. In the counseling sessions, the client did not use any technical terms such as sensitivity or positive predictive value. For instance, instead of asking about the sensitivity of the test procedure, he first asked a lead question: "How well does the test detect the virus?" Thereafter he asked, "If I have the virus, is it possible that I nevertheless test negative? How often does that occur?"

A pilot study for the original research showed that counselors have the tendency to provide vague and noninformative answers (e.g. "The test is quite reliable; you can trust the test"). Furthermore, asking for clarification more than twice irritated the counselors, who may have experienced the client's insistence on clarification as a violation of social norms of communication. Therefore, the client used the following scheme for clarification questions: If the counselor replied with a quantitative estimate or indicated that he/she could not (or did not want to) provide a quantitative estimate, the client insisted no further and moved on to the next question. If the counselor's reply was qualitative (e.g. "very reliable"), then the client asked for further clarification and, if necessary, repeated his request for clarification once more. Thus, the client never asked more than two clarification questions after posing the original question per section of the interview. If the counselor did not adequately respond to the client's second clarifying enquiry, the next question was asked. This procedure was also followed when the counselor avoided answering the question. In order to record the data, we trained the client to use a coding system that enabled him to write down relevant information and sentences quickly during/after the counseling sessions. This coding system reported which of the four questions was being addressed, the total number of questions asked (including initial question and clarifying enquiries), and the counselor's answer to each repeated question. The following is an illustration for question 1) on the sensitivity: "1; 2; Very well, the ELISA is a test with high sensitivity; 99.9%".

3.3. Analysis

Estimates for sensitivity, specificity and positive predictive value provided by the US Preventive Task Force Services report were used to evaluate counselors' accuracy [8]. Because estimates of these could vary, we allowed for a deviation of +/- 2 percentage points (excluding 100%) in counselors' estimates. Estimates within this range were classified as "correct", while "100%" and corresponding verbal assertions such as "absolutely certain" or "totally certain" were classified as an illusion of certainty. For instance, given that the US Preventive Task Force Services estimates a sensitivity of 99.7%, any response between 97.7% and <100% was classified as correct. For the positive predictive value, which is about 96% for a low-risk client in Germany, all estimates from 94% - 98 % were rated as correct. For prevalence, estimates in the range of 6,000 -10,000 [22] were rated as correct. When counselors gave inconsistent answers, such as mentioning that false-positive results could occur after having asserted before that the specificity was 100%, we coded the answer in favor of the counselor, that is, not as an illusion of certainty. However, if counselors did provide a correct estimate on sensitivity or specificity but then denied the possibility of falsenegative/false-positive results, their replies were rated as incorrect.

Of the 32 counselors interviewed, two counselors, both social workers, refused to provide answers; one feeling that it was not her duty to answer questions about the reliability of the HIV test and the other openly admitting that she did not know the false-negative or false-positive rates. These two counseling sessions were excluded from the data analysis. Records of all sessions can be found in the supplementary material (see *Appendices A - D*).

4. RESULTS

4.1. Sensitivity (False-Negative Results)

The client asked, "How well does the test detect the virus? If I am infected, is it possible that I nevertheless test negative? If so, how often does that occur?" In their responses, 15 of 30 counselors stated that the test is 100% certain or absolutely certain (Table 1). For example, one counselor replied: "After the window period, it is 100% certain. "Seventeen counselors provided quantitative estimates for the sensitivity, seven of which were incorrect or an illusion of certainty. The remaining 13 counselors gave qualitative information to the client. Nine of these 13 counselors denied the possibility of false-negative results. In total, 14 of 30 replies (53%) were correct (Table 1).

Among those counselors who mentioned the window period (required diagnostic gap of about twelve weeks between the potential infection and the HIV test), most claimed that the possibility of false-negative results is limited to that period. The window period was said to be only 3 to 4 weeks by one counselor and 10 by another. Six counselors did not inform the client at all about the window period and its diagnostic implication. Altogether, the client had to ask on average 2.7 questions to receive the information he needed.

