

Freedom to Adhere:

Democracy, wealth disparity, social capital as factors influencing HIV medication adherence

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Background

Structural challenges that impede Human Rights approaches to managing HIV

- National level democracy rankings
- HIV criminalization
- Wealth disparity
- Social capital

Limited evidence of relationship between structural challenges and health promoting behavior

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Theoretical framework

Ecosocial Theory

- Postulates that for every intervention or policy there is near simultaneous and reciprocal effects across social environmental levels of influence
- Requires dialog among ALL stakeholders to develop solutions

Social Epidemiology Methods

- Allows for a more balanced approach to explain contextual features of disease states observed in human populations
- Combines multiple sources of evidence not just health sector related

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Research Aims

Among an international sample of PLHIV

1. Determine if there are observable effects between the social structural factors of **democracy, HIV criminalization, wealth disparity**, perceived **social capital** and individual **ART adherence**
2. Describe the nature of associations observed between social structural factors of **democracy, HIV criminalization, wealth disparity**, perceived **social capital** and individual **ART adherence**

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Methods


Cross-sectional survey of PLHIV from August, 2009 to January, 2012

Convenience sample of adult PLHIV recruited from infectious disease clinics and AIDS Service Organizations

Protocol approved by coordinating site at UCSF and local sites

Data analysis included


- Descriptive statistics
- Correlational analysis
- Regression analysis



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Results—Sample Surveyed

2,182 PLHIV at 16 sites in 5 countries and Puerto Rico



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Results—Sample Characteristics

Selected Demographics		
	Freq (%)	Mean (SD)
Age (years)		45.1 (±9.5)
Gender		
Male	1486 (68.7)	
Female	623 (28.8)	
Transgender/Other	54 (2.4)	
Ancestry (Race/Ethnicity)		
African Am/Black	854 (39.6)	
Latina/Latino	425 (19.7)	
White	488 (22.6)	
Other	389 (17.8)	
Education		
11 th grade or less	601 (27.8)	
High School	804 (37.2)	
2+ yrs College	759 (34.2)	
Income Adequate	472 (22)	

HIV Disease Indicators		
	Freq (%)	Mean (SD)
Years since HIV diagnosis		14 (±7.6)
Prescribed ART	1775 (83.5)	
Has AIDS diagnosis	942 (44.4)	
Undetectable Viral Load	1034 (51.8)	
Viral Load (N mean)		20,930 (± 79,297)
HIV transmission method		
Sex HIV+ man	1458 (73.3)	
Sex HIV+ woman	521 (29.9)	
Sharing needles	508 (29)	
Blood transfusion	180 (10.9)	
Don't know	185 (12.3)	

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Research Aims 1 & 2: Evidence

Studied 4 explanatory and 1 outcome variables to:

1. Determine if there are observable effects between social structural factors of **democracy, HIV criminalization, wealth disparity**, perceived **social capital** and individual **ART adherence**
2. Describe the nature of associations observed between social structural factors of **democracy, HIV criminalization, wealth disparity**, perceived **social capital** and individual **ART adherence**

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Explanatory Variable & Results–Democracy

Site	N	Overall Democracy (range 1–150)	Political Rights (range 1–7)	Civil Liberties (range 1–7)	Press Freedom (range 0–150)	Corruption (range 0–149)
Canada	100	8	1	1	16	10
China	107	121	7	6	139	56
Namibia	102	42	2	2	44	40
Thailand	100	84	5	4	99	61
United States	1673	15	1	1	14	17
Puerto Rico	100	15	1	1	14	17
Total	2,182	--	--	--	--	--

World Audit (www.worldaudit.org) data aggregated from: Freedom House, Transparency International, Amnesty International, Human Rights Watch, and the International Commission of Jurists

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Results–Criminalization, Wealth, Social Capital

Site	N	HIV Criminalization (# prosecutions)	Wealth Disparity	Social Capital
Canada	100	Disclosure (114/13)	38.1 (British Columbia)	2.55
China	107	Yes, Disclosure (unk)	41.5	2.56
Namibia	102	No data (unk)	70.7	2.94
Thailand	100	No data (unk)	53.6	No data
California	300	Yes (10)	46.9	2.53
Hawaii	100	No (0)	42.2	2.73
Illinois	95	Yes (18)	46.6	2.66
Massachusetts	200	No (4)	46.7	2.67
New Jersey	100	Yes (4)	46.4	2.64
New York	100	Other Diseases (4)	50	2.69
North Carolina	200	Yes (4)	46.5	2.79
Ohio	150	Yes (25)	44.8	2.59
Texas	228	Reporting (22)	47.3	2.64
Washington	200	Yes (8)	44.4	2.54
Puerto Rico	100	No (0)	54.4	2.74
Total	2,182	-- (195)	--	2.65

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Outcome Variable & Results

Antiretroviral therapy adherence

For the following two questions, please mark how often you were able to take your medications. Here is an example of how to mark your response:

If you felt that you took your medications about 75% of the time, please make a mark like this:

- 30-day Visual Analog Scale for Medication Adherence, mean = 86.8%; median = 95%

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Results–Spearman’s Correlation

Variable	ART Adherence 30-day
Social Capital	.154**
Democracy	.096**
Political Rights	.106**
Civil Liberties	.106**
Press Freedom	.094**
Corruption	.095**
Gini – Wealth Disparity	.063**
HIV Exposure/Transmission Law	-.052*
HIV Disclosure Law	.069**

Note: ** p<.01 (2-tailed), *p<.05 (2-tailed)

