ABSTRACT

Projections estimate 1,000,000 HIV infected by 2015 in Indonesia. Key behaviors to HIV prevention and care are determined by a complex set of individual/environmental factors. This paper presents empirical data, local evidence and theoretical concepts to determine the role of social sciences in HIV prevention/care.

Injecting Drug Use (IDU) is a social and very risky activity: 95% injected in the presence of peers and 49% reported needles sharing. 82% of IDUs do not use condoms consistently. Poor adherence to ARV treatment is related to a complex set of, mostly behavioral, factors beyond effective influence by standard professional skills of medical staff.

Meta-analysis indicated that about 1/3 of the variance in behaviour can be explained by the combined effect of intention and perceived behavioral control, the two cornerstones of the Theory of Planned Behavior (TPB). It is advisable to adapt TPB in the light of the Indonesian context.

Current theories of behavior and behavior change give professionals of all disciplines, working in HIV prevention and care, effective tools to change behavior and to improve HIV prevention and access & quality of HIV care.

Key words: VCT, ARV adherence, injecting drug use, AIDS/HIV, theory of planned behavior, intervention mapping.

INTRODUCTION

According to UNAIDS and WHO estimates, in Asia around 5 million people are living with HIV (range: 3.7 million–6.7 million). Some Asian countries (Thailand and Cambodia) managed to halt the HIV epidemic resulting in an overall declining trend of new infections: from 450,000 in 2001 to 440,000 in 2007.1 Injecting drug use (IDU) has been identified as a major cause of the current expansion of the HIV epidemic in Asia.2,3

During the first two decades of the HIV pandemic, Indonesia was relatively unaffected by the virus.4,5 It was not until 1999 when a sharp rise in HIV infection in several subpopulations was recorded. The groups most affected were intravenous drug users (IDUs) and Sex Workers (SW) and their clients. An anonymous sentinel surveillance in Indonesia revealed that in 1999 16% of IDUs were HIV-infected. This figure rose to 41% in 2000 and to 48% in 2001. In urban areas, HIV-transmission through needle sharing showed an eightfold increase from 1997 to 2003.6

Current estimates of total HIV infections in Indonesia range between 190,000 to 400,000 in a nation of 220 million inhabitants, while prevalence rates of HIV among different IDU subpopulations in Jakarta range from 18% to over 90%7-10 and unsafe injecting practices are estimated to account for over 75% of all new HIV infections.9,11 Around the year 2000, approximately one quarter of IDUs in Bandung, Jakarta and Bali were reported to have engaged in unprotected sex

Behavioral Aspects of HIV Prevention and Care in Indonesia: A Plea for a Multi-disciplinary, Theory- and Evidence-based Approach


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with commercially sex workers (SW) in the previous year. After Jakarta and Papua province (where the HIV epidemic is primarily heterosexually driven), West Java is the third worst affected province having an estimated 22,000 IDUs of which up to 52% are HIV-positive and 21% incarcerated. Unlike other countries, Indonesia has a quite unique HIV epidemic: HIV patients – mostly (ex-) IDUs and their spouses – are young: 40% of nationally reported AIDS cases were between 15 and 24 years and were rather well educated: in Jakarta 73% of the IDUs had higher education (high school or beyond) while in Bandung about 70% had finished senior high school, and 14% of the IDUs had a university degree. In the Bandung RSHS methadone clinic, about 42% of the patients have a senior high school degree and 31% of the patients have an academic degree.

According to the Indonesian National Narcotics Board, approximately 1% of Indonesia’s total population use intravenous drugs, resulting in a concurrent HIV and IDU epidemic, fuelling – through sexual contact between injecting and non-injectors – the Indonesian HIV epidemic. Unless effective harm reduction targeted at the most at-risk groups is put in place – including clean needle distribution and adequate condom distribution – scenario studies project at least 1 million HIV infections by the year 2015.

On the biomedical front, also in Indonesia, much has changed in the last decade: multi-drug antiviral (ARV) regimens have become available, more convenient, less toxic and, due to generic and off-patent production with pharmaceutical subsidies and government distribution to 148 designated ARV treatment hospitals, less expensive. In Bandung, this development is paying off: compared to the current national mortality figure of 20%, the Bandung mortality rate now is 7% one year after starting ARV.

