

Review

Harm reduction theory: Users' culture, micro-social indigenous harm reduction, and the self-organization and outside-organizing of users' groups

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Abstract

This paper discusses the user side of harm reduction, focusing to some extent on the early responses to the HIV/AIDS epidemic in each of four sets of localities—New York City, Rotterdam, Buenos Aires, and sites in Central Asia. Using available qualitative and quantitative information, we present a series of vignettes about user activities in four different localities in behalf of reducing drug-related harm. Some of these activities have been micro-social (small group) activities; others have been conducted by formal organizations of users that the users organized at their own initiative. In spite of the limitations of the methodology, the data suggest that users' activities have helped limit HIV spread. These activities are shaped by broader social contexts, such as the extent to which drug scenes are integrated with broader social networks and the way the political and economic systems impinge on drug users' lives. Drug users are active agents in their own individual and collective behalf, and in helping to protect wider communities. Harm reduction activities and research should take note of and draw upon both the micro-social and formal organizations of users. Finally, both researchers and policy makers should help develop ways to enable and support both micro-social and formally organized action by users.

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Harm reduction is often thought of as a set of policies and programmes together with a focus prioritizing the reduction of drug-related harm. Thus, the website of the International Harm Reduction Association (as of 24 July 2006) ends its discussion of what harm reduction is with: "IHRA recommends that the term harm reduction should be understood to mean, 'policies and programmes which attempt primarily to

reduce the adverse health, social and economic consequences of mood altering substances to individuals drug users, their families and their communities."

This formulation has long been contested by those of us who see drug users themselves as the primary practitioners of harm reduction, aided, to be sure, by a wealth of policies and programmes (de Jong, 1987; Friedman, 1996; Friedman & Des Jarlais, 1987; Friedman, Des Jarlais, & Sotheran, 1986; Friedman et al., 1987). We have seen users themselves as the ones with primary agency in harm reduction. It is their actions that do or do not transmit infections, do or do not result in overdoses, do or do not create problems for their neighbours.

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Agencies like syringe exchanges can provide risk-reduction supplies, information and counselling, but users themselves – individually and in groups – take the decisive actions.

This paper discusses the user side of harm reduction. It does this primarily through a series of vignettes about user activities in different localities in behalf of reducing drug-related harm, focusing primarily upon the HIV/AIDS epidemic. Some of these activities have been micro-social (small group) activities; and others have been conducted by formal organizations of users that the users organized at their own initiative. They are presented in rough chronological order.

We see this paper as contributing to a critical reflection on the history and practice of harm reduction. Certainly, debates over this issue have been a recurrent theme over the past two decades.

User-based harm reduction in localities on four continents

New York vignette

The setting

At the time HIV entered New York City's IDU population in approximately 1975 (Des Jarlais et al., 1989) IDUs were living in a particularly hostile legal and sociopolitical environment. The Rockefeller Drug Laws, passed in 1973, posed a constant threat of long-term imprisonment. New York City government's fiscal crisis led to the closing of many social services. Partly because of this, massive waves of arson-induced and other fires ravaged impoverished and minority areas of the city, leaving behind considerable community demoralization, overcrowding and many half-destroyed structures that became the sites of shooting galleries in which HIV spread rapidly among IDUs (Friedman, Curtis, Neaigus, Jose, & Des Jarlais, 1999; Wallace & Wallace, 1998). Residents in minority areas also had to cope with the recent demoralizing defeat of the Black and Brown Power movements, which led some former activists and youth to drugs and also reduced organizational capacity to deal with the new AIDS threat (Quimby & Friedman, 1989). Syringe possession was illegal; syringe purchase was only legal with a prescription.

During the 1980s, New York IDUs also faced increased stigmatization, incarceration rates, community hostility, and police pressure due to an enhanced Federal government "War on Drugs" and then to an emerging large-scale "crack epidemic" among poor minority youth (and others). Violence among crack dealers and other drug dealers soared, further increasing adverse actions towards IDUs.

The HIV epidemic among New York IDUs and the public health response

Fig. 1 provides an overview of HIV incidence and prevalence during the early years of the epidemic (Des Jarlais et al., 1989, 1994, 2000; Friedman et al., 1999) (for more on Fig. 1) as well as of both IDUs' and the public health sys-

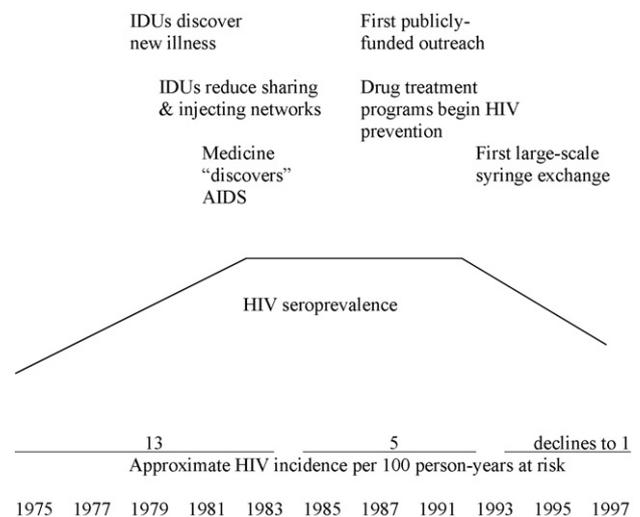


Fig. 1. Schematic history of the New York City HIV epidemic among people who inject drugs, 1975–1997.

tems' responses. (IDUs' response appears in the next section.) HIV spread rapidly (with an estimated incidence of 13 per 100 person-years at risk) during the late 1970s and very early 1980s, but incidence then declined to approximately 5/100 person-years by the mid-1980s. It declined rapidly again in the 1990s after large-scale syringe exchange began.

