

AIDS counselling for low-risk clients

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Abstract *This study addresses the counselling of heterosexual men with low-risk behaviour who, voluntarily or involuntarily, take an HIV test. If such a man tests positive, the chance that he is infected can be as low as 50%. We study what information counsellors communicate to clients concerning the meaning of a positive test and whether they communicate this information in a way the client can understand. To get realistic data, one of us visited as a client 20 public health centres in Germany to take 20 counselling sessions and HIV tests. A majority of the counsellors explained that false positives do not occur, and half of the counsellors told the client that if he tests positive, it is 100% certain that he is infected with the virus. Counsellors communicated numerical information in terms of probabilities rather than absolute frequencies, became confused, and were inconsistent. Based on experimental evidence, we propose a simple method that counsellors can learn to communicate risks in a more effective way.*

Former Senator Lawton Chiles of Florida reported at an AIDS conference in 1987 that of 22 blood donors in Florida who were notified that they tested HIV-positive with the ELISA test, seven committed suicide. In the same medical text that reported this tragedy, the reader is informed that ‘even if the results of both AIDS tests, the ELISA and WB (Western blot), are positive, the chances are only 50–50 that the individual is infected’ (Stine, 1996, pp. 333, 338). Situations like this can occur when people with low-risk behaviour, such as blood donors, test positive. The discrepancy between what clients believe a positive HIV test means and what it actually does mean seems to have cost human lives in addition to the toll the disease itself has taken. One of the goals of AIDS counselling is to explain the actual risk to the client. This article deals with pre-test HIV counselling of low-risk clients concerning the meaning of a positive HIV test in German public AIDS counselling centres. We address three questions: What information do counsellors communicate to the client concerning the chances of an HIV infection given a positive test? Is this information communicated in a way the client can understand? How can the communication and the accuracy of the information be improved?

Counselling clients with low-risk behaviour

We are interested in the counselling that members of the largest population group receive: heterosexuals who do not engage in risky behaviour, such as IV-drug use. These people take

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HIV tests for various reasons: voluntarily, because they want to find out whether they are infected before getting married, having children, or for other reasons; or involuntarily, because they are immigrants, applicants for health or life insurance, military personnel, blood donors, or members of other groups that are required by law to take the test. The Swedish government, for instance, has encouraged voluntary testing to the point that 'people who are unlikely to be infected are the ones who take the test, in droves' (Månsson, 1990). Involuntary testing is a legal possibility in several countries, which insurers exploit to protect themselves against losses. For instance, in 1990, Bill Clinton (then Governor of Arkansas) had to take an HIV test to get his life insurance renewed (*Der Tagesspiegel*, 16 Sept/96, p. 4). People with low-risk behaviour may be subjected to HIV tests not only involuntarily but also unknowingly. For instance, large companies in Bombay have reportedly subjected their employees to blood tests without telling them that they were being tested for AIDS; when a test was positive, the employee was fired (*Der Tagesspiegel*, 8 July/96).

Counselling people at low risk requires paying particular attention to false positives, that is, to the possibility that the client has a positive HIV test even though he or she is not infected with the virus. The lower the prevalence of HIV in a group, the larger the proportion of false positives among those who test positive. In other words, if a client with high-risk behaviour tests positive, the probability that he actually is infected with HIV is very high, but if someone with low-risk behaviour tests positive, this probability may be as low as 50%, as indicated above. If clients are not informed about this fact, they tend to believe that a positive test means that they are infected with absolute certainty. The case of a young man from Dallas that circulated in the US press is one example. This man tested positive on a routine HIV test, became depressed and contemplated suicide, and moved to California. After some 18 months of anguish, a Californian doctor made him take the test again, and it came back negative (*Chicago Tribune*, 5 March/93). If the young man had committed suicide, as the blood donors in the Florida case did, we might never have found out that his test was a false positive. Emotional pain and lives can be saved if counsellors inform the clients about the possibility of false positives.¹

We do not know of any study that has investigated what AIDS counsellors tell their clients about the meaning of a positive test. We pondered long over the proper methodology, such as sending questionnaires to counsellors or asking them to participate in paper-and-pencil tests. However, we decided against questionnaires and similar methods because they are open to the criticism that they tell us little about actual counselling sessions. For instance, these methods have been criticized for not allowing physicians to pose their own questions to get further information, to use their own estimates of the relevant statistical information rather than those provided by the experimenter, and for removing the element of actual concern for the patient, because either the patient is fictional or the case was resolved years ago (Phelps & Shanteau, 1978; Yates, 1990).

