

# The Utilization of Testing and Counseling for HIV: A Review of the Social and Behavioral Evidence

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Against the background of debates about expanding HIV testing and counseling, we summarize the evidence on the social and behavioral dimension of testing and its implications for programs.

The discrepancy between acceptance of testing and returning for results and the difficulties of disclosure are examined in light of research on risk perceptions and the influence of gender and stigma. We also summarize the evidence on the provision of testing and counseling, the implementation of practices regarding confidentiality and consent, and the results of interventions.

We demonstrate that social factors have a considerable impact on testing, show that the services linked to testing are key determinants of utilization, and consider the implications of these findings for HIV testing programs. (*Am J Public Health*. 2007;97:1762–1774. doi:10.2105/AJPH.2006.096263)

Testing for HIV is the gateway to treatment, care, and prevention. To scale up treatment and prevention, rapid increases in both the volume of testing and the ability to counsel those who are tested are needed. The use of testing globally, however, is very low. Recent estimates based on surveys in 12 high-burden countries in sub-Saharan Africa indicate that a median of just 12% of men and 10% of women in the general population have been tested for HIV and received the results.<sup>1</sup> Even in more developed countries, about 20% to 30% of seropositive individuals are unaware that they are HIV positive.<sup>2</sup> This means that most people living with HIV get testing and counseling only when they already have advanced clinical disease. Concerns over the gap between needs and reality have led to urgent calls for dealing with this important “unfinished business” and expanding testing in developing countries.<sup>3</sup>

*HIV testing* is often used as an umbrella term to refer to both testing and counseling services. Diagnostic testing refers to HIV testing that occurs within a clinical care setting to aid in patient care management. Voluntary counseling and testing emphasizes the need for voluntary, informed consent prior to testing as well as pre- and posttest counseling. Routine testing in clinical settings, whereby patients are asked if they would like to be tested (“opt-in testing”) or are informed that

they will be tested as part of routine procedures unless they refuse (“opt-out testing”), is increasingly advocated. This is different from “routinely” conducting tests in medical settings without informing patients or seeking their consent. The terminology reflects ongoing debates about consent, as well as the tension between safeguarding individual rights and protecting public health: should testing be universal, routinely practiced, routinely offered, or only performed at an individual’s request and where indicated for individual cases? Is voluntary counseling and testing the only way to ensure consent?<sup>4–6</sup>

In an effort to avoid the potential confusion of earlier terminology, the World Health Organization (WHO) has recently proposed a formulation that distinguishes between 2 types of HIV testing, both voluntary: client-initiated testing, corresponding to what is usually referred to as voluntary counseling and testing, and provider-initiated testing. The latter is conducted at health facilities as part of clinical care to diagnose patients who present with signs and symptoms suggestive of HIV or to aid in providing care to nonsymptomatic patients in areas of high prevalence or at clinics used by populations that may be at special risk of HIV.<sup>7</sup>

The history of HIV testing shows that the issue has always stirred much controversy. In the mid-1980s, when tests became available,

public health measures that were commonly accepted for other diseases (such as compulsory testing, contact tracing, and quarantine) were called into question. Fears of the social and political consequences of mandatory reporting of HIV-positive status, and concerns that such measures could lead to discrimination and “drive the epidemic underground,” prevailed over traditional public health approaches, and only confidential and anonymous testing was considered acceptable.<sup>8</sup> With the availability of treatment, however, such exceptionalism came to be less defensible, and scaled-up testing is increasingly advocated both as a gateway to treatment and prevention and as a way to “normalize” and destigmatize HIV.<sup>9–11</sup>

Support has been growing for incorporating HIV testing and counseling into routine health care, including prenatal care, care for sexually transmitted infections, hospitalization, or even general primary care. Research showing that voluntary counseling and testing is associated with the adoption of preventive behavior,<sup>12,13</sup> and that routine screening for HIV is cost-effective<sup>14</sup> has bolstered the position of those in favor of expanding testing programs. Some observers, however, continue to express caution over the potential stigma, discrimination, and violence that may be associated with disclosure of HIV-positive status.<sup>15,16</sup> Supporters argue that concerns over the protection of individual rights should not prevail over the public health benefits of expanded testing.<sup>10,17</sup>

In 2004, WHO and the Joint United Nations Program on AIDS (UNAIDS) had recommended the routine offer of testing with the choice to opt out<sup>5</sup>; in 2007, they issued a Guidance for Provider-Initiated Testing and Counseling in Health Facilities.<sup>7</sup> In 2006, the Centers for Disease Control and Prevention (CDC) called for routinely testing people aged 13 to 64 years and for simplifying the process of obtaining consent.<sup>18</sup> Recommendations to expand testing

raise numerous questions about the application of the policy and its consequences in different settings. These questions relate to the feasibility of providing the needed referral, treatment, and prevention services related to HIV testing; the protection of individuals identified through testing; whether it is truly possible to “opt out” of testing; ensuring consent and confidentiality; and the extent to which routine testing encourages prevention, reduces stigma, and promotes behavior change.

The evidence needed to inform debates about the best way to implement testing and counseling programs is patchy. Although statistics are increasingly available, and there have been comparative studies of the effectiveness of voluntary counseling and testing,<sup>12</sup> less is known about the factors that influence utilization in different settings, with some studies casting doubt on the notion that the positive effects observed in small studies are necessarily replicated as testing expands.<sup>19</sup> Nor do we understand the reasons for differential use, even though discussions often refer to gender, stigma, or poverty as obstacles to the utilization of testing. The issue of HIV testing is often addressed as if all HIV tests were conducted for the same purposes and under the same circumstances.