By the early to mid-1980s, not only had the epidemic been recognized by the scientific community, AIDS among IDUs was clearly visible on the streets. It could not be ignored. The mass media were covering AIDS fairly well, and were an important source of information about AIDS (Friedman et al., 1986, 1987). AIDS was demonstrably a horrible way to die—painful, debilitating and disfiguring. In this it may have been the total opposite of an overdose death. The visibility and the characteristics of AIDS helped generate a lot of motivation to change behaviour among drug users as among gay men and others.

The public health response to the epidemic among IDUs was long-delayed and limited because: (1) New York was the "first city" to confront epidemic HIV among IDUs (Des Jarlais, Friedman, & Sothoran, 1991); (2) the massive demonization of drug users made both officials and communities slow to react, and led to opposition from higher authorities that slowed the beginning of syringe exchange for years. Opposition to syringe exchange included sections of the African-American community (Anderson, 1991; Cohen, 1999). Even outreach and treatment-based educational efforts for IDUs began to emerge only in 1986, and they were slow to develop.

IDUs' response to the New York HIV epidemic

Our data on IDUs' response to the epidemic is drawn from several sources. First, one of us, Don Des Jarlais, worked at the New York State Division of Substance Abuse Services (DSAS) research offices in New York City during the 1970s and later. In 1978, DSAS investigated a dramatic increase

in pneumonia deaths among city IDUs to determine if this represented an increase in heroin use. No other indicators showed evidence of an increase in heroin use. Later research (Stoneburner et al., 1988) showed that this increased mortality was associated with HIV infection. The DSAS Street Research Unit later heard reports of IDUs' discussing a new "walking pneumonia" they were encountering. Third, starting in 1984, Des Jarlais and Friedman studied questionnaire data and other materials that documented what IDUs knew and were doing (Des Jarlais & Hopkins, 1985; Des Jarlais, Friedman, & Hopkins, 1985; Friedman & Des Jarlais, 1987; Friedman et al., 1986, 1987). Third, Rockwell recently conducted an oral history of IDUs' response to the epidemic (Rockwell, Joseph, & Friedman, 2006).

A massive city-wide, semi-public illegal street market in sterile syringes began in the late 1970s and rapidly expanded in the early 1980s (Rockwell et al., 2006). The market evolved from individual, homemade works routinely shared for free with others (Des Jarlais, Friedman, & Strug, 1986), to resale and/or rent of needles (both to those seeking to make their own set, and to operators of shooting galleries), to semi-public markets for purchase of (mainly) sterile, cheap, disposable, plastic syringes. The mechanism of this evolution was a spontaneous and powerful demand that grew out of IDUs' developing awareness of AIDS (Des Jarlais et al., 1985).

Milton Helpern, the Chief Medical Examiner of New York City, described the state of art injection equipment among local IDUs prior to this market, during the mid-1960s:

The injection apparatus is usually improvised from an easily obtainable medicine dropper, its tip fitted tightly with a paper flange into the hub of a hypodermic needle, the latter usually obtained either by theft or illegal purchase. More recently, addicts have come into possession of discarded disposal syringes, preferring to use only the needle in combination with a medicine dropper, the rubber bulb of which is easier to manipulate than the rigid plunger of a syringe for self-injection into a vein (Helpern & Rho, 1966).

Anthony, 49, an African-American man who grew up in Brooklyn and Queens, said that between the years 1967 and 1976 his group of 14 "running buddies" were:

Lucky to have 2–3 sets [of works] between us. Sometimes you would keep them in Sucrets [tin] boxes, carry them with you when you traveled, and use them over and over . . . Needles [used to make works] were for sale and resale until the late 1970s or early 1980s, when [diabetic] syringes become more available.

William, 50, an African-American man who grew up in Brooklyn, said

You would keep them in a Sucrets can and use it [the works] for months on end . . . from the early 1970s on often stores [in the Bedford Stuyvesant section of Brooklyn] wouldn't

sell them [products with glass eye-droppers] [to people they suspected of injection drug use].

Several problems inherent in this homemade injection equipment quickly became urgent as IDUs' knowledge of AIDS developed. One was the relative difficulty and/or complexity associated with gathering together the various components necessary for assembling a set of works. The initial costs involved in making these works were high—in money, time, and potentially embarrassing or stigmatizing encounters; in addition, all the components might not be available on demand. IDUs were often faced with a dilemma—to carry works around with them, which increased the risk of arrest and prison, or to go to shooting galleries where works were "for rent".