4.2. Specificity (False-Positive Results)

The client asked, "If I don't have the virus, is it possible that I nevertheless test positive? If so, how often does that occur?" Sixteen counselors claimed that false-positive results are not possible because the test procedure includes two tests and/or claimed that the test is absolutely or 100% certain (Table 1). Two counselors provided correct basic information on the question. For instance, one counselor correctly informed the client about the fact that the proportion of false-positive results to true-positive results (the inverse of the PPV) increases as the prevalence of HIV in the population decreases but could specify neither the false-positive rate nor specificity. Twelve counselors' (40%) replies were correct (Table 1).

Eighteen of 30 counselors used numerical estimates in their replies, of which 13 were not within the range of a correct estimate or were an illusion of certainty. One of those counselors misunderstood the question and (incorrectly) informed the client about the positive predictive value of the HIV test. Of the remaining 12 counselors who provided qualitative information, 5 provided an illusion of certainty. Altogether, the client had to ask 2.5 questions to receive the information he needed.

4.3. Prevalence

The client asked, "How many men in Germany who share my characteristics have HIV?" In total, there were 23 numerical replies, out of which 13 were correct. The majority estimated the prevalence around 10,000, while some indicated the prevalence by stating: "three quarters are men who have sex with other men, one quarter heterosexual" or "73% homosexuals, 27% heterosexuals". The remaining 7 replies were qualitative and were classified as incorrect. Some counselors implied that there are no reliable statistics but instead only misleading estimates. Altogether, 13 of 30 (43%) replies were correct. The average number of questions asked by the client was 1.6.

Table 1. Information provided by professional HIV counselors.

	Illusion of Certainty (100%)	Incorrect Estimates Or "Don't Know"	Correct Estimates
Sensitivity	15 (of 30)	1	14
Specificity	16 (of 30)	2	12
Positive Predictive Value	18 (of 30)	11	1

Note: Not all counselors provided numerical answers. Verbal assertions such as "absolutely certain" and "totally certain" were classified as an illusion of certainty (100%). All statements implying some uncertainty were rated as <100% and correct.

4.4. Positive Predictive Value

The client asked, "If I test positive, how likely is it that I have the virus?" 29 counselors provided incorrect information on the positive predictive value or no information at all. Eighteen of these counselors stated that the client would be HIV-positive with absolute or 100% certainty if the Western Blot was positive (Table 1). Ten of the 29 counselors provided answers that included statements such as "99%" or claimed that the positive predictive value is independent of the risk group (low-risk versus high-risk clients). One counselor stated that she could not answer this question. Ultimately, only one out of all the 30 counselors provided a correct estimate. The average number of questions asked by the client was 1.4.

4.5. Internal Consistency

Ten counselors gave internally inconsistent information. For example, when asked about the test's specificity, one counselor (ID 15; see *Appendices A-D*) stated that it is "98% specific" but then said that no false positives can occur, thereby implying 100% specificity. When asked about the positive predictive value, he responded, "Yes, the result is then absolutely certain." Another said that the sensitivity is less than 100% but then said that false negatives (the complement of sensitivity) do not occur. These inconsistent responses document that the counselors do not fully understand the constructs of test statistics such as sensitivity, specificity, or predictive values.

In addition to repeating the analyses performed by Gigerenzer and colleagues, we checked counselors' individual ratio of correct answers out of all answers. Six of 30 counselors did not provide any correct reply to any of the four questions. Eleven counselors provided one correct answer, ten counselors provided two correct answers, and the remaining three provided three correct answers. None were able to correctly answer all of the four questions. Counselors mostly provided correct replies for the client's question about sensitivity and specificity but then failed to give a correct answer to the questions about prevalence and positive predictive value (Table 2).

4.6. Information Formats Used by Counselors

The majority of counselors (27 of 30) used percentages or qualitative information when asked about sensitivity, specificity, and positive predictive value. Only three counselors conveyed information in natural frequencies, one of them correctly. The other two counselors used natural frequencies to bolster their claim that false positives may occur with the ELISA but that these would be sorted out after the Western Blot test was performed. Only when asked about prevalence did the majority of counselors use frequencies instead of percentages and probabilities.

