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MCIS BRIEFINGS

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Comparative Program on Health and Society Lupina Foundation Working Papers Series 2006-2007

Edited by
Jillian Clare Cohen-Kohler
and
M. Bianca Seaton
Comparative Program on
Health and Society
University of Toronto

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The Munk Centre for International Studies at the University of Toronto seeks to be an internationally recognised leader in interdisciplinary academic research on global issues and to integrate research with teaching and public education. We place special emphasis on the fostering of innovative interdisciplinary knowledge through the exchange of ideas and research among academics as well as the public, private, and voluntary sectors.

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The CPHS Working Papers Series

The Comparative Program on Health and Society maintains a collection of academic papers which we call our Lupina Foundation Working Papers Series. These works can range from research papers to thought pieces; and from statistical analyses to historical case studies. Our series represents a snap-shot of the work being done by our Lupina Fellows, past and present. Taken together, our Working Papers Series encapsulates the wide-ranging approaches to the study of the social determinants of health. We hope that you will find the individual papers in our series thought-provoking and helpful.

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Foreword

We are delighted to present in this Munk Centre for International Studies Briefings Series, the third collection of papers from researchers affiliated with the Comparative Program on Health and Society (CPHS). The CPHS, which was founded in 2000, is a dynamic research institute based at the Munk Centre for International Studies at the University of Toronto. The CPHS is funded by the Lupina Foundation and supports innovative, interdisciplinary, comparative research on health, broadly defined through our extensive range of fellowships. These papers are testament to the richness and diversity of the Program.

This volume contains papers on some of the most provocative issues to date. We hope that as your read through them you will gain insights into areas of contemporary health research that may be entirely novel to you or will strengthen your knowledge in areas for which you are already familiar.

Paul Jackson in his paper examines the timely issue of how national insecurity has been taken up by entrepreneurial biomedical researchers to produce biodefense research. His paper importantly develops a map of bioterrorism preparedness projects that he argues has led to a profit making enterprise. "Protection" as a result of a generalized fear of defenselessness against bioterrorism has resulted in pharmaceutical commodities and technologies and uneven distribution of funding for specific regions. This in turn has also resulted in a politically reconfigured urban space.

The reconfiguration of urban space is also taken up by Angela Loder in her paper, "Shifting Edges and Moving Up: Green Roofs, Health, and the Nature/City Divide in Toronto and Chicago". Loder presents a thoughtful analysis of the ideological and political context surrounding the urban greening strategies of these two cities. Different and sometimes competing views of the appropriate place, form, and benefits of "nature" in relation to urban environments are apparent in policy documents from these cities and have shaped both the articulation and relative success of their respective green roof projects – with Chicago emerging as the clear leader in this endeavour. Her case study of the complex interplay of geography, ideology, policy, and politics affecting green roof projects in Toronto and Chicago suggests lessons for other cities attempting to become more "green".

Maritt Kirst and Lauren Classen turn our attention to the ways that we conceptualize and conduct health research on members of vulnerable populations. In her paper, "Social Networks and Harm Reduction: The Influence of Social Capital on Substance-Use-Related Health Behaviours", sociologist Maritt Kirst explores the decision-making practices of injection drug users and crack smokers, which she asserts are not only shaped by an individual's knowledge and beliefs, but also by the micro-social environment in which drug taking occurs. Accordingly, Kirst advances the social capital framework as a novel approach to the study of health risk and protective behaviours of drug users. Social capital theory moves beyond examination of individual-level factors for risk-taking and instead focuses on the influence of relationships and the structurally embedded resources available to individuals and members of social networks. In doing so, it helps to illuminate how social network and resource-related dynamics, such as trust, social support, and closeness, may encourage risk or promote protective responses. Ultimately, Kirst argues, the knowledge generated by incorporating this framework into research on the risk-related

behaviours of drug users will help to improve the peer-based harm reduction programs already in place.

Lauren Classen further develops this critique of individual-level approaches to the study and management of health risk for vulnerable populations. Her paper, "On Route to Participatory Health Evaluations: Local Women's Responses to AIDS in Africa and the Value of Participatory Interventions" draws upon recent anthropological research to demonstrate the important and often overlooked role of social capital and local context in shaping the health related behaviours of women in sub-Saharan Africa. In contrast to the individualistic, culturally inappropriate HIV prevention initiatives that are most common in sub-Saharan Africa, such as the "ABC approach" to HIV/AIDS education that encourages abstinence, faithfulness, and condom use, Classen passionately makes a case for initiatives that employ a "participatory approach", engaging local people and local ownership at every phase of the research process. In her view, participatory approaches to such initiatives have the distinct advantage of contributing solutions appropriate to particular local contexts while also building social networks and trust – key factors in women's own HIV prevention strategies.

The CPHS supported a number of scholars in 2006-2007 who are engaged in comparative health research in international settings. For example, Monir Moniruzzaman pushes us to think about a topic that is little discussed and in urgent need of better understanding. His paper, "Underground Fieldwork with Kidney Sellers: Issues of Access and Methods", is based on his courageous as well as path-breaking "underground" research in the area of kidney transplants, which harshly affects the most vulnerable members of society. Through conviction and tenacity, he gained access to a hidden population of 33 kidney sellers in Bangladesh in order to probe the complex and morally troubling area of organ commodification.

The issue of medical tourism which also demonstrates the commodification of health care services globally is investigated well by Leigh Turner. He points out in particular that uninsured and underinsured Americans unable to afford health care in the United States fly to other countries for treatments which they can afford because of price differentials in services and the relatively stronger power of the American dollar. He notes that there are medical tourism companies which are marketing the increasingly common combination of "sun and surgery" packages to international hospitals in India, Singapore, Thailand, and other destination nations. His paper raised amongst other issues the importance of recognizing that the development of a global market in health services will have deep consequences for the traditional model of health care services.

Maureen Murney's paper, "Our women are *Berehynia*: (In)Authentic Femininity and Addiction in Western Ukraine", draws our attention to the importance of gender as a social determinant of health. Based on her ethnographic study of men and women addicted to alcohol, she demonstrates how prevailing norms about appropriate "masculinity" and "femininity" – and the moral ideas that underpin these constructions – fundamentally shape the social experience of addiction and medical treatment of alcoholism for people living in Western Ukraine. Her paper contrasts the permissive attitude towards alcoholism in men with the stigma and discrimination that women face when battling this addiction. Murney urges us not to underestimate the extent to which this differential treatment contributes to women's burden of suffering.

Daniel Sahleyesus illuminates the issue of how fertility levels in most urban areas of Ethiopia have declined dramatically whereas rural fertility remains at high levels. By using both quantitative and qualitative research methods, he investigates perceptions about reproduction, including perceived benefits and costs of childbearing. He also probes how reproductive behavior is transforming in urban areas in order to explain fertility drops, and the extent to which demographic, proximate and sociocultural factors can explain urban-rural fertility differences.

The issue of access and equity is taken up strongly by Lisa Forman in her paper. She devotes attention to the issue of how trade rules impact access to medicines and the movement to counter this with advocacy for the human right to health. She puts forward that there a growing legal and normative force illustrated in both global jurisprudence on the right to health which has been put into practice in many jurisdictions as a result of the need to provide antiretroviral medicines to HIV/AIDS patients in least developed and developing countries. Forman helps us to understand the issue in depth by explaining how theoretical accounts of why states comply with law is a useful framework for this analysis and offer important strategic guidance for the realization of this right's potential.