The significance of the rapidly expanding city-wide illicit market in syringes was certainly not limited to its economic dimension, important for the syringe sellers as that might have been (Friedman et al., 1998), nor to the threat to the public health, though there were indeed reports, current throughout the 1980s, of the repackaging and selling of used needles, which street sellers represented as new and sterile (Des Jarlais et al., 1985). Perhaps most important was IDUs' rapidly evolving awareness that reliable access to sterile syringes was a life or death issue. As their knowledge of AIDS spread, IDUs realized that the old handmade syringes, as well as the traditional distribution systems (a good part of which relied on intimate personal relationships and a large degree of mutual trust), were no longer viable in sheer survival terms.

Maria, a Latina woman who grew up on the Lower East Side, offered some insight into what may have been a contributing factor in the establishment of the New York City illicit market in injection equipment in the late 1970s–early 1980s:

I don't know why the bobo [baby's pacifier sometimes used in place of medicine droppers] went out, and then came the [diabetic] syringes. Maybe it was because a lot of Spanish people have diabetes [and therefore legal access to diabetic syringes]. Somehow there was just easier access. And now you could sell them so easily. You get to know the market—like I would get up early to get the working people, sell them syringes and drugs, they were the best because they had the money, and wouldn't be saying like, "I'll pay you later, give me credit", et cetera.

New York vignette, closing remarks

Had HIV incidence rates continued at the 10+ percent rates of the last years of the 1970s, HIV prevalence among IDUs would have reached levels of 70 percent or more by the time large-scale outreach began in 1987 and even higher rates by the time syringe exchange began.

Luckily, this tragedy was mitigated to a degree by the grass-roots, micro-social actions of many IDUs themselves, so HIV prevalence never reached above 50 percent or, in some local areas of New York, perhaps 60 percent.

The high degree of repressiveness and, indeed, police repression, towards IDUs at this time probably prevented the emergence of users' groups or other representative bodies of active users of the kind that emerged in Rotterdam. In the late 1980s, Friedman attempted to jump-start such organizing as part of a NIDA-funded outreach project, but this led to no lasting organization because the organization that was sub-contracted to do it used techniques that would not succeed in organizing IDUs (Friedman, Sufian, Curtis, Neaigus, & Des Jarlais, 1991). On the other hand, starting in 1990, a group of activists that contained both current and former IDUs, members of ACT UP, and NDRI researchers on their "free time," organized themselves and set up a number of underground syringe exchanges in several locations in the City. This created circumstances that facilitated New York State's making them legal and then funding them later on.

Rotterdam vignette

The setting

Rotterdam as one of the biggest ports in the world, is a working class, multi-ethnic city. In 1985, when the first IDU in the Netherlands was diagnosed with AIDS, Rotterdam had an estimated 3000 regular heroin users, of whom about 30 percent injected drugs. In 1986, the first HIV study among Rotterdam IDUs found 12 percent HIV-positive. This rate never got any higher. In Amsterdam, one hour's drive from Rotterdam, HIV-prevalence among IDUs was already 30 percent in 1986, a figure which gradually declined to 26 percent in the second half of the nineties (Beuker et al., 1999).

In the early 1980s, before HIV was known to be prevalent in the Netherlands, the Dutch government had changed its drug policy from a psycho-therapeutic and detoxification-oriented approach towards harm reduction, including large-scale methadone maintenance programmes. Absolute priority was given to keeping IDUs from penury, malnutrition, homelessness and bad health. This context was relatively supportive for self-organization of drug users. Most drug users had homes. Police were harsh, but there was no extreme scapegoating of drug users. Methadone maintenance provided addicted users with new options for spending their time, including organising protest against 'old' policies and programmes which were considered harmful. Drug users who started to organize also found allies, including church groups, who gave them places to meet and other resources.

In January 1981, a group of Rotterdam heroin users ('junkies') formed the first so-called 'Junkiebond' in reaction to a proposal for forced detoxification of users. They were able to do this, in part, due to the relatively less hostile environment in which they were working. Their own pre-existing social relationships with each other, and politics, were also important: A crucial portion of their initial core group had known each other during adolescence and also had considerable experience in political and activist thinking. Initial activities of the Junkiebond included mobilizing hundreds of users to demonstrate over drug policies, producing a

critical booklet on procedures within methadone prescription programmes, pressuring drug treatment agencies to change how they related to patients, and pressuring policy makers to reduce health risks of IDUs due to syringe sharing and the use of polluted heroin. The Junkiebond started an underground needle exchange to protect against hepatitis B. This programme lasted until 1987, after local authorities decided to implement needle exchange programmes on a large scale (de Jong, 1987; de Jong & van Noort, 1987). In its early actions, the Junkiebond received considerable favourable media coverage but distrust by municipal authorities and drug treatment institutions. The national health ministry, however, supported the junkiebonden, and later funded the bureau of the Dutch National Federation of Junkiebonden after users in dozens of cities in the Netherlands initiated informal and formal groups. By 1985 there were at least 35 junkiebonden in 28 cities. In Amsterdam three junkiebonden were operating independent from each other: the Amsterdam, Surinamese and German Junkiebonden. Many junkiebonden did not last long, though, due to organizational weakness and discontinuity in the efforts of members. After 1985, the Rotterdam Junkiebond was weakened by frequent leadership turnover and by the inconsistent performance by members of agreed-upon tasks. For example, it happened quite often that the office was closed when it was scheduled to be open, hampering its ability to run the needle exchange (Friedman, Jong, & Des Jarlais, 1992).