5. DISCUSSION

The present study revealed that the quality of counseling has not improved since Gigerenzer *et al.*'s study in 1998. First, many counselors were not able to provide correct estimates for the sensitivity, specificity, and positive

predictive value of the HIV test procedure. Instead, many counselors provided our client with illusions of certainty, namely that 1) false-positive results do not occur and 2) a positive test result implies HIV infection with absolute certainty. The observed inconsistencies in several counselors' replies additionally suggest that many do not understand the exact meaning of sensitivity, specificity, positive predictive value and false-positive/-negative results.

Second, most did not know the prevalence of the HIV infection in low-risk men. Considering the importance of the prevalence of the disease for evaluating the HIV test's performance, it was astonishing that only two of the 30 counselors actually made explicit and detailed inquiries to assess the client's risk group beyond asking whether he was in a monogamous relationship and if he had tested himself for HIV before. The client often had to provide this information unasked in order to give the counselor the necessary background details for judging his risk group. Yet, even though given this information explicitly, 57% of the counselors were not informed about the prevalence for the client's risk profile and thereby overestimated the prevalence of HIV in his group. One may argue that counselors are mainly exposed to high-risk clients and thus have difficulties adjusting their knowledge to a low-risk client. Nevertheless, a considerable amount of HIV testing for low-risk clients takes place on a regular basis, as well (e.g., HIV testing is part of German pregnancy screenings), and these clients clearly need to be counseled adequately, too. Effective counseling requires counselors who are able to accurately inform whatever risk group is sitting in front of them.

Third, almost nobody used natural frequencies when communicating numbers, although by now a plethora of studies document that experts and laypeople alike comprehend information about test performance much better when it is presented in natural frequencies rather than conditional probabilities [11-15].

Comparing our results to the original results from 1998, we can see no consistent improvement. Whereas only 5 of 19 (26%) counselors denied the possibility of false-negative results in the original study, 15 of 30 (50%) counselors did so in our study. The understanding of the false-positive rate was about the same. When asked about the HIV prevalence among the client's risk group, 16 of 20 (80%) counselors provided incorrect information back then, compared to 17 of 30 (57%) in the present replication. No improvement was found in counselors' replies to the question concerning the positive predictive value of HIV-testing. In the original study, 15 of 18 (83%) counselors provided an incorrect estimate; 28 of 29 (96%; one counselor could not answer the question) did so in ours. The most important comparison involves the illusion of certainty: In 1998, 55% of the counselors (10 out of 18) stated that a person is definitely infected with HIV when the test result is positive. In the present study this high percentage was even exceeded, with 62% of the counselors (18 out of 29) conveying the illusion of certainty.

CONCLUSION

Except for information on prevalence, our replication of the study by Gigerenzer et al. found no significant

Table 2. Correct-incorrect ratio within-subjects.

ID	Profession	Sensitivity	Specificity	Prevalence	Positive Predictive Value	Ratio (Correct/Total)
3	Physician	•	•	•	X	3/4
11	Physician	•	•	•	X	3/4
9	Social Worker	•	•	•	X	3/4
4	Social Worker	•	•	X	X	2/4
8	Social Worker	•	•	X	X	2/4
16	Physician	•	•	X	X	2/4
19	Social Worker	X	•	•	X	2/4
22	Social Worker	•	X	X	•	2/4
24	Nurse	X	•	•	X	2/4
25	Social Worker	•	X	•	X	2/4
28	Physician	•	•	X	X	2/4
29	Social Worker	•	•	X	X	2/4
30	Social Worker	•	•	X	X	2/4
27	Physician	•	X	X	X	1/4
6	Physician	X	х	•	X	1/4
20	Social Worker	X	X	•	X	1/4
17	Social Worker	х	x	•	X	1/4
23	Physician	X	•	x	X	1/4
18	Social Worker	X	x	•	X	1/4
15	Social Worker	х	X	•	X	1/4
13	Social Education Worker	х	x	•	x	1/4
10	Social Worker	•	x	X	X	1/4
5	Physician	•	X	x	X	1/4
2	Physician	Х	X	•	X	1/4
1	Social Worker	Х	X	X	X	0/4
7	Physician	Х	X	x	X	0/4
14	Social Worker	Х	X	X	X	0/4
12	Physician	Х	X	X	X	0/4
21	Social Education Werker	Х	X	X	Х	0/4
26	Physician	x	x	X	X	0/4