Ron Bouchard in his paper explores how federally-funded medical research has transformed during the past three decades. He shows us importantly how governments are moving away from their traditional gate-keeping roles, adopting instead a stance where both public health considerations and economic activity resulting from commercialization of innovative research are advocated equally. He illuminates how there is growing concern about whether the actual benefits of an increasingly privatized medical research enterprise are equitably distributed amongst the various public and private actors responsible for product development. He argues provocatively and convincingly that benefits are directed mainly towards private firms and universities and do not promote the public interest.

Acknowledgements

The research and publication of these working papers would not have been possible without the generous support and patronage of Margret Hovanec and Peter Warrian of the Lupina Foundation, and the intellectual support and leadership of Janice Stein and Carolyn Tuohy. We are also profoundly grateful to Marketa Evans and Janet Hyer for all of their encouragement, patience, guidance, and assistance with the preparation of this publication.

The Editors

Jillian Clare Cohen-Kohler and M. Bianca Seaton

Contributors

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Ron Bouchard, PhD, is a doctoral candidate in the Faculty of Law at the University of Toronto. He has been involved in the prosecution, acquisition, financing and litigation of intellectual property rights, appearing before the Federal Court of Canada on trial and appeal matters and the Supreme Court of Canada. Before entering law, Ron completed a PhD in Pharmacology & Therapeutics and a Post-Doctoral Fellowship in the area of ion channel biophysics and intracellular ion imaging.

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Lisa Forman, PhD, is a CIHR and CPHS Post-Doctoral Fellow. She holds an SJD from the University of Toronto. Dr. Forman qualified as a lawyer in South Africa with a BA and LLB from the University of the Witwatersrand, and has an MA (Human Rights Studies) from Columbia University. Her work focuses on human rights, HIV/AIDS, global health and access to medicines.

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Maritt Kirst is a doctoral candidate in the Department of Sociology at the University of Toronto, and is also a member of the Collaborative Program in Addiction Studies. She holds a BA from McMaster University and an MA in Criminology from the University of Ottawa. Her research interests pertain to substance use and misuse, harm reduction, social capital, social networks, protective health behaviours, and crime and deviance.

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Monir Moniruzzaman is a doctoral candidate in the Department of Anthropology at the University of Toronto and a CIHR Strategic Training Doctoral Fellow in Health Care, Technology and Place. He holds an MSS and BSS from Jahangirnagar University of Bangladesh and received his MA from the University of Western Ontario. He taught for three years as a full-time faculty member in the Department of Anthropology at Shahjalal University in Bangladesh. His major research interests include: new biomedical technology, kidney commodification, healthcare services in post-tsunami Thailand, perception of poverty, and educational curricula in Bangladesh.

Maureen Murney is a doctoral candidate in the Department of Anthropology at the University of Toronto. She received a BSc in Biology from the University of Western Ontario and holds an MA in Anthropology from the University of Toronto. She draws upon social-cultural, medical and linguistic anthropology to explore gendered notions of health, illness, morality and citizenship in her research. Her doctoral research focuses on addiction, stigma, reproduction, nationalism, and the ambiguities involving access to and the utilization of medical knowledge in western Ukraine.

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Leigh Turner, PhD, is an Associate Professor in the Biomedical Ethics Unit and Department of Social Studies of Medicine at McGill University. Dr. Turner received his PhD from the School of Religion and Social Ethics at the University of Southern California. Prior to joining the McGill faculty, Turner worked at The Hastings Center and the University of Toronto Joint Centre for Bioethics. His current research interests include ethical issues related to migration of health care providers, globalization and international health, and medical tourism.

Funding Biodefense: Public Health, Bioterrorism, and the Emerging Infrastructure of Biosecurity Research

Paul Jackson

Abstract

This paper attempts to complicate the act of deeming the present moment "The Age of Bioterrorism." The fear of national insecurity has been taken up by entrepreneurial biomedical researchers to produce biodefense research institutes called "Regional Centres of Excellence for Biodefense." These biodefense projects dovetail with the political economy of competitive cities. The hype around national insecurity has become an act of speculation in which it is possible to invest. By following the funding of specific biomedical researchers and their institutions, this paper maps bioterrorism-preparedness projects that invest in a securitized future. Preparedness and speculation result in profits and infrastructures that attempt to tackle the feeling of vulnerability. The protection against a generalized fear of defenselessness against bioterrorism has resulted in pharmaceutical commodities and technologies. Most importantly, this emerging biodefense research shows an uneven distribution of funding for specific regions. This undergirding of funding for certain states, cities, and institutions creates a politically reconfigured urban space. The shifting politics, economics, and urban spaces transformed by bioterrorism and biodefense should be engaged while they congeal. This paper maps the geographies of militarization, neo-liberalism, and science studies to show the further entrenchment of the biomedical model of health.

Introduction

On November 9, 2001, the Centre for Disease Control (CDC) produced a video for the Internet called "Coping with Bioterrorism — The Role of the Laboratorian." The video begins with images of clunky three-dimensional logos sweeping across the screen and of a

computer-generated globe with satellites and red explosions, accompanied by ominous drum-beats and synthesized piano. The opening ends with the logo "Public Health Training Network:" a map of the United States that is cut into slices by an Aladdin-type lamp. Slow fade to the talking head of Dr. Jeffrey P. Koplan, then director of the CDC. In neutral beige suit and blue shirt, Koplan introduces the video with: "[W]e must be constantly vigilant to protect our nation's health and security. The war on terrorism is being fought on many fronts, and we must have a strong, robust public-health system…Like our system of national military preparedness, our public-health armaments, a skilled professional work force, robust information and communication systems, strong public-health departments and laboratories, and effective private medical and community partnerships must be in a constant state of readiness. Because health threats know no boundaries, we can afford no weaknesses in our public-health line of defense. Either we are all protected or we are all at risk" (Koplan 2001).

The video then outlines: how the detection of anthrax takes place; how laboratories work with one another; a map of public-health laboratories; and detailed scientific procedures of pathogen detection. The jargon and management-speak of the video is delivered in such a neutral tone that the result — for an outsider — is simultaneously obscure, bureaucratic, comforting, and banal.

This paper attempts to complicate Koplan's statement, to complicate the state of no-weakness. In the face of health threats that "know no boundaries" — be they disease outbreak or bioterrorism — specific political and cultural work needed to be done to co-mingle national health and military security. And more work was done by funding agencies such as the National Institute of Allergy and Infectious Diseases (NIAID) and the CDC to incorporate professionals working away in laboratories as a 'line of defense.' This work needs unpacking. The shifting politics, economics, and urban spaces transformed by bioterrorism and biodefense should be engaged while they congeal. This paper investigates how the fear of national insecurity is taken up by entrepreneurial biomedical researchers that produce biodefense research institutes within the political economy of competitive cities. The protection against a generalized fear of vulnerability to bioterrorism has resulted in pharmaceutical commodities and technologies. The hype around national insecurity has become an act of speculation in which it is possible to invest. By following the funding of specific biomedical researchers and their institutions, this work maps bioterrorism-preparedness projects that invest in a securitized future, no

matter how uncertain that future may be. Preparedness and speculation result in profits and infrastructures that attempt to tackle the feeling of vulnerability. Most importantly, this emerging biodefense research shows an uneven distribution of funding for specific regions. This undergirding of funding for certain states, cities, and institutions creates a politically reconfigured urban space. This paper will explore the present context of bioterrorism and biodefense; explain the funding and policy environment; unpack the win-win discourse of biodefense; focus on how these discourses and policies transform cities in the U.S.; and discuss how the speculation of bioterrorism stabilizes investments in research and cities.