The HIV epidemic and the public health response

When HIV visibly entered the Rotterdam IDU community, neither authorities nor drug treatment institutions responded quickly. The Rotterdam Junkiebond, however, quickly extended its controversial needle exchange programme through distributing syringes in the streets and providing dealers with bulk amounts of syringes. It soon thereafter published the first HIV prevention brochure for IDUs in the Netherlands ('Junkies Blood', May 1986). This brochure was produced and distributed without any support from local authorities or professionals. The Junkiebond also pressured authorities to change their policy approach and demanded an increase in the supply of clean syringes. With the help of alarming media coverage and national health authorities, the public health response in Rotterdam rapidly changed.

While Rotterdam authorities were still sceptical towards the demands of the Junkiebond, the national Ministry of Health quickly understood the positive impact needle exchange could have on the epidemic and fully supported the claims of the junkiebonden. When the Ministry decided to provide additional funding for needle exchange programmes, cities all over the Netherlands (including Rotterdam) adopted needle exchange. By the end of the 1980s needle exchange programmes were operational in 60 cities (de Jong, 1991).

IDUs responses in Rotterdam to the HIV epidemic

Little is written and published on early individual and micro-social responses of IDUs to the HIV epidemic. In the

summer of 1986, when there were still relatively few AIDS cases in the Netherlands, we observed scepticism and ignorance about AIDS among drug users in Rotterdam and other cities (Friedman, de Jong, & Des Jarlais, 1990). In the same year, an early study on the Rotterdam Junkiebond needle exchange found that 72 percent of the exchangers discussed the subject of AIDS with friends, compared with 32 percent of a control group of local IDUs who did not engage in the exchange (Kaplan, Morival, & Sterk, 1986).

Rotterdam vignette, closing remarks

There are strong indications that the first micro-social responses to the HIV epidemic among IDU in Rotterdam occurred among IDUs in direct contact with the Junkiebond. With the early needle exchange programme and the production of written and experience-based prevention materials, the Junkiebond considerably stimulated the discussion of HIV and AIDS by users. Through the vehicle of the Junkiebond, drug users showed leadership in promoting internal change within the drug user subculture. This probably helped stabilize HIV prevalence at 12 percent.

Due to its action-oriented and political approach, the Junkiebond had a strong impact on formal policy responses, both in approach and in speed. Before the onset of the HIV epidemic, the Junkiebond had strongly argued for conditions and policies which would reduce health risks for active IDU. The initially underground and controversial needle exchange programme against hepatitis B set the path for the response of the local authorities. By the time treatment institutions and municipal health services started to implement needle exchange programmes, the acceptance and public support for these programmes was already there.

Buenos Aires vignette

The setting

In Brazil, Uruguay, and Argentina, injecting practice is more widespread than in other South American countries (Magis-Rodriguez, Marques, & Touzé, 2002). Nevertheless, in all these countries very little was known about injecting drug use before the HIV epidemic. The importance of injecting use in HIV transmission in Argentina became evident both in the AIDS cases diagnosed and the high HIV prevalence among injection drug users (Rossi, 2001). Harm reduction programmes began in the late 1990s in the Buenos Aires Metropolitan Area conducted by NGOs. It took several years more to involve governmental agencies in the acceptance and development of harm reduction strategies.

The HIV epidemic and the public health response in Buenos Aires

Argentina has 30,498 reported AIDS cases from 1982 to December 2005. Initially, in the 1980s, AIDS was concentrated among men who have sex with men (MSM); in the 1990s, it spread among groups of injecting drug users (IDUs); and, in the past 3–4 years, it has crossed

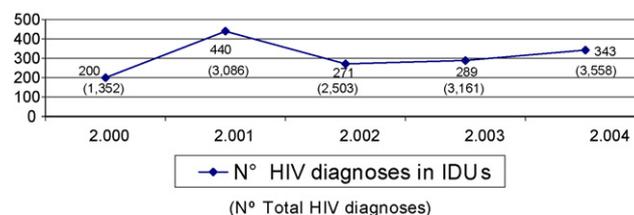


Fig. 2. Number of notified HIV-positive serology diagnoses in IDUs. Argentina, 2000/2004. Source: Marcelo Vila, Intercambios Civil Association, based on data from National AIDS Program, Ministry of Health and Environment, Argentina, 2005.

over into the heterosexual population at large (Ministry of Health and Environment, National AIDS Program, 2005). Approximately two-thirds (68.8 percent) of all AIDS cases reported in the year 2004 were attributed to sexual transmission (50.8 percent among heterosexuals and 18.0 percent among MSM), followed by transmission among IDUs (16.6 percent). This pattern of transmission has been principally caused by an increase in high-risk sexual practices of heterosexuals with IDUs and non-injecting cocaine users (NICUs) (Weissenbacher, Rossi, Martínez Peralta, et al., 2003; Weissenbacher, Rossi, Radulich, et al., 2003).

