Rethinking HIV exceptionalism: the ethics of opt-out HIV testing in sub-Saharan Africa

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Abstract Opt-out testing for the human immunodeficiency virus (HIV) incorporates testing as a routine part of health care for all patients unless they refuse. The ethics of this approach to testing in sub-Saharan Africa is a source of controversy. Opt-out HIV testing is expected to improve survival by increasing case detection and thus linking more HIV-infected people to earlier treatment, provided there is effective patient follow-up and programme sustainability. At the population level, these benefits will likely outweigh the potential negative consequences of individuals experiencing HIV-related stigma. These justifications appeal to consequentialist moral theories that the acceptability of an action depends upon its outcomes. On the other hand, liberal moral theories state that the autonomy of individuals should always be protected unless restricting autonomy is necessary to protect the welfare of others. Opt-out consent may restrict autonomy and it is unclear whether it would benefit people other than those being tested. Yet, the doctrine of libertarian paternalism proposes that it is justifiable and desirable to use unobtrusive mechanisms to help individuals make choices to maximize their own welfare. Central to this idea are the premises featured by supporters of opt-out consent that individuals will not always make the best choices for their own welfare but they may be influenced to do so in ways that will not compromise their freedom of choice. Also important is the premise that all policies inevitably exert some such influence: opt-in consent encourages test refusal just as opt-out consent encourages acceptance. Based on these premises, opt-out testing may be an effective and ethically acceptable policy response to Africa's HIV epidemic.

Une traduction en français de ce résumé figure à la fin de l'article. Al final del artículo se facilita una traducción al español. الترجمة العربية لهذه الخلاصة في نهاية النص الكامل لهذه المقالة.

Introduction

Sub-Saharan Africa is the epicentre of the modern pandemic of the human immunodeficiency virus (HIV), accounting for 67% of people living with HIV and for 75% of deaths due to the acquired immunodeficiency syndrome (AIDS).[1] While the availability of life-extending antiretroviral treatment (ART) throughout Africa has improved dramatically in recent years, low levels of testing have been barriers to expansion of treatment. Indeed, it is estimated that fewer than one in five HIV-infected Africans know their serostatus.[2] In May 2007, the World Health Organization (WHO) released guidelines recommending expanding testing to all adults accessing health-care facilities in settings with high HIV prevalence (antenatal prevalence > 1%) unless they explicitly opt out.[3] Opt-out testing is a marked departure from the "exceptionalism"[4] that has long distinguished HIV testing from screening for other communicable diseases in two important respects. First, HIV testing has traditionally been client-initiated, requiring patients to request testing. Second, HIV testing consent has historically been "opt in", requiring formal counselling and patient signatures on forms.[5]

The ethics of the WHO guidelines has emerged as a source of contention. HIV exceptionalism was the common approach to testing in the early days of the epidemic in the United States of America (USA) during which the lack of treatment and threat of HIV-related stigma led to the prioritization of informed consent over case detection.[6] Supporters of opt-out testing argue that HIV exceptionalism is no longer an appropriate response to the modern epidemic, given its severity and the availability of ART.[7] Critics of opt-out testing question first whether the survival gains achieved by expanding testing will outweigh the negative social consequences, particularly if diagnosed people are not linked to ART, and second whether opt-out consent may restrict patient autonomy.[8] The outcome of this debate will have important implications for health policy worldwide, but nowhere more so than in Africa where high HIV prevalence means greater potential for both positive and negative consequences of expanded testing.

This paper considers the objections to opt-out testing in sub-Saharan Africa in two parts. First, it addresses the expected positive and negative consequences of expanded testing. Second, it uses the doctrine of libertarian paternalism[9] as a framework for assessing the ethical acceptability of opt-out testing given its effect on patient autonomy, irrespective of consequences. Ultimately, it concludes that there are powerful ethical arguments in support of the WHO guidelines.