According to the Trust for America's Health — not considered a fear-mongering group — the present period is the "Age of Bioterrorism." To declare the present time an "age" both obscures continuities and heightens the anxiety of imminent attack. Bioterrorism is not new. Yet Tom Ridge, speaking as Secretary of the U. S. Department of Homeland Security (DHS 2003), succinctly summarizes and frames the present political and policy environment thus: "Terrorism forces us to make a choice. We can be afraid. Or we can be ready." In the United States, specifically in regards to the threat of bioterrorism, how is this fear and preparedness negotiated? Ridge's declaration is a very clear "or" statement: afraid or prepared. Yet the choice is nonsensical. No one chooses fear, so everything must be centred on "ready." How "ready" is framed, funded, used, and discussed will be the focus of this paper. Stephen Graham (2004, p. 168) raises this issue, and declares that "contemporary warfare and terror now largely boil down to contests over the spaces, symbols, meanings, support systems, or power structures of cities and urban regions. As a result, war, 'terrorism,' and cities are redefining each other in complex, but poorly explored, ways." This paper explores how public health has become intertwined with discrete technologies, integrated systems, and urban utilities. Since 9/11, health, the military, and disease outbreaks have been reconfigured both inside and outside the state.

Prepare All Systems

To unpack Koplan's "public-health armaments," the literature on biodefense must be outlined. Anthropologists Collier, Lakoff, and Rabinow head a research cluster that theorizes security, the state, and the life sciences.[1] *Vital systems security or critical infrastructure protection* has emerged in Collier and Lakoff's work, and describes the state's response to threats such as terrorist attacks or pandemics. The focus

is on the protection of key infrastructures (roads, electric grids, communications, food, and water), key institutions (markets, governmental entities), and key public services (hospitals). These are geographic sites where population health and national security merge. For vital systems security, the definition of threat has a low probability of taking place, but whose consequences are immense. Threats can be foreseen, but never predicted. Since the state cannot predict threats, the emphasis must be on mitigating the enormous consequences. The activity of preparedness is constant, but only sporadic intervention is necessary (Collier and Lakoff 2006, pp. 4–8). For Collier and Lakoff, the fruitful question is: What kinds of expertise are being mobilized to provide security, and how are the politics of security changing? The expertise to be examined is at the level of Foucault's "specific intellectuals," bureaucrats or researchers whose knowledge has far-reaching effects (Collier and Lakoff 2006, p. 17). For this paper, biomedical experts' influence, suggestions, and recommendations are tracked beyond their limited scientific domains. My position is that this expertise can be tracked through the funding of biodefense research, producing an urban geography of preparedness.

Lakoff has taken apart the category of "preparedness." In the process of framing bioterrorism under preparedness, a vision is projected of a future worst-case scenario. To develop a defense strategy, threats are transformed into vulnerabilities that must be planned for. Bioterrorism (threat) is incorporated into the state as biodefense (vulnerability). Even the Department of Homeland Security uses the discourse of preparedness. Preparedness looks toward crisis, to sites of disorder or disruption (Lakoff 2006, p. 33). Preparedness searches for where bioterrorism might happen: what places, what agents, which targets. Importantly, preparedness is *not* focused on the health of the general public. For Collier, Lakoff, and Rabinow, the attacks of September 11, 2001 were a catalyst that introduced "a sense of urgency to cast pre-existing elements into new formations of security, geopolitics, and epochal significance. Such fashioning, not surprisingly, was most easily accomplished in the discursive realm" (Collier et al. 2004, p. 4). This paper follows how urgency and fear shaped the discursive realm and then produced a markedly different biodefense research environment. National research funding shifted, which, in turn, has reformulated the cities where biodefense takes places. This paper extends the insights above into geography by showing how these vital systems, particularly biodefense systems, become embedded in urban spaces within the political economy of neo-liberalism.

Leading Up to the Catalyst: Bioterrorism's Context

The current atmosphere of fear around bioterrorism has been fostered over the last 30 years by massive and minor events. Terrorism is defined as the systematic use of terror as a policy; thus, bioterror is the intentional release of harmful biological agents as a policy. While internationally, over 285 biological and chemical agents have been used as weapons since 1976, most incidents have done little harm to humans. In the U.S., bioterrorism, or more specifically, the fear of bioterrorism, was the tactic of choice for domestic, extreme right-wing neo-conservatives such as anti-government militia groups and anti-choice groups. From 1997 to 1999, approximately 200 mailed or telephoned bioterrorism hoaxes took place. The targets were diverse, including courthouses, IRS offices, churches, news organizations, libraries, federal buildings, a Wal-Mart store, and a fashion magazine. Planned Parenthood, Women's Health, and abortion clinics were targeted most often (Cole 2000). The result in the policy sphere was recognition of vulnerability. Mail could be dangerous. Internationally, the largest attack in an urban public space was in 1995 when the Aum Shinrikyo cult released a chemical nerve gas in the Tokyo subway system that resulted in twelve deaths. The daily commute was not immune from terrorism; urban systems were deemed ill-prepared.

However, in the United States, the number of terrorist acts carried out using disease as a weapon against the general public is two. The first bioterrorism event took place in 1984 in the small town of The Dalles, Oregon. Followers of the Rajneeshee cult infected salad bars in ten local restaurants with *salmonella typhimurium*. The attack caused illness in 751 people, but there were no fatalities. The goal was to disrupt the county election process (Sidel et al. 2002, p. 83). The resulting change to national biodefense procedures was minimal.

The second bioterrorism attack had a markedly different effect. The post 9/11 anthrax attacks started on October 15, 2001. Anthrax-laced letters — explicitly connected to 9/11 by invoking international politics and religion — were sent to a variety of sites within the U.S. The U.S.'s ability to respond to bioterrorism had major gaps that needed to be filled. By November 20, 2001, 22 cases of anthrax inhalation had been identified and five people had died from anthrax exposure (Blanchard et al. 2005; Ozonoff 2002; Jernigan et al. 2002). This event was not local. These attacks were the first biologic pathogen in modern U.S. history that was distributed in a widespread and intentional manner, and the first to result in fatalities (Partridge et al. 2003). What

must be noted is that the anthrax used in these attacks was traced to a bio-safety laboratory in Fort Detrick, Maryland, and no evidence has come to light of any link to foreign terrorists (Richardson 2004, p. 2122). Arguably, the anthrax attacks were not a huge escalation from the extreme right-wing groups of the previous decade. Yet the anthrax attacks accelerated the call for preparedness and the creation of an infrastructure to deal with these incidents.

After September 11, 2001, the United States was deemed vulnerable. What followed was the very problematic search for weapons of mass destruction in Iraq, including biological and chemical weapons, and a massive refiguring of state powers and institutions, most importantly, the Department of Homeland Security and the Patriot Act. Concurrently, the global SARS outbreak in 2003 also fed into bioterrorism fears as fictitious links between SARS and Iraq were made (Zhan 2005, p. 36). Now, with avian influenza, the fear and tracking of disease are regularly reported in the media. While these events are not directly related to bioterrorism, bird flu and biodefense are conflated in the response of vital system security to general threats. Yet the fear of "threats" did not emerge fully formed post 9/11, and neither did the biodefense policy and research.