There are, however, important differences between voluntary counseling and testing, testing conducted for diagnostic purposes among ill patients, routinely offered testing at health facilities, testing for purposes of surveillance among healthy populations, and mandatory testing that is carried out when required by law—each of which may require different information and different standards to ascertain consent and ensure confidentiality. The epidemiological context in which testing is conducted also makes a difference—high- or low-prevalence settings have different implications for the identification of HIV-positive individuals or so-called “risk groups.”

In general, the operational evidence to inform policies is insufficient, and little is known about how guidelines about testing are in fact implemented, especially in high-prevalence countries, which factors facilitate utilization, and to what extent testing is accelerated when treatment becomes available. And yet it is information about context, attitudes, and

behaviors that is most urgently needed to improve programs. After all, whether testing does open the gate to treatment and promotes prevention depends in large part on the extent to which fears of testing are overcome, adverse consequences of disclosure are avoided, and providers can connect clients to appropriate treatment and prevention services. This, in turn, requires an understanding of the contextual factors that facilitate or hinder testing, both within health facilities and elsewhere.

We focus on 1 set of factors related to the utilization of testing and counseling, namely those related to the users and providers of services, their interactions, and the context of those interactions. Our analysis, based on a review of the literature on the sociobehavioral dimension of testing and counseling, is designed to complement analyses that focus on the epidemiological, managerial, and policy dimensions. Given that the evidence is disparate and that the goal of the analysis was not to test a specific hypothesis, it was neither feasible nor desirable to carry out a proper meta-analysis; we thought a systematic summary was more appropriate for highlighting the main themes that emerge from existing studies.

## METHODS

We included sources on all the different approaches to testing and refer to the process by the term *testing and counseling*, which implies that counseling is provided along with testing, unless otherwise indicated. The literature on HIV testing and counseling is vast. For example, a MEDLINE search on HIV infections with a focus on diagnosis retrieved 6547 references for the period January 1996 to April 2005; a similar search using EBSCO retrieved 11 338 titles. Such large numbers make it difficult to thoroughly review all the sources. Interestingly, as illustrated by the Prevention Research Synthesis Project of the CDC, searching selected sources by hand can often be more productive than simply relying on computerized searches.<sup>20</sup> Hence, a combination of focused computerized retrieval and hand searching was adopted here.

The following databases were searched for articles on HIV testing that have appeared since January 1996: PubMed, Psyc Info,

SocioFile, and Social Science Index. We used the intersection of 2 sets of keywords: *HIV infections* and *HIV antibodies*, and *test(ing)* and *diagnosis*. To exclude purely biomedical and microbiological studies, we narrowed down our search through use of the keywords *behavior*, *risk factor*, *surveillance*, *interview*, *focus group*, and *social science*, thereby retaining articles with social and behavioral information on providers or clients. Titles were scanned, and 550 abstracts and articles dealing with behaviors related to HIV testing were retrieved.

After the database searches were completed, we conducted focused searches, based on prior knowledge of particular research projects and the suggestions of experts in the area. We also reviewed bibliographies of major articles; collected documents by UNAIDS, WHO, and the CDC; and searched Web sites of key organizations whose work deals with HIV testing. In this way, we further retrieved 150 abstracts and 35 articles, for a total of about 700 abstracts and 200 articles. We also made an effort to include the main results from conference abstracts and articles that appeared between acceptance of the manuscript and publication date, thus adding about 150 more sources to the database.

## THE EVIDENCE ABOUT TESTING

A considerable proportion of the information on the levels and demographic determinants of testing comes from studies of specific groups at risk. In low-HIV-prevalence countries of the Northern Hemisphere, attention has been directed primarily at men who have sex with men, as well as migrants and intravenous drug users. In Africa, most studies come from programs for pregnant women and high-risk groups such as mine workers, truck drivers, and sex workers.

The statistical evidence on HIV testing is growing, thanks both to national surveys and surveys among particular populations. It shows that coverage is low everywhere, including in many high-prevalence countries.<sup>4,21,22</sup> Despite the wealth of statistics, however, comparative analyses have been limited. Few analyses have investigated differentials in utilization to derive general

patterns, such as the association of education, income, or gender with behavior regarding testing. Most studies tend to focus on measuring the statistical associations among variables that are detached from their social context. These explanatory frameworks, often inspired from psychology, have tended to be individualistic and to assume a rational and unidirectional connection between ideas and behaviors—an assumption that is not always tenable. A few studies have used microlevel ethnographic or qualitative methods, but they tend to be limited to small samples whose representativeness is unknown. As has been observed for research on sexual behavior and HIV, few studies have overcome the barriers between disciplinary boundaries and integrated qualitative and quantitative approaches.<sup>23,24</sup>

The diversity of policies regarding testing and counseling underscores the multiplicity of approaches to testing and what it means in different contexts. For example, in Botswana since 2004, prenatal care programs began to implement opt-out testing and counseling; this resulted in higher rates of testing, raising questions about the ethical aspects of scale-up.<sup>25</sup> In Uganda, where the Ministry of Health has revised its policy guidelines, several models for providing testing and counseling co-exist: the routine offer of testing at health facilities, home-based voluntary counseling and testing whereby individuals are offered testing and given results in their home, and traditional freestanding voluntary counseling and testing centers. In Burkina Faso, the rate of testing has increased, despite very limited treatment.<sup>26,27</sup> India's private hospitals are said to conduct mandatory testing on prospective surgical patients, and some studies have in fact documented that many Indian patients are tested without consent.<sup>28,29</sup> In Holland, opt-out testing in prenatal care clinics has been implemented for several years.