In the end, we decided to take a direct route. One of us went as a client to 20 counselling sites and took a series of counselling sessions and HIV tests. We were interested in one important issue that AIDS counsellors have to explain to the client: What does a positive test result mean? To answer this question, one needs to know: (a) the base rate of HIV in heterosexual men with low risk, which is referred to as the *prevalence*, (b) the probability that the test is positive if the client is infected, which is referred to as the *sensitivity* (or hit rate) of the test, and (c) the probability that the test is positive if the client is not infected, which is known as the *false positive rate* (or $1 - \text{specificity}$). From this information, one can estimate what a positive test actually means, that is, the probability of being infected if one tests positive, also known as the *positive predictive value* (PPV). Let us first get the best estimates for these values from the literature.

Prevalence

Germany has a relatively small number of reported AIDS cases. The cumulative number by the end of 1995 was 13,665, as compared to some 30,000 in Italy, 38,000 in France, and more than 500,000 in the USA (WHO, 1996). Thus one can assume that the prevalence of HIV is also comparatively low. The client in our study was 27 years old, a German heterosexual male who did not engage in risky behaviour. What is the prevalence of the HIV virus in 20- to 30-year-old heterosexual men in Germany who do not engage in risky behaviour? A reasonable estimate is about one in 10,000, or 0.01%.² This figure is in the range of the prevalence of HIV in blood donors in the USA (a group with low prevalence within the USA), which has been estimated at one in 10,000 (Busch, 1994, p. 229) or two in 10,000 (George & Schochetman, 1994, p. 90).

Sensitivity and specificity

In Germany, as in most Western countries, HIV testing typically involves the following sequence. If the first test, ELISA, is negative, the client is notified that he or she is HIV-negative. If positive, at least one more ELISA (preferably from a different manufacturer) is conducted. If the result is again positive, then the more expensive and time-consuming Western blot test is performed. If the Western blot is also positive, then the client is notified of being HIV-positive, and sometimes a second blood sample is also tested. Thus, two errors can occur. First, a client who is infected is notified that he is HIV-negative. The probability of this error (false negative) is the complement of the sensitivity of the ELISA test. The estimates for the sensitivity typically range between 98% and 99.8% (Eberle *et al.*, 1988; George & Schochetman, 1994; Schwartz *et al.*, 1990; Spielberg *et al.*, 1989; Tu *et al.*, 1992; Wilber, 1991). Second, a client who is not infected is notified of being HIV-positive. The probability of this second error (false positive) is the complement of the combined specificity of the ELISA and Western blot tests. Although all surveys agree that false positives do occur, the quantitative estimates vary widely.³ This is in part due to the fact that what constitutes a positive Western blot test has not been standardized (various agencies use different reagents, testing methods, and test-interpretation criteria (Stine, 1996, p. 335)), that the ELISAs and the Western blot tests are not independent (that is, one cannot simply multiply the individual false positive rates of the tests to calculate the combined false positive rate, Spielberg *et al.*, 1989), and that the higher the prevalence in a group, the lower the specificity seems to be for this group (Wittkowski, 1989). For instance, 20 samples—half with HIV antibodies and half without (the laboratories were not informed which samples were which)—were sent in 1990 to each of 103 laboratories in six WHO regions (Snell *et al.*, 1992). About 70 different combinations of tests were applied. Of the samples without HIV antibodies, 1.3% were incorrectly classified as positive. A combined specificity of only 98.7%, as in this blind proficiency testing, however, is an unusually low estimate. Most of the estimates in the literature are considerably higher, usually higher than 99.9% (Burke *et al.*, 1988; Eberle *et al.*, 1988; Peichl-Hoffman, 1991; Tu *et al.*, 1992). For instance, the German Red Cross achieved for first-time blood donors a combined specificity of 99.98% (Wittkowski, 1989). From the figures published, a reasonable estimate for the combined specificity seems to be about 99.99%. That is, the false positive rate is about one in 10,000. This is an estimate, and more accurate numbers may be available from future research.

Positive predictive value

What the client needs to understand is the probability of being infected with HIV if he tests positive. The predictive value of a positive test (PPV) can be calculated from the prevalence $p(\text{HIV})$, the sensitivity $p(\text{pos}|\text{HIV})$, and the false positive rate $p(\text{pos}|\text{no HIV})$:

$$\text{PPV} = \frac{p(\text{HIV})p(\text{pos}|\text{HIV})}{p(\text{HIV})p(\text{pos}|\text{HIV}) + p(\text{no HIV})p(\text{pos}|\text{no HIV})}, \quad (1)$$

where $p(\text{no HIV})$ equals $1 - p(\text{HIV})$. Equation 1 is known as Bayes's rule. This rule expresses the important fact that the smaller the prevalence, the smaller the probability that a client is infected if the test is positive. What is the predictive value of a positive test for a 20- to 30-year-old heterosexual German man who does not engage in risky behaviour? Inserting the previous estimates—a prevalence of 0.01%, a sensitivity of 99.8%, and a specificity of 99.99% (repeated ELISA and Western blot)—into Bayes's rule, the PPV results in 0.50, or 50%.