Research, Funding, Policy

Bioterrorism preparedness, as a policy, was already in the works well before 9/11. While biodefense existed hand-in-hand with Cold War expansions in biological warfare programs (for an excellent overview, see Fearnley 2006), this was accelerated in the 1990s. The Clinton administration publicly announced the U.S. population to be vulnerable to attack. Guillemin (2005, p. 202) makes the case that there are four reasons why this announcement happened: the U.S. became the lone global superpower; international and domestic terrorism rose; secret Soviet biological weapons programs became known; and Washington bureaucratic and policy think tanks rose in numbers. The key civil defense legislation was the 1996 Defense Against Weapons of Mass Destruction Act that provided funding for domestic preparedness programs for cities and states. In 1998, Clinton announced new initiatives to address bioterrorism that included the integration of the public health and national security systems (Sidel et al. 2002, p. 86). After Clinton's announcement, money went to various government departments, resulting in the rise of budgets (around $1. 5-billion in total). This money allowed for the germination of what is now called civilian biodefense. By the end of the 1990s, there were new programs,

institutes, conferences, and publications on biodefense (Guillemin 2005, p. 205). These think tanks and policies relied heavily on problematic discourses of fear-mongering. This set the stage for a post 9/11 acceleration of the civilian biodefense associations with the state.

But how to illustrate this reconfigured realm of biosecurity to bring to light the construction of critical infrastructure protection? The rest of this paper will examine the funding of biodefense research. This investigation reveals how these discourses are productive and have material effects. If after 9/11, everything accelerated into a new configuration of state security around bioterrorism, to track the change at the site of Foucault's "specific intellectuals" would be a fruitful place of inquiry. The specific intellectuals, in this case, are those scientists who invoked bioterrorism in their winning grant abstracts.[2] NIAID has a specific organizing and enabling role in biodefense research, and post 9/11, clearly and proudly states that their research programs have been "accelerated".[3] The result is the explicit embedding of biodefense and security research within the university. This financial investment by NIAID produced research spaces and networks that cannot, and should not, be de-coupled for national security or disaster management. In some ways, this paper is follow-the-discourse; but this work is equally follow-the-money.

From 1996 to 1999, all funding that explicitly mentioned bioterrorism was awarded to a sole scholar: Sophia Dyer from Boston University. Dyer's project examined whether paramedics could perform medical interventions while in chemical protection gear (Grant Number [GR]: 5M01RR000533-320368). After 9/11, the number of researchers awarded funding by NIAID who directly cite bioterrorism in their proposals spiked dramatically (see Graph 1). The dollar amount awarded spiked just as dramatically, yet differently. The number of grants that mention "bioterrorism" in their abstract, from 1996 to 2005, consisted of 1,794 entries. The total dollar amount awarded for these grants was $1,776,371,913.[4] There is no debate that an increase in the funding of biodefense research has taken place. Yet the investments do not take place in an arbitrary manner; rather, they are part of a U.S. defense policy framework. The creep of preparedness and security is revealed in specific policies and actors entangled in these national shifts in funding. The year of dramatic change was 2003, and that is directly due to a NIAID policy.

The key policy document that opened the funding floodgates was the NIAID Strategic Plan for Biodefense Research. This report provided

the present structure of biodefense policy and funding. The problem: lax biosecurity. Under the directorship of Anthony Fauci, this document positioned NIAID as the agency to fix this negligence. The solution: enter NIAID. The report's introduction begins with the anthrax attacks, which "uncovered an unmet need for tests to rapidly diagnose, vaccines and immunotherapies to prevent, and drugs and biologics to cure disease caused by agents of bioterrorism" (NIAID 2002, p. 1). A helpful concept of NIAID's action is *policy window* (Avery 2004, p. 275), which encapsulates how, at critical times, policy entrepreneurs match problems with solutions. For bioterrorism, the "solution" selection process has been limited by the political situation. Avery explains that "to avoid worst-case scenarios, the executive and legislative branches have authorized virtually any program claiming a tie to anti-terrorism…Terrorism preparedness is something no one can argue with and survive politically" (2004, p. 282). Fauci's positioning of NIAID allowed their specific knowledge and expertise to help buttress a security agenda with biomedical solutions. The keystone document from NIAID is about specific diseases "recognized as having bioterrorism potential," not about the health of the population. The research then focuses on the biology of the microbe, the host response, vaccines, therapeutics, and diagnostics. But most revealing is that "NIAID is committed to an agenda of basic and translational research for bioterrorism defense, working with partners in academia, industry, and other private- and public-sector agencies" (NIAID 2002, p. 2). This is an expansive project, not one confined to 'pure' scientific discovery. The type of research was set: focus on the disease. The result of the research: focus on translating research into products. The type and the results of the research are both connected to the win-win arguments circling around biodefense.

Biodefense Is Win-Win 1: Target Disease

The assertion of a win-win argument or dual-use strategy for biodefense is constant. Simply put, the more research in weaponized diseases that takes places, the more innovations for disease prevention will be found. In the NIAID plan, under the title 'Implications of Biodefense Research for Other Diseases,' "The positive spin-offs for other diseases that will result from the large investment in research on biodefense will be substantial" (NIAID 2002, p. 14). The spin-offs from biodefense are: helping public health in the developing world; curing common diseases; advancements in diagnosis that will trickle down into all aspects of healthcare; and basic research that

will help us understand immune systems for both immune-mediated disease and organ transplants (NIAID 2002 p. 14). The wish list of cures includes cancer, HIV/AIDS, malaria, tuberculosis, lupus, and arthritis.

Yet this crisis-centred approach cannot be the best approach for high-quality healthcare or research. Fee and Brown (2002, p. 31) explain that public health has been always discounted while high-technology medicine is seen as the answer. The championing of genetic and pharmaceutical solutions undermines the authority of local or national public-health endeavours. Fee and Brown suggest that the investment in high-tech responses is organized episodically to respond to particular threats and then dropped when the crisis is over (2002, p. 42). However, the public-health and research communities are challenging this win-win discourse from within. The microbiology community is debating whether bioterrorism is an exaggerated risk. Enserink and Kaiser (2005) ask the question: "Does biodefense deserve all this money? Natural deaths from many other biodefense agents…are also low, if not zero. Is it worth spending billions of dollars on these agents when flu alone causes more than 30,000 deaths a year in the United States, and food poisoning some 5000?" Additionally, does the target-disease framework lead to good research? In a special March 2005 issue of *Science* magazine, microbiologists expressed objections to the new direction of funding by the National Institutes of Health (NIH). The community sent a protest letter to the head of NIH with 750 signatures, supporting the statement: "The NIH peer-review process, and the research sector responsible for [science and public-health] achievements, are threatened by unintended consequences…to prioritize research of high biodefense, but low public-health significance" (Altman et al. 2005). From the microbiologists' perspective, a new biosecurity research agenda has resulted in special funding being set aside; new review panels being instituted; and new review procedures that exist explicitly in the name of biodefense and homeland security. The microbiologists had witnessed the number of grants decreasing, yet the grants for six bacterial diseases — tularemia, anthrax, plague, glanders, melioidosis, and brucellosis — had risen. All of these diseases are on the priority bio-weapons list, yet are extremely rare in humans (Enserink and Kaiser 2005).