Despite this progress, huge challenges still remain in the field of behavioral aspects of HIV prevention and care in Indonesia. “It is not who a person is but what he or she does that determines whether one exposes oneself and/or others to HIV”. (after Fishbein, 2000)

Behaviors considered key to HIV prevention and care are determined by a complex set of individual and environmental factors. For practical reasons and in order to gain a better understanding of these individual and environmental factors, behavioral sciences use theoretical concepts to model, determine and explain cognitions, barriers and environmental conditions that affect behavior of (ex-) IDUs, and other groups at risk, and their access to and use of services. The development of HIV prevention and care should be a well planned evidence and theory-based activity in order to be effective. Especially the use of behavioral models facilitates all professionals working in the HIV field to critical analysis of the situation of the individual, group or the environment in order to develop, implement and evaluate appropriate and effective prevention and care interventions.

This paper presents empirical data and theoretical concepts to determine the role of behavioral sciences in HIV prevention and care in Indonesia and covers the following chapters: 1. analysis of the situation/problem; 2. analysis of the behavior at individual and environmental level (e.g. risky injecting behavior, condom use), 3. analysis of the determinants of the behavior (e.g. group/peer pressure, self-efficacy), 4. development and pilot testing of the intervention (e.g. school-based prevention curriculum, counseling), and 5. implementation of the intervention (e.g. at schools or at ARV clinics). We will follow the steps of the Intervention Mapping method to discuss empirical data and theoretical concepts related to behavioral aspects of HIV prevention and care, such as: knowledge, attitudes, social norms, risk perception regarding HIV-related risk behaviors, and perceived skills related to risk reduction behaviors and ARV treatment (safer sex; safe injecting, adherence to ARV treatment).

**EVIDENCE ON BEHAVIORAL ASPECTS OF SEXUAL AND DRUG RELATED RISK BEHAVIORS SUCH AS VCT, ARV UPTAKE AND ARV ADHERENCE**

Next, we will present data of sexual and drugs related risk behaviors among IDUs, leading to health hazards like HIV or HCV infections, as well as local behavioral evidence related to the uptake of VCT, ARV treatment and adherence.

**Sex-related Risk Behavior Among IDU**

A 2006 in-depth study of 321 active IDUs in Bandung revealed that about 15% had a steady partner, that 47% bought sex in the last year, and that 89% ever had casual sex partners. Of all respondents, 37% never used a condom in any sexual contact, 51% did not use a condom during the last sexual intercourse, 45% reported to have had unprotected sex with SW the year before. Of the 321 surveyed IDUs only 10% of this group had been tested for HIV. According to the 2007 national bio-behavioral survey, 82% of the Bandung IDUs did not use condoms consistently and 45% do not use a condom when having sex with a sex worker.

**Drug-related Risk Behavior Among IDU**

The above mentioned 2006 Bandung survey further showed that the average age of this specific survey
sample was 19 years. The mean age of first illicit drug use (including alcohol, mushrooms, inhalants, codeine, ecstasy, marihuana, tranquilizers, cocaine and amphetamines but excluding tobacco smoking and injecting drug use) was 16 years and first injection drug use was at 19 years. Individual risk behavior often is influenced others: 95% of the IDUs injected in the presence of peers in 95% of cases and high risk injecting behavior was common: 49% of IDUs reported needle sharing in the previous month.18,26,28

Difficulties with VCT utilization have also been reported in other countries. Ugandan researchers evaluating home-based VCT (health workers going door to door) stated that besides inconvenience of the testing site, fear of stigmatization and emotional vulnerability and lack of confidentiality: receiving results in a public facility (hospital/health centre) were the most common explanations for the relative popularity of home-based VCT.36 Dutch research points out that the main reason for not taking an HIV test among Men who have Sex with Men (MSM) was fear of a positive test result and the perceived psychosocial consequences of this test result.37 Recent Bandung research points out that IDUs do not go for VCT because of perceived lack of confidentiality offered at the VCT sites, the costs related to testing (travel and additional service costs) and perceived lack of benefits of VCT.38

