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12-28-2010

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Recommended Citation

Wahlert, L., & Fiester, A. (2010). The Queering of HIV Testing Practices and the Reinforcement of Stigma. Retrieved from http://repository.upenn.edu/bioethics_papers/70

Suggested Citation:
Wahlert, L. and Fiester, A. "Re-Queering HIV Testing Practices and the Reinforcement of Stigma," *American Journal of Bioethics*, Volume 11, No. 4, April 2011: 41-43.

Preprint version.
This is an electronic version of an article published in *American Journal of Bioethics*. *American Journal of Bioethics* is available online at: http://www.tandfonline.com/doi/abs/10.1080/15265161.2011.560356.

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Disciplines
Medicine and Health Sciences

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"The Queering of HIV Testing Practices and the Reinforcement of Stigma"

by Lance Wahlert and Autumn Fiester

Present-day practices and protocols on the standards for HIV-testing with regard to matters such as informed consent, opt-out clauses, and counseling services owe their existence to 1990s policies on how to test gay-male and anonymous blood samples for the HIV virus. Nearly 25 years ago, the burden on clinicians and ethicists when testing persons for HIV was this: "What services are we obliged to provide these persons in exchange for letting us test their blood samples for HIV?" Accordingly, we guaranteed them the right to know their sero-status, confidentiality at all costs, and sexual health counseling regardless of the results of their HIV tests so that their future health would be improved.[1]

And now we have the most recent CDC policy, and the support of it by Celada et al, that seems to have forgotten this ethical history.

Authors Celada et al. are highly supportive of the revised 2006 CDC guidelines for HIV testing practices, arguing that the new policy-recommendations are ethically sound and that the only ethical concerns raised by the policy would be their potentially improper implementations. In a shallow and short-sighted ethical review devoid of

[1] Several footnotes here from the journal *HIV Counselor Perspectives* (1999, 2002, 2006); as well as from *FOCUS: On HIV Antibody Test Counseling* (1993, 1999); and "Ethics and Malpractice: AIDS & HIV Infection Update" which sites AIDS Health Project 1989, IOM report of 1989, and Coates 1988 study on the ethics of AIDS antibody testing at-large.

historiographical nuance, the authors view the CDC's move to universalize HIV testing as de-stigmatizing, because the so-called "high-risk" groups are no longer specifically targeted. But the authors fail to recognize that the CDC's ostensibly "de-queering" of HIV testing is now coupled with a recommendation for queer-targeted prevention counseling, indicating that the only population that puts the sero-negative general population at risk is sero-positive queers, a spurious conclusion given that their own data shows that 32% of new HIV infections resulted from high-risk heterosexual contact (CDC 2009). The CDC's recommendations that prevention counseling be provided only to "persons at high risk for HIV" and only in settings "in which risk behaviors are assessed" thereby reinforces how sexually dangerous they supposedly are – i.e., the STD clinic – not only reinforce the societal stigma against gay men, but reveal the CDC's own inherent biases.

On the surface, the 2006 CDC policy looks ecumenical—a one-size-fits-all approach that appears to universalize and, hence, de-stigmatize. Accordingly, the CDC's non-targeted testing looks non-discriminatory because it claims to treat all cases the same. This is the interpretation of Celada et al, who, taking a strongly pro-CDC position, write: "HIV-related stigma might decrease as HIV testing becomes accepted by society as universal and routine and not perceived to be associated with particular at-risk groups" (Celada et al. 2011, 10). But this is a very naïve use of the word "might", one that supposes a beneficial outcome without evidence, especially since this interpretation focuses only on the testing-recommendations of the CDC policy, not on its broader counseling-recommendation changes.

In fact, the testing-recommendations are best understood not as "universalizing," but rather as "de-queering," that is, no longer concentrated on the specific needs and threats of queer populations (sero-positive or sero-negative). Does such a strategy really improve the ethical **justification** of HIV-testing for queer and non-queer populations? We argue that it does not, since, while the testing-recommendations take a "de-queering" approach, the recommendations on prevention counseling utterly re-marginalize the queer test-subject, exclusively targeting an already highly stigmatized group. In this regard, the policy (despite its noble intentions) actually differentiates sharply among populations and, therefore, re-stigmatizes high-risk groups (namely, gay men). Therefore, the supposedly non-discriminatory CDC testing recommendations now come partnered with the decoupling of prevention counseling, whereby there remains only targeted counseling of queer persons who are being treated in certain settings, like the STD clinic. Consider the following prose from the 2006 CDC report:

> Prevention counseling should not be required as a part of the HIV screening programs in health-care settings. Prevention counseling is strongly encouraged for persons at high risk for HIV in settings in which risk behaviors are assessed routinely (e.g., STD clinics) but should not have to be linked to HIV testing (Branson et al. 2006, 11; quoted by Celada et al. 2011, 5).