An estimated PPV of about 50% for heterosexual men who do not engage in risky behaviour is consistent with the report of the Enquete Committee of the German Bundestag, which estimated the PPV for low-risk people as 'less than 50%' (Deutscher Bundestag, 1990, p. 121).

How to communicate the positive predictive value. Even if a counsellor understands this formula, ordinary people rarely do (Gigerenzer & Hoffrage, 1995). Moreover, we know from paper-and-pencil studies in the USA and in Germany that even experienced physicians have great difficulties when asked to infer the PPV from probability information (Casscells *et al.*, 1978; Dawes, 1988; Eddy, 1982; Hoffrage & Gigerenzer, 1996; Windeler & Köbberling, 1986). But we also know from a recent study with 48 physicians in Munich that physicians' performance can be substantially improved, by a factor of more than four, if the information is presented in *natural frequencies* rather than in terms of probabilities or percentages (Gigerenzer, 1996; Hoffrage & Gigerenzer, 1998). By natural frequencies we mean information represented in terms of absolute (not relative) frequencies, that is, in the way a physician would have actually experienced the frequencies if she had sampled the individual cases herself (Gigerenzer & Hoffrage, 1995). More precisely, natural frequencies are frequencies which have not been normalized with respect to the base rate (prevalence) of the disease. Normalized frequencies, such as probabilities and percentages, have only emerged in the last few centuries as tools to represent degrees of uncertainty (Gigerenzer *et al.*, 1989), whereas through most of human history and evolution, minds had to deal only with natural frequencies.

How would a counsellor communicate information in natural frequencies? She might explain to the patient the meaning of a positive test in the following way: 'Imagine 10,000 heterosexual men like you being tested. One has the virus and he will with practical certainty test positive. Of the remaining non-infected men, one will also test positive (the false positive rate of 0.01%). Thus we expect that two men will test positive, and only one of them has HIV. This is the situation you are in if you test positive; the chance of having the virus is one out of two, or 50%.'

This simple method can be applied whatever the relevant numbers are assumed to be. If the prevalence is two in 10,000, the PPV would be two out of three, or 67%. The numbers can be adjusted; the point is that clients can understand more easily if the counsellor communicates in natural frequencies than in probabilities. With a frequency representation the client can 'see' how the PPV depends on the prevalence. If the prevalence of HIV among

German homosexuals is about 1.5%, then the counsellor might explain: 'Think of 10,000 homosexual men like you. About 150 have the virus and they all will likely test positive. Of the remaining non-infected men, one will also test positive. Thus, we expect that 151 men will test positive, and 150 of them have HIV. This is the situation you are in if you test positive; the chance of having the virus is 150 out of 151, or 99.3%.'

In general, the PPV is the number of true positives (TP) divided by the number of true positives and false positives (FP):

$$PPV = \frac{TP}{TP + FP} \quad (2)$$

The comparison between equations (1) and (2) shows that natural frequencies make mental computations easier. Frequencies are fairly accurately and almost automatically monitored in humans and animals (e.g. Cosmides & Tooby, 1996; Jonides & Jones, 1992). From this research it follows that physicians and lay people alike can understand risks better when the information is communicated in natural frequencies rather than in probabilities or percentages.

Public HIV counselling

Some 300 German public health centres ('Gesundheitsämter') offer free HIV tests and AIDS counselling for the general public. By 1990, these centres had hired 315 counsellors, 43% of whom were physicians, 22% social workers and 7% psychologists. The rest had various professional training (Fischer, 1990). As in other countries, counselling before testing is designed to make sure that the client understands the testing procedure, the risks for HIV infection, and the meaning of either a positive or negative test (Ward, 1994). The report of the Enquete Committee of the German Bundestag (Duetscher Bundestag, 1990, p. 122) directs the counsellor explicitly to perform a 'quantitative and qualitative assessment of the individual risk' and to 'explain the reliability of the test result' before a test is taken. If the client decides to take a test, anonymity is guaranteed in all German states (unlike in the USA, where in 25 states the patient's name is reported, Stine, 1996, p. 346). Counselling requires both social tact and knowledge about the uncertainties involved in testing, and the fact that in 1990 about 37% of clients tested at publicly funded clinics in the USA failed to return for their test results suggests that counselling is not always successful (Doll & Kennedy, 1994).

What information concerning the meaning of a positive test do counsellors in German public health centres give a client with low-risk behaviour? How is this information communicated (e.g. in probabilities or in natural frequencies)?

Methods

Counselling centres

The 'client' visited 20 public AIDS counselling centres in 20 German cities, including large cities such as Berlin, Hamburg and Munich. Two additional counselling centres were visited in a pilot study that was conducted to design the details of the interview. The 20 counselling centres were distributed over nine German states in former West Germany. Of the 20 counsellors, 14 were physicians and six social workers; 12 were female and eight male.