### Uptake of VCT

Voluntary Counselling and Testing (VCT) is a method whereby clients or patients with risk behavior (like IDUs and Sex Workers) are informed about the risks of being HIV-infected and stimulated to take an HIV test. VCT is a well proven and cost effective way to increase knowledge of HIV transmission, to promote behavioral change, and to stimulate the uptake of health care services like ARV treatment.32-34 Despite the increase of VCT testing sites in Indonesia it is estimated that as many as 70% of the most at risk populations have not yet found their way to a VCT site.3 Also in Bandung, VCT is the entry point to HIV services. Ideally VCT should be accessed before people develop opportunistic infections or other signs of a diminished immunological status, but the year before most patients in the Bandung RSHS decided to go for a VCT test only after being diagnosed with advanced stage of HIV infection (median CD4 cell count=193 mm$^2$/cell and majority being advised by health care workers to go for VCT in the hospital.35

Access and Adherence to ARV Treatment

As a result, the well education IDUs have a rather good knowledge on HIV/AIDS.27 But barriers like drug addiction and/or lack of knowledge about opioid substitution or ARV treatment probably prevent about 75% of current and former Bandung IDUs having tested HIV+, to accessed addiction- ARV treatment.39

Access to the Bandung ARV clinic requires, like in all Indonesian ARV treatment sites, that drug users stop injecting, abstain from drugs or join a substitution service. In addition, adherence to ARV treatment is expected. In the case of ARV for HIV-infection adherence should be very high (i.e. at least 95% of the doses taken, and on prescribed times). High adherence is essential for optimal suppression of the virus load.40,41 Lower adherence is considered as medication failure which may result in virological failure and ARV drugs resistance. More recent, research however, indicates that lower adherence levels (lower than 95%) may achieve durable viral suppression.42 Poor adherence is common in short-term treatment regimens like antibiotic courses.43 Reaching and maintaining appropriate adherence levels to ARV treatment is quite a challenge because ARV treatment is meant to be life-long. Poor adherence to ARV treatment is related to a complex set of factors: regimen related factors like the fit of a complex regimen to the day to day routines, psychological and physical adverse/side effects, of the treatment itself, socio-economic factors like lack of social support from family and friends, patient related factors like: low self-efficacy and lack of self-control of the requirements of the ARV treatment, psychological distress, depression, inadequate confidence in treatment and providers, knowledge, perceived norms (patients perception of what others expect him to do) perceived benefits of treatment related to health outcomes and other values (being a good parent/partner), forgetfulness, alcohol and drug use, stigma and fear of discrimination, poor literacy and cognitive impairment,44,46,47 health system related factors like lack of clear instruction, inadequate knowledge about relation between adherence and resistance and poor follow-up and feedback,44 and condition-related factors like low viral load and symptoms of HIV like wasting and opportunistic infections.
International research indicates that patients with an IDU history on ARV treatment, have a lower treatment adherence level and resulting in poor response rate.\textsuperscript{48,49} However, ongoing research in Bandung cannot confirm this: ex-IDU patients on both methadone substitution and ARV are doing at least as good (in terms of self reported adherence, and viral/immunological response) as patients without an IDU history that are on ARV treatment only.\textsuperscript{29} It would be worth while relating the self-reported adherence to a gold standard like electronic pill registration devices in order to validate the self reported adherence.

**THEORY OF PLANNED BEHAVIOR: A PRACTICAL MODEL TO ANALYZE COMPLEX BEHAVIOR**

There is a general recognition that behavioral sciences, theory and research can play an important role in protecting and maintaining public health.\textsuperscript{51} However, a recent review indicated that most of the many behavioral interventions developed in the HIV field, neither use an evidence-based approach nor draw explicitly on theories of health behavior. The review further showed that the Theory of Planned Behavior (TPB) had its limitations but was one of the most used and useful theoretical models to determine factors and mechanisms influencing various HIV related behaviors.\textsuperscript{52} A meta-analysis indicated that about 1/3 of the variance in behaviour can be explained by the combined effect of intention and perceived behavioral control, the two cornerstones of the TPB.\textsuperscript{53}