The first AIDS case from injecting drug use in Argentina was diagnosed in 1985. All the country's provinces have reported cases, but the largest percentage is concentrated in the province of Buenos Aires and in the City of Buenos Aires. Information about new HIV diagnoses in the country is very recent. Fig. 2 shows the curve of new diagnoses in IDUs in Argentina.

In 2003, a comparative analysis was published of 22 studies on HIV seroprevalence in IDUs, conducted in Argentina from 1987 to 1999. It found that more than 95 percent of IDUs injected cocaine and there was a high HIV infection rate in this population, ranging from 27 percent to 80 percent (Sosa-Estani, Rossi, & Weissenbacher, 2003). HIV seroprevalence in a study of IDUs from the Buenos Aires Metropolitan Area in 2000 was 44.3 percent, although no incident cases were detected (Vignoles et al., 2006).

Although the most frequently injected substance is cocaine, IDUs used other substances in the past, such as amphetamines salt. This substance was replaced in the mid-1980s by cocaine because it became highly available in the drug market.

Buenos Aires IDUs' responses to the HIV epidemic

Changes in injecting drug use from 1998 to 2003 were studied in a population of current IDUs in Buenos Aires Metropolitan Area (Rossi & Rangugni, 2004; Rossi et al., 2006). Some of the reasons found for changes in IDU are:

A decrease in frequency related to the low quality of the cocaine as compared to the quality obtained at the same price before the devaluation of the Argentine peso with the economic crisis in 2001. The decrease in frequency was also associated with care for self and others.

“When I started consuming, a paper [dose of cocaine] cost 20 pesos. It cost 20 pesos and weighed a gram. Nowadays it costs five pesos and weighs less than half a gram. But what’s the deal? It’s not the same quality. And when I started shooting up, I consumed more than I do now. Thing is, I’d have six papers, and with each paper I’d shoot up once, and so that made a total of six hits. And you get used to it, because it’s not good quality. What I’m buying now is not bad, but it’s not good, either. So not long after you shoot up, you come down. So what used to get you high six times is now just good for three hits” (man, 35 years).

“First I started shooting up cocaine all the time, and Ketalar for a while, too. But it wasn’t cool, because I was living just to get high, but now I have other priorities. I can say, ‘No, I don’t feel like it today, I’m not going to shoot up, not today, not tomorrow, either.’ Now I have the power to decide” (man, 34 years).

Injecting use has become a more hidden and individual practice. In many cases the IDUs do not talk about their injecting practice even with their partners. Their silence is related to the stigma that associates drug injecting with AIDS and death.

The circumstances and place for injecting drugs also changed. A few years ago, injecting locations were not exactly public spaces, but they were also not the domestic environment as now, according to the majority of the interviewees. IDU networks not only knew each other, but were also linked to other networks from other territories, often procuring drugs or other kinds of interactions. Currently it is very difficult to find broad injecting use networks. Those who continue to shoot up with others are doing so mainly with their friends.

The impact of the AIDS epidemic among IDUs has been observed in other studies in the region (Caiaffa & Bastos, 1998; Osimani & Guchin, 2004). In the case of Buenos Aires, the collected data reflects its influence on changes in injecting patterns. The following excerpt from a discussion group of male IDUs and former IDUs ranging from 24 to 50 years of age shows this association: “Many died. There was a huge scare, ten years ago. People were scared by so many deaths, basically more from HIV than from overdose” (man, 35 years).

Many of the older IDUs participating in the study considered themselves “survivors” of various groups of friends and family with whom they were linked in drug injecting. These data are similar to those from the first study on seroprevalence of HIV and other viruses with 174 non-institutionalized IDUs in Buenos Aires Metropolitan Area, in which 82 percent had lost friends or relatives due to AIDS (Weissenbacher, Rossi, Martínez Peralta, et al., 2003; Weissenbacher, Rossi, Radulich, et al., 2003).

The mortality rate from AIDS shows an upward curve until 1996 (when HAART began to be available), beginning to drop and stabilize in the subsequent years. However, compar-

ing this with the information provided by the IDUs, it would appear that among the peers and relatives of this population, many deaths were concentrated in recent years. Although the impact of more recent deaths may have influenced the interviewees’ recall, one hypothesis emerging from this information is that IDUs have had little access to HIV treatment. There may have been an impact from the social distance between the IDUs and the health system, often aggravated by the refusal of many Departments of Infectious Diseases to provide antiretroviral treatment to individuals who continue to use drugs (Linás & Vila, 2002; Moscatello, Campello, & Benetucci, 2003). The high mortality rate in this population was also verified by a study analysing the profile of AIDS deaths in 100 patient histories in a Buenos Aires hospital from June 2003 to March 2004, 41 percent of whom had a history of injecting drug use (Maulen, 2004).

The death of friends and acquaintances due to AIDS also led to changes in condom use. Many IDUs emphasized how the HIV/AIDS epidemic led them to care for themselves and to spread ways of preventing HIV transmission among their peers, especially the younger ones.

“When AIDS came on the scene, a lot of people didn’t give a shit, and there they are. But many of us opened our eyes and said: ‘No, wait, did you see how that dude died?’ Yeah, we’d better all wise up, or we’re going to kill each other! And this was back in 1989 and 90, because before that we didn’t know anything. There was no information of any kind. We had to get wise because a friend died of AIDS, not because they handed us a leaflet, like now when we fight to pass out leaflets or share condoms. We all dig it now. But back in 90 there was nothing. Nobody knew what sharing your works could do to you, let me tell you, not a single rubber, or what rubbers were good for” (man, 33 years).