The client first contacted the health centres by telephone and made an appointment. He could visit two centres in short sequence, followed by a break of at least two weeks to allow

the hematomas from the perforation of the veins in his arms to heal. These breaks were necessary, otherwise signs in the arm might have suggested to the counsellor that the client was a drug addict.

Investigating AIDS counsellors' performance without their knowledge raises ethical problems. We consulted the Ethics Committee of the German Association of Psychology, which informed us that in the present case the expected utility of the results of the study could justify deceiving of the counsellors. Public counselling is public behaviour; nevertheless, in deference to the Ethics Committee's interpretation of German privacy laws, we decided not to tape the sessions. Moreover, we protect the anonymity of the counsellors. We apologize to all of the counsellors for having used this covert method, but believe that the results of this study justify the approach by revealing what can be improved in future AIDS counselling.

The interview

The client asked the counsellor the following questions in the order indicated (unless the counsellor provided the information unprompted):

- (1) *Sensitivity of the HIV test.* If one is infected with HIV, is it possible to have a negative test result? How reliably does the test identify a virus if the virus is present?
- (2) *Specificity of the HIV test.* If one is not infected with HIV, is it possible to have a positive test result? How reliable is the test with respect to a false positive result?
- (3) *Prevalence of HIV in heterosexual men.* How frequent is the virus in my risk group, that is, heterosexual men, 20 to 30 years old, with no known risk such as drug use?
- (4) *Predictive value of a positive test.* What is the probability that men in my risk group actually do have HIV after a positive test?
- (5) *Window period.* How much time has to pass between infection and test, so that antibodies can be detected?

The pilot study indicated a tendency in counsellors to provide vague and non-informative answers, such as, 'Don't worry; the test is very reliable; trust me'. It also indicated that if the client asked for clarification more than twice, the counsellors were likely to become upset and angry, experiencing the client's insistence on clarification as a violation of social norms of communication. Based on these pilot sessions, the interview included the following scheme for clarifying questions: If the counsellor's answer was a quantitative estimate (a number or a range) or if the counsellor said that he or she could not (or did not want to) give a more precise answer, then the client went on to the next question. If the answer was qualitative (e.g. 'fairly certain') or if the counsellor misunderstood or avoided answering the question, then the client asked for further clarification and, if necessary, repeated this request for clarification one more time. If, after the third attempt, there was still no success, the client did not push further and went on to the next question. When the client needed to ask for clarification concerning the prevalence of HIV (Question 3), he always repeated his specific risk group; when asking for clarification concerning the PPV (Question 4), he always referred to the specific prevalence in his risk group.

As mentioned above, when the client asked for the prevalence of HIV in his risk group, he specified this group as 'heterosexual men, 20 to 30 years old, with no known risk such as drug use'. When counsellors asked for more information, which happened in only 11 of the sessions, the client explained that he was 27 years old, monogamous, and that neither his current nor his (few) previous sexual partners used drugs or engaged in risky behaviour. In two of these 11 cases, the client was given a detailed questionnaire to determine his risk; in

Table 1. Information provided by the counsellors

	100% certainty	≥ 99.9%	≥ 99%	≥ 90%	Range
Sensitivity	5 (of 19)	5	6	3	90–100%
Specificity	13 (of 19)	3	3	0	99.7–100%
Prevalence	—	—	—	—	0.0075–6%
PPV	10 (of 18)	5	1	2	90–100%

Note: Not all counsellors provided numerical estimates. The verbal assertion ‘absolutely certain’ is treated here as equivalent to 100% certain; verbal assertions such as ‘almost absolutely certain’ and ‘very, very certain’ are classified as $\geq 99\%$, and assertions such as ‘very reliable’ are classified as $\geq 90\%$.

one of these cases the counsellor did not look at the questionnaire and the client still had it in his hands when he left the site.

The client was trained in simulated sessions to use a coding system (question number; number of repetitions of a question; the counsellor’s answer at each repetition; e.g. “1; 2; 99.9%”) that allowed him to write down the relevant information in shorthand during the counselling, or, if the session was very brief, to rehearse the code in memory and write it down immediately after the counselling session.

After the counselling session, the client took the HIV test, except for three cases (in two he would have had to wait several hours to take the test, and in one case the counsellor suggested that the client might first consider it over night before making the decision of whether or not to take the test).

Results

Four counselling sessions are shown, for illustration, in the Appendix. The client’s questions are abbreviated (e.g. sensitivity?), and the information provided by the counsellor directly follows the question. The counsellors’ answers to the client’s clarifying questions are preceded by a hyphen in subsequent lines.

