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Authors

Friedman, Samuel
Downing, Martin
Smyrnov, Pavlo
et al.

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Socially-Integrated Transdisciplinary HIV Prevention

Samuel R. Friedman,

Institute of Infectious Diseases Research, National Development and Research Institutes, Inc., 71 West 23rd Street, 8th Floor, New York, NY 10010, USA

Martin J. Downing Jr.,

Institute of Infectious Diseases Research, National Development and Research Institutes, Inc., 71 West 23rd Street, 8th Floor, New York, NY 10010, USA

Behavioral Sciences Training in Drug Abuse Research Program Sponsored By Public Health Solutions and National Development and Research Institutes, Inc., New York, NY, USA

Pavlo Smyrnov,

International HIV/AIDS Alliance in Ukraine, Kyiv, Ukraine

School of Public Health, National University of Kyiv-Mohyla Academy, Kyiv, Ukraine

Georgios Nikolopoulos,

Institute of Infectious Diseases Research, National Development and Research Institutes, Inc., 71 West 23rd Street, 8th Floor, New York, NY 10010, USA

Hellenic Centre for Diseases Control and Prevention, Athens, Greece

John A. Schneider,

Department of Medicine, University of Chicago, Chicago, IL, USA

Department of Health Studies, University of Chicago, Chicago, IL, USA

Britt Livak,

Department of Health Studies, University of Chicago, Chicago, IL, USA

Gkikas Magiorkinis,

Department of Zoology, University of Oxford, Oxford, UK

Department of Hygiene, Epidemiology and Medical Statistics, Medical School, University of Athens, Athens, Greece

Liudmyla Slobodanyk,

International HIV/AIDS Alliance in Ukraine, Kyiv, Ukraine

WHO Country Office, Kyiv, Ukraine

Tetyana I. Vasyljeva,

International HIV/AIDS Alliance in Ukraine, Kyiv, Ukraine

Dimitrios Paraskevis,

Department of Hygiene, Epidemiology and Medical Statistics, Medical School, University of Athens, Athens, Greece

Mina Psychogiou,

Department of Hygiene, Epidemiology and Medical Statistics, Medical School, University of Athens, Athens, Greece

1st Department of Internal Medicine, Propaedeutic, Laikon General Hospital, University of Athens, Athens, Greece

Vana Sypsa,

Department of Hygiene, Epidemiology and Medical Statistics, Medical School, University of Athens, Athens, Greece

Melpomeni M. Malliori, and

Psychiatric Department, Athens University Medical School, Athens, Greece

Organization against Drugs (OKANA), Averof 21, Athens 10433, Greece

Angelos Hatzakis

Department of Hygiene, Epidemiology and Medical Statistics, Medical School, University of Athens, Athens, Greece

Samuel R. Friedman: friedman@ndri.org

Abstract

Current ideas about HIV prevention include a mixture of primarily biomedical interventions, sociomechanical interventions such as sterile syringe and condom distribution, and behavioral interventions. This article presents a framework for socially-integrated transdisciplinary HIV prevention that may improve current prevention efforts. It first describes one socially-integrated transdisciplinary intervention project, the Transmission Reduction Intervention Project. We focus on how social aspects of the intervention integrate its component parts across disciplines and processes at different levels of analysis. We then present socially-integrated perspectives about how to improve combination antiretroviral treatment (cART) processes at the population level in order to solve the problems of the treatment cascade and make “treatment as prevention” more effective. Finally, we discuss some remaining problems and issues in such a social transdisciplinary intervention in the hope that other researchers and public health agents will develop additional socially-integrated interventions for HIV and other diseases.

Keywords

HIV prevention; Social networks; Combination prevention; Treatment as prevention; Cascade; Community; Socially-integrated intervention

HIV transmission is a social process that involves the transmission of the virus from one person to another through either interpersonal transfer (as in sex or breastfeeding) or through the direct or indirect passing of an infectious object such as a syringe from one person to another. As many have argued [1–5], HIV transmission through communities usually depends on the sexual and injection networks in communities. The rate of transmission and

the social and behavioral distribution of who gets infected are shaped by the interaction of the network location of ongoing and past transmission and the locations of risk behaviors within the network.

Since viral load is positively associated with infectivity, variations in viral load during the course of HIV infection in an individual can interact with network and behavioral factors. The probability of transmission is highest for untreated acutely infected people before they develop antibody, and then decreases for those with recent infection, and reaches a relatively stable low plateau about a year after they were infected [6–10]. The acute and recently infected periods roughly correspond to having been infected no more than 1 month and having been infected between 1 month and 1 year, respectively. (We will sometimes use “early infection” to indicate infection within the first 6 months since this is how the TRIP project is operationalizing it.)

Friedman et al. [11] and Khan et al. [12] have shown that this higher infectivity of people with acute or recent infection interacts with the topologies of sexual and injection networks to affect the extent to which highly infectious people who have recently become infected engage in risk behavior with uninfected people. To the extent that long-term infected people have lower infectivity, they can form “network firewalls” that slow further spread of HIV outbreaks powered by the high viral loads of recent infection.

In addition, *social networks* (such as friendship and kinship networks) shape behavioral norms and beliefs about treatments for HIV and other diseases and conditions [2, 3, 13]; and socially situated cultural differences [14–18] are associated both with different levels of high risk behaviors and with the spread of normative communication that may affect risk and treatment behaviors through networks.

Much attention is currently being paid to the concepts of “Treatment as Prevention” (TasP) and of “Combination Prevention” [19–23]. Combination antiretroviral therapy (cART) can reduce viral load, infectiousness and thus HIV transmission [23–26]. However the effectiveness of cART as prevention is expected to depend on social network and macrosocial processes and structures, and individual characteristics, that affect whether or not people seek HIV testing, get their results, seek and receive care (rapidly), receive cART, and succeed in adhering to treatment and in suppressing their viral loads and thus infectivity [27]. Research is also needed on the extent to which behavioral changes after diagnosis and over time thereafter reinforce or counteract the prevention effects of TasP [28].