improvement but in fact deterioration in the quality of HIV counseling. Although HIV tests have considerably improved in quality over the last 16 years, counseling has not kept step. Given that after the original study in 1998, all HIV centers in Germany received the results along with a guideline on how to improve HIV counseling, these findings are particularly disheartening. The current key problems are:

- 1) Use of ineffective statistical formats: Almost all counselors communicated information in terms of percentages and probabilities or just qualitatively, instead of providing natural frequencies that would ease comprehension on both sides.
- 2) Ignorance of statistics and their implications: Counselors confused the positive predictive value

with sensitivity or specificity and did not account for HIV prevalence when talking about HIV test performance. Only one of 30 counselors correctly stated that the positive predictive value increases with an increase of the prevalence of the disease in a group.

3) Illusion of certainty: Most counselors believe that the combination of the ELISA and Western Blot renders HIV test results absolutely certain.

Our replication study should be viewed in the light of some limitations. First, in contrast to the original study, the current study differs in sample size and selection, as well as the actual performance of the HIV test (PPV 1998 = 50% vs PPV 2014 = 96%). This limits the analysis and interpretation

of potential differences between these two studies. Second, our data reflect the performance of HIV counseling in Germany and may not be generalizable to HIV counseling in other countries. However, many studies conducted elsewhere on doctors' understanding of test performances show similar difficulties doctors have in working with tests statistics and calculating the positive predictive value so that similar problems are likely to exist in other settings, as well [5, 13-15].

Where does the counselors' lack of understanding come from? Part of the problem might be the official information pamphlets. Counselors seem to be equipped with a reference book on HIV counseling distributed by the *Deutsche AIDS-Hilfe* (German Aids Aid) or *Bundeszentrale Für Gesundheitliche Aufklärung* (the Federal Center for Health Education in Germany). During two sessions, counselors took a look at the reference book to find information about the possibility of false-negative results. Based on this information, both counselors concluded that there are no false negatives when the test has been taken twelve weeks after the last risk of infection. An assessment of the brochure

made apparent why the counselors arrived at this conclusion: Its content (created by the *Deutsche AIDS-Hilfe*) consists mainly of qualitative information, which does not enable counselors to retrieve appropriate quantitative estimates.

It should be an ethical imperative that every professional HIV counselor is adequately taught transparent HIV counseling and equipped with brochures that enable to fully understand what a positive test result means. We hope that our study stimulates both better training for HIV counselors and better information in leaflets on HIV testing. Only then can people trust in receiving the transparent and trustworthy information on HIV test results they are seeking.

CONFLICT OF INTEREST

The authors confirm that this article content has no conflict of interest.

ACKNOWLEDGEMENTS

Declared none.

APPENDIX A: COUNSELORS' RESPONSES ONSENSITIVITY

"How well does the test detect the virus? If I am infected, is it possible that I nevertheless test negative? If so, how often does that occur?