Consequences of HIV testing

Consequentialism, a moral theory in which the right action is held to be that which results in the best outcomes, is a common approach to public health ethics. The choice of how best to quantify those outcomes for public health policies is controversial but generally entails some measure of years lived, ideally modified to reflect quality of life.[10] The following discussion weighs the desirable and undesirable consequences of opt-out HIV testing by projecting its expected effects upon both the quantity and quality of years lived by HIV-infected people.

Medical benefits

Treatment provision is currently the most important benefit of HIV testing. ART especially yields dramatic decreases in morbidity and mortality in African patients commensurate with those observed in industrialized settings.[11] Survival gains are amplified when treatment is initiated earlier in the course

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of infection[12] and this amplification is the basis for the expected survival gains associated with opt-out screening in sub-Saharan Africa.[13] Given the importance of these medical benefits, treatment availability should be a precondition for opt-out testing. ART may not be available to all African patients, but even the most resource-limited settings are likely to have access to comparatively inexpensive alternative services which improve health outcomes for HIV-infected people.[14] To ensure that even patients in the most resource-limited settings have access to some treatment, WHO recommends opt-out screening wherever basic care and support services (including opportunistic infection prophylaxis)[15] are available and there is a "reasonable expectation that [ART] will become available" eventually.[3] The remainder of this paper presupposes these conditions in discussing opt-out screening.

It is less obvious whether expanded testing and treatment may also yield additional benefits for society at large. Widespread ART provision may decrease population HIV transmission by reducing the infectiousness of HIV-infected individuals.[16] However, modelling predicts that such transmission effects are highly dependent upon reducing risky sexual behaviour as well.[17] The effect of HIV testing and treatment on risky behaviour in sub-Saharan Africa is unclear, with some studies finding little change[18] and others finding decreases.[19] Data are similarly inconclusive regarding the potential for expanded testing and treatment to alleviate the disintegration of African communities[20] and erode societal views fuelling HIV-related stigma.[21] For the time being, any justification for opt-out testing must rely on the expected medical benefits for those individuals being tested and treated.

These medical benefits hinge upon the ability of opt-out programmes to provide treatment to those HIV-infected people who would have otherwise remained undiagnosed. Rennie et al.[8] worry that these "gap patients" – who represent the gap in testing uptake between opt-in and opt-out consent – may not yet be ready to commit to addressing their infections and so will be less likely to receive care. However, studies examining linkage-to-care rates in Africa, when antenatal clinics introduced opt-out consent, suggest that gap patients are linked to care as often as any other patient. Opt-out consent increases the proportion of pregnant women tested and has no statistically significant effect upon the proportion of identified HIV-infected women receiving short-course ART for prevention of mother-to-child transmission (PMTCT).[22,23] The experience of pregnant women may not be representative of the general population but, in the absence of better data, it appears that the increased case detection achieved by opt-out testing will not come at the expense of linkage to care.

A related concern that these antenatal clinic data do not address is the possibility of loss to follow-up during the period between diagnosis and treatment initiation. The pregnant women in the aforementioned studies received short-course ART for PMTCT soon after diagnosis. In contrast, a comprehensive opt-out testing programme will identify many patients years before they are eligible for treatment. If these patients are identified early in the course of infection but are subsequently lost to follow-up and do not receive treatment until late-stage disease, then the added survival gains associated with earlier detection due to opt-out consent will be negligible. Consequently, mechanisms to track, educate and monitor diagnosed patients are imperative for any expanded testing programme and may be particularly important for gap patients if these individuals are less inclined to attend follow-up appointments, as suggested by Rennie et al.[8] A recent longitudinal study in South Africa found that, as rates of diagnosis rose, an increased proportion of newly-diagnosed HIV-infected people were successfully followed up over time and started on ART once eligible.[24] This study did not consider patients diagnosed by opt-out testing, but nevertheless provides proof in principle that African health-care systems may be able to track and link to care the increased caseload that would be identified by expanded testing.