The CDC HIV Care engagement cascade [29, 30] (Fig. 1), that shows the proportions of HIV-infected people who get diagnosed and then the proportions at each stage on the way to undetectable viral loads [31], demonstrates that major improvements are needed in such care provision. Although much of psychological and sociological theory around treatment has focused on the Health Belief Model and other cognitive-behavioral models [32], there are clearly many other social, cultural and economic processes that influence the HIV treatment cascade. These include the economics and geography of access [33], macro-economic and related political processes [34, 35], racial/ethnic and other structures of fear or exclusion [15], organizational dynamics [36], and perhaps community-organizational interaction

patterns that affect whether people who are lost to care or sub-optimally adherent become re-connected to care or more adherent due to pressure or assistance from peer, family or community-based organizations [37, 38].

In spite of these well-documented social aspects of HIV transmission, care, and prevention, research and action on HIV prevention has overwhelmingly focused on targeting individuals for messages and treatments [39]. More recently, there have been many calls for “combination prevention” [19–21, 23, 26], named that way as an analogy with combination treatment. Most models of combination prevention, however, focus on creating and implementing menus of individually focused interventions and treatments [19].

In this article, we first describe one socially-integrated transdisciplinary prevention project, the Transmission Reduction Intervention Project (TRIP) [40]. We focus on how social aspects of the intervention integrate its component parts across disciplines and processes at different levels of analysis. We then present socially-integrated perspectives about how to improve cART treatment processes and programs at the population level in order to solve the problems of the treatment cascade and make “treatment as prevention” more effective. Finally, we discuss some remaining problems and issues in such social transdisciplinary intervention in the hope that other researchers and public health agents will develop additional interventions for HIV and other diseases.

An Example of Socially-Integrated Transdisciplinary HIV Prevention

From a prevention perspective, one important task is to develop ways to locate people with acute or recent infection as quickly as possible and then take actions to reduce the probability that they will transmit the virus to anyone else. TRIP uses network and community intervention techniques to do this.

Figure 2 is a schematic of a fictitious network diagram. Embedded within it are hypothetical infection chains that present the history of HIV transmission so far. We consider three categories of patients with respect to the natural history of the infection among those who are not receiving cART treatment. These are the acutely, recently and nonrecently infected. Network ties that connect infected people to uninfected people represent potential paths for viral transmission, with the probability of such transmission highest for people with acute infection, lower (and decreasing over time) for those with recent infection, and lowest for those with non-recent infection [6–8, 10]. Although the viral loads of people with long-term HIV infection vary, and may reach high levels (e.g. if they stop cART or if they become infected with other agents)[41–43], there is considerable evidence that a large proportion of transmissions from individuals take place within the first six months to one year of their becoming infected [7, 44, 45]. We note that there is some controversy over the distribution of these transmissions whether they occur during acute infection or later on in the first year [8, 46, 47].

Thus, to prevent transmissions, TRIP begins by trying to locate and intervene with those with early infection. This is not easy [48]. TRIP first locates “index cases”—who are people with early infection whom we locate by referral from allied groups. Potential index cases are generally newly diagnosed HIV+ cases who are referred to TRIP from voluntary counseling

and testing centers, allied research projects, or clinical allies. In some cases, these collaborating groups refer people whose antibody testing history indicates they are recent seroconverters. Samples from potential index cases are tested to see if they have early infection as described below. Once an index case with early infection is identified, TRIP interviews them about their social and risk networks, and also about the “venues” where they meet sex or injection partners or where they engage in sex or injection drug use in the presence of other people. TRIP staff then work with index cases to recruit network and venue members as quickly as possible to be tested for early infection.¹ The assumption here is that the networks and venues of people with early infection are more likely to include people who have recently been infected than networks or venues of other people (even members of other risk groups). (See Fig. 2.) This is because the networks of people with early infection are likely to contain infection chains that include “downstream” people a given index case may have infected (and those they in turn may have infected); “upstream” people such as the person who infected the index case and the person who infected her or him; and “side stream” people who are in infection chains that stem from an upstream infector.

Whenever TRIP locates an index case or network member with early infection, TRIP works with them to recruit their network and venue members so as to locate other recently/acutely infected people rapidly.²

An important interdisciplinary component of TRIP is its use of up-to-date assays for determining whether participants have recently become infected. (TRIP also checks HIV testing records to locate index cases who are seroconverters.) This is done with the limiting avidity (LA_g) (SEDIA™ HIV-1 LA_g-Avidity) assay [49].³ Tests for acute infection include HIV RNA or DNA tests and other tests that look for antigen or a combination of HIV antibody and antigen (fourth generation). (As a research project, TRIP will estimate HIV infection chains and the dates of the most recent common ancestor of the viral lineages within each chain using current state of the art phylogenetic and phylodynamic analyses.)

How Does TRIP Try to Reduce HIV Transmission by People with Early Infection?

TRIP combines social and behavioral risk reduction techniques with TasP to try to reduce HIV transmission. Behavioral risk reduction techniques are used here, with an important informational component: As well as educating at-risk communities about acute and recent infection, we are counseling participants with early infection that they should be especially

¹Participants who are uninfected or have long-term infection are referred for prevention and clinical follow-up using locally standard techniques except that the research component of TRIP does recruit some of them for further study as comparison group members. To the extent that TRIP assists long-term infected people get into care, this has both medical and prevention benefits.

²This part of TRIP differs from contact tracing in that it recruits more broadly from people’s social networks than simply their direct injection or sexual partners; it focuses on early infection rather than just whether or not a person is infected; and in its network recruiting, it does not stop when it encounters and uninfected network member but continues to trace the network for at least one additional step. In addition, TRIP also includes community alerts and innovative efforts to get people with early infection into effective medical care and help them make effective use of it.