Numerically Correct	Numerically Incorrect	Qualitatively Correct	Qualitatively Incorrect
"No test is 100% certain, hence, this may happen."; "This test is 99.9% certain. Therefore, false-negative results are relatively rare."	"The test is absolutely certain"; "100%"	"Yes, that may occur, especially when people do not account for the window period."; "People with many sexual contacts are prone to that, too. This happened here once, but one did not account for the window period back then."; "Also, this is relatively common for people who have immune system deficiencies, e.g. after chemotherapy."	"After 12 weeks, no. Afterwards, the test provides a certain result."; "Very certain, the test is very reliable."
"This happens very rarely, but I have never experienced it here. After the diagnostic gap, this is certainly impossible."; "Absolutely. Well, 100% certainty is never given, but 99% certain." ₁₀	"After the window period, it is 100% certain." 2	"The test is very certain. It is relatively improbable that you are infected if it is negative."; "Well, as I said, the test is very certain but theoretically, no test is 100% certain."	"I don't know the accurate numbers."[picks up article]; "After 12 weeks a false negative is impossible. It doesn't specify any numbers here either." ₁₂
"That isn't possible after 12 weeks. Never say never, but this test is very certain."; "It has a high sensitivity and is therefore 99% certain."; "False negative result has never occurred here."	"The test is very certain after 12 weeks."; "Actually, it is already certain after 10 weeks."; "100% significant." ₁₄	"That's impossible after 12 weeks, unless you belong to the group of those who do not produce antibodies."; "Not 100% because exceptions may happen."; "I don't know the accurate numbers by heart",22	"You can absolutely rely on the test after 12 weeks."; "We do not communicate in numbers here." ₁₃
"Happens, but very unusually. You have to wait 3 months before taking the test, otherwise it is not 100% significant."; "After 3 months you have a 99% certain result."; "False negative results happen, but I don't know how many. It happens much less than false-positive results."	"This is impossible after the window period."; "100%." ₁₇	"The test is very sensitive, it reacts to antibodies immediately. If the detection test is reactive, you will be informed in order to perform a confirmatory test."; "If we don't contact you, then there is no infection." ₃₀	"This happens in the rarest cases, with people who do not produce antibodies."; "I am not good with numbers, but I can look it up." (Gets DAH counselors brochure) "No, it says here that the result is certain after 12 weeks, no exceptions." 15
"The test is very good, but nothing can be excluded for certain."; "It happens because this test is not 100% certain. Instead it has 99% certainty."; "I don't know how often false-negatives occur." ₂₅	"This is possible if you test yourself before 12 weeks or if you have an immune deficiency."; "Afterwards, it's absolutely certain."; "100% certain." ₁₈		"Not if you keep the window period."; "Afterwards it is a safe result.; "Very certain." ₁₉

(Appendix A) contd.....

(Appendix A) contd Numerically Correct	Numerically Incorrect	Qualitatively Correct	Qualitatively Incorrect
"That happens rarely if you account for the 12 weeks after having been in a risky situation."; "The test's sensitivity is 99.9%, so, it may happen exceptionally, e.g., with people whose immune system is malfunctioning, because it is so sensitive."; "I don't know the exact frequency." ₂₈	"Well, conditionally no. After the diagnostic gap, the result will be significant and a false negative is impossible."; "100% certain. Although you never meet absolute certainty anywhere." ₂₁		"Absolutely impossible after 12 weeks." ₂₀
"Possible, but rare."; "You have to wait 3 months after you were in a risky situation, otherwise, the test is not 100% significant."; "After 3 months it is 99% significant."; "Such results happened even after 3 months, but I don't know how many. False-negative results occur generally less than false-positive results." 29	"If taken after 12 weeks, it isn't possible."; "The test is very reliable."; "The test is 99.9% certain.",		"I am not very familiar with these questions."; "After 12 weeks, no false negative should occur."; "No it doesn't occur."; 23
"The test is significant when taken after 12 weeks."; "This means that the test is 99.9% negative if you are negative.",			"If you account for the 3 months, no."; "False positives may occur with the ELISA, but no false negatives." ₂₄
"The test is very certain, if you account for the 12 weeks."; "If the test is negative, then you are negative, too."; "We are not allowed to say 100%, but instead we say 99.9%, although the test is really very certain.",			"Theoretically, one should stick to the window period, but antibodies are already produced after 3-4 weeks.";"There won't be any falsenegative results after the window period."; "The test is very sensitive and false negatives are, if you account for the window period, impossible. ₂₆
"The test is reliable after 12 weeks since you have been exposed to infection risk."; "In medicine, we never say that something is 100% certain, but this test is 99.9% certain."; "False-negative results after the window period have never happened as far as I know."; "You undergo double checking."27			

APPENDIX B: COUNSELORS' RESPONSES ON SPECIFICITY

"If I don't have the virus, is it possible that I nevertheless test positive? If so, how often does that occur?"