Debates about policies reflect the shifting context of testing as a result of the availability of treatment. They also serve to illustrate the difficulty of reconciling the protection of the privacy of HIV-positive individuals with concerns for the safety of others who may be endangered if information is withheld. The possibility of allowing health workers to disclose patients' status to their partners has

been discussed in African countries, where it is referred to as "beneficial disclosure."<sup>30,31</sup> In Singapore, the Health Ministry makes it mandatory to inform the spouses of HIV patients.<sup>32</sup> Such examples underscore the need for information about the implementation of guidelines regarding consent and confidentiality in different settings.

In the remainder of this article, we summarize the evidence on the social and behavioral dimension of testing and the statistical evidence implications for programs. In the first part of the analysis, we consider statistics on testing and individuals' reluctance to be tested, get results, and disclose their status. We examine patterns of testing and disclosure in light of research on social and behavioral determinants, including the role of risk perception and the influence of gender and stigma. In the last part of the article, we shift attention to health facilities and review the evidence on how services linked to testing are provided, the role of providers, the provision of counseling, the implementation of practices regarding confidentiality and consent, and the results of interventions.

### ACCEPTANCE OF TESTING AND RETURNING FOR RESULTS

An examination of statistics on testing and counseling reveals a large discrepancy between levels of acceptance of testing and levels of returning for results (Table 1). This discrepancy reflects the conditions that prevailed with the first generation of tests, still used in some low-prevalence countries, which require delays of about 2 weeks between testing and results, in contrast to recent tests, which can give results in about 20 minutes. A comparative analysis indicates that with delayed results, the percentage of the population agreeing to be tested frequently reaches 80% or 90%, but the percentage who return to get their results is much lower, around 60% of those who get tested.<sup>60</sup> An international mailing survey on attitudes toward testing in 13 sites in Asia and Africa found near-universal acceptance of testing but lower rates of returning for results.<sup>61</sup>

In studies in the United States, primarily among clients at clinics for sexually transmitted infections, between 10% and 66% of individuals did not return for results.<sup>40,52,57,62</sup>

In African settings, it has often been shown—for example, in a Dar es Salaam study,<sup>45</sup> in a study of Rwanda antenatal clinics,<sup>46</sup> and in another of Kenya antenatal clinics<sup>44</sup>—that approximately one third of clients do not return for results. In some African studies, the proportion was even higher. In a study of male factory workers in Zimbabwe, almost one half did not return for results.<sup>48</sup> In Abidjan, Ivory Coast, where 78% of women attending prenatal care expressed acceptance of testing, only 58% returned for results.<sup>34</sup> In Zambia, acceptance of testing was about 50%, but rates of completing the process and returning results was as low as 12%.<sup>37</sup> Among South African women who did not accept antenatal screening, none wanted to know their status, and 44% were in fact HIV positive.<sup>63</sup> Often, those less at risk tend to be more interested in knowing their status.<sup>51,64</sup> Even in Burkina Faso, where the increase in voluntary testing and counseling has been phenomenal, utilization is higher among low-risk groups, and many pregnant women do not return for results.<sup>34,53</sup> The fact that this discrepancy between testing and returning for results holds across settings underscores the importance of the problem and the need for a better understanding of the factors that account for it.

Refusal to be tested or to obtain test results has been attributed in part to obstacles of cost and transportation and to the burden of having to return to health facilities. Rapid tests and home testing have been advocated to address these difficulties. We summarize recent evidence about these new approaches in the last part of this article.

### PERCEPTION OF RISKS AND CONSEQUENCES OF HIV

Although it is clear that practical constraints, delays in test results, and lack of knowledge hinder the utilization of HIV testing, the major barrier is individuals' reluctance to acknowledge that they are at risk even when in fact they are; this has been documented in studies in the United States and Canada,<sup>65–67</sup> rural Tanzania,<sup>68</sup> Ethiopia,<sup>55</sup> northern Thailand,<sup>69</sup> among pregnant women in the United Kingdom,<sup>70–72</sup> and among poor Brazilian women whose partners are HIV positive.<sup>73,74</sup>

**TABLE 1—Studies on Rates of Patients Who Return for HIV Test Results and Rates of Disclosure of Test Results to Partners**