Like the CDC, authors Celada et al view this new policy on prevention counseling as a non-biased, data-driven decision. Following the CDC, Celada et al argue that prevention counseling is of questionable benefit to most patients (the non-queer?) who are tested and, ostensibly, only necessary in the queer-subgroup. This is a curious interpretation of the existing data on the effectiveness of prevention counseling for both the sero-negative and the sero-positive. Such a rationale is flawed on many counts. Are the "persons at high risk for HIV" a clearly defined subset? If they are, does this not reveal clinical prejudice?

And, perhaps most strikingly, if there is a clear "high risk" subset, is it not clinically and ethically reckless for us to assume that there is *no overlap* sexually or otherwise between such populations? Supposed "high-risk" persons (and queers, specifically) do not inhabit a separate place nor live on a separate plane than the general population. The 2006 CDC policy on HIV-testing, sadly, fails to realize this.

Before taking a closer look at data behind the CDC's recent policy, it is worth scrutinizing Celada et al's troubling conclusion that if we don't know definitively that counseling is helpful, it is ethically unproblematic to omit it from clinical care. They write, "In the absence of a definitive answer to questions about the value of providing prevention counseling to all, and in the light of this practice serving as a deterrent to widespread HIV screening, then the CDC's recommendation is not ethically troubling" (Celada et al. 2011, 20). On the contrary, if we are uncertain about whether an existing intervention policy might be helpful in stopping the spread of a disease – especially one where the stakes are as high as they are in the devastating AIDS epidemic – then we have an ethical obligation to the public to find out whether the intervention is or is not effective before such a service is discontinued. In fact, Celada et al (along with the CDC) should be calling for more research if the data do not speak definitively on this question. It is neither clear that counseling is a deterrent to widespread screening, nor that counseling is ineffective in preventing the spread of the disease, therefore it is premature to offer a verdict on the CDC recommendations as "not ethically troubling."

Perhaps most problematic is the fact that there *is* data that prevention-counseling is beneficial in both sero-negative and sero-positive patient populations, and the most compelling data ironically comes from the CDC's own earlier studies (Kamb et al 1998).

Celada et al blindly follow the CDC's new report, misrepresenting the very studies they cite. Because much is made about the differences in the efficacy of counseling those who test negative versus those who test positive (not to mention how we define "efficacy"), we will look at the data on each group, starting with the seronegative.

Celada et al reaffirm the conclusions reached by the 2006 CDC report (Celada et al 19), where the CDC concludes: "HIV counseling and testing as implemented in the studies had little effect on HIV-negative participants" (Branson 2006). This conclusion comes from a 1999 piece from the *American Journal of Public Health*, in which Weinhardt's meta-analysis (Weinhardt 1999) contradicts the findings of the CDC's Project RESPECT Study (intended to study the efficacy of HIV counseling prevention) found that prevention counseling had a beneficial impact in sero-negative populations (Kamb et al 1998). In fact, at that time the CDC *immediately* criticized the Weinhardt et al study and cautioned against changing *any* recommendations based on it. But why? The authors of the CDC RESPECT Study, in a letter to the editor in the issue of *American Journal of Public Health* that published the Weinhardt study, argued that the meta-analysis was flawed because it did not properly distinguish between more effective modes of counseling from less effective ones (Kamb 2000). Similarly, in the *Journal of Infectious Disease* in 2007, authors Holtgrave and McGuire (2007) analyzed the flaws of the Weinhardt et al study, explaining that the study design made it impossible to judge whether counseling was effective because it didn't compare testing-alone to testing-with-counseling (there were two arms of the study: "counseling-plus-testing" and "no-testing, no-counseling"). Holtgrave and McGuire drew the same conclusion that the CDC had in 2000, namely, that the RESPECT Study demonstrated the clear benefit of client-centered

counseling for the seronegative (Holtgrave and McGuire 2007). What is most striking about the 2006 CDC recommendations is that the Kamb et al study's test population was HIV-negative *heterosexuals* (Kamb et al 1998), the very population that will now receive *no prevention counseling* on grounds that it is not beneficial. Queer stigma aside, then, are we not doing a disservice to the entire HIV-testing population with the jettisoning of counseling services?

When we turn to the issue of prevention counseling for sero-positive patients, the current CDC recommendations seem downright bizarre. With sero-positive patients, there isn't even a controversy about the benefits of counseling, with Weinhardt et al clearly stating, "HIV testing and counseling appears to provide an effective means of secondary prevention for HIV-positive individuals" (1999, 1397). Citing this very study, the 2006 CDC report draws the spurious conclusion that "[t]he benefit of providing prevention counseling in conjunction with HIV testing is less clear" (Branson et al 2006).