Finally, the benefits of programmes expanding testing and treatment will also depend upon the sustainability and affordability of these programmes. Low-income countries may not be able to afford treatment for increasing numbers of identified HIV-infected people. Moreover, even if treatment is offered free at the point of access, patients in resource-limited settings may struggle to meet the indirect treatment costs associated with travel and time away from work. Indeed, African studies have demonstrated that the factors most commonly associated with non-adherence are patient financial constraints and treatment availability.[25,26] Fortunately, in recent years the funding available for testing and treatment programmes has risen dramatically, in large part due to the Global Fund to Fight AIDS, Tuberculosis and Malaria, and the United States President's Emergency Plan for AIDS Relief.[27] Simultaneously, research continues to inform how best to optimize programme efficiency[28] and provide financial assistance to patients,[29] ensuring affordability for programmes and patients alike. Given this tremendous ongoing progress, it is inadvisable for decision-makers to wait until long-term sustainable and efficient treatment rollout can be guaranteed before accelerating case detection and treatment (as is the objective of opt-out consent).

Social consequences

There may be undesirable consequences resulting from expanded HIV testing due to the social repercussions accompanying a positive diagnosis. These repercussions may range from denied job opportunities or commercial services to verbal abuse and physical violence.[30,31] Expanded testing may also result in a "gender bias" of stigmatization:[8] women in sub-Saharan Africa are more likely to be living with HIV and to access health-care facilities offering testing.[30] The experience of Gugu Dlamini, an HIV-infected woman living in South Africa stoned and stabbed to death just hours after publicly announcing her serostatus, epitomizes the concerns of critics of opt-out testing and highlights the importance of maintaining client confidentiality.[32] Although there are no comprehensive data available on the frequency of confidentiality breaches that result in stigmatization, HIV-related stigma remains a serious concern.

Therefore, any decision to implement expanded HIV testing in sub-Saharan Africa must weigh the desired biomedical outcomes of testing against the possibility of discrimination. We can broadly define three types of patients: (i) accepters, who will always accept testing; (ii) decliners, who will always refuse testing; and (iii) gap patients whose decisions to accept test offers depend upon whether those offers are opt-in or opt-out. Naturally, it is the gap patients who determine the outcomes of changes to HIV testing consent policy. Imagine then one such individual living in sub-Saharan Africa who does not know her serostatus but is quite aware of the stigma attached to an HIV-positive diagnosis. Under an opt-in programme, she remains oblivious of her infection and avoids any immediate repercussions from her community. Yet, this only delays the consequences – she will inevitably progress to AIDS. In societies with high HIV prevalence, as in much of sub-Saharan Africa, it is all but certain that her community will find out the cause of her suffering. It will be precisely at the time of her greatest physical ailing and need for emotional support that she will suffer the burden of HIV stigma and discrimination. In the case of an opt-out programme, although her decision to test may not have been borne of her own initiative, her decision not to decline testing will empower her to control the circumstances of her disclosure and formulate a plan for addressing her disease.

There will undoubtedly be some individuals for whom even this empowerment will not outweigh the stigmatization they experience following diagnosis. Thus, there is an undeniable conundrum: while expanded testing is expected to yield a net benefit to populations, it is impossible to know whether the consequences of testing will bring more harm than benefit for each individual. But this uncertainty is equally problematic for opt-in testing. Just as opt-out testing may expose some HIV-infected individuals to stigma outweighing the survival gains of treatment, so might the survival losses incurred by individuals receiving opt-in testing outweigh the stigma avoided by remaining undiagnosed. Given this uncertainty for each individual, public health policy should focus upon expected aggregate outcomes at the population level, a measure by which opt-out testing is likely to outperform alternative testing strategies.