Authors (Year)	Place	Sample	Patients Returning for Results, %	Patients Disclosing HIV-Positive Status to Partners, %
Antelman et al. (2001) <sup>33</sup>	Dar es Salaam, Tanzania	1078 HIV-positive pregnant women	...	36
Cartoux et al. (1998) <sup>34</sup>	Burkina Faso and Ivory Coast	9724 pregnant women	58-82	...
D'Angelo et al. (2001) <sup>35</sup>	United States	317 HIV-infected adolescents	...	47-77
Erwin et al. (2002) <sup>36</sup>	London, England	102 Black Africans	...	85
Fylkesnes and Siziya (2004) <sup>37</sup>	Urban Zambia	2445 urban residents	20 (clinic testing), 56 (home testing)	...
Gielen et al. (2000) <sup>38</sup>	Baltimore, Md	50 HIV-positive women	...	98
Heyward et al. (1993) <sup>39</sup>	Kinshasa, Zaire	187 HIV-positive and 177 HIV-negative mothers	...	...
Hightow et al. (2003) <sup>40</sup>	Southwest United States	101 HIV-positive patients in STD clinic	42	...
Hope (2004) <sup>41</sup>	Kenya and Zambia	Women in antenatal clinics	51-89	58-81
Kalichman and Nachimson (1999) <sup>42</sup>	Atlanta, Ga	266 HIV-positive people	...	59
Keogh et al. (1994) <sup>43</sup>	Kigali, Rwanda	55 HIV-positive women	...	79
Kiarie et al. (2000) <sup>44</sup>	Nairobi, Kenya	399 pregnant women	69	...
Killewo et al. (2001) <sup>45</sup>	Dar es Salaam, Tanzania	288 HIV-positive pregnant women	68	17
Ladner et al. (1996) <sup>46</sup>	Kigali, Rwanda	1233 pregnant women	69	51
Lie and Biswalo (1996) <sup>47</sup>	Tanzania	611 HIV-positive patients	...	86
Machekano et al. (1998) <sup>48</sup>	Zimbabwe	3383 male factory workers	56	...
Maman et al. (2001) <sup>49</sup>	Dar es Salaam, Tanzania	15 females, 17 males, 15 couples at a VCT clinic	...	69
Maman et al. (2003) <sup>50</sup>	Dar es Salaam, Tanzania	245 female VCT clients	...	64
Mkaya et al. (2005) <sup>51</sup>	Rural South Africa	628 rural residents	80	...
Molitor et al. (1999) <sup>52</sup>	California	366 280 clients	84	...
Nebie et al. (2001) <sup>53</sup>	Burkina Faso	306 HIV-positive pregnant women	...	18
Passin et al. (2006) <sup>54</sup>	United States	Systematic review	...	...
Sahlu et al. (1999) <sup>55</sup>	Ethiopia	751 factory workers	63	...
Stein and Nyamathi (2000) <sup>56</sup>	Boston, Mass	203 HIV-positive adults	...	60
Sullivan et al. (2004) <sup>57</sup>	7 US states	2241 people at high risk of HIV	73-90	...
Wolff et al. (2005) <sup>58</sup>	Uganda	National serosurvey data from home testing	37-46	...
Wurcel et al. (2005) <sup>59</sup>	Boston, Mass	203 patients	40 (standard testing), 60 (rapid testing)	...

Note. STD = sexually transmitted disease; VCT = voluntary counseling and testing.

The fact that individuals' perceptions of their risk of HIV do not match objective assessments, and that information does not necessarily translate into risk avoidance, is consistent with the literature on health behavior in general. Studies repeatedly show that correct and erroneous notions of transmission and treatment coexist; they also document behaviors that are at odds with professional perspectives, such as doubting the existence of HIV, denying dangers, inexplicable optimism, the exaggerated concerns of those not at risk, failure to adopt protective behaviors, and stigmatization of victims.<sup>23,24,75-79</sup> Whether or not there is something about HIV that has made it a more fertile terrain for apparently "irrational" beliefs and behaviors—

the mystery surrounding its origins, the uncertainty of prognosis, or its association with human relationships—the point is that information about HIV is often confusing, has emotional connotations, and cannot simply be reduced to its medical content.

A recurrent finding is that the main reason people do not take HIV tests or return for results is fear. This is not surprising, since HIV is life threatening. But fear is also about the social consequences of the illness—rejection by loved ones, loss of job or housing, discrimination, and violence.<sup>80</sup> In addition, where it is a terminal illness, HIV represents a breakdown in the ties of reciprocity that link individuals, because it is not worth "investing" in a relation-

ship with someone who will not be around for long; this may lead to ostracism and isolation.<sup>81</sup>

A frequently observed pattern is the discrepancy between intent to be tested and actual behavior. Because of worries about consequences, individuals often do not execute their plan to take HIV tests.<sup>72</sup> In 6 African countries, a reported two thirds or more of respondents stated they would like to get tested, but the proportion of those who reported being tested was much lower, around 15% in some settings.<sup>19</sup> Rates of failure to be tested among those who intended to be can be as high as 70%.<sup>82</sup> Individuals may plan to inform partners and return for joint counseling but then change their minds. In a study of mothers in Zaire, such intentions were as high

as 70%, but only 2% followed up 12 months later.<sup>39</sup> Although several of the studies have limitations in that they ascertained intent through simple direct questions, the disconnect between intentions and behaviors makes sense if considered in light of the difficulty of dealing with the multiple social and medical consequences of the illness.

The significance of HIV tests goes well beyond the information about serostatus that they provide; their results have a powerful impact on patients' lives, often leading to a complete redefinition of a person's social relationships. It is in this light that one needs to consider appeals to the "right to know" one's HIV status as implemented in some programs.<sup>17,83,84</sup> Although this approach may work in some settings, the effectiveness of casting HIV tests in a rights discourse needs to be assessed against evidence about how it resonates with local views. Where individuals, far from feeling entitled to know their status, are fearful of results and ambivalent about tests, complementary approaches should be explored.

## MEANINGS OF TESTING AND DIFFICULTIES OF DISCLOSURE

Levels of disclosure and partner involvement after tests are variable and generally low. In Tanzania, one study found that only 22% of women had told their partners of their status after 2 months, and 40% had disclosed their status after 4 years<sup>33</sup>; another study found that 64% of HIV-positive and 80% of HIV-negative women had disclosed their status to their partners.<sup>50</sup> In Burkina Faso, only 18% of women made disclosure to their partners<sup>53</sup>; in Zaire, only 2% of women brought their partners for testing<sup>39</sup>; in a US study of gay men, 41% had not disclosed their status to their partners.<sup>42</sup>

Qualitative studies that interview people who have been tested indicate that test results have meanings that are tied to relationships, faithfulness, and trust, and that they may be interpreted in relation to the love or loyalty of a partner. As individuals take HIV tests when they are ending a relationship or starting a new one, disclosure of test results serves to mark such life transitions.<sup>85–89</sup> Disclosure, therefore, is not simply about

conveying medical information. It is often not a definitive move but rather an iterative process fraught with hesitations and retractions.<sup>90–93</sup> In some settings, there are also fears that speaking about the disease may accelerate its course,<sup>94,95</sup> and silence seems a safer option. When disclosure does take place, it may be not to the partner but to another member of the family or to a friend.<sup>47</sup>