Fauci and Zerhouni (2005), the directors of NIAID and NIH, disagree that biodefense concerns are of 'low public-health significance,' stating: "[t]he United States has experienced an anthrax attack, and security experts repeatedly express concern that future attacks with

biological weapons are likely, if not inevitable." David Walker of the University of Texas translated this into: "Biodefense is what Congress wants us to do" (Enserink and Kaiser 2005). The phrases 'inevitable' and 'wants us to do' suggest the policy and research environment. The use of the anthrax attacks as justification asserts vulnerability. The political climate and the fear allowed the line of reasoning to run from Congress directly into the laboratory, affecting the type of research and the amount of funding. Interestingly, the debate has been flipped on its head, turned into a discussion over competing budgets, and encapsulated in cost-benefit analysis. NIH and NIAID state that no money is being taken away from existing funding because the government has increased budgets post-9/11. All new funding is targeted toward new biodefense research. However, Avery (2004, p. 279) states that "[t]here is no data available on returns from using bioterrorism funds to strengthen the general public-health infrastructure." The debate has been diverted from whether disease-targeted biodefense is the correct choice for public health. The dollar debate distracts from how these investments in biodefense have shifted the scientific and research culture. This is how Nature magazine wrote about the issue in 2002:

> Today, [biological scientist] Welch is in the vanguard of the 'war on terrorism'…has aligned himself with a group of researchers…[O]ne of thousands of U.S. biologists who have begun recasting their work over the past year in response to the unprecedented funding opportunities for biodefense research (Check 2002).

For individual researchers writing grants in a competitive research climate, attaching grants to the biodefense wagon and recasting their work as vital security is a leg up. The shift in research funding signals that within an environment of fear, stability is created from compatible biosecurity research programs. The win-win arguments further pollute the murky waters of "pure" versus "applied" research, along with the role of translational research that moves from universities toward industrial products. The shift toward biodefense has led to specific technological and pharmaceutical responses.

Biodefense Is Win-Win 2: Target Commodities

Pharmaceutical solutions — pill-based security — to weaponized diseases are the new norm of biodefense research. Pharma-defense is yet another reinforcement of the biomedical model of health (Jones and Moon 1987). The causes of disease are discovered by biomedical research and technological intervention is deemed effective treatment. Yet the question arises: Is a technological or pharmaceutical interven-

tion the cure to political ailments? This complicates the win-win arguments. Deliverables, new-generation products, and the relationships between private industry and public research are not new phenomena. Healthcare, science, and research directed at communicable diseases can learn a lesson from Kloppenburg's (2004) history of the subversion of plant biotechnology research. The interaction between scientific innovation and political economy shapes the relationship between public and private science. Genetic-seed technologies were supported by public funds, including NIH. The state undergirded scientific research and development. Kloppenburg shows that financial benefits from genetic innovations were not evenly distributed (2004, p. 44): the benefits of public research were reaped by private applied-science, through industrial products. Yet the division between pure and applied science is false. In the words of Pasteur: "There is no category of sciences which can be called applied sciences. There is science and the application of science bound together like the fruit and the tree which bears it" (in Kloppenburg 2004, p. 41). Kloppenburg's message is that research priorities and agendas should not be left to research directors, managers, or even scientists (2004, p. 278) — Foucault's "specific intellectuals." The field of "pure" biodefense research cannot be hived off from the security results that may arise. The path from pure to industrial research must be seen for what it is: the production of commodities or 'deliverables.'

These insights directly relate to the win-win scenario of biodefense in that "basic and translational research aimed at [a certain disease] will have direct and obvious benefit to the people threatened by them" (NIAID 2002, p. 14). After curing a disease in the laboratory, time is the only factor before curing the disease in the field. The turnover time between pure and applied science is ten years. If this delay holds, biodefense has not ended that cycle. As one biodefense grant stated, the "immediate goal…will be to translate existing scientific information into deployable technology" (GR: 5U54AI057159-03). For Kloppenburg, industrial research is directly connected to the commodity form. To debate whether the role of public research facilities such as universities are, or are not, ideologically and structurally profit-making institutions is not within the scope of this paper. More importantly, these researchers create knowledge that directly contributes to and creates exchange-values (Kloppenburg 2004, p. 226). Scientific knowledge is linked to products, and those products are exchanged and profit is derived. State-funded biodefense research innovations, either anti-disease or anti-terrorism, become commodified.

The clearest example is vaccines for the Strategic National Stockpile. The stockpiling of drugs against disease and bioterrorism is a federal project.[5] The linchpin of this project is the availability of state funding to purchase commodities. But even the research process itself needs examining.

Marx noted that under capitalism, "invention becomes a business." Landes followed by stating we "can now order technological and scientific advances as one orders a commodity" (in Kloppenburg 2004, p. 45). NIAID's policy that shifted toward biodefense research structured and supported certain scientific advancements. Importantly, Wendy Brown, speaking of another, albeit related, example, states: "There is no scandal. Rather, there is only market rationality, a rationality that…treats close state-corporate ties as a potentially positive value — maximizing the aims of each, rather than as a conflict of interest" (2003, p. 40). This is a key insight. There is no scandal or conspiracy connected to these investments and their private-sector profits. This is the procedural fulfilment of national science-research plans. To proceed with what can be seen is the growth of a specific geography of this biodefense research. The relationship between security, universities, federal funding, and cities — through the institutions of Regional Centres of Excellence — is the next step for this paper.

From Abstracts to Infrastructures: The Geography of Biodefense Research

When reviewing the grants that invoke bioterrorism, what emerged was an urban geography of biodefense research. Many of the grants showed substantial investment in specific cities and universities. These investments are geographically organized not by state, but in regional configurations and institutional clusters.[6] In NIAID's 2002 plan, one of the goals was the construction of bio-containment facilities "for the handling of these potentially lethal agents in a manner aimed at eliminating the threat to laboratory and clinical personnel or to adjacent communities" (NIAID 2002, p. 4). The plan called for the development of six to twelve regional "Centres of Excellence for Bioterrorism and Emerging Diseases Research." As the plan was implemented, the word "bioterrorism" was replaced by the more upbeat-sounding "biodefense." The official map for these RCE's implied an even funding of biodefense across the country. This is not an accurate description of the investment. This paper offers a visualization (Diagram 1) of biodefense funding that shows a landscape proportional

to the financial amount awarded to those research facilities.[7] What these research clusters will do is more important. A general goal of these facilities is to create:

> The ability to develop the tools and interventions needed in a public-health emergency...The development of centralized sources of generalized as well as specific expertise in bioterrorism areas…will be required to speed the development of new-generation products (NIAID 2002, p. 11).

One of the explicit goals is "encouraging and developing relationships between academia and industry" (NIAID 2002, p. 11). The Centres' mandate is full of talk about innovative technologies and translational deliverables. From the beginning, private companies and the development of products have been promoted. The centres have two sides: the embedding of laboratories and science as a line of security and the strategic position of these clusters as a line industrial innovation.

How the researchers and institutions position themselves is quite revealing. Fully established by 2005, the description of the Regional Centres for Excellence is "a consortium of universities and complementary research institutions serving a specific geographical region." The purpose is to build a strong scientific infrastructure to support "translational research capacity required to create the next generation of therapeutics, vaccines, and diagnostics" (NIAID 2005c). These RCE's will be a "focal point" for federal, state, and local agencies, in tandem with pharmaceutical and biotechnology companies (NIAID 2005d). In the words of the Texas-based RCE:

> In response to NIAID's call for the creation of strong infrastructure and multifaceted research and development activities applying the best basic, translational, and clinical science to the generation of new diagnostic, therapeutic, and vaccine countermeasures …22 institutions in Texas, New Mexico, Oklahoma, Arkansas, and Louisiana have combined their energy, creativity, and resources to propose creation of the Region VI Centre of Excellence… (GR: 1U54AI057156-01).