Numerically Correct	Numerically Incorrect	Qualitatively Correct	Qualitatively Incorrect
"Around 1-5 false positives in 1000 tests. But it also depends on the window period."; "After the window period you would not normally get a false-positive result."; "We also have the quicktest but that has a lower sensitivity than the normal test. The normal has 99.8."3	"You also have to wait 12 weeks. There may be a cross reaction, but after the diagnostic gap, the result is 100% certain."; "There are two tests anyway",	"That may happen. For example, the first test, the ELISA, can be positive, and the confirmatory test is negative."; "I cannot tell you how often that occurs.";	"That never occurred during the 5 years I have worked here. This means that false positives are possible after the search test, but after the confirmatory that's impossible."; "The Western-Blot removes those false positives."; "After the confirmatory test you can be absolutely certain that you are really infected."10
"The first test is rarely positive although you are negative. Specific frequencies do not exist."; "If you are positive, the Western Blot is performed. If this test is still positive, the same procedure will be repeated with new blood, so possible human errors can be avoided, e.g., in the laboratory. Afterwards, the test is 99.9% certain."; "Exceptions can always occur." 9	"There will be a second test anyway if you are positive. Afterwards, the test is certain and significant, 100%"; "The Elisa would already be positive after 4 weeks.".	"That happens. Two tests will be performed if the first is positive, due to cross reactions. But the test is generally very significant." ₈	"There are two tests that are absolutely certain."; "If the first is incorrect - this can happen here - then the confirmatory test is performed."; "The confirmatory test is very sensitive and therefore, the result afterwards is significant." ₁₃

(Appendix B) contd.....

Numerically Correct	Numerically Incorrect	Qualitatively Correct	Qualitatively Incorrect
"Happens, but only after the ELISA test. If that one is positive, a confirmatory test follows. Afterwards, the chance ofgetting a false-positive result does almost not exist, because the test is 99.9% certain."; "I have never seen a false positive."	"The PPV is 99%, the test is therefore very certain." ₁₂ Wrong information, "PPV"	"That happens with the ELISA. After the confirmatory test that's impossible because the ELISA has a higher sensitivity and the WesternBlot confirms this result."; "If the WB is positive, a repetition should be done."; "Human errors that happen inside the laboratory are the only possibility."; "As I said, it happens but the test is very, very, very certain. We have used this test for 30 or 40 years." 19	"False positives with the ELISA are possible but after the second test, the confirmatory test, not anymore."; "That is impossible after the test procedure."; "As I said, I don't know the numbers."22
"That is relatively impossible. If you are tested positive, then a second check is performed."; "99.9% certainty because of the double check." ₂₉	"The same: after 12 weeks 100% certainty and therefore false positives are impossible." ₁₄	"Theoretically, yes."; "I have never experienced one. There are specific anomalies, therefore we advise taking an additional test if the first one turned out positive."	"The same is applicable here: If you receive a positive result, then you will have to donate blood again."; "Afterwards, you can be absolutely certain." 25
"False-positive results are possible after the 1st test."; "The test is 99% certain, but I experienced it twice."; "There are 4 tests performed in total, if there is no human error in the laboratory, then the result is certain."21	"False-positive results happen with the search test, but after that one, the confirmatory test deletes those."; "The test is 98% specific, therefore, the result is relatively reliable."; "No, false positives do not occur after the confirmatory test." ₁₅	"The ELISA sometimes produces false-positive results, but I have never experienced that."; "The Elisa is very sensitive, the Western Blot, the second test, very specific."; "If the result is still positive after the Western Blot, then you will have to provide a blood sample again and this one is tested, too. Afterwards, the result is very certain."; "There can always be exceptions. The smaller the prevalence of an illness within a group, the more false-positive results occur. One can say that for low-risk people, there are as many false positives as there are true positives. We have around 5 positive results per year, mostly homosexual men." 28	"The first test is very sensitive, therefore, a false-positive may occur, but after the second test the result is certain."; "False positives don't exists, I mean, after the second test they don't exist."; "But this second test procedure will be performed anyway, so you can be absolutely certain." 26
	"False-positive results rarely occur. I experienced 2 cases during the Mexican flu. But then the immunoblot test follows and deletes those. If there are any more doubts about the result, you can make a PCR."; "The result is 100% certain after the immunoblot."17	"Also possible, depends on the virus infections."; "When there is a risk of a false-positive result, then we generally advice not taking the test." 30	
	"False-positive results occur with the ELISA, that one is 99.9% certain. There are around 1 in 100 false-positives, but those will be detected with the ELISA combi-procedure, which also tests for a specific virus-related protein."; "Afterwards, the test is absolutely certain." 18	"If someone tests positive, a second test is doneas a double-check. Afterwards you have a certain result."; "False-positives results occur, but usually not after the Window period."4	
	"We test around 300-500 per year and there are 3-4 false positives."; "After the window period those will be negative, too."; "You can absolutely rely on the test." 20		
	"A false positive can occur with the ELISA test sometimes, but there is always a confirmatory test and afterwards it is certain."; "After the search and confirmatory test, the result is absolutely significant."; "100% certain." ₂₁		
	"This happens with cheap tests, but not after the confirmatory test"; "After the 2 nd test it is a 100% certain result." ₂₄		