Based upon a solely consequentialist ethical framework and consideration of the literature, the previous discussion is compelling justification for opt-out screening. However, if one believes that the rightness of an action depends upon more than just its consequences, then questions regarding the ethics of opt-out screening remain. To what extent might opt-out consent unduly affect patient autonomy? Is any sacrifice of autonomy justifiable given that opt-out screening seeks to influence patients' choices to improve their own welfare but not necessarily that of other members of society? The next section considers these questions.

Liberalism and libertarian paternalism

In contrast to consequentialism, liberalism refers to a moral theory in which the right action is held to be that which protects individuals' rights. (Note that the word liberal here has no political connotation). Particularly germane to this discussion is the right of autonomy, or a patient's ability to act "freely in accordance with a self-chosen plan".[33] A powerful notion in modern liberalism is that violation of this right to autonomy may only be justified if that violation is necessary to protect others' welfare. In the words of John Stuart Mill, "the only purpose for which power can be rightfully exercised over any member of a civilized community, against his will, is to prevent harm to others. His own good, either physical or moral, is not a sufficient warrant."[34] Attempts to interfere with an individual's autonomy which are, like opt-out testing, "justified by reasons referring exclusively to the welfare...of the person being coerced" exemplify "paternalism" and are generally opposed by advocates of liberal ethics.[35]

However, the doctrine of libertarian paternalism proposes that it is justifiable and desirable to use certain unobtrusive mechanisms to encourage individuals to make choices that will improve their lives. This is precisely the objective of opt-out consent. Underlying the moral justification of libertarian paternalism is the premise that individuals are not always effective at making choices to maximize their own welfare.[9] For example, as argued above it is likely to be true that the survival gains generally outweigh the decrements in quality of life resulting from HIV testing, yet many people living with HIV do not opt in to testing.[5,7,14]

The second premise of libertarian paternalism is that it is possible to encourage people to make welfare-maximizing choices without being coercive.[9] Consistent with Mill's sentiment that outright coercion should never be used to compel people to make decisions, libertarian paternalism instead advocates framing life choices in ways to encourage decisions that will lead to better outcomes while preserving individuals' freedom to make alternative decisions. Indeed, Mill himself was amenable to influencing others' decisions through "reasoning", "persuading" and "entreating".[34] The imperative is that each individual ultimately maintains the freedom to make a choice. To this end, the WHO guidelines emphasize that each patient should be informed that he or she "has the right to decline the test",[3] making opt-out consent a far cry from coercive or mandatory testing. Disenfranchised patients offered opt-out screening by comparatively affluent health-care providers may nevertheless feel subtly coerced into accepting,[8] but this effect has been observed in settings of opt-in consent as well and may often be unavoidable.[36] The WHO guidelines are designed to minimize such coercion, recommending that all patients be notified that the decision to decline testing "will not affect the patient's access to services that do not depend upon knowledge of HIV status".[3]

While these first two premises of libertarian paternalism have featured prominently in the literature advocating opt-out HIV testing in sub-Saharan Africa, a third premise has received far less attention but has very important implications for the debate. This final premise is that there are no viable alternatives to making policies that will influence individuals' choices because peoples' preferences are always affected by how choices are framed by policymakers.[9,37] If this is true, then the most attractive option is to frame choices in ways that help individuals to choose the "best" options. In other words, it cannot be said that opt-in HIV testing is any more protective of patients than opt-out testing because both policies encourage patients to make a particular decision: opt-in consent encourages patients to refuse testing just as opt-out consent encourages them to accept. If it is impossible to avoid influencing patients' choices, then surely that influence should be applied in ways that lead to better outcomes.

These premises justifying libertarian paternalism are not without controversy.[38] Yet there is no conclusive data suggesting that any of the premises underlying the doctrine are inherently flawed. In the absence of data contradicting in particular the claim that any policy will inevitably affect individuals' decisions, public health policy should seek to encourage individuals to make decisions that will improve their lives. While not without potentially negative consequences, opt-out consent for HIV testing represents one such policy that could promote the survival of millions of individuals throughout sub-Saharan Africa.