³LA_g is calibrated to detect which antibody-positive people have been infected for (on average) up to 130 days since they seroconverted. Seroconversion confirmation dates may vary depending on the tests used, but 30–35 days is not unusual. TRIP may use a slightly higher optical density (OD_n) cut-off point in order to extend the recency period we are using to 6 months after infection.

careful not to transmit the virus until their infectiousness has gone down (which is phrased as “during the next 6 months.”) We hope that (and are evaluating whether) some participants will incorporate risk-avoidance in their behavioral repertoire during this time so that it becomes normal for them; but even if they return to higher transmission-risk behavior thereafter, reductions in transmission behavior during the first months of infection will probably have particular impact on incidence rates. In addition, TRIP assists them to get under cART as rapidly as possible to bring their viral load down and to protect their long-term health [50–52].

Another way to reduce transmission is social: the issuing of “Community Alerts.” From Fig. 2, it is evident that preventing transmission can be accomplished if the network and venue contacts of a person with early infection are able to avoid all risk behavior. It is also evident that if one person is recently infected, then other people in the network or venue are likely to be. TRIP thus works with each participant with early infection (and his/her network and venue contacts) to have them pass out Community Alerts, or alternatively to have TRIP staff pass out Community Alerts, to people in their networks and venues. The Community Alerts tell people that someone in their “social neighborhood” has recently been infected, and that this means that others may be too—and may not know it. It urges people to get tested by TRIP for undiagnosed early infection, and it also urges them to be super-careful not to take any HIV risks for the next six months.

One potential risk in the TRIP design as described so far is that of stigmatization of, or violence against, people who become perceived to be recently infected. TRIP conducts community education (through distributing leaflets, through group sessions and through Community Alerts) about early infection and the value of supporting rather than stigmatizing those with early infection during the few months when they might be highly infectious. Staff are constantly on the alert for indications of any difficulties of this sort, and also are constantly trying to figure out more effective ways to prevent such problems. This includes addressing stigma that individuals may face in health care settings where they seek out HIV prevention and treatment options—whether this stigma is due to their being recently infected, HIV infected, sexual minorities, drug users, sex workers or members of racial/ethnic/national/religious “minorities.”

The Problem of the Cascade

An important part of any intervention like TRIP is getting people with early infection onto cART quickly and effectively so as to reduce their viral load and hence their infectiousness. At the present time, it is unclear whether a 48 months course of therapy or life-long therapy will be needed to protect participants’ health [53, 54]. From the perspective of reducing transmission to others, however, treatment during the early infection period may prevent large numbers of transmissions if it reduces viral loads even if it lasts only for 6 months to a year rather than for life [54, 55]. As much discussion of the “treatment cascade” demonstrates [29, 56, 57], getting people into effective care and keeping them there poses many problems. Figure 1 presents figures on the treatment cascade in the United States. As can be seen, at every stage of the cascade, sizable numbers of people do not receive effective needed services.

Current Approaches to Addressing the Cascade

Turning now to focus on efforts to improve the cascade, Table 1 [58–92] presents some of the obstacles and resources that affect people with HIV and those who help them to use treatment effectively over the long term. This table attempts to summarize some of what has been learned by practical experience and by (primarily behavioral) research. As such, it is a useful presentation of obstacles, barriers and disconnections—and techniques or resources used to overcome them—as conceptualized primarily in individual terms. The table does incorporate the insight that communities and medical institutions vary in the extent to which they have effective communication, and that ways can sometimes be found to increase such contact, avoid difficulties, and improve patient care [38, 93]. It does not incorporate the power imbalances among these various actors, nor does it incorporate organizational needs and structures, and it certainly does not include the macrocontexts (and their crises and contradictions) in which organizations and communities are embedded. And finally, the cascade focuses on the outcomes for the individual, which fails to incorporate other important aspects that affect community members, such as the success of partner services, disclosure, and STI treatment and prevention.

Individuals with early infection may face obstacles that, if unresolved, can impede or delay their entry into, and retention in HIV care (Table 1). Potential obstacles at the patient/client level include micro-social (e.g., lack of transportation, marginalized living situations, inability to pay for health services, lack of documentation, lack of access to the internet and important e-services, arrests) and personal barriers (e.g., denial, pessimism, substance use, low self-efficacy, fear and distrust of health care). These individuals may also experience community level obstacles including backlash from peers or social network members, and police sweeps targeting drug users, sex workers or men who have sex with men (MSM) that disrupt access to care. Furthermore, clinic settings may pose a threat to participants who are concerned about their confidentiality, may have a reputation for stigmatizing HIV-positive clients and members of high-risk groups (e.g., IDUs, MSM), and/or may present a host of administrative hurdles that ward off individuals greatly in need of care.

As shown in Table 1, much more research has focused on the implementation of resources at the clinic level in an effort to improve linkage to, and retention in care, as well as HIV treatment adherence. This includes providing patient navigation assistance, convenient and patient-friendly procedures for scheduling medical appointments, appointment reminders, and adherence support. There is a paucity of community-level work, which we argue in this paper, is a critical element to cultivating communication among directly involved people and ultimately improving care outcomes.

Thoughts About Improving the Cascade

Thus, a socially-integrated transdisciplinary approach may be useful for improving the cascade. Our description of such an approach starts with a more macro-level perspective than is sometimes done in order to set the context for interventions on the ground.

One part of these contexts are the communities in which HIV is likely to be spreading the most. At least at this stage of the global HIV epidemic, these communities are usually

impoverished, stigmatized and/or excluded—and perhaps are also actively repressed by police and/or traumatized by recent “big events” like revolutions, wars or economic collapses. Within these communities, but analytically distinct from them, there are usually one or more community organizations that attempt to defend the interests of community members—although in practice, these may focus on subsets of the community and even oppose the interests and needs of other parts of the community [94, 95].