The adverse consequences that may follow disclosure have frequently been highlighted, but the evidence is limited and somewhat contradictory. In the United States, a recent systematic review of partner notification services found few negative consequences overall, whereas individual studies have reported negative reactions, including violence, in around 4% of cases.<sup>38,54</sup> A study in Tanzania found that about 50% of women experienced positive responses, and other studies (in Kenya and Zambia) found that most HIV-positive women reported positive outcomes, including some who feared they would not receive support.<sup>41,50,101</sup> A review of 17 studies in developing countries found that negative consequences of disclosure, including violence, were reported in 3% to 15% of cases.<sup>96</sup> Violence and abuse, however, are only the most dramatic of the adverse consequences of disclosure; other reactions ranging from exclusion to expulsion may be more common (see "Influence of Stigma on Testing").

It is difficult to assess to what extent negative reactions relate to testing per se, since often those who suffer them live in difficult conditions where they may be habitually mistreated. Although the evidence does not allow comparisons of levels of abuse before and after notification, the distinction could be useful, because negative reactions that directly result from HIV testing may respond to specific interventions linked to testing, while those that reflect societal discrimination are less amenable to change without broader interventions.

## THE ROLE OF GENDER IN SHAPING MOTIVATIONS AND REACTIONS

Research indicates that everywhere, gender powerfully shapes attitudes toward testing (Table 2). Men tend to underestimate their risk for HIV infection more than do

women, despite reporting more high-risk behaviors, and women have more fears about testing than do men.<sup>55,56</sup> Some studies have found that men are more responsive to mass communications, leaflets, and peer pressure, and women to personal and emotional considerations, rather than objective risk assessments.<sup>99,106–108</sup> Although these studies are of uneven quality, this evidence is consistent with others showing that HIV risk perceptions are strongly influenced by gender.<sup>56,109</sup> A national survey of France showed that women seek to reduce risks by focusing on the personal dimension of their situation, such as trying to find out more about their partners and building trust with them; men, by comparison, are more inclined to adopt specific behaviors such as condom use.<sup>110</sup> Intervention studies show that the information–motivation–behavior models that are usually successful in explaining men's responses to behavior change interventions appear to fall short when trying to predict women's responses.<sup>103</sup>

The negative consequences of testing and fears of disclosure are more frequently documented for women, and this fits with the evidence that outside of prenatal care programs, women are tested less frequently than men.<sup>111</sup> Much of what we know, however, comes from studies of HIV testing among pregnant women. Because pregnancy is a time when women need special support and are fearful of abandonment, it is among this group that fears of abuse are most manifest and the gap between testing and getting results greatest.<sup>33,38,49,68,81,84,94,112–116</sup>

Although not all studies confirm gender differences in general attitudes toward testing,<sup>37,117</sup> differences in specific motivations are consistently documented. Women's decisions about testing appear to be complicated by their plans to have children, their husband's opinion, and their breastfeeding plans.<sup>55,97,100</sup> A recent comparative study in 4 Asian countries (India, Indonesia, the Philippines, and Thailand) found that men were more likely to be tested if they had HIV-related symptoms, whereas women were more likely if their partner tested positive,<sup>105</sup> a pattern that confirms gender differences in exposure to HIV and women's more vulnerable position.

**TABLE 2—Studies on Role of Gender in HIV Testing**

Author (Year)	Sample	Results by Gender, %	Gender Factors That Influence Testing	Conditions and Consequences of Disclosure
Aka-Dago-Akribi et al. (1999) <sup>97</sup>	21 HIV-positive women at antenatal clinic in Abidjan, Ivory Coast	...	Women's social and familial obligations more important than own health status	...
Coulibaly et al. (1998) <sup>94</sup>	100 pregnant women in Abidjan, Ivory Coast	...	Pregnancy a difficult time to find out serostatus	...
Bond et al. (2005) <sup>98</sup>	1116 men and 527 women in Pennsylvania	Women, 85; men, 77	Perceived risk of HIV increases testing for men but not women	...
Das et al. (2004) <sup>99</sup>	250 male and 250 female patients in Birmingham, England	Test acceptance lower among females	...	...
de Paoli et al. (2004) <sup>100</sup>	500 pregnant women in Kilimanjaro, Tanzania	...	Women's perceived benefits for child	Fear of blame and rejection
Fylkesnes and Siziya (2004) <sup>37</sup>	2445 urban residents in Zambia	Men, 12; women, 10	...	...
Gaillard et al. (2002) <sup>101</sup>	290 HIV-positive pregnant women in Mombasa, Kenya	...	...	One third disclosed to their partners; 10% of those who disclosed experienced violence or disruption
Gielen et al. (2000) <sup>38</sup>	310 HIV-positive women enrolled in primary health care at urban teaching hospital in USA	...	...	45% reported emotional or sexual abuse, 4% physical abuse
Laver (2001) <sup>102</sup>	204 adults (102 females) in Zimbabwe	...	Women more worried about HIV, fearful of HIV test	...
Kalichman et al. (2005) <sup>103</sup>	432 men and 193 women at STI clinic in Milwaukee, Wisc	...	"Information-motivation-behavior" interventions more effective for men	...
Maman et al. (2003) <sup>50</sup>	245 female VCT clients in Dar es Salaam, Tanzania; 64% HIV positive and 80% HIV negative disclosed	...	...	52% of women feared partner's reaction; 49% of HIV-positive women received support; <5% reported negative reactions
Murphy et al. (2002) <sup>104</sup>	246 HIV-positive and 141 HIV-negative adolescents in USA	Women, 74; men, 68	No significant differences	...
Paxton et al. (2005) <sup>105</sup>	HIV-positive individuals India (302), Indonesia (42), Thailand (338), and Philippines (82)	...	Men more likely to be tested because of symptoms (37% vs 10%), women because partner is HIV positive (42% vs 11%)	Women more likely than men to be excluded from social interactions and events, forced to change residence, or physically assaulted
Sahlu et al. (1999) <sup>55</sup>	751 (344 female, 407 male) factory workers in Ethiopia	No difference in uptake of posttest counseling	Women: plans for the future; men: previous sexual behavior and health status	...
Stein and Nyamathi (2000) <sup>56</sup>	Disadvantaged women (621) and men (428) in California	No significant predictors of uptake by gender	...	...