This is crucial: the researchers are responding to NIAID's call. The compiled abstracts for the RCE grants, and associated funding, indicate a wide variety of research directions with terms such as: primate core, animal colony, zoonotic origin, host organism interaction, micro-organism genetics, building/facility design and renovation, and isolation/quarantine capabilities. Many applicants direct their grants along the lines of specific disease, illustrating the win-win discourse within the very grants themselves.

Yet the research projects should not be seen in isolation. The funding establishes research networks. The grants fund the construction of new facilities called bio-containment laboratories within "research parks." Location itself is used to validate why an institution or a city should get funding. For example, the presence of existing institutions such as the military:

> Hawaii serves as a principal U. S. gateway to and from Asia, and as a major tourist destination for people worldwide. It is also home to some of the Nation's most strategic Army, Navy, Air Force, and Marine Corps military bases. Because of the heavy tourist traffic from Asia and elsewhere, and the presence of military forces, Hawaii is at high risk for natural and deliberate introductions of exotic infectious diseases (GR: 1UC6AI066845-01).

Compared to other grants, Hawaii's is extreme in making overt links to military, tourism, and Asia. Yet the expansive component in these research networks can be seen in the grant from the northeastern RCE: "The fund will be used to attract investigators who are not working in the area of biodefense" (GR: 1U54AI057159-010011). Another explicit purpose is to train the next generation of researchers for this growing biodefense field, both inside the university and in careers "in the field" (GR: 5T32AI007536-08). Facility investment, research networks, new-generation products, talent attraction, and expansion: biodefense is not contained in the laboratory.

This undergirding of funding for certain states, cities, and institutions creates a politically reconfigured urban space. The RCE's speak of a new national infrastructure or network of biodefense (symbolized by Diagram 1). This multi-city network is based on the relationship between research clusters under the rubric of national security. The centres are research infrastructures, government institutions, and public services that are central to *critical infrastructure protection* within an urban political economy. Mike Davis, in his drastic manner, dubs this the 'Fear Economy,' declaring "the discrete technologies of surveillance, environmental monitoring, and data processing will grow into a single integrated system. 'Security,' in other words, will become a full-fledged urban utility like water and power" (2001, p. 45). These facilities are witnessing the self-perpetuating escalation in security. One grant entitled "Improvement of Security for North (Research) Campus" suggests these laboratories have become targets themselves, for international terrorists and domestic animal rights activists who may attack these animal testing facilities (GR: 1G20RR021381-01). This is almost a local arms race. Who the campus security is racing

against is unclear. The facility is supposed to make the United States more secure, and yet needs more funding to increase security. This NIAID-approved logic gets funding — a far cry from 'curing HIV in Africa.'

The RCE research infrastructure can be slotted quite easily into a competitive city agenda. Leitner and Sheppard (2002, p. 496) state that the key to urban futures is presented as "[n]etworks, in the form of public-private partnerships and inter-urban cooperation." They complicate the influential policy ideas of Michael Porter, who claims that urban prosperity and advantage can be found in the clustering of leading-edge firms. These networked industrial districts promote competitiveness. In this neo-liberal governance environment (or in a kinder, gentler term, "third way"), local decisions are taken away from the democratic process; self-organization and collaboration are crucial to entrepreneurial places. The funding for these RCE facilities is granted to research entrepreneurs who capitalized on the opportunity after 9/11. The biggest winners, the universities of Texas and Boston, promised $50-million in matching funds to sweeten the deal. The return on their investment is equally, if not more, lucrative. In the case of Boston, the National RCE is estimated to generate up to $1.7-billion in research grants over the next 20 years, as well as the creation of around 2,000 new jobs, 600 of which will be permanent research positions (Richardson 2004, p. 2121). The report entitled 'The Impact of the National Bio-containment Laboratory and Related Initiatives at The University of Texas Medical Branch (UTMB) on Business Activity in Texas' clearly states: "In addition to the substantial contributions these [biodefense] efforts will make to the health, safety, and security of the U.S. and, indeed, the world, these programs also result in a notable contribution to the economy of Texas" (Perryman Group 2003, p. i). The report projects that over 20 years, the total contribution from the RCE to gross state output will be $1.1 billion. This consulting paper goes on to project that this "will enhance the competitiveness of Texas for attracting pharmaceutical firms, emerging biotechnology enterprises, and other related firms" (Perryman Group 2003, p. ii). This is clearly an expansive project beyond 'pure' science or 'pure' defense. While the consultants frame this as state windfall, cities or regions will benefit the most. NIAID deems this a national biodefense investment, yet the developments are urban. Additionally, the opposition to these projects from community groups in Boston and Davis (California) has targeted city politics (Richardson 2004). So the RCE's, as an example of vital systems security, are a

public-private partnership that benefits specific urban locations. The competition for grants feeds directly into the competition between cities. Science, neo-liberalism, competitive cities — all work within a speculative environment that seeks direction and stabilization.

Speculation and Science

Rajan's term "biocapital" helps illuminate these dense relationships. For Rajan, biocapital is not only "the systems of exchange and circulation involved in the contemporary workings of the life sciences, but also a regime of knowledge pertaining to the life sciences as they become increasingly foundational epistemologies for our times" (2005, p. 21). For biodefense, the regime of knowledge, solidified by NIAID, is directly connected to the circulation of money (for research or purchase of vaccines), based on the assumption that bioterrorism or a pandemic is inevitable. In Rajan's work there is a connection between speculation, circulation, and value. Potentiality, risk, and fear are not merely a floating ether of discourse; rather, they stabilize investments. As Rajan (2005, p. 24) says, "hype cannot simply be cynical but is a discursive mode of calling the future into account of the present. Instead of being opposed to reality, hype constitutes the discursive grounds which reality unfolds." For biodefense, hype over future attacks produces science and deployable pharmaceutical technologies. But this potential does not need to be realized or put into use to create profits or products. The intense investment and mobilization of capital for biodefense research funding, as Rajan (2005, p. 24) says, is "to generate a value in the present to make a certain kind of future possible; a vision of the future has to be sold." To repeat, a future vision — "Age of Bioterrorism" — has to be sold. To build on Rajan, there also must be a historical precursor to get people to buy in. Speculation cannot be based on merely anything. For biodefense, 9/11 and the anthrax attacks were needed to spark investment in biodefense researchers. All NIAID did was to stabilize the speculation environment. This returns to Lakoff's discussion on preparedness. Both speculation and preparedness rely on investment in an uncertain future. Preparedness results in infrastructure. Speculation results in profits. Both tackle the feeling of vulnerability.

Stephen Graham christens the combination of vulnerability and urban space as "homeland cities." Cities are constructed as endlessly vulnerable. This works to underline the necessary integration of U.S. cities into state-led processes of neo-liberalism. As Graham says, "military geographies and technologies are actually themselves key drivers of

neo-liberal globalization" (2006, p. 272–273). While Graham focuses on transnational geographies, this paper connects these insights to the geographies of science research. In relation to critical infrastructure protection, Collier et al. ask: "To what extent, then, can the threat be successfully technologized?" (2004, p. 5) This paper suggests that the extent is related to speculation and the reduction of financial risk — dollars and where those dollars come from. The funding of the technologization of biosecurity is directly tied to the military. Biodefense research shows an uneven distribution of funding that allows speculation and hype to lead to a certain type of research, a certain type of product, and a certain type of laboratory.