The core of TPB, as illustrated in Figure 1, is the concept that attitude, subjective (social) norms and perceived behavioral control (which is similar to Bandura’s self-efficacy concept) are the determinants of motivation, which is usually assessed as the intention to perform a specific risk or health behavior.\textsuperscript{54} As an illustration: the attitude toward learning one’s HIV status is primarily a function of the beliefs about positive and negative consequences of knowing one’s HIV status. Despite some people knowing about VCT and the availability of free and easy accessible VCT centres, they still have certain beliefs (mostly influenced by others) that influence the balance of perceived positive and negative consequences of a possible HIV+/HIV- result of the test. Herewith, the TPB recognizes that individuals are embedded within interpersonal relationships, organizations, community and society, and addresses socio-cultural aspects and incorporates factors outside the individual’s control (like peer pressure or the opinion of an other important) that may influence the intention and the actual behavior. As a result, individuals’ HIV preventive behaviors, such as taking up VCT services (in order to know their HIV status), is a function of individuals’ cognitions and of the environment they live in.\textsuperscript{24} In Bandung, most people going for a VCT in RSHS only went for VCT after a physician or other health care worker told them to check their status, which suggests negative attitudes towards testing.\textsuperscript{35}

Subjective or social norms refer to the perceptions of approval or disapproval of learning of one’s HIV status from significant others (peers, partner, parents). Ongoing research in Bandung indicates that perceived lack of confidentiality at the VCT site (individual factor) and the travel expenses to reach the VCT site (environmental factor) and perceived fear for discrimination (individual factor), are the major barriers to VCT uptake for people at risk. Other Bandung-based research explains well the distinction between individual and environmental factor from the research; cost could
be perceived as expensive or cheap to the subjects while they compare it to the most or less benefit offered by the services (individual factor) and not by the real evidence of far or near distance (environmental factor) they could reach VCT clinic from their residence.\textsuperscript{38} Self-efficacy/PBC refers to the conviction to be able to perform the behavior required (coping with bad news or changing one’s life-style or dealing with discrimination) in learning one’s HIV status, whether HIV+ or HIV-.

**DEFINING THE BUILDING BLOCKS OF AN EVIDENCE–AND THEORY BASED INTERVENTION: ADHERENCE TO ARV AS EXAMPLE**

Behavioral interventions aiming at changing complex behavior like sexual risk taking or improving ARV adherence, are likely to be more effective when based on evidence of former research and focus on causal determinants of that specific behavior and when based on a theoretical concept of behavior and behavior change. Evidence- and -theory-based interventions also facilitate evaluation and understanding of the effect of behavioral interventions, which in their turn feed in the process of further development of the theoretical foundations of behavioral interventions. TPB is the most used and strongest founded theoretical model to predict a range of behaviors.\textsuperscript{55,56} Godin and Kok\textsuperscript{57}, reported in their meta-analysis of 87 TBP studies applied to health behavior that TPB accounted for 41% of the variance in behavioral intentions and 34% of the variance in behavior for a broad range of behaviors. However, TPB mostly is used as background to understand and explain the behavior and what to change within the behavior. However, other theories are mostly used to explain the behavior change and how to design behavioral intervention.\textsuperscript{58}

Adherence to ARV, often, (also in Bandung) measured through self-report is, when linked to more objective measures like viral load, sub-optimal in about half of the patients.\textsuperscript{58,59,60} Very few rigorous evaluations of interventions to improve ARV adherence are available.\textsuperscript{52,61} From a recent Cochrane review we learn that interventions aiming at improving and strengthening medication management skills tend to be the most effective approach to adherence improvement.\textsuperscript{52} As discussed before, adherence is embedded, supported, facilitated and often frustrated by complex behaviors.\textsuperscript{63}