(Appendix B) contd.....

Numerically Correct	Numerically Incorrect	Qualitatively Correct	Qualitatively Incorrect
	"False-positive results happen, but only after the first blood sample. A second test is performed if the first test was positive. Afterwards, errors are impossible."; "It's a total of 4 tests with a 99.9% certain test and false positives are avoided." ₂₇		
	"Two tests are performed, therefore the result is very certain."; "Also 100%. "1		
	"After the window period the result is also 100% certain."; "75% false positives occur when you perform the test during the window period or because you belong to a certain group with very high virus load or cross reactions."2		

APPENDIX C: COUNSELORS' RESPONSES ON PREVALENCE

"How many men in Germany who share my characteristics have HIV? (Provide further information: heterosexual, no risk behavior such as intravenous drug abuse)"

Numerically Correct	Numerically Incorrect	Qualitatively Correct	Qualitatively Incorrect
"Three quarters MSM, one quarter heterosexual."18	"28,000 men, mostly homosexuals." ₄		"I don't know any numbers by heart. In America the numbers are increasing and in Germany the numbers are decreasing. You can look it up in the RKI epidemiological bulletin."
"73% homosexuals, 27% heterosexuals."; "3,500 new infections per year." ₂₀	"I don't have any number for Germany. In XX we have 12-20 new infections per year.",		"There is no statistic for this."; "No complete statistic available."; "The RKI does not cover all either."
"We have relatively few HIV-infected, the least inthe EU."; "Italy, Spain, Portugal have the most HIV-positives because they are conservative Catholic "Of the 70,000 infected men in Germany, 50% are gay, 14% IV drug abusers and the rest are heterosexuals.",	"I don't have any accurate information."; "In total, there are 70,000 HIV-infected people in Germany."		"You'll have to look this up in the RKI epidemiological bulletin."22
"Yearly, there are 2,500 new infections, mostly homosexual."; "Around 9,000-10,000 heterosexuals." ₂₄	"The number has increased."; "There are 70,000 in Germany but I don't know the specific number for heterosexuals." ₈		"I am not sure about the numbers." 28
"60% are homosexual, men who sleep with other men."; "3,500 infections per year, 2,000 of those are MSM, 1,000 heterosexual and the rest are women or intravenous drug abusers."; "About 10,000 in Germany."	"I have to look this up."; "You can have a look at the RKI statistics."; "About 9 in 999." ₁₂		"I cannot tell you the numbers right away."; "There are good statistics for homosexuals. Specific for age and your risk group I definitely don't know the numbers." ₂₉
"63,000 MSM and ca. 10,000 heterosexuals." ₁₃	"3,500 infections per year, 1,800 of those are gay. The rest are men like you."14		"I don't know the numbers, you will have to look them up in the RKI statistics." 30
"78,000 in Germany and 10,000 of those heterosexual."15	"Among 40,000,000 in Germany, only 70,000 have HIV. Three quartersare homosexual, one quarterIV drug abusers and a few heterosexuals." ₂₁		"There are more homosexual men with HIV than there are heterosexual men with HIV."; "No idea what the accurate numbers are." ₁₀