Note. STI = sexually transmitted infection; VCT = voluntary counseling and testing.

**INFLUENCE OF STIGMA ON TESTING**

A recurrent theme in the literature on HIV concerns the role of stigma in impeding the

utilization of testing. As the mark of a socially undesirable characteristic that leads to a "spoiled identity," stigma has long received attention from the social sciences, starting with

the analyses of Goffman<sup>118</sup> and more recently with operational research on stigma and various diseases.<sup>119,120</sup> Heightened awareness of the potential for discrimination against people

living with HIV/AIDS has given stigma a central role in policy and program discussions. Stigma against HIV is reported to be pervasive and to be the main reason for the reluctance to be tested, to disclose HIV status, or to take antiretroviral agents. This has been documented in numerous countries, including South Africa, Indonesia, Tanzania, Botswana, Ethiopia, Ghana, India, Uganda, Thailand, and Zimbabwe.<sup>121–135</sup> Even in health care settings, health workers may stigmatize patients by treating them differently, using excessive precautions, or withholding appropriate care.<sup>105,136–139</sup>

Although stigma and discrimination against people living with HIV/AIDS have been amply documented, and although fear of stigma is consistently reported to be a deterrent of testing, few studies provide quantifiable measures of the effect of stigma on HIV testing.<sup>140</sup> Part of the reason is related to the dominance of psychological models in HIV behavioral research, which results in a preponderance of cognitive measures of stigma (e.g., what percentage of a given population hold particular negative beliefs about people living with HIV/AIDS) rather than measures of actual stigmatizing behaviors and their consequences. This tendency is reinforced by the ease with which information on beliefs can be collected in surveys, compared with the difficulty of observing behaviors or analyzing the broader societal forces that influence stigma.<sup>141,142</sup>

Some observers have also noted a degree of “conceptual inflation” in analyses of stigma, whereby many consequences are attributed to it without a thorough examination of alternative explanations and related factors.<sup>141</sup> The various disadvantaged groups that tend to be stigmatized suffer the simultaneous consequences of a multiplicity of undesirable characteristics—for example, poverty, drug use, and HIV-positive status. It is thus difficult to disentangle the effect of these different “layers” of stigma and to assess the specific impact of stigma related to HIV status, as compared with other characteristics.<sup>143</sup>

These points are not simply academic but have implications for programs designed to increase treatment and care utilization. If stigma and discrimination specific to HIV impede testing, then evidence is needed on

those factors that are amenable to change and that would encourage people to use needed services—what economists would refer to as “demand” factors; conversely, if “normalization” of testing reduces stigma, then the emphasis would be on increasing and improving the “supply” of testing. Recent summaries of the multiple measures of stigma and of interventions to reduce it provide useful conceptual and methodological tools<sup>144–147</sup> and can advance our understanding of the links between stigma, the utilization of HIV testing, and the “normalization” of HIV.

### WHO COUNSELS THE COUNSELORS?

Counseling has, until recently, been an integral part of HIV testing. It typically involves a face-to-face session in which a trained counselor provides information about HIV (what the test means and how to prevent transmission), helps clients identify ways to avoid the behaviors that put them at risk, and where appropriate, refers them to services. Under the voluntary counseling and testing model, some counseling is provided before the test, designed to give information and obtain consent; in posttest counseling, the balance of information, encouragement of preventive behavior, and referral depends on whether test results are positive or negative. Because of the nature of HIV and the implications of a positive diagnosis, in communicating about the test great care must be taken to avoid misunderstandings, convey the seriousness of the diagnosis without leading the patient to despair, and encourage appropriate behaviors.

Although numerous guidelines have been formulated to improve counseling, the limited evidence about how testing and counseling are implemented shows great variations in quality. There are considerable differences between well-resourced facilities that provide voluntary counseling and testing and those where HIV testing and counseling are added to the already stretched health services. Where health systems are weak and resources limited, providers may have had insufficient training, and their workloads may be so heavy that they do not find the time or space for counseling. Even when recommended, testing and counseling may not be

systematically provided,<sup>60</sup> and decisions about whom to test are made on the basis of providers’ perceptions of clients’ ability to take potentially bad news.<sup>148</sup> Some studies find that time for counseling is insufficient,<sup>149</sup> the information often not adequate, and the quality of counseling lower for clients from the less-privileged segments of society.<sup>150</sup>

Increasingly, staffing constraints, overloaded facilities, and doubts about usefulness appear to be eroding support for the provision of pretest counseling at health facilities and building support for concentrating on posttest counseling. The latest CDC guidelines on HIV testing in health care settings make counseling advisable but not mandatory, and they streamline pretest informed consent into a standard requirement for consent to all medical tests. A recent Journal editorial called for skipping pretest counseling altogether on the grounds that it is not useful.<sup>10</sup> It is unclear whether the omission of pretest counseling facilitates testing by eliminating a possibly cumbersome practice or whether it hinders testing because clients do not receive needed advice or information. Clearly, more evidence is needed to inform guidelines and tailor requirements to the particular type of testing, whether at voluntary counseling and testing facilities or in the context of clinical care or services to prevent mother-to-child transmission.