Hospitals, clinics and public health agencies form another part of the context. These can be viewed in sociological terms as complex organizations (with their own sets of roles, status systems, hierarchies, rules, resource levels, and entry and exit criteria) within complex economic and political environments—all of which affect their front-line staff.

In many HIV-impacted communities, there also exist a number of HIV-related prevention and care focused community-based organizations, public health agencies, research projects, or clinical projects. Here, again, the extent to which these projects and the “organizational fields” defined by their totality in interaction with other related organizations and institutions [96, pp. 30–34] cover all relevant sectors of the community population, and the extent to which they exclude or ignore some sections, varies from project to project and locality to locality.

The structures, cultures, processes and interactions of communities, general community organizations, medical and public health organizations, and HIV-specific projects form a macro-level context (which is embedded in larger-scale international and national contexts) within which social interactions and processes of a more specific nature take place. These are the interactions of what we can call the “directly involved people”—who typically may include the focal person (and perhaps patient) who has just learned she or he has early infection; her or his family members and/or peers, including perhaps members of her/ his sexual and injection networks; community health outreach workers or similar community-based front line staff; patient navigators within medical or community organizations; medical gatekeepers such as receptionists and appointment schedulers; and people like physicians, physicians assistants or nurses who may be responsible for the (potential) patient’s clinical care. Most attention in the HIV/AIDS field has focused on these “directly-involved people” as persons and on their interactions and constraints. The large extent of fall-off in participation that is evident in the cascade, however, suggests a need both to improve what happens among those directly involved and also to improve the macro-contexts in which they function.

Towards New Conceptualizations

These concepts help us understand why establishing and maintaining medical care for many people with HIV is difficult. One important perspective in understanding and coping with this focuses on the competing systems that come into the picture. Medical organizations have their own organizational dynamics, needs and routines—and have considerable power to impose them on patients. The consequence is that patients with conflicting needs or capacities fall out of care (if they ever get it) and, in this case, maintain high infectivity for a longer period and later on get sick and die more quickly. Many people with early infection

are parts of other institutions with other demands on their time or attention. Some work, perhaps far away from the hospitals. Some have family obligations. Some have legal obligations like court dates. Many impoverished African American MSM, many people who inject drugs, and many members of the urban or rural poor who become infected have relatively unstructured (but very busy) lives to hustle resources to live on—and this creates a time structure and perhaps a lack of hygiene that can be very difficult for hospitals to adjust to. The power imbalance, with hospitals and other institutions having the power, is one reason why many of the community groups exist. This usually takes two uneasily coexisting forms within community organizations—on the one hand, these organizations seek to build counter-power in the community, and on the other, they seek to help their members or clients to fit into the needs of the medical (and other) powerful institutions.

There is a tendency for the “directly involved people,” whether patients, their families and peers, front-line workers in community organizations, or front-line (and often low-influence) workers in medical centers to get crushed by these competing needs. They are subjected (differentially, by their roles) to conflicting demands from each power center. The ways in which they conceptualize these conflicts, and the institutions and organizations behind them, have occasionally been described [97] but insofar as we are aware have not been studied as the worldviews produced by a system of competing demands. Such research would be very useful for HIV interventions and also for more general scholarly purposes. In the context of HIV, both the existence of these conflicts, the ways they impinge on the people directly involved, and the ways in which the people directly involved conceptualize these conflicts and the other people directly involved can all have important consequences both in terms of the health of the infected and the greater spread of HIV.

At least some aspects of the medical-community power imbalance perspective just presented have in many ways been an important thread in HIV/AIDS discussions for many years. This has led to many discussions around a “community perspective,” community engaged research [98], and community based participatory research [82, 99], and to policies such as increasing the involvement of people with HIV in medical and policy decision-making. These discussions, and actions and programs based on them, have not yet solved the problem of the cascade, however, community-based clinics such as Federally Qualified Health Centers are increasing in number in the United States. These clinics, which are driven by the Affordable Care Act, are helping to fill in gaps in care that were previously relegated to overburdened safety net government and county hospitals.

It is important to note, however, that much of what has been done in this area has focused on improving service provision by basing some of it in community-based organizations or by developing more effective collaboration between such organizations and medical providers. Few projects, other than those based on organizing the collective power of communities, such as the Sonagachi project among Calcutta sex workers [100], the Treatment Action Campaign in South Africa [101], and efforts to organize [102] drug users around HIV, hepatitis C and other issues, have focused on transforming the economic and social resources and relationships of communities and within communities. Thus, broader perspectives on how to theorize community and on how to act at the community level might be fruitful for HIV prevention.

A Social Perspective on Community Action

One such perspective on community action is implicit in the TRIP design towards Community Alerts and network tracing, and may also be important in efforts to get people to take cART, adhere to it, and remain on it. This is to motivate these actions in terms of community solidarity, community survival, protecting others (and perhaps also altruism) [13, 103, 104] as well as in terms of self-interest for individuals who are not (yet) infected and self-survival for individuals who have recently been infected. This is likely to be particularly effective in communities with a strong sense of shared fate such as exists in many gay communities, among some networks of people who inject drugs, and some networks of sex workers [13, 105]. In these communities, often, there is a well-based distrust [106–108] of what medical institutions and other authorities say, and this sometimes leads to skepticism about public health messages about how not to get infected and also to distrust of medical care like vaccinations and cART. Campaigns that have attempted to change cultures of risk and to build solidarity have nonetheless been successful in such communities [18, 109–111].