In this uneven distribution of funding, hospitals are left out in the cold. To end with hospitals sobers the discussion, directing it away from competitive homeland cities and laboratories. As Avery (2004, p. 281) reminds us, "bioterrorism is a public-health crisis until evidence mounts that it is something more." Hospitals are a very practical and productive site to fund to mitigate the consequences of bioterrorism. If a bio-weapon is released and people get sick, they will go to the hospital first. Avery advocates moving away from low-frequency events such as bioterrorism attacks and channelling funding toward day-to-day public-health functions. The U.S. policy environment illustrates how hospitals and a democratic public-health system are the real losers in these "homeland cities." The literature repeatedly states that hospitals are not part of government investment in biodefense (Avery 2004; Hearne et al. 2004). The future does not indicate any change in direction. Sadly, even with all this massive infusion of homeland defense funding — the amounts discussed above are only a small part — "nearly one-third of states cut their public health budgets in Fiscal Year 2003-2004, and states still do not have adequate resources to address their preparedness gaps" (Hearne et al. 2004, p. 10). The U.S. General Accounting Office stated that while emergency plans have been written, there has not been the necessary investment in hospitals. The GAO continues: "[m]any of the capabilities required for responding to a large-scale bioterrorist attack are also required for response to naturally occurring disease outbreaks. Such a 'dual-use' response infrastructure improves the capacity of local public-health agencies to respond to all hazards" (United States General Accounting Office 2003, p. 4). The win-win argument rears its head again; but if that line of argument raises nurses' wages, reduces the working day in emergency rooms, or increases workplace safety, you won't hear a peep from me.

Notes

1.The Anthropology of the Contemporary has a working paper series at http://anthropos-lab.net/documents/.

2. In the fall of 2005, after doing some exploratory searches and investigating some of the grant abstracts related to bioterrorism, I organized some of the more illustrative findings from these public databases: NIH: "ERA Commons," CRISP, crisp.cit.nih.gov (accessed December 11, 2005); The Sunshine Project, "CRISP-ER." CRISP-ER, www.sunshine-project.org/crisper/ (accessed December 11, 2005). A database was created of all grants that mention "bioterrorism" in their abstract from 1996 to 2005 (1,794 entries). In organizing these findings by both the number of grants per year and the amount awarded in millions, Graph 1 gives a highly visual indicator of the shift in policy and funding toward bioterrorism.

3. Some explanation of these funding institutions is needed. The National Institutes of Health (NIH) is comprised of 27 Institutes and Centers and has a $28-billion budget (NIH 2005). The biodefense funding from the NIH is channelled through the National Institute of Allergy and Infectious Diseases (NIAID), who conducts and supports basic and applied research in infectious, immunologic, and allergic diseases. NIAID sets the goals and priorities for the biodefense research (NIAID 2005a and 2005b).

4. To put in perspective, these amounts are a drop in the bucket for U.S. domestic security, and are not indicative of the total amount of public funding for bioterrorism and biodefense research. The Department of Homeland Security had a $37.7-billion budget for 2003; $5.9-billion (16%) of that amount was devoted to biodefense (Richardson 2004, p. 2121). The projected FY2006 funding on civilian biodefense is $5.1-billion; this would be a $2.5-billion decrease from 2005. Just the NIH funding for biodefense research was $1.8-million for FY2004 (Schuler 2005, p. 96; this report recognizes some of the difficulties in the data).

5. In tandem with the Strategic National Stockpile, Project Bioshield is a 10-year antiterrorism legislation, with a $5.6-billion budget. The Bioshield bill provides funding to drug companies and the Department of Health and Human Services to purchase potential treatments, such as vaccines. The U.S. government creates contracts with companies five years before the drug product is expected to be delivered to the Strategic National Stockpile. WHO has looked at Project Bioshield as a possible model for a state-led procurement of drugs for the HIV/AIDS crisis. WHO frames Project Bioshield as "a package of 'push' and 'pull' incentives to accelerate the availability of drugs and vaccines to combat bioterrorist threats" (Towse and Kettler 2005, p. 303).

6. Through the investigation of the results from the keyword "bioterrorism," sorting by amount awarded revealed the big winners in biodefense. These results were the beginning of a second database comprised of some, but not all, of the largest investments and grants found using the combinations of the keywords: regional, biocontainment, laboratory, national, center, excellence, and biodefense. The growing database of 149 grants showed that there had been coordinated effort among many institutions. To be clear, this database is not complete since many grants have obscure names and some do not have abstracts. Sixty-two of the abstracts were reviewed and selected for regional location, highest amount of funding, or provocative title.

7. The diagram is matched to geographical location of each city and the size of each circle is proportional to financial investment.

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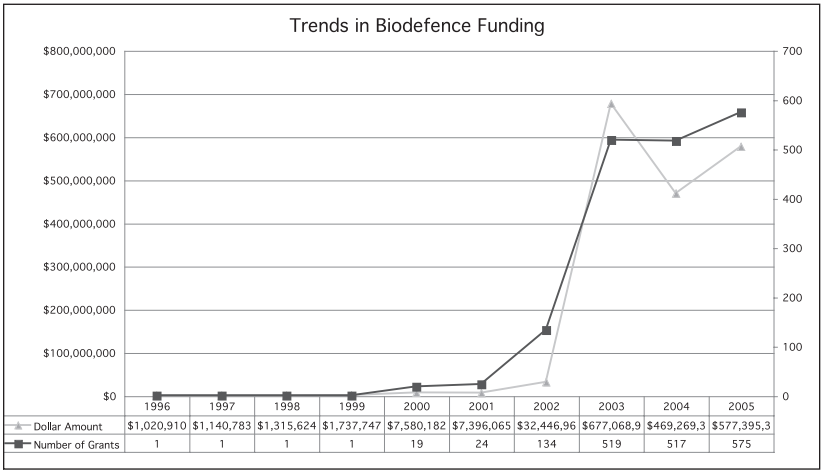
Appendix



	1996	1997	1998	1999	2000	2001	2002	2003	2004	2005
Dollar Amount	$1,020,910	$1,140,783	$1,315,624	$1,737,747	$7,580,182	$7,396,065	$32,446,96	$677,068,9	$469,269,3	$577,395,3
Number of Grants	1	1	1	1	19	24	134	519	517	575

Graph 1

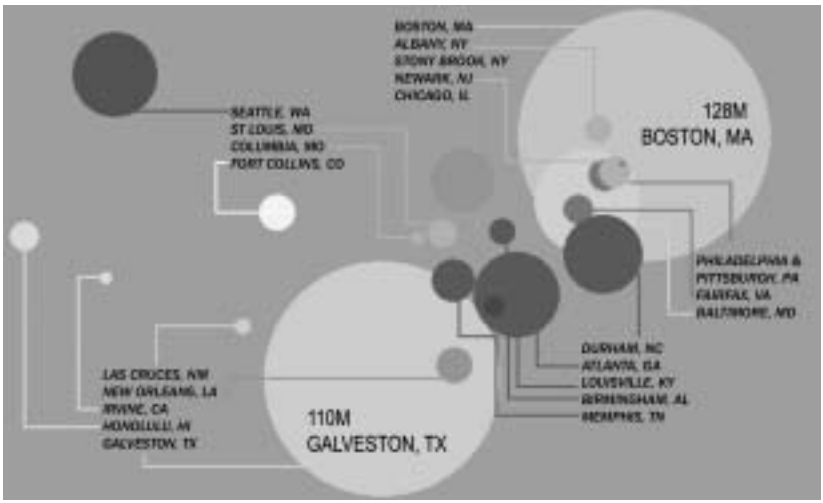


Diagram 1

Shifting Edges and Moving Up: Green Roofs, Health, and the Nature/City Divide in Toronto and Chicago