The issues surrounding counseling represent a major challenge for the utilization of testing. Much is expected of providers “on the front lines,” but little is known about how they cope. In addition to practical difficulties, they must deal with their own emotional issues regarding HIV.<sup>151</sup> They may be reluctant to be tested and themselves suffer stigma<sup>138</sup>; they may fear contamination and feel helpless, pessimistic, and doubtful of their ability to provide care.<sup>151–154</sup> This makes it difficult to communicate with clients and encourage them to adopt appropriate behaviors. Conversely, good rapport between providers and clients is an important determinant of patients’ acceptance of clinic-based interventions, including testing.<sup>54,67,155</sup>

Attention should therefore be directed at providers to define the needed services and ascertain the training, time, and resources necessary to deliver them. The question of how to support providers so that they gain

clients' trust is an important one, and answers are likely to refer to both the characteristics of the providers themselves and the functioning of the health system in which they operate.

## CONSENT AND CONFIDENTIALITY IN PRACTICE

Testing for HIV has long elicited concerns regarding the costs and benefits to patients, the implementation of informed consent, and the protection of privacy. Proposed moves to expand testing have heightened awareness of the ethical dimension of testing and counseling. Because debates about ethics often take place without the benefit of evidence, there have been calls for "evidence-based bioethics" and for information from the field as a "reality check" for "principled" discussions.<sup>156–158</sup> Accordingly, we focus here on practices, particularly those related to consent and confidentiality.

Information about how ethical principles are applied to HIV testing is mostly indirect, coming principally from studies of informed consent to research. Although the principles are not the same for research and testing, the evidence suggests that informed consent is a social process shaped by power relationships and by culture<sup>159</sup> and that participants often do not understand the information given to them.<sup>160–163</sup> Studies of testing in Europe indicate that 10% to 20% of respondents are tested without their knowledge.<sup>164–166</sup> Participants may agree to be tested because they are used to agreeing to health professionals' requests,<sup>167</sup> think that they will receive improved care,<sup>168</sup> do not think they can decline,<sup>169</sup> or have a diffuse sense that refusing would have adverse consequences.<sup>170–172</sup>

Practices to protect confidentiality are unevenly applied. Confidentiality may not be viewed positively, especially if it is seen to protect irresponsible individuals.<sup>173</sup> The difference between confidential and anonymous testing may not be understood, and providers have to negotiate a potential tension between the program advantages of confidential testing and their clients' preferences.<sup>174</sup> A number of studies show that confidentiality is often compromised by established practices in health services and by differential regard for clients' rights,<sup>125,150</sup> with poor women at a

distinct disadvantage.<sup>153</sup> In a comparative study in India, Thailand, the Philippines, and Indonesia, breaches of confidentiality by health care workers were reported by 34% of respondents.<sup>105</sup> There is evidence that perceptions of how confidentiality is handled influence clients' willingness to be tested.<sup>37</sup>

The acute need to balance efforts to scale up testing with the protection of individual rights has repeatedly been underlined, and empirical evidence on practices and attitudes in multiple settings is needed to identify innovative ways to adapt ethical principles to local situations.

## IMPLICATIONS OF INTERVENTIONS FOR PROGRAMS

Research on programs provides useful insights into the interventions and the features of services that are associated with the uptake of testing. Several studies include detailed information about what seems to work—for example, that information per se is not sufficient, that the effectiveness of written materials compared with verbal communication depends on the setting, that targeted media campaigns are effective for some risk groups, and that efforts to adapt decisionmaking to clients' preferences can be effective.<sup>99,107,113,175–177</sup> Although not unexpected, these results show that it is possible to modify health services to make them more responsive to clients' needs and preferences and hence promote the utilization of testing. Improving the quality of testing and counseling services can lead to significant increases in rates of testing, as documented in South Africa<sup>178</sup> and Brazil.<sup>179</sup>

Intervention studies of the conditions under which testing is administered document the effect of provider–client interactions on the utilization of testing. Clients' responses are influenced by providers' background characteristics (such as gender or ethnic group), attitudes, and perseverance and the extent to which they are trusted by their clients.<sup>180,181</sup> Several studies underscore the importance of the personal element and the context in which testing takes place. When the risks of HIV are personalized and messages are framed in terms of personal gains and losses, the intervention appears to be

more effective. This is consistent with research showing that individuals need to translate statistics and abstract notions of risk into personal terms, and that stigma and prejudice are decreased when individuals have personal acquaintances who are HIV positive.<sup>182–184</sup>

New approaches to the delivery of testing services have had positive effects on utilization. Using rapid tests and providing tests in locations and in conditions that are convenient to clients—such as at workplaces, health facilities, and mobile clinics and at night—have been shown to increase utilization; home-based voluntary counseling and testing facilitates reaching family members, and the routine offer of testing in clinical settings appears to overcome many of the barriers that hindered earlier efforts.<sup>178,179,185–189</sup> In Demographic and Health Surveys, the vast majority of respondents consent to giving blood samples for HIV tests and receiving results at home, and qualitative studies conducted in parallel with these surveys have not uncovered major problems of understanding or coercion.<sup>190</sup> In Uganda, home testing increased acceptance of testing from 10% to 46% and eliminated differences in acceptance between women and men. Interviews and focus group discussions indicate that home testing avoids the inconvenience, fears, and costs of facility-based tests.<sup>58</sup>