Among the individuals who tested HIV-positive, this fact led to changes in their lives such as greater care with their own body and mode of injecting, care to avoid transmission, and fear of (or even abstinence from) sexual relations. Some reported changes in the drug consumption route.

“Today they tell me to go shoot up like I used to. No. What’s changed is that now I watch out for myself, because now I know what HIV means. I know what it is. The sharing has changed, and I tell my friends, ‘Dude, watch out, cause you can get infected’. Because a lot of my friends are gone, a heap of my friends died of HIV. And not just from shooting up” (woman, 29 years).

Death of injecting friends or acquaintances due to AIDS, fear of HIV, or living with HIV appear repeatedly as the basis for new precautions by IDUs in relation to sharing injecting equipment, even though such precautions have been adopted unevenly.

“You see a lot of people are gone, it’s crazy, I know a lot of them are gone. But dude, nobody forces you to do anything. If you want to shoot up, whammo, you do it, dude? To snort instead of shooting up is in your mind. When I shoot up, I use my own works, dude. You shoot up, and you don’t share the hit with anybody, just you” (man, 35 years).

The habit of sharing syringes among injectors seems to be declining, and is less frequent among younger injectors.

“As time passed, a lot of things changed. Today you can get syringes here [a peer educator’s home]. You used to have to beg all over the ‘hood for forty cents, because you already had the five bucks for the paper. If you didn’t beg for the forty cents for the syringe, you didn’t shoot up. That’s how it is if you don’t bring your syringe, I’m not lending mine or borrowing from anybody either. It used to be one syringe for everybody, it was always like that” (man, 34 years).

Closing remarks on Buenos Aires vignette

Friendship groups of drug injectors in Buenos Aires reacted to HIV infections and AIDS deaths in their social networks by reducing their risk behaviours beginning in the late 1980s when they began to develop an understanding of the disease. This was well before harm reduction programmes began there in the late 1990s. In addition, harm reduction programmes have facilitated risk and health management, particularly among users who have been in contact with such programmes for several years, even though the 2001 Argentine economic crisis also had a negative impact on services in different harm reduction programmes. The positive impact of harm reduction programmes was observed in the decrease in sharing syringes, which is related to the increase in information on health risks and the continuous provision of preventive elements like injecting materials and condoms, with free and continuous access.

Central Asia vignette

The setting

The injection-driven HIV epidemics in countries of the former Soviet Union constitute the fastest growing HIV epidemics in the world. In Uzbekistan, a sharp increase in newly registered cases of HIV infection was noted between 1999, when 25 cases were reported, and 2005 when more than 2198 new HIV cases were reported, bringing the total accumulated cases to 7810; 64 percent were associated with injection drug use. The number of IDUs nationwide is estimated to be over 100,000, with the majority between the ages of 16 and 34 (Republican AIDS Center, U., 2006). Use of homemade opiates in medicinal teas, a practice indigenous to Uzbekistan’s villages, has, since the collapse of the Soviet Union, been largely overtaken by injection of opiate preparations including heroin trafficked from Afghanistan and bound for markets in Russia and the west.

Public health response: government sanctioned harm reduction

Unlike some other countries, Uzbekistan appeared to embrace the implementation of syringe exchange. Since 2002, the Uzbek Ministry of Health has established 221 puncte daveria or “trust points” for the exchange of syringes. Unfortunately government support has neither meant access to syringes nor widespread use of these trust points by injection drug users, since the creation of needle exchange was accompanied by government decree that state “narcological” (drug treatment) centers were the only ones authorized to implement the HIV prevention strategy.

A legacy of Soviet era psychiatry, the psychiatrist/narcologists and the narcological dispensaries in which they work are more linked to government drug control than to health services. The trust point embodies Lefebvre’s antagonism between administered space and lived space (Lefebvre, 1991). Emphasis in the trust point is on administration: the space is organized around a desk on which sits a large ledger book for counting. Walls are covered with posters equating drug use with AIDS, the grim reaper, and skulls and crossbones. Paid staff are largely untrained in harm reduction, much less counselling; they have little or no experience working with drug users; and are frequently clothed in the starched medical costumes and hats worn in narcological dispensaries offering heavily medicated detoxification.

Non-governmental contributions to harm reduction are blocked by the Uzbek government’s aggressive campaign to block NGO access to bank funds, subject them to tax audits, and require foreign NGOs to prove in court that they have not exceeded the mandates of their missions. This crackdown is part of a broader government effort to prevent engagement of civil society in the public sphere with particular restrictions applied to those activities that try to fill the vacuum left by government. The net effect has been to shut down needle exchange programmes developed by community based NGOs.