Sensitivity and window period

Nineteen of 20 counsellors gave the client information concerning sensitivity. (The twentieth refused to give any information concerning sensitivity, specificity, and the predictive value before the test result was obtained. When the client picked up the test result, he got no information either.) Most counsellors gave the client realistic information concerning the sensitivity (Table 1). However, five of the 19 counsellors incorrectly informed the client that it would be impossible to get a false negative result, except during the window period. Fifteen counsellors provided information concerning the window period when asked for the sensitivity. The median estimate for the window period was 12 weeks.

False positives

Thirteen of 19 counsellors informed the client incorrectly that false positives do not occur (e.g. Session 1). Eleven of these explained that the reason is that repeated testing with ELISA and Western blot eliminates all false positives. Five of these 13 counsellors told the client that false positives had occurred in the 1980s, but no longer today, and two said that false positives would occur only in foreign countries, such as France, but not in Germany. In

addition to these 13 counsellors, three other counsellors first suggested that false positives would not occur, but became less certain when the client repeated his question, and admitted the possibility of false positives (Sessions 2 and 3). Only the three remaining counsellors informed the client right away about the existence of false positives. One of them (Session 4) was the only counsellor who informed the client about the important fact that the proportion of false positives to true positives is particularly high in heterosexuals such as the client.

Prevalence

The question concerning the prevalence of HIV in heterosexual men with low-risk behaviour produced the most uncertainty among the counsellors. Sixteen of 20 (all counsellors responded) expressed uncertainty or ignorance, or argued that the prevalence for heterosexual men with low-risk behaviour cannot be determined (e.g. because of unreported cases), or that it would be of no use for the individual case (e.g. Session 2). Several counsellors searched for publications in response to the client's question but found only irrelevant statistics, such as the large number of HIV positives in West Berlin: 'The Wall was the best condom for East Berlin', one counsellor answered. Twelve counsellors provided numerical estimates, with a median of 0.1%. The variability of the estimates was considerable (Table 1), including the extreme estimate that in people such as the client an HIV infection is, 'less probable than winning the lottery three times' (we have not included this value in Table 1). Four counsellors asserted that information concerning prevalence is of little or no use: 'But statistics don't help us in the individual case—and we also have no precise data' (see also Sessions 2 and 3). Two counsellors said that they have problems remembering numbers or reasoning with numbers, for instance: 'I have difficulties reasoning with statistical information. It's about groups and the transfer is problematic. It reminds me of playing the lottery. The probability of getting all six correct is very small; nevertheless, every week someone wins.'

Positive predictive value

Recall that under the currently available estimates, only some 50% of heterosexual German men with low-risk behaviour actually have HIV if they test positive. The information provided by the counsellors was quite different. Half of the counsellors (ten of 18; two repeatedly ignored this question) told the client that if he tested positive it was absolutely certain (100%) that he has HIV (Table 1 and Session 1). Five told him that the probability is 99.9% or higher (e.g. Session 3). Thus, if the client had tested positive and trusted the information provided by these 15 counsellors, he might indeed have contemplated suicide, as many have before (Stine, 1996).

How did the counsellors arrive at this inflated estimate of the predictive value? They seemed to have two lines of thought. A total of eight counsellors confused the sensitivity with the PPV (a confusion also reported by Eddy, 1982, and Elstein, 1988), that is, they gave the same number for the sensitivity and the PPV (e.g. Sessions 2 and 3). Three of these eight counsellors explained that except for the window period, the sensitivity is 100% and therefore the PPV was also 100%. Another five counsellors reasoned by the second strategy. They (erroneously) assumed that false positives would be eliminated through repeated testing and concluded from this (consistently) that the PPV is 100%. For both groups, the client's question concerning the PPV must have appeared as one they had already answered. In fact, more than half of the counsellors (11 of 18) explicitly introduced their answers with a phrase such as, 'As I have already said ...' (e.g. Sessions 1–3). Consistent with this observation, the

answers to the question concerning the PPV came rather quickly, and the client did not need to ask for clarification as often as before. The average number of questions asked by the client on the PPV was only 1.8, compared to 2.4, 2.4 and 2.5 for sensitivity, specificity and prevalence, respectively.

Table 1 lists two counsellors who provided estimates of the PPV in the correct direction (between 99% and 90%). Only one of these (Session 4), however, arrived at this estimate by reasoning that the proportion of false positives among all positives increases when the prevalence decreases. She was also the only one who explained to the client that there are reasons for false positives that cannot be eliminated by repeated testing, such as that the test reacts to antibodies that it confuses with HIV antibodies. The second counsellor first asserted that after a positive test an HIV infection is 'completely certain', but when the client asked what 'completely certain' meant, the physician had second thoughts and said that the PPV is 'at least in the upper 90s' and 'I can't be more exact'.

How is the information communicated?