From the community perspective, one implication of this is that projects should also try to build solidarity around programs that make transmission-reduction technologies available in safe ways. Such technologies include safe-injecting supplies like syringes and cookers, condoms, female condoms, and easy access to and both institutional and community assistance with cART and perhaps PrEP (pre-exposure prophylaxis) and PEP (post-exposure prophylaxis). In this model, community members would provide assistance (and normative pressure) on infected community members to use these technologies appropriately, and also would provide social and political pressure on institutional providers to make these available in a community-friendly manner.

Another Perspective on Power—and a Proposal for “Horizontal Discussions”

Next, we want to look at these points in an even broader perspective, which we will label as “increasing horizontal discussion among those with low power” perspective. This comes out of our experience in working with many different kinds of “directly involved people” over the last 30 years. We have noticed that a great many (and perhaps almost all) “front line workers” share a sense of frustration and alienation due to the difficulties of their work and their lives. Outreach workers find that medical gatekeepers are obstacles to helping poor and dispossessed people who need medical care, whereas medical gatekeepers get frustrated at the inability or unwillingness of many people with HIV to be able to keep appointments. People with HIV and their families and networkers feel disrespected by medical gatekeepers, nurses and doctors, and often by community outreach workers as well—and each of these groups feels disrespected by the others as well. All of the groups of front-line workers (with the exception of nurses and doctors in some countries) face economic hardships and limited or blocked career paths—as do a large proportion of people with HIV and their family and network members. Additionally, some front-line workers are people with HIV or their family members, particularly in community-based clinic settings or within hospitals/clinics located in areas with high rates of HIV.

Each of these groups thus often spends a great deal of time and effort in trying to figure out how to get the others to do what they think needs to be done. In doing this, hostile interactions often break out, fed both by their frustrations with each other and, to some extent, by their frustrations from being at the bottom levels of economic, power and respect in their society (again, with the partial exception of some higher-level nurses and some doctors in some places). This leads us to offer the following speculation:

An approach that helps lower-level medical workers, community-based workers, people with HIV, and their family and network members to reach out to each other in wide-ranging patterns of horizontal consultation and discussion can open up new ways to help people with HIV obtain and benefit more fully from medical treatment. (This will also reduce HIV transmission by lowering their viral loads.) We also suggest that such horizontal communication meetings can lead to many other improvements in the lives of all involved.

As we currently envisage it, these would NOT be “patient conferences,” but community consciousness-raising and network-building meetings. To enable freer expression and creativity by lower-level workers and by community members, such meetings would probably work best if no managers or doctors were present at them, at least until agreed upon purposes and procedures have been established. Nurses might be useful at them, but this probably varies widely depending on the situations and actions of various occupational levels of nurses in different locations. (See Fig. 3.) Clearly, considerable exploration and development work is needed to make this idea a reality, including developing cadres of indigenous and/or research-based organizers to help establish them.

We also envisage the possibility that these meetings might embrace wider issues than just HIV. Many of the same people have or are at risk for other sexually transmitted infections such as syphilis, blood-borne viruses such as hepatitis C, and tuberculosis, for example. This suggests that horizontal communication among these workers and community members might be most successful with a broader disease focus—although it might be best to start more narrowly around HIV and only then expand.

Summary and Implications

This article proposes that HIV prevention can be greatly improved by using social science as an integrative tool in transdisciplinary research and practice. The first part of the TRIP model, which uses social network methods and socially based community intervention techniques to integrate the application of developing assays for recent infection, psychologically developed methods of behavioral counseling, and experience-based outreach techniques to locate people with early infection rapidly and then to reduce the probability that they will transmit HIV to others, clearly exemplifies this approach. In practice, this approach will be most effective where there are already large HIV testing programs in place that can use LAg or other techniques to locate people with early infection to serve as index cases. The TRIP approach is likely to be most efficient in epidemics with high HIV incidence rates, although it may also be useful in heading off local “transmission hot spots” in more stabilized epidemics.

We presented several fairly broad socially-integrated frameworks with which to think about integrating and developing better ways to provide medical care to HIV-infected people. The need for improvement is evident from the cascade. Implicit in Table 1 and Fig. 3, and our discussion of them, is the wide set of barriers and disconnections between medical institutions, community service agencies and the groups of people among whom HIV is spreading the most. Such barriers and disconnections are different in detail for people who inject drugs, men who have sex with men, and the rural and urban poor people most at risk in much of Africa. But in all of these places, such barriers and disconnects are widespread.

How can we address them? There are three issues that stand out in our minds. One is a lack of resources in these communities and in the medical providers that serve them, another is power imbalance, and a third is the ways in which different groups of directly involved people function as obstacles to resolving each others' goals. The lack of resources is beyond the scope of this article. It involves macro-politics and macro-economic forces that should not be ignored. It is not, however, so much a lack of knowledge that produces this lack of resources but rather a question of conflicting interests (at least in the short- and medium-term). Such issues are decided by political debate and/or social movements and widespread mass action [112, 113]. Groups and people who are involved in HIV-related issues will undoubtedly be involved on all sides in such struggles, and developing norms of community survival may assist in creating outcomes that support public and social health. Nonetheless, these struggles are not the focus of this paper.

Power imbalances in the community are more manageable. Resolving them can remove many of the barriers presented in Table 1 and Fig. 3 and can also facilitate cooperative efforts to find ways to bridge disconnects. This is because power imbalances breed distrust on all sides and the need for secrecy among both the more and the less powerful [114–118]—which greatly impedes cooperation and the sharing of information that can help patients. Within organizations, whether hospitals or community groups, power imbalances between leaders and those on the front lines can have similar effects, and this too might usefully be addressed [116].

Our proposal for horizontal meetings of different categories of “lower level” directly involved people is in many ways a speculation based on years of experience. It opens a host of research questions that have rarely if ever been taken account of in HIV-related research. First, of course, are project development and evaluation questions that might best be addressed by pilot programs to begin to develop meetings of this type and see what they lead to. After that, more formal evaluations of such meetings might be attempted.