**Figure 2. Behavioral model for medication adherence (De Bruin & Hoppers 2005)**
Ideally, an intervention to optimize adherence, uses all three factors as building blocks to design a tailor-made intervention in order to influence the intention and actual adherence behavior: use peers, partner, or professional to influence the patient’s norm, change the attitude of the patient through effective and/or persuasive communication. In order to influence PBC and self-efficacy (the last building block) it is advisable to breakdown desired outcome behavior in sub goals, facilitate this behavior (using adherence organizers like pill boxes, electronic reminders), plan together with the patient the execution of the desired adherence behavior (fitting ARV treatment into the patient’s daily life) and introduce self-monitoring and feedback mechanisms to improve the awareness, reinforce desired behavior and develop routine in ARV medication. De Bruin & Hospers developed a 9 step intervention protocol using all above mentioned behavioral determinants: knowledge improvement, definition of desired behavioral outcome and HIV status, joined planning and reinforcement of desired adherence behavior introducing adherence data and self-monitoring as feedback mechanism, defining causes of (non-) adherence. This multi-disciplinary intervention implemented in the Amsterdam Academic Medical Centre outpatient clinic, resulted in an increase of mean adherence from 82% to 93%. The Bandung ARV clinic currently is developing a protocol, based on TPB, to study and subsequently to design an intervention to improve adherence to ARV.

According to the medication adherence model, demographic and social/cultural aspects are minor variables and are supposed to play an indirect role in influencing behavior. However, current Bandung research on access to VCT indicates that HIV patients only seek VCT only after receiving the advice from a physician to go for HIV testing. This observation confirms Conner and Armitage advise to extend the TPB towards inclusion of two new variables: self-identity: the way a person relates his/her behavior to societal goals and moral norms: the persons feeling to perform or not to perform a particular behavior. In Indonesia social, cultural, societal goals and societal influenced (group) norms strongly determine behavior and it would be advisable to adapt TPB and redefine these variables in the light of the Indonesian context. When applied appropiatiely and used in the perspective of the targeted population, TPB can be cultural specific.

DISCUSSION

Also in Indonesia, professionals face challenges to change behaviors that are relevant in the field of HIV. Behaviors considered key to HIV prevention and care are determined by a complex set of individual and environmental factors. As pointed out, a well planned, multi-disciplinary, evidence- and theory based approach to influencing behavior can contribute a lot to improve HIV prevention and access and quality of HIV care. In order to identify determinants of specific risk- or health behavior, current theories of behavior and behavior change give all professionals working in prevention and care effective tools to change behavior. TPB stands out as particular useful for the HIV field but for practical and theoretical reasons it needs more and appropriate conceptualization, definition and explanation. For instance: Bandung-based research, based on the TPB indicates that IDU’s intention (behavioral intention) is more affected by the significant others (i.e, parent, peers) when they ask them to do so (subjective norms) instead of taking VCT as self-awareness (perceived behavioral control), despite they have enough relevant knowledge about the VCT services. This result illustrated nicely that in decision making on what to do or not to do (behavior intention) Indonesians are strongly influenced by the value of collective culture, (based on what others say) to a specific issue. This cultural specific information, is very important input in the design process of behavior (change) interventions that work in Indonesia. As explained before, adherence to ARV as another example, while description by TPB model is embedded, supported, and facilitated by complex behaviors, which can be explained and described through the intercorrelation of each components in TPB model. Anyhow, more evidences needed further explanation of how variance of socio-demographic characteristics and personality traits, correlated with behavior intention; which sometimes means as limitation of TPB explanation or application, so in practice need further study and research to the approach itself to empower the utility of the concept. It is advisable to adapt TPB in the light of the Indonesian context.

CONCLUSION

As mentioned above, high risk behaviors to HIV/AID (i.e. sharing needles, and sex-related behavior) can not only be explained by a merely medical conceptual approach. It needs also explanation based on behavioral science concepts, as well as medical, and even cultural concepts to describe the behavior intention, attitude, perceived belief, or subjective norms, to gain a clear picture and understanding of the behavior and to make plan and conduct intervention for behavioral change in further action. For this purpose researchers can use the
advantages of TPB as a useful overall model to describe the relation and link of many important components as reflected by the theory. Therefore, researchers, medical-and behavioral sciences practitioners and interventionists are challenged to better understand and correctly utilize existing empirically supported behavioral theories like TPB, in the process of developing and evaluating effective behavioral interventions in HIV prevention and care.

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