As mentioned above, experimental studies have shown that information about uncertainty and risks is better communicated and understood if presented in natural frequencies rather than in terms of probabilities and percentages. How did the counsellors communicate the information to the client? There was not a single counsellor who communicated the information in natural frequencies, the representation physicians and lay people can understand best. Except for the prevalence of HIV, all numerical information was communicated to the client in terms of percentages. The four sessions in the Appendix illustrate this fact. As a consequence, clients will most likely not understand, and several counsellors also seemed not to understand the numbers they were communicating. This can be inferred from the fact that several counsellors gave the client inconsistent pieces of information but seemed not to notice.

Two examples illustrate this fact. One physician told the client that the prevalence of HIV in men such as the client is 0.1% or slightly higher, and the sensitivity, specificity and the PPV are each 99.9%. To see that this information is contradictory, we represent it in natural frequencies. Imagine 1,000 men taking an HIV test. One of these men (0.1%) is infected and he will test positive with practical certainty. Of the remaining uninfected men, one will also test positive (because the specificity is assumed to be 99.9%, which implies a false positive rate of 0.1%). Thus, two test positive and one of them is infected. Therefore, the odds of being infected with HIV are 1 to 1 (50%), and not 999 to 1 (99.9%). (Even if the physician assumed a prevalence of 0.5%, the odds are 5 to 1 rather than 999 to 1.)

Next consider the information the client received in Session 2. Assume for the prevalence (which the counsellor did not provide) the median estimate of the other counsellors, namely 0.1%. Again imagine 1,000 men. One has the virus and he will test positive with practical certainty (the counsellor's estimated sensitivity: 99.8%). Of the remaining uninfected men, three will also test positive (the counsellor's estimated specificity: 99.7%). Thus we expect four to test positive, one of whom actually has the virus. Therefore, the probability of being infected if the test is positive is 25% (one in four), not 99.8% as the counsellor told the client.

If the counsellors had been trained to represent information in natural frequencies, these inconsistencies could have been easily detected. But the counsellors seem to have had no training in how to represent and communicate information concerning risk. A hypothetical session in which an 'ideal' counsellor uses natural frequencies is shown below. Because the client did not find such a counsellor, the following session is fictional:

Sensitivity? The test will be positive in about 998 of 1,000 persons with an HIV infection. Depending on circumstances, such as the specific tests used, this estimate can vary slightly.

False positives? About 1 in 10,000. False positives can be largely reduced by repeated testing (ELISA and Western blot), but not completely eliminated. Among the reasons for false positives are ...

Prevalence? About 1 in 10,000 German heterosexual men with low-risk behaviour is HIV infected.

Positive predictive value? Think about 10,000 heterosexual men like you. One is infected and he will test positive with practical certainty. Of the remaining non-infected men, one will also test positive. Thus we expect that two men will test positive, and only one of them has HIV. This is the situation you are in if you test positive. Your chance of having the virus is about 50%.

Do the brochures available in AIDS centres, a source from which the counsellors might draw, provide help in understanding what a positive test means when prevalence is low? We studied 78 different brochures from the 20 centres, some of them handed to the client by counsellors, ranging from publications of the federal government to reports from the local counselling sites. These brochures contained a flood of useful pieces of information, such as facts concerning the media through which the virus can and cannot be transmitted, but very little about what a positive test means when prevalence is low. In particular, there was no information about the prevalence in men and women with no risky behaviour. The most frequently available literature was a series of ten issues edited by the Federal Centre for Health Education (Bundeszentrale für gesundheitliche Aufklärung, 1988–1993). In the first issue, the problem of false positives is mentioned, and it is remarked that the repeated test is 'reliable'. In the second issue, false positives are again briefly mentioned and the reasonable recommendation is made that people who have no known risk and nevertheless test positive should head for a second test, for instance in a public counselling site. (One might wonder what those counsellors who believe that a positive result is absolutely certain will tell such a person.) The third issue promises 'in the near future' antibody tests that identify HIV-1 and HIV-2 infections with certainty—in contradiction to the statement of the Enquete Committee of the German Bundestag (Deutscher Bundestag, 1988, p. 79) that there will be no absolute certainty in identifying HIV, as there is none with other viral infections. Nor do the remaining issues provide quantitative estimates of the uncertainties involved with the test. Quantitative estimates are only made for the window period, which is irrelevant for the number of false positives. In no case is an attempt made to explain to the reader the relation between prevalence, sensitivity, false positives and the positive predictive value in an understandable way. Thus, based on these brochures, neither the counsellor nor the client can learn what a positive test means when prevalence is low.

Conclusions

This study shows, for a sample of public AIDS counselling centres in Germany, that counsellors were not prepared to explain to a man with low-risk behaviour what it would mean if he tested positive for HIV. This is not to say that the counsellors were generally ignorant; on the contrary, several counsellors gave long and sophisticated lectures concerning immunodiagnostic techniques, the nature of proteins and the pathways of infection. But when it came to explaining to the client the risk of being infected if he tests positive, there was a lack of information as well as a lack of knowledge of how to communicate risks.