In conducting such research, we need to be aware that most HIV-related research has looked at individual factors in non-adherence and at programs to increase empowerment or communication of one kind or another. Little attention has been paid to institutional factors. Furthermore, insofar as we are aware, no attention has been paid to characteristics of the worker-management (owner) relationships or to the institutional crises of the medical agencies or of the community organizations in the front line. Further, individual-level variables that describe the socioeconomic and personal situations of individual frontline workers have not been used in HIV research that we know of. Such variables as those used

by Randy Hodson [116] in his work on workers' dignity should be included in many research projects on this issue.

One of our main foci in TRIP, which is a 5 year exploratory and developmental project, will be to apply our overall framework to develop practical ways to integrate and strengthen linkages among patients, their social networks, their community and agencies based on that community, and medical institutions. In doing so, we will try to face the real issue of "empowerment," which is not to develop the patient's personal prowess (though that is part of it), but rather to address the various power imbalances in ways that improve the care of the infected without leading to unnecessary confrontations and conflicts of the directly involved people (who include some staff of medical institutions) and their allies with powerful medical institutions or with the even more powerful institutions and interests that fund them. Our proposal for horizontal meetings of the directly involved people is one such idea.

We are by no means sure that this effort will be successful. The research base for it is very weak because few projects have ever attempted to do this in a scientific framework. *We thus suggest that finding ways either to overcome these power imbalances or to find better ways to work within them is a public health research priority.*

More generally, we would like to invite researchers, funding agencies and practitioners from a wide variety of disciplines to dedicate time and resources to developing socially-integrated transdisciplinary prevention and care methods for HIV and for related diseases. This is not a new suggestion—we and others have made it before, and have pointed out that the individual-focused models of prevention and care have been developed far more extensively (and to the point of diminishing returns) whereas social research and socially-integrated transdisciplinary programs have been neglected [119–123]. But the continuing massive spread of HIV in many African, Asian and Eastern European countries, the recent HIV outbreak among injecting drug users in Greece (which had a low-level HIV epidemic until recently) [124, 125], and the high transmission rates among young MSM, and particularly young African American MSM, in the United States and elsewhere, all point to the need for improved prevention methods. The cascade shows the need for more effective methods to provide care to the infected and to retain them in care.

Developing such research will not be easy. Finding the resources and the will to conduct it will be challenging. In addition, methods for such research are either very expensive (as in randomized controlled trials in which the unit of randomization is geographical communities) or are subject to the controversies that beset non-randomized designs [121, 126]. Nonetheless, such research seems necessary if we are to respond adequately to the HIV epidemic and move towards HIV elimination.