Facing regular police shakedowns that preclude the possibility of any public association, even hanging out in parks, drug users organize in small pre-existing clusters of close friends, and siblings. Unlike the West, where sharing is largely analysed in terms of injection equipment or drug doses, sharing in this context extends to communal preparation of batches of drugs, often cooked from juice of the poppy or the dried straw. Day to day, group members organize themselves into different roles, with one member providing the money needed to purchase raw materials, another familiar to the local *baryga* or drug dealer (often a drug user himself) and able to come into his home, another going to secure the chemical ingredients needed to break down the poppy, and a third providing his home for cooking. These groups are not a subculture so much as folded into existing structures of ‘relatedness’, often including brothers, sisters, parents, wives. Within the same family, it is even possible to see the mother dealing drugs on a small local level and some of her children entering drug use from another door.

Popular responses to the HIV epidemic

Harm reduction responses based on community participation are more available just across the Uzbek border in Kyrgyzstan and Tajikistan. In Osh, a border area of Kyrgyzstan populated by many ethnic Uzbeks, the relatives and neighbours of drug users, called social workers, participate in a needle exchange programme ironically entitled “Parents Against Drugs”. (“Social workers” in Central Asia generally refers to community members who respond to a health problem, usually through NGOs funded by international donors. In harm reduction programs they are frequently experientially motivated family members and neighbours of drug users. Although they may receive some specific training, they do not necessarily have any higher education or formal education or degrees in social work.) Social workers conduct needle exchange from their homes, or work with drug users and family members within their informal social networks.

One social worker conducts needle exchange within the social network of his two nephews who use drugs. They are luli or gypsies, who live in an enclave in Osh. Both drug dealing and drug use exist in the community but acknowledgement is a taboo, and the drug users fear for their lives should their drug use become known. In another example, Nadia (not her real name), whose husband is a drug user, provides needles to drug using friends of her husband who sit with him in front of her house. Her husband is blind from an injection-related infection. Nadia, describing herself as initially ‘squeamish’ about needles and blood, learned how to inject her husband to keep him healthy.

In Panjakent, a town in the Zeravshan Mountains of Tajikistan, two outreach workers have transformed a small narrow shed of a family tobacco farm. Once the shed was the yama – literally a hole – slang for a shooting gallery, of Odile (not his real name), one of the outreach workers. Now 8–15 young men come regularly to exchange new needles for used ones, and hang out to talk.

On one occasion, Odile spread out a cloth and men squatted on mats a round him. Odile set down around crusty flat bread, cookies, a big plastic bag of sugar and a small jar of Nescafe, and the other outreach worker poured hot water into little bowls. Abukhadir (not his real name) wearing a cap at a rakish tilt, slipped in and two others made room for him to crouch down. Known affectionately as the ‘doctor’ because he could find their veins even when they could not, Abukhadir, a tall slender man in his twenties, said he had had 3 months of no drugs, and another time had gone without for 9 months, but he was still left with the craving and he went back. He said he did not even have enough money to get married, which he reflected did not permit him to fulfil his role as a man, as a son, as a family and community member. He said he feels hopeless. “All the money we spend on buying drugs . . .”.

Another said, “I have a daughter; my wife left me, my wife left me taking my daughter, and now there is even no money to buy *nos*.” (*Nosvai* is a mix placed under the tongue or in

the gum consisting of very fresh green tobacco leaves minced together with ephedra [ephedrine] that grows in the mountains, and lime or ash that breaks it down. Like the reported effects of chewing coca and lime among South Americans, *nosvai* provides energy and calm, diminishes hunger and fatigue, and its use is very common. It is sold along with chewing gum, loose cigarettes, and sunflower seeds on small street stands.) “One of my classmates died,” another said. And another added, “One of our guys went to Russia and died there [of overdose].” The high prevalence of overdose makes it a more immediate concern to drug users than HIV, but neither data nor funding to address it exists. “So they are going to bring his body today. We will go to a funeral after this.” Another announced, “After the funeral, we will go to a wedding late this afternoon!” When these men speak of the wish to quit heroin use, the outcome they are looking for is not abstinence in a culture of recovery, but fitness to function within the social worlds in which they continue to live.

Reflections on central Asian vignette

The American notion of addiction and the moral character of abstinence, assumed to be universal and stable, do not migrate well across Central Asian borders. There is no recovery culture, nor even a stable notion of drug users, and often, no stable drug supply. Users like Abukhadir cycle in and out of dependence. Opiate users, including those who are dependent, experience irregular availability of drugs, dramatic fluctuations in price, and variation in purity. A study of risk management among drug users in Kazakhstan documented shifts between substances used, including over-the-counter drugs and vodka, and concluded that drug users are focused on managing the multiple effects of their drug use and were developing, among themselves, informal forms of substitution therapy as strategic responses to the contingencies of everyday drug use (Zhussupov & Favorov, 2004).

Studying accounts of epilepsy among people he interviewed in Turkey, Byron Good (Good, 1994) demonstrated that the story of the disease was neither limited to or positioned exclusively with the individual experiencing the disease or to a physiological process of the body where biomedicine might place it. In Central Asia, similarly, addiction is not a condition of the individual. Drug users do not as a group step out of the moral economy of obligations, expectations, mutual self-help and collective participation of their Moslem cultures in Central Asia.

Effective responses to drug use, similarly, are social; Friedman (Friedman et al., 2004) advanced the notion of “invention” as an alternative to the limits of the individual-behavioural intervention and a description of how a community transforms risk into risk reduction. In Central Asia, rather than construct the drug subculture as a distinct entity parallel or in opposition to the family and normative culture, it may be more practical to understand the family within the mode of drug user interaction and the drug user interaction within the mode of the family so that they are in a dynamic relation to each other.