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Results–Regression Analysis

Variables associated with **self-reported 30-day HIV antiretroviral therapy adherence**
($F=7.265$, $p<0.01$, adjusted $R^2=0.061$)

- Block 1: demographic controls
- Block 2: social structural context & social capital
- Block 3: Legal context

Total **social capital** score & demographic control variables (age, gender, ancestry, & education) were the only significant predictors of 30-day adherence

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Summary of Findings

Among PLHIV, living in more democratic societies with more political freedom is associated with better adherence than those in less democratic and politically unfree societies

Among PLHIV, living in jurisdictions where HIV is criminalized was associated with lower adherence than those living where HIV is not criminalized

PLHIV with more social capital were more adherent than those with less social capital

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Discussion

Factors at the social structural and legal context level were associated with HIV antiretroviral therapy adherence

We observed small effect sizes among social structural and legal context level

Observed effects we may indicate that social structural and legal context influences health promoting behaviors among PLHIV

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Discussion

Our lack of predictive findings between 30-day HIV antiretroviral therapy adherence and social structural and legal context variables may have resulted from vastly different social systems represented across our study sites

These differences may account for the differential findings observed between PLHIV in China, Namibia, and Thailand when compared to North America

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Limitations

- Large number of surveys from U.S.
- Non-random recruitment may introduce bias
- Self-report survey data collection and lack of biological markers of adherence
- Use of U.S. Census bureau ancestry (race/ethnicity) categories complicates interpretation of international samples
- Challenge obtaining accurate and current legal and policy information related to HIV

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Conclusions

Our results demonstrate interconnectedness of political, social and biomedical spheres in addressing PLHIV health care needs

Decontextualized biomedical advances and models of intervention efficacy are insufficient for future HIV management

Our results provide evidence for the importance of using intersectoral human rights based approaches to the management of HIV and its intersecting vulnerabilities globally

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Implications for Policy and Practice

Policy

- Nurses should continue to work *with communities* to address structural factors and “make the law work for the HIV response”

Practice

- Inform health care providers about their legal obligations in contexts of HIV criminalization
- Collaborate to reduce the harms caused by structural factors and address human rights violations

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Implications for Research

Research

- Study multi-level effects of structural factors influencing health outcomes among PLHIV and other vulnerable groups
- Determine baseline knowledge of HIV criminalization among health care workers, patients, and communities
- Develop strategies to intervene in contexts where structural factors may influence HIV prevention

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Selected References

- Bourdieu, P. (1985). The forms of capital. In J.G. Richardson (Ed.), Handbook of theory and research for the sociology of education (pp. 241-58). New York, NY: Greenwood.
- Bourdieu, P. (2001). The forms of capital. In M. Granovetter & R. Swedberg. (Eds.), Sociology of economic life (2nd ed., pp. 96-111). Cambridge, MA: Westview Press.
- Center for HIV Law and Policy. (2012). Ending and Defending Against HIV Criminalization: A Manual for Advocates (2010). Retrieved from <http://www.hivlawandpolicy.org/resources/view/564>
- Coleman, J. (1988) 'Social Capital in the Creation of Human Capital', American Journal of Sociology, 94 (supplement): 95-120.
- Global Commission on HIV and the Law (2012), Risks, Rights & Health. United Nations Development Programme: New York. Retrieved from <http://www.hivlawcommission.org/resources/report/FinalReport-Risks,Rights&Health-EN.pdf>
- GNP+. (2010: <http://www.gnpplus.net/criminalisation/>). Global Criminalization Scan. Retrieved from <http://www.hivpolicy.org/Library/HPP001825.pdf>
- Helliwell, J., & Putnam, R. (2004). The social context of well-being. Philosophical Transactions: Biological Sciences, 359(1149), 1435-1466.
- Hsieh, C. (2008). A concept analysis of social capital within a health context. Nursing Forum, 43(3), 151-159.
- Kawachi, I. (1999). Social Capital and Community Effects on Population and Individual Health. Annals of the New York Academy of Sciences, 896(Socioeconomic Status And Health In Industrial Nations: Social, Psychological, And Biological Pathways), 120-130.

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Selected References

- Lazzarini, Z., Bray, S., & Burris, S. (2002). Evaluating the impact of criminal laws on HIV risk behavior. *The Journal of Law, Medicine & Ethics*, 30(2), 239-253.
- Onyx, J. & Bullen, P. (2000). Measuring Social Capital in Five Communities. *Journal of Applied Behavioral Science*, 36(1), 23-42.
- Phillips, J. C. (2011). Antiretroviral therapy adherence: Testing a social context model among Black men who use illicit drugs. *Journal of the Association of Nurses in AIDS Care*, 22(2), 100-127. doi: 10.1016/j.jana.2010.07.008
- Pitkin Derose, K., & Varda, M. (2009). Social Capital and Health Care Access. *Medical Care Research and Review*, 66(3), 272-306.
- Portes, A. (1998). Social Capital: Its Origins and Applications in Modern Sociology. *Annual Review of Sociology*, 24(1), 1-24. doi:10.1146/annurev.soc.24.1.1
- UNAIDS. (2010). Making the law work for the HIV response: A snapshot of selected laws that support or block universal access to HIV prevention, treatment, care and support. Author, Geneva.
- Webel, A.R., Phillips, J.C., Dawson-Rose, C., Holzemer, W.L., Chen, W.T., Tyer-Viola, L., . . . Voss, J. (2012). A Description of Social Capital in an International Sample of Persons Living with HIV/AIDS (PLWH). *BMC Public Health*, 12, 188. doi: 10.1186/1471-2458-12-188 (URL <http://www.biomedcentral.com/1471-2458/12/188>).