With all of this data as the evidentiary backdrop for the new CDC policy, we are skeptical that clinical effectiveness could really be the reason for the current recommendations. And by turn, the ethics of the Celada et al article are also questionable. In fact, such slash-and-burn cuts to HIV-testing and counseling policies from both parties read more like the recommendations of budgetary panels, whereby expanded testing mandates a curtailing of supplementary services from that testing. One is left to wonder: Is cost efficiency (not clinical efficacy or medical ethics) the true motivation behind the new targeted counseling recommendations? And yet, the cost of counseling seems to be minimal (Holtgrave and McGuire 2007; Kamb et al 1998), and the CDC's own press release in 1998 argued that such counseling was at one time cost-effective (CDC 1998).

If this is a new policy not about clinical efficacy or financial responsibility, as an alternative interpretation of their rationale, we question whether there is an inherent and invested queer bias at work here.

Before the 2006 policy revisions, the CDC recommendation was targeted testing (which, of course, revealed its own bias) coupled with prevention-counseling. According to ethical debates before 2006, the counseling provided to tested persons (especially those in high-risk or confidential target-groups) was deemed an ethically necessary and humane benefit in exchange for testing those who could be potentially stigmatized. In other words, in exchange for being tested involuntarily or voluntarily (with a stealthily invoked "opt-out" clause), our clinical duty was to repay such parties being tested with the counseling and services to ensure their individual better health, if not the health of larger populations. Has the ethical necessity of counseling tested parties expired? Is this based on the naïve assumption that AIDS is now always a chronic, manageable disease (which it is not)? And even if it were true that AIDS is always chronic, does this render obsolete the obvious clinical and educational values of counseling persons who are tested for HIV? Do we render persons worthy of counseling only when their test results might result in a fatal diagnosis? What precedent does this set for how we test those with diabetes, sickle cell anemia, Tay-Sachs disease, and hypertension, to name a few other conditions? Most importantly, do we find permissible the elimination of universal counseling for universal HIV testing (in the face of still asking for high-risk queers to be counseled) because we really want to assuage our notions that there are not two different kinds of HIV: queer and non-queer?

Now that testing is no longer targeted but counseling is, the logic of this methodology follows that being "eligible" for counseling is already to be placed in the category of a "danger to society" because no others – sero-negative or sero-positive – appear to need it. Only sero-negative and sero-positive queers are recommended to receive counseling, and at a site (the STD clinic) where their supposed threat to society is already proven by virtue of needing access that type of sexually-sensitive healthcare. If this is the CDC's view, then these queer individuals have shown themselves to be both contagious and a threat to social well-being, by the very nature of their desires and sexual practices. Accordingly, queers are always sick or potentially sick, so they are in need of HIV prevention-counseling that others do not require. By contrast, all others – regardless of sero-status or safe/safer/unsafe sexual activities – presumably need no counseling to protect themselves or other people from HIV-transmission. The CDC's conclusion seems to be that in supposedly "safe" populations, there is no need for counseling to prevent the spread of HIV, even though some of the members of that population may have just tested positive. This is clinical and pathological naïveté of the highest order.

Celada et al admit that some will see some of these flaws – though they don't elaborate on or cite any adherents to these views. As an almost trivial after-thought, they add: "Also, some worry that if prevention counseling is provided only to a select group of patients, stigma about HIV testing might be increased" (Celada et al. 2011, 19). Invoking another naïve use of the word "might," Celada et al again propose optimistic conclusions about their ethical justifications without considering the historical and contemporary stakes of such claims. Indeed, there is good reason to believe that queer-targeted counseling will absolutely re-stigmatize queer persons, since the policy-makers

themselves – and their apologists like Celada et al – instinctively continue to see them as truly dangerous and sero-differnent when they conveniently single them out. The new CDC testing and counseling recommendations may aim to *de*-queer HIV testing policies, but they do so without vested interest in the long-standing needs and sensitivities of the queer persons themselves. As a result, the CDC (and Celada et al, by turn, in their ethical treatise-cum-press-release for the CDC) merely reinforce stigma by marginalizing the queer parties in question. If this is a fiduciary matter, one wishes all parties would just say so. In the absence of that admission, parties tested for HIV (especially suspicious queers) of the past 25 years who have contributed to such studies will remain skeptical contributors to this epidemiological work. How are we serving the general public health? How are we being rewarded for that service? How are we being served personally? And in the cases of queers, how are we being pathologized, marginalized, and segregated even when we test negative?

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