The key problems identified in this study are:

- (1) All counsellors communicated information in terms of probabilities and percentages rather than in a format which helps the clients (and themselves) to understand, such as natural frequencies.
- (2) Only one of 20 counsellors (Session 4) explained the fact that the lower the prevalence, the higher the proportion of false positives among positive tests.
- (3) A majority of counsellors incorrectly assured the client that false positives would never occur. Counsellors had a simple, deterministic explanation: false positives would be eliminated through repeated testing (and similarly, false negatives would be eliminated after the window period).
- (4) Half of the counsellors asserted incorrectly that if a low-risk person tests positive, it is absolutely certain (100%) that he is infected with the virus. Counsellors arrived at this erroneous judgement by one of two strategies. One group confused the sensitivity of the test with the PPV. A second group assumed that there are no false alarms because of repeated tests, which implies that a positive test indicates an infection with absolute certainty.

We do not know how representative these results are for AIDS counselling of low-risk client groups in other centres in Germany, or in other countries. This study seems to be the first one of this kind, but there is no reason to believe that the sample of counselling centres visited is not representative of Germany (precisely, former West Germany). The lesson of this study is the importance of teaching counsellors how to explain to clients in simple terms the risks involved. The counsellors need rough estimates of false positives, sensitivity, and the prevalence of HIV in various risk groups. Then they can be taught to communicate this information in an understandable way. Experimental evidence suggests that the most efficient and simple method is to train counsellors to represent the relevant information in natural frequencies, and to communicate it to the client in the same way.⁴ Such training takes little time and is cost-effective. For instance, a computerized tutorial that teaches how to construct frequency representations lasts less than two hours, including evaluation (Sedlmeier & Gigerenzer, 1998). Most importantly, participants in this training do not show the usual decay of what they had learned over time.

The competence to explain in simple words what a positive result means is certainly not all that a counsellor needs to be able to do, but it is an important part. Proper information may prevent self-destructive reactions in clients. These reactions are avoidable, an unnecessary toll on top of the one the disease itself takes from humankind.

Acknowledgements

This work has been financially supported by the Fonds zur Förderung der Wissenschaften (P8842-Med) and by the Deutsche Forschungsgemeinschaft (Ho 1847/1-1). We also thank Christian Fiebach, Adam Goodie, Andreas Stoltze and Anita Todd for their help and comments on previous drafts.

Notes

- [1] In their review of suicidal behaviour and HIV-infection, Catalan and Pugh (1995) conclude that 'suicidal ideas, completed suicide and deliberate self-harm are not uncommon in people with HIV-infection' (p. 119). However, as they themselves point out, the evidence is far from conclusive: many reports are anecdotal or involve few cases, results vary between countries, and methodological problems make matching with comparison groups difficult (e.g., Marzuk & Perry, 1993; Pugh *et al.*, 1993). A recent prospective cohort study that controlled for several

factors found a 1.35-fold increase in suicides in HIV-positives relative to HIV-negatives, whereas earlier studies reported a 7- to 36-fold increase in risk for HIV-positives (Dannenberg *et al.*, 1996).

- [2] This is a crude estimate, given that there seem to be no published figures for the prevalence of HIV for 20- to 30-year-old men with low-risk behaviour in Germany. This value is based on two approximations. One is to estimate the unknown prevalence by the known prevalence in first-time male blood donors (as opposed to repeat donors, who are a highly selected group). The proportion of HIV-positives in some 130,000 first-time male blood donors (1986–1991, state of Baden-Württemberg) was 1.5 in 10,000 (Maurer *et al.*, 1993). For comparison, the proportion among repeat donors was one order of magnitude smaller, about 1.2 in 100,000 (Maurer *et al.*, 1993). Because false positives occur, the proportion of men actually infected is smaller than 1.5 in 10,000. This estimate is crude in several respects; for instance, it does not differentiate by age group and assumes that men with low-risk behaviour are comparable to first-time blood donors.

A second way to estimate the unknown prevalence is by the proportion of HIV-positives who report infection through heterosexual contact. Dietz *et al.* (1994, p. 1998) found that 3.8% of HIV-positives reported that they were infected by heterosexual contact, as opposed to homosexual/bisexual behaviour, injecting drug use, and other risks (for similar figures see Glück *et al.*, 1990; Hoffman-Valentin, 1991; Schering AG, 1992). In 1994, when our study was begun, the number of HIV-positives in Germany was about 65,000, of which some 29% were in the 20- to 30-year-old age group. If one assumes that the figure of 3.8% also holds for this age group, this results in an estimated 700 HIV-positives in this age group reporting infection through heterosexual contact. Because in 1994 there were an estimated 6,000,000 German men between 20 and 30 who were in no known risk group (a total of 6,718,500 men minus an estimated 11% who belong to one or more of the known risk groups, see Statistisches Bundesamt, 1994), the proportion of HIV-positives who report infection through heterosexual contact can be estimated as 1.2 in 10,000.