That drug users are embedded in the Central Asian family helps place them beyond the reach of the Uzbek narcological system. Suspicion of users and people associated with drug use leads narcologists to disregard the positive value of social connections users form in the process of obtaining or injecting drugs. Ironically, the “anti-social behaviour” of the narcological system (Wolfe, 2006) impedes the peer-to-peer interaction and support which drug users repeatedly identify as most important to modifying or stopping illicit drug use. Tolerance of community engagement, as in Tajikistan or Kyrgyzstan, underscores the value of needle exchange programmes that recognize – in ways that American or European harm reduction programmes often do not – that drug use is relational and collective, and that solutions must also be.

Conclusions

This review is subject to several limitations. First, it reviews a relatively small number of localities out of the many places where drug users have had to deal with HIV/AIDS and related diseases. Formal users groups, for example, are very widespread, existing in Latin America, Canada, the USA (often underground or hiding as service providers), Europe, Asia, and Australia. Second, this review is limited by the relatively narrow research base on drug users’ micro-social responses to the epidemic as collective and socially embedded actors. Most of the available research either focuses on drug users’ responses as dependent variables that reflect the actions of public health agencies or other non-user NGOs; or else examines risk behaviours and transmission behaviours epidemiologically. Third, although the research base on formal organizations of drug users is of course somewhat larger, here, too, the research base is limited. There is an almost total lack of research, for example, on those users’ groups that hide the fact that they are a collective organization of drug users and have public existence only as service provider agencies. Another limitation is that the research leading to the vignettes was not coordinated across the different sites, which limits our ability to compare and contrast the different sites. Finally, our ability to reach conclusions about the effectiveness of these actions is limited not only by the scarcity of relevant research but also by a fundamental issue of research methods: The self-organized activities of groups of people to protect their communities are not subject to randomized controlled trials; and, often, the lack of pre-existing longitudinal research projects means that observational epidemiologic research methods are limited in what they can conclude.

Nevertheless, in spite of these research design issues, the epidemiologic data in the above vignettes give us substantial reason to suggest that users’ activities can limit the ravages of HIV and perhaps other epidemics. These data show that users’ activities were followed both by considerable behaviour change (often involving approaches that public health agencies had not even begun to discuss yet)

but also suggest that in New York, at least, these actions may have limited HIV spread.

It is clear that drug users’ networks, and drug users’ responses to HIV, take place within broader social contexts. As is evident from the vignette on Central Asia, these contexts affect micro-social responses. In Central Asia, at least, these responses do not take place within a socially isolated set of users’ networks; but instead take place within broader networks that include non-using family members and friends.

Similarly, broader political contexts, as well as the actions and initiatives of users themselves, influence formal users’ groups. In Rotterdam, for instance, the presence of social welfare programmes that enabled drug users not to be in total poverty, plus the existence of supportive church groups, greatly facilitated users’ ability to organize. Importantly, however, the organization of the Rotterdam drug user movement was also an act of human agency and human self-determination. The leadership of a group of users around Nico Adriaans was important both in starting the movement and leading it from success to success.

Perhaps most evident in this review is the fact that grassroots drug users have often acted for themselves to find ways to protect themselves and each other from HIV and other harms. This has several implications:

1. The view of “the IDU” that emerges from these cases is very different from the US official doctrine that sees users as incompetent and pathological, and thus as objects of intervention rather than as allies and participants in their own individual and collective health.
2. Harm reduction theory and practice should take more account both of micro-social and formally organized users’ groups, and also should pay more attention to the variety of ways in which users’ networks intersect with or include non-users.
3. Much more research is needed on existing forms of micro-social forms of collective self-protection by drug users and their social networks and also of users’ formal organizations. Such research should include descriptive studies; studies of how both outside forces and the conscious initiatives of users shape these activities; and studies of their social, political and epidemiologic impacts. As discussed above, impact assessment of users’ protective micro-social activities and formal organizations poses difficult issues of research design. Furthermore, this research is complicated in another way: in conducting such research, it might be tempting to rely primarily on external conditions as predictors. However, our data show that the beliefs, structures, and leadership patterns of user communities also are important. Such issues of human agency imply non-deterministic models of what their effects will be.
4. Those discussing harm reduction programming and strategy, whether users or not, should explicitly take into account pre-existing forms of activity and organization that users are involved in; need to consider whether

their plans will weaken these indigenous responses; and consider ways in which they and already-existing user activities can assist each other (see also Friedman et al., 2004).

5. Similarly, users' responses are a critical part of harm reduction history and theory. They have sometimes been downplayed or ignored during the history of the harm reduction movement, and we think that this has had harmful effects both on users and on the harm reduction movement itself. Just as "top-down" analyses of labour movements and other social movements have been critiqued by historians and social analysts, so too should research and strategies on harm reduction (and other issues concerning users) be critiqued if they do not deal adequately with users' own collective activities.

Finally, this review suggests that both researchers and policy makers should help develop ways to enable and support both micro-social and formally organized action by users.

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