Conclusion

Opt-out testing would be an effective public health response to Africa's epidemic that is ethically acceptable by criteria of both consequentialist and liberal moral theories. Consideration of the literature indicates that, although increased testing may expose some diagnosed people to stigma, these negative consequences are likely to be overshadowed by the significant improvements in health and survival for HIV-infected people due to earlier treatment with ART. If any testing policy will invariably affect patients' autonomy by influencing their decisions to test, then an approach such as opt-out testing that encourages testing while preserving patients' right to decline is superior to opt-in testing both in terms of its health consequences and moral basis. ■

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ملخص

إعادة التفكير في الصفة الاستثنائية لفيروس العوز المناعي البشري (فيروس الإيدز): أخلاقيات اختبار الكشف عن الفيروس مع مراعاة رفض الخضوع له في المناطق الواقعة جنوب الصحراء الأفريقية

إن مراعاة رفض الخضوع لاختبار الكشف عن فيروس الإيدز تعني إجراء الاختبار روتينياً كجزء من الرعاية الصحية لجميع المرضى ما لم يرفض المريض ذلك. ولكن أخلاقيات هذا الأسلوب في إجراء الاختبار في المناطق الواقعة جنوب الصحراء الأفريقية تعد مصدراً للجدل. فمن المتوقع أن يؤدي خيار رفض الخضوع للاختبار إلى تحسين البقاء على قيد الحياة عن طريق زيادة الكشف عن الحالات وبالتالي ربط المزيد من المصابين بفيروس الإيدز بالعلاج المبكر، بافتراض توفر متابعة فعالة للمريض وضمان استمرار البرنامج. وعلى صعيد السكان، من المرجح أن تفوق هذه المزايا العواقب السلبية المحتملة نتيجة تعرض الأفراد للوصمة المرتبطة بفيروس الإيدز. وهذه المبررات تقود إلى نظريات التبرير الأخلاقية والتي توضح أن قبول أي إجراء يعتمد على نتائجه. ومن ناحية أخرى، تقر النظريات الأخلاقية الليبرالية على ضرورة مراعاة حماية الاستقلالية الذاتية حماية دائمة لدى الأفراد ما لم يكن الحد من هذه الاستقلالية ضرورياً لحماية مصالح الآخرين. وقد يؤدي مراعاة رفض الخضوع للاختبار إلى الحد من الاستقلالية الذاتية بالرغم من عدم وضوح جدواه لغير من يجرى عليهم الاختبار. إلا أن مبدأ تأييد حرية الإرادة الأبوية (الإرشادية) يوضح أنه من المبرر والمرغوب فيه اللجوء إلى آليات غير متطفلة لمساعدة الأفراد على اتخاذ القرارات التي تعظم من مصالحهم الشخصية. وفي محور هذه الفكرة هناك أساس لمؤيدي مراعاة رفض الخضوع للاختبار من حيث أن الأفراد لن يتخذوا دائماً أفضل الخيارات لمصلحتهم الشخصية ولكنهم قد يتأثرون ويقومون بذلك من خلال طرق لا تقوّض حريتهم على الاختيار. والأساس المهم أيضاً هو أن جميع السياسات تؤدي حتمياً إلى بعض هذا التأثير: فالموافقة على الخضوع للاختبار تشجع على رفض الاختبار مثلما يشجع رفض الخضوع للاختبار على قبوله. وبناء على هذين الأساسين، يمكن لمراعاة رفض الخضوع للاختبار أن تكون سياسة فعالة ومقبولة أخلاقياً للتصدي لوباء فيروس الإيدز في أفريقيا.