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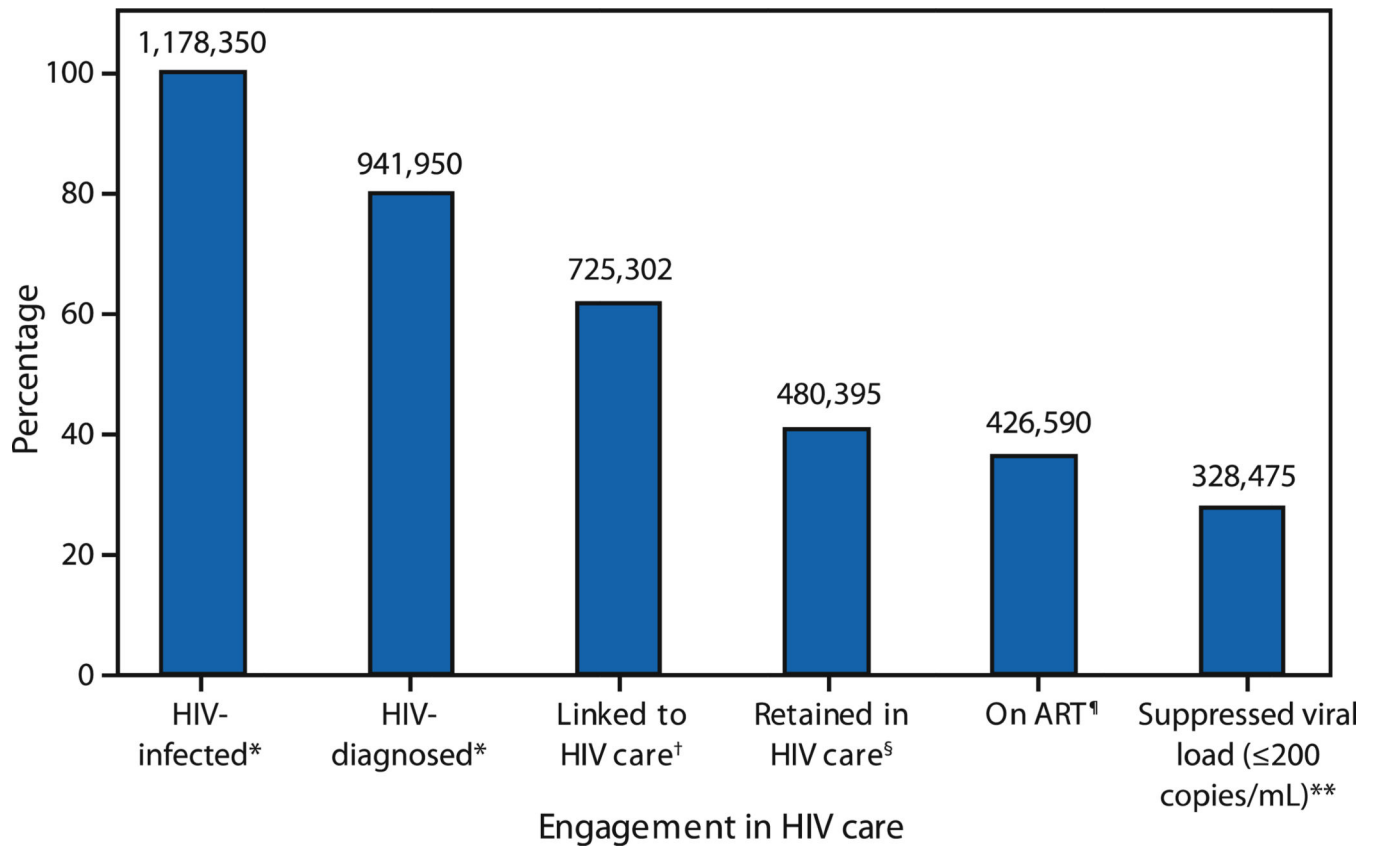
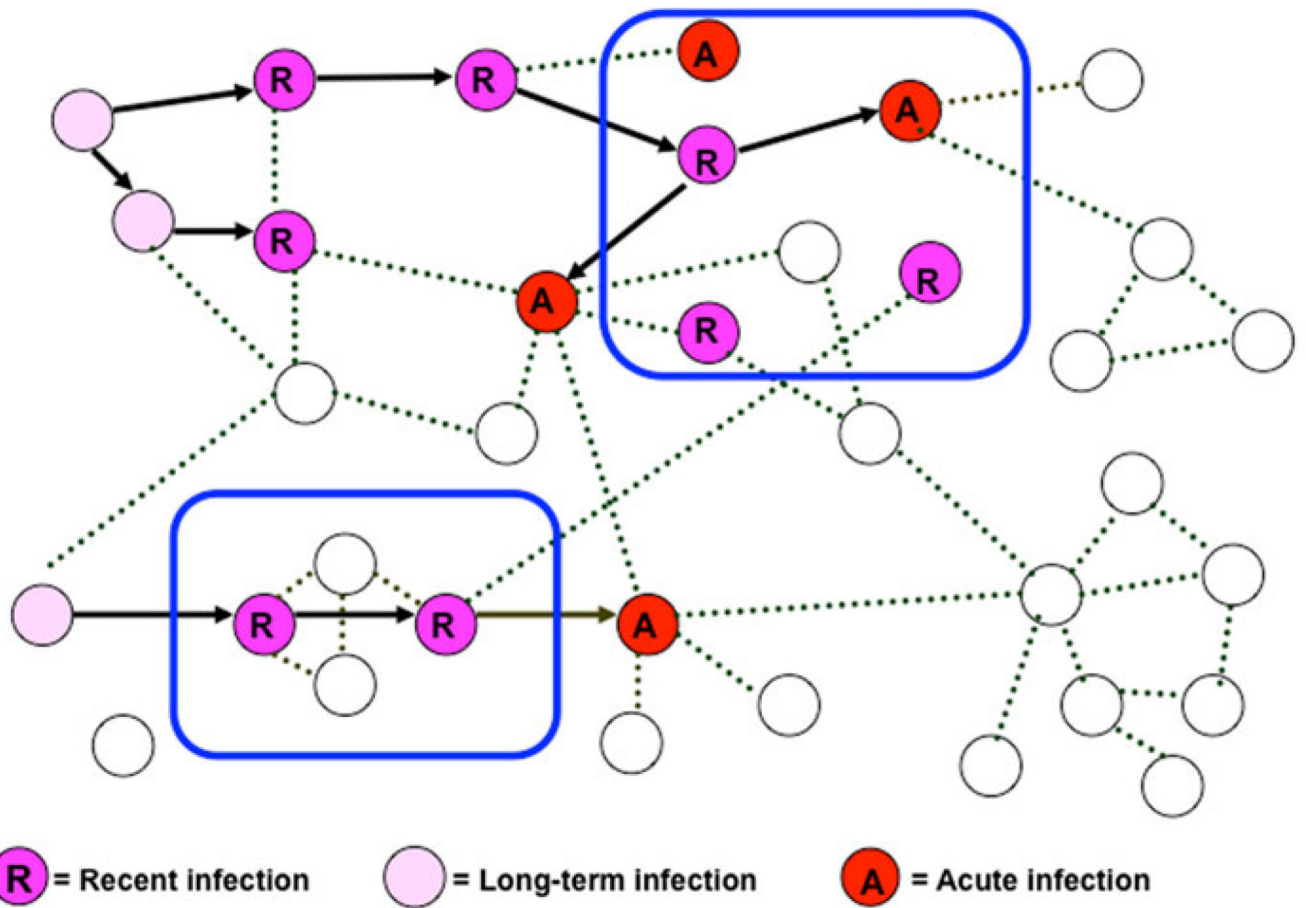


Fig. 1.

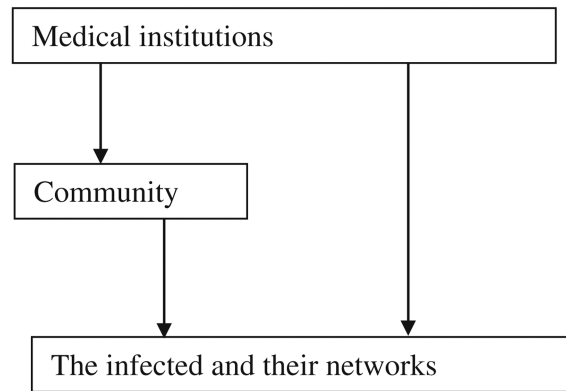
Number and percentage of HIV-infected persons engaged in selected stages of the continuum of HIV care—United States. HIV human immunodeficiency virus, ART antiretroviral therapy. *HIV-infected, $N = 1,178,350$; HIV-diagnosed, $n=941,950$ *Source* [127]. [†]Calculated as estimated number diagnosed ($941,950$) \times estimated percentage linked to care (77%); $n = 725,302$ *Sources* [128, 129]. [§]Calculated as estimated number diagnosed ($941,950$) \times estimated percentage retained in care (51%); $n = 480,395$ *Sources* [128–131]. [¶]Calculated as estimated number retained in HIV care ($480,395$) \times percentage prescribed ART in MMP (88.8%); $n = 426,590$. *Source* Data from the Medical Monitoring Project. **Calculated as estimated number on ART ($426,590$) \times percentage with suppressed viral load in MMP (77.0%); $n = 328,475$ (28% of the estimated $1,178,350$ persons in the United States who are infected with HIV) *Source* Data from the Medical Monitoring Project. *Source* [30]



Solid arrows represent sexual or injection risk links that have been paths for HIV transmission. Dotted lines represent sexual or injection risk network links. Blue boxes represent venues.