(Appendix C) contd.....

Numerically Correct	Numerically Incorrect	Qualitatively Correct	Qualitatively Incorrect
"A small number of heterosexual men, around 10,000." ₁₇	"Ca. 2,500 new infections per year."; "Individually, specific to your risk-group, no idea." ₂₃		
"In total around 60-70,000. Men like you relatively few, ca. 10,000"25	"Around 78.000 HIV-infected, yearly 3300 new infections." ₂₆		
"There are ca. 10,000 heterosexual men who are HIV-positive.",	"According to the RKI bulletin: 16,000"27		
"The annual infection rate is 3,000"; "There are 10,000 heterosexuals who are HIV-infected. Homosexuals who are infected are by far more common." ₂			
"About 10,000 heterosexuals."3			
"About 70,000 in Germany, of whom 50,000 are homosexual and 10,000 heterosexual.",			

APPENDIX D: COUNSELORS' RESPONSES ONPOSITIVE PREDICTIVE VALUE

"If I test positive, how likely is it that I have the virus?"

Numerically Correct	Numerically Incorrect	Qualitatively Correct	Qualitatively Incorrect
	"As I said, 100%" ₁	"As I said, very certain."22	"If you account for the 12 weeks, then the result is absolutely certain."
	"If you were tested after the window period, then the result is 100% significant."2		"If the test's final result is positive, then you are positive."
	"The result is 99.8% significant, or 98.5% for the quicktest."		"Yes, and if you are positive, then the whole procedure will be repeated. The test is double-checked and therefore, absolutely significant." ₈
	"As I said, 99.9%",		"If the second test, the confirmatory test, is positive, then you are definitely HIV-positive." ₁₃
	"Yes, as I said, the test is 99.9% certain after the window period. But a second test will be conducted anway."5		"Yes, the result is then absolutely certain. How many HIV-infected people there are in your group doesn't matter anyway." 15
	"As I said, 99.9% that you actually have HIV."9		"The result is definite, after the two tests." 20
	"As I said, absolutely certain, 100% so to speak."10		"As I said, you can be absolutely certain."25
	"99%"।		"As mentioned before, the test is absolutely certain." 26
	"99.9%" ₁₂		"I cannot calculate the PPV. Did that at a seminar once, the whole thing about percentages and prevalences, but I forgot how it works. I cannot remember percentages and formulas." 28
	"100%" ₁₄		"After the window period? Yes, you are positive." ₃₀

(Appendix D) contd.....

Numerically Correct	Numerically Incorrect	Qualitatively Correct	Qualitatively Incorrect
	"After the first test, a second test follows. After the second test it is 99.9%, certain, because it is impossible to get a false-positive result twice." 16		
	"As I said, 100%" ₁₇		
	"100%" ₁₈		
	"99.9% certainty." ₁₉		
	"False-positives may occur with the ELISA, but it always follows a confirmatory test, and then the result is certain."; "After search and confirmatory test, the result is absolutely significant. 100% certain."21		
	"After 4 tests, 99.9% certain." ₂₃		
	"If the 12 weeks were accounted for and the Western Blot has been performed: 100%."24		
	"As I mentioned before, after the two tests it's 100% that you are positive." 27		
	"With 99.9% certainty."29		

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