Résumé

Repenser l'exceptionnalisme du VIH : l'éthique de pouvoir refuser un test VIH en Afrique subsaharienne

Le dépistage du virus de l'immunodéficience humaine (VIH), avec option de refus, est incorporé à la procédure habituelle des soins médicaux pour tous les patients, à moins qu'ils ne s'y opposent. L'éthique de cette approche du dépistage en Afrique subsaharienne est source de controverses. On s'attend à ce que le dépistage du VIH avec option de refus améliore la survie en augmentant la détection des cas et donc le rattachement de plus de personnes infectées par le VIH à un traitement précoce; ceci à condition qu'il y ait un suivi efficace des patients et une durabilité du programme. Au niveau de la population, ces avantages l'emporteront vraisemblablement sur les conséquences négatives potentielles des individus qui éprouvent un stigmate lié au VIH. Ces justifications vont dans le sens de théories morales conséquentialistes pour lesquelles l'acceptabilité d'une action dépend de ses résultats. D'autre part, les théories morales libérales veulent que l'autonomie des individus soit toujours protégée à moins qu'une autonomie restrictive ne soit nécessaire pour protéger le bien-être d'autrui. Le consentement à l'option de refus pourrait restreindre l'autonomie et il est difficile de dire s'il pourrait bénéficier à d'autres personnes que celles testées. Néanmoins, la doctrine du paternalisme libertaire propose qu'il soit justifiable et désirable d'utiliser des mécanismes discrets pour aider les individus à faire des choix qui optimisent leur propre bien-être. Au cœur de cette idée se trouvent les arguments avancés par les personnes favorables au consentement de l'option de refus, que les individus ne font pas toujours les meilleurs choix pour leur propre bien-être, mais qu'ils peuvent être influencés à les faire par des biais qui ne compromettent pas leur liberté de choix. Un autre argument important est que toutes les politiques exercent inévitablement une certaine influence de ce genre: le consentement à l'option de refus encourage le refus du test tout comme le consentement à l'option de refus encourage à l'accepter. Sur base de ces arguments, l'option de refus du test peut être une politique efficace et moralement acceptable de réponse à l'épidémie du VIH en Afrique.

Resumen

Replanteamiento del excepcionalismo del VIH: ética de las pruebas de exclusión voluntaria del VIH en el África subsahariana

Las pruebas de exclusión voluntaria del virus de la inmunodeficiencia humana (VIH) incluyen pruebas asistenciales rutinarias para todos los pacientes, a menos que renuncien a ellas. La ética de este criterio terapéutico es un tema polémico en el África subsahariana. Se prevé que la prueba del VIH de exclusión voluntaria puede mejorar la supervivencia mediante la detección temprana de los casos, gracias a la cual se podrá vincular a las personas infectadas por el VIH con el tratamiento temprano, siempre y cuando se cuente con un seguimiento eficaz del paciente y con la sostenibilidad del programa. Estos beneficios pueden superar las posibles consecuencias adversas de las personas que sufren el estigma del VIH a nivel de la población. Estas justificaciones apelan al consecuencialismo moral, para el que la aceptación de un hecho depende de sus resultados. Por otra parte, el liberalismo moral afirma que la autonomía del individuo debe quedar siempre protegida, a menos que deba restringirse para proteger el bienestar de los demás. El consentimiento de exclusión voluntaria podría restringir la autonomía y no queda del todo claro si únicamente beneficiaría a las personas tratadas. Es más, el paternalismo libertario propone que está justificado y es conveniente utilizar mecanismos discretos para ayudar a los individuos a tomar decisiones en favor de su bienestar máximo. En el núcleo central de esta idea se encuentran las premisas que ofrecen los partidarios del consentimiento de exclusión, según las cuales, los individuos no siempre adoptarán la mejor opción para su propio bienestar, pero se les puede influir para que lo hagan de manera que no quede comprometida su libertad de elección. También es importante la premisa según la cual todas las políticas ejercen inevitablemente alguna influencia: el consentimiento de inclusión voluntaria favorece el rechazo a la prueba, así como el consentimiento de exclusión voluntaria favorece su aceptación. En base a estas premisas, las pruebas de exclusión voluntaria pueden constituir una política eficaz y éticamente aceptable como respuesta a la epidemia por VIH en África.

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