Fig. 2.
Social network and venue recruiting

a Power imbalance perspective



b Consciousness-raising perspective *

Overall economic and political context

Medical system management and elites—
and their problems

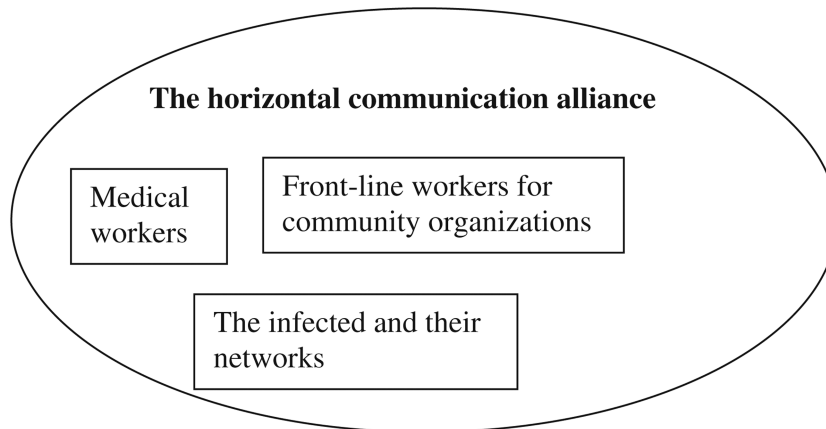


Fig. 3. Perspectives on relevant actors and forces. **a** Power imbalance perspective. **b** Consciousness-raising perspective. *Uncertain intermediate roles include higher-level nurses, non-elite doctors, directors of community organizations

Table 1

Facilitating and improving the treatment cascade: A brief review of what we know and of relatively easy next steps

Client-level obstacles that impede entry into (or retention in) care

Lack of transportation/cost of transportation [58–63]; inability to pay for services/lack of insurance [58, 61, 64]; inadequate documentation [65]; marginalized living situation [61, 64, 66]; arrest/incarceration [63, 66, 67]; difficulty maintaining contact with community staff or medical providers [68]; substance use [63, 64, 66, 67, 69]; distrust of health care [70]; past negative experiences with providers [71]; denial of HIV status/not able to accept diagnosis [58, 64, 66]; pessimism; fear of rejection or stigmatization due to HIV status, substance use, sexual preference, race or ethnicity [58, 64]; adherence side effects [69, 72–75]; low adherence self-efficacy [72]; mental health [64, 69]

Client-level resources for improving care outcomes:

Social support [64]; self-efficacy [76]; empowerment [77]

Community-level obstacles that impede entry into (or retention in) care

Inadequate information about HIV care and where to access services [62]; negative peer pressure; stigmatization; rumors about difficulties getting into care or about negative effects of seeking or getting care; police sweeps

Community-level resources or actions to improve care outcomes

Directory of culturally competent, supportive service providers [78]; information about available health services and care [79]; peer health advisers and navigators [80–83]; provide transportation [64]; reassurance and support [64]; ability to speak to peers and linkage to peers [64]; maintain contact with participants in care (e.g., follow-up phone calls, focus groups, support groups); inform clinics about emerging social or health trends in the community that may affect outcomes, adherence, etc.; inform clinics that a patient is on the verge of dropping out of treatment and see if the clinic can intervene; inform clinics why a given patient misses appointments; feedback to clinics about obstacles to adherence and getting into or out of medical care; pressure clinics to mend their ways; ability to help clinics find patients who disappear

Clinic-level obstacles that impede entry into (or retention in) care

Location/distance to [59–63, 69, 72]; gateway/front desk staff [84]; unfriendly environment (for drug users, MSM, women, racial/ethnic minorities, etc.) [85]; extensive wait times [58–61, 69]; inconvenient appointment scheduling [58, 61]; cost of services and HIV care [61, 63, 69]; lack of doctors or poorly trained doctors [59, 61]; uncooperative, disrespectful or discriminating doctors, nurses and other staff [58, 61, 64]; administrative hurdles (e.g., red tape, siloed care) [61]; shortage of medicines [63, 69]; lack of service integration or coordination with other services [63, 69]; confidentiality [61, 84]

Clinic-level resources for improving care outcomes

Patient navigators and other supportive and encouraging staff [60, 64, 86, 87]; patient-friendly procedures for scheduling appointments or rescheduling missed appointments [60, 63]; cultural competency [88]; support tools (e.g., mobile messages, appointment cards, appointment reminders) [60, 63, 64, 69]; adherence education and support (e.g., increasing treatment self-efficacy) [63, 64, 69]; pill boxes and electronic medication reminders [73, 89]; patient-friendly help in managing treatment side effects [63, 73]; task-shifting (from doctors to nurses) [63, 69, 90]; perhaps directly-observed therapy [91, 92]; satellite clinics or mobile services; extended hours; informing

community workers about patient appointments

We are unaware of research on items without citations, but wish to bring them to readers' attentions as ideas for possible research and/or implementation