Both ways to estimate the unknown prevalence give consistent numbers; nevertheless, they should only be taken as rough approximations. Because not all of these HIV-positives have the virus (due to false positives), we need to correct these numbers downward. A prevalence of about 1 in 10,000 seems to be a reasonable estimate for the unknown prevalence of the HIV virus in 20- to 30-year-old heterosexual German men with low-risk behaviour.

- [3] Among the reasons for false positives are the presence of cross-reacting antibodies (Stine, 1996); false positive reactions with non-specifically 'sticky' IgM antibodies (Epstein, 1994, p. 56); false positives from samples placed in the wrong wells; and contamination of wells containing negative specimens by positive samples from adjacent wells. In addition, heat-treated, lipemic, and hemolyzed sera may cause false positives; false positive results have been reported to occur in 19% of haemophilia patients and in 13% of alcoholic patients with hepatitis (George & Schochetman, 1994, p. 69). People who have liver disease, have received a blood transfusion or gamma globulin within six weeks of the test, or have received vaccines for influenza and hepatitis B may test false positive, as well (Stine, 1996, p. 333).
- [4] There is also experimental evidence that the error made most often by AIDS counsellors in this study, confusing the sensitivity with the PPV of the test, is markedly reduced (from 19% to 5% of all diagnostic inferences) when information is represented in terms of frequencies rather than probabilities (Hoffrage & Gigerenzer, 1998).

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Appendix

Four sample counselling sessions. After each question, the answer of the counsellor is given. The following lines (beginning with a ‘—’) are the counsellor’s responses to the client’s request for clarification.

Session 1: The counsellor is a female social worker

Sensitivity? False negatives really never occur. Although, if I think about the literature, there were reports about such cases.

—I don’t know exactly how many.

—It happened only once or twice.

False positives? No, because the test is repeated; it is absolutely certain.

—If there are antibodies, the test identifies them unambiguously and with absolute certainty.

—No, it is absolutely impossible that there are false positives; by repeating the test it is absolutely certain.

Prevalence? I can’t tell you this exactly.

—Between about 1 of 500 to 1 of 1,000.

Positive predictive value? As I have now told you repeatedly, the test is absolutely certain.

Session 2: The counsellor is a male physician

Sensitivity? When there are enough antibodies, then the test identifies them in every case. Two tests are performed; the first test is in its fourth generation and is tuned to be very specific and sensitive. Nevertheless, it is tuned in a way that it is more likely to identify positives than negatives.

—99.8% sensitivity and specificity. But we repeat the test, and when it comes out positive, then the result is as solid as cast iron.

False positives? With certainty, they don’t occur; if there are false results, then only false negatives, occurring when the antibodies have not formed.

—If you take the test here, including a confirmatory test, it is extremely certain: in any case the specificity is 99.7%. This is as solid as cast iron. We exclude confusions by using two tests.

Prevalence? The classification of individuals into risk groups is by now outdated, therefore one cannot look at it that way.

—I don’t remember this. There is a trend of the virus spreading in the general public. Statistics are of no use for the individual case!

Positive predictive value? As I already have said: extremely certain, 99.8%.

Session 3: The counsellor is a female physician

Sensitivity? The test is very, very reliable, that is, about 99.98%.

False positives? The test will be repeated. After the first test, one does not speak of positive, but only of reactive. When all tests are performed, then the result is sure.

—It is hard to say how many false positives occur.

—How many precisely? I would have to look up the literature to see if I could find this information there.

Prevalence? That depends on the region.

—Of the circa 67,000 infected people [in Germany] 9% are heterosexual.

—In Munich we have 10,000 infected people, that is, 1% of the population. But these are only numbers, which tell you nothing about whether you have the virus or not.

Positive predictive value? As I already have mentioned, the result is 99.98% sure. If you get a positive result, you can trust it.

Session 4: The counsellor is a female social worker

Sensitivity? Very, very reliable.

—No, not absolutely sure, such a thing doesn't exist in medicine, because it may be possible that the virus cannot be identified.

—Close to 100%; I don't know exactly.

False positives? They exist, but are extremely rare.

—In the order of a tenth of a percent. Probably less. However, in your risk group, compared to high-risk groups, false positives are proportionally more frequent [than true positives].

—I don't know the exact value.

Prevalence? With the contacts you had, the infection is unlikely.

—Generally one can't say. In our own institution, among some 10,000 tests in the last seven years, there were only three or four heterosexuals, non-drug addicts, or similar non-risk-group persons who tested positive.

Positive predictive value? As mentioned, the test is not 100% sure. If the test confuses the [HIV] antibodies with others, then other methods such as repeated tests do not help. And if someone like you does not have a real risk, then I could imagine that even 5% to 10% of those who get a positive result will have gotten a false positive result.