A somewhat unexpected finding of studies that have examined different models of provision is that provider-initiated testing and counseling in the context of medical care elicits little opposition. Pregnant women are inclined to be tested if they think it can benefit their baby,<sup>71,191–193</sup> and utilization increases rapidly when testing is routinely discussed and offered and is well integrated into antenatal care.<sup>192,193</sup> Under such circumstances, routine testing seems to be acceptable and to cause less anxiety for women than "opt-in testing."<sup>70,193</sup> A possible reason is that unlike opt-in testing, routine testing, ostensibly done for the benefit of the baby, does not make assumptions about women's behaviors and hence does not threaten women's sense of moral worth.<sup>89</sup>

Similar positive attitudes toward routinizing tests are observed outside of prenatal care. When hospitalized patients in the United States were asked how they would feel about



an unsolicited HIV test, most responded positively.<sup>194</sup> A comparison of 3 models of provider-initiated HIV testing and counseling in a tuberculosis clinic in Kinshasa, Congo, found that more than two thirds of clients preferred “opt-out” testing, where the test would be performed unless they declined, notwithstanding common perceptions that it would be difficult to decline the test.<sup>195</sup>

In general, findings about provider-initiated testing in care settings are also encouraging. The acceptance of testing increases considerably after it is routinely offered by providers, as documented in postpartum wards in Botswana,<sup>196</sup> pediatric wards in Zambia,<sup>197</sup> tuberculosis clinics in Congo,<sup>195</sup> and Ugandan pediatric wards,<sup>198</sup> maternity wards,<sup>199</sup> and STI clinics.<sup>200</sup> In Uganda, increased HIV testing appeared to be associated with clinical benefits for patients; people diagnosed as HIV positive after provider-initiated testing and counseling was introduced at Mbarara Hospital were at an earlier clinical stage and had higher CD4 counts than those identified beforehand and were therefore more likely to be referred to treatment at an appropriate time.<sup>201</sup>

There are concerns that provider-initiated HIV testing and counseling could deter clients from accessing health services. Although limited, the available evidence does not support those fears. The introduction of provider-initiated HIV testing and counseling in antenatal care clinics in Botswana appears to have caused neither reduction in the use of prenatal care nor decline in the proportion of people receiving test results,<sup>202</sup> and in Zimbabwe it has had no negative effects on posttest counseling rates or the delivery of antiretroviral prophylaxis.<sup>203</sup>

These results are encouraging but raise questions about their applicability in different settings. To what extent does acceptance of routine testing in the context of prenatal care truly benefit the mother and baby by ensuring that results are obtained and referrals for prevention and care are in place? Will the positive outcomes of testing, as conducted through well-funded efforts and by combining testing and health care, be replicated in settings with fewer resources? Similarly, situations where the rate of voluntary counseling and testing is high despite limited

treatment—as in Burkina Faso and Malawi,<sup>26,27,155</sup> and in the context of seroprevalence surveys conducted by Demographic and Health Surveys, where treatment is not provided—raise questions about what level of treatment needs to be ensured before testing is expanded. What does the routinization of testing mean for clients and potential clients—does it encourage testing, as suggested by the evidence on provider-initiated testing and counseling, or discourage it, as some observers fear?<sup>25,169</sup> Answers to these questions will require both more evidence from various settings and policy discussions about the ethics of scale-up under different circumstances.

## CONCLUSIONS

This review highlights the multiple influences on the utilization of HIV testing. It is clear that practical obstacles of cost and transportation hinder clients’ use of testing, and that constraints of training, time, and resources limit providers’ ability to offer quality services. Social factors related to clients’ attitudes and perceptions also make a difference, in particular the discrepancy between real and perceived risks, the emotional connotations of HIV tests, gender differences in motivations for and consequences of testing, and fears related to stigma and negative reactions to disclosure; similarly, providers’ concerns, their interactions with clients, and the level of trust in the provider–client relationship also appear to influence the utilization of testing.

The evidence, however, is patchy, particularly regarding the effect of stigma, the consequences of disclosure, and the extent to which practices related to confidentiality and consent have an effect on the utilization of testing.

The provision of testing has been changing. Rapid tests have eliminated some of the obstacles to returning for results observed in earlier studies; home testing is making it easier for individuals to accept testing; the routine offer of testing in prenatal care settings appears to elicit positive responses. The routinization of testing in medical settings, through provider-initiated testing and counseling, has tended to lead to positive outcomes in terms of acceptance of testing and linkage to services, but questions remain

about the place of counseling in the testing-and-counseling package and the gradual erosion of pretest counseling—how much counseling is necessary, who will provide it, and under which conditions. More information is needed about how changes in the provision of information and counseling and in the process of securing consent will affect the utilization of testing, the quality of the care provided, and the appropriate referral of clients to care and treatment services.

Regardless of the specific model that is adopted, 2 things are clear. First, providers are under increased pressure to provide quality services. They will need support to provide them with the ability, resources, and motivation to inform, support, refer, and treat those who are diagnosed with HIV. Secondly, a one-size-fits-all approach is unlikely to work, and attentiveness to the personal dimension, local context, and social context of testing and counseling is necessary to identify best practices and malfunctions and to take this information into account in the planning of services. ■

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## Contributors

C.M. Obermeyer conceptualized and directed the review and wrote the article. M. Osborn conducted the searches, managed the database, provided summaries, and contributed to writing parts of the article.

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