Angela Loder

Abstract

The green city movement has seen city planners, the green building industry, and activists argue for the re-greening of the densely-built downtown cores of cities as part of initiatives to make cities healthy and sustainable. Though adding greenspace to cities has been a common, and often desirable, feature of the Anglo-American urban landscape since Frederick Law Olmstead's urban park movement, recent movements in urban greening initiatives have seen cities begin to add vegetation to hard urban landscapes in previously unused spaces. Green roofs, vertical walls, and roof gardens, often part of green buildings, are re-defining the traditional edges and boundaries between 'nature' and the city. They are also challenging traditional understandings of health, sanitation, and nature/city boundaries. Underlying their implementation, however, are narratives and values on what kind of 'nature', and what kind of green roof, is desirable and appropriate in the city. Both Chicago and Toronto are currently embarking on significant green roof implementation programs, and they are using different justifications, narratives, and policy tools to achieve their goals. Using these two cities as case studies, this paper explores the intersection of discourses surrounding nature, the city, and the implementation of green roofs in the context of Anglo-American narratives on nature, health and the sustainable and competitive city. It concludes by examining other political and economic factors further influencing the differing levels of success in each city's urban greening programs.

Introduction

Although adding greenspace to cities has been a common, and often desirable, feature of the Anglo-American landscape since Frederick Law Olmstead's urban park movement, recent articulations of the green city have seen the addition of vegetation to hard urban landscapes in previously unused spaces. Increasingly popular in North America, green roofs, living vertical walls, and roof gardens are redefining the traditional edges and boundaries between 'nature' and the city. In doing so, they are challenging the perception of nature planted on the surface of buildings as a symbol of neglect, to one of innovation, ecological progress, and public health. Implementing new types of nature into the city, however, collides with values and narratives about the kind of 'nature' that is valued and seen as appropriate in the city. This is further complicated by the fact that the relationship between nature, the city, and human health has oscillated between a perception that contact with nature is good for humans and one of nature as threatening, dirty, and unsanitary (Tuan 1990; Ashton 1992). Thus, the implementation of green roofs must negotiate with, and is influenced by, underlying values and narratives on nature, health, and the city that have traditionally helped shape urban policy. Toronto and Chicago are currently embarking on significant green-roof-implementation programs, using different justifications, narratives, and policy tools to achieve their goals. While both cities have won awards for leadership in making their city greener (City of Toronto 2007, p. 3; Gorrie 2007), Chicago is much further ahead on its green-roof agenda, and has been classed a "runaway first among North American Cities of the Future" (Gorrie 2007). Understanding the contexts, both ideological and political, behind each city's differing rates of success can help us to understand why some cities are more successful than others in implementing urban greening programs. Through examining public policy documents and selected interviews with key municipal stakeholders, this paper aims to understand the impact that Toronto's and Chicago's public policy narratives around nature, its benefits, and its imagined place in the city has on their green-roof policies. The paper concludes by examining other potential factors that might be influencing Toronto's and Chicago's urban greening strategies and their implications for other cities embarking on similar paths.

This paper is organized as follows. The first section examines how nature is discussed and imagined in Toronto's public policy, its place in relation to the city, and its perceived benefits, particularly as nature

relates to public health. This is followed by an examination of Toronto's green-roof policy, particularly the perceived benefits of green roofs, their relationship to nature, where in the city they are imagined to belong, and what kind of programs and policies the city has set up to implement them. The third and fourth sections examine Chicago's public discourse on nature and green roofs under the same criteria. The paper concludes with a discussion about public policy on nature and green roofs, and outlines some other socio-political and economic factors that might be influencing the different outcomes in each city.

Toronto

Introduction

Located on the northeastern shore of Lake Ontario, Toronto is a leading business, educational, and cultural hub, and is known as one of the most culturally diverse cities in the world. With an urban area population of 4,753,120 (Statistics Canada 2006a), Toronto is Canada's largest city, and with its surrounding regional municipalities, is also the country's fastest growing city (Statistics Canada 2006b). Although originally covered with dense forest (City of Toronto 2004b, p. 11), most of the land surrounding the Greater Toronto Area (GTA) is long-cleared Grade-A farmland under intense pressure from suburban development, especially the highly desirable cottage country, with its iconic pines and lakes, a few hours north of the city. Toronto has also been known as a 'green city,' by virtue of its environmental activism in the 1970s (Sewell 1993), its prominent role in the development of the Healthy Cities movement (Hancock 1992), and its leadership in municipal strategy to deal with greenhouse gases, among other factors. Toronto's position as a culturally diverse city dealing with rapid population growth and urban sprawl while framed by an iconic hinterland strongly influences its position on nature, environmental initiatives, and green roofs.

Toronto and Nature

In this section, I will be examining Toronto's municipal policy documents with the following questions in mind. First, what kind of nature is being discussed, and where is its place in relation to the city? Second, what are the perceived benefits associated with nature(s), and for whom are these benefits? Understanding a city's framing of nature when discussing its urban greening policy is important for two reasons. First, as mentioned above, values and symbolism associated with nature in rela-

tion to the city influence public perceptions about what counts as "nature," and where. This can complicate the implementation of urban greening projects such as green roofs. Second, there are extensive bodies of literature that point to the psychological need of humans to have contact with nature (Kaplan and Kaplan 1989) and open space (understood here as a synonym for parkland) (Morris 2003). Nature as a public and social amenity (Westphal 1999; Kuo 2001), as such, is directly and indirectly seen to be an important element of a city's health and quality of life (Ashton 1992; Hancock 1993) and, as we will see below, its competitiveness. The following analysis is based on Toronto's Official Plan, thematic policy documents such as the Toronto Green Development Standard (2007), web-based municipal policy documents, and interviews with selected public officials and green-roof industry members. In examining the discourse surrounding Toronto's framing of nature, the city, and green roofs, the themes of preservation, a clean, beautiful, and competitive city, and an ambiguity regarding where green roofs fit into Toronto's greening program emerge as prominent.

The Place of Nature(s) in Toronto: The Preservation of Natural Heritage, Green Infrastructure, and Urban Parks

Toronto's mottos are "City Within a Park" and "Diversity is Our Strength" (City of Toronto 2004b), and the image of a city surrounded by parkland is upheld in the framing of nature in Toronto's policy documents. In these documents, nature is viewed primarily in two ways: first, as natural heritage surrounding the city, and second, as a system of urban parks and forest. Nature described as "natural heritage" is catalogued extensively and depicted as surrounding and bisecting the city, and the city is imagined and contextualized in relation to this green network (see Figure 1).

> The natural features of the city, such as the Lake Ontario shoreline, the Lake Iroquois escarpment, woodlots, ravines, and valley lands, will be connected to the surrounding city by improving physical and visual access from adjacent public spaces and by designing these into a comprehensive open space network. (Official Plan, Policy 3.1.1.4)

Public policy on nature focuses partly on preserving existing "natural" features in and around the city that are considered important, such as ravines, waterways, the lakeshore, the Niagara Escarpment, and the Oak Ridges Moraine, and partly on creating and maintaining public access to these natural features through a system of green corridors. Although the city has numerous education and environmental restoration programs

Figure 1. Toronto's natural heritage
Source: Toronto's Official Plan

aimed at connecting Torontonians to the natural heritage surrounding them (City of Toronto 2004b; Denney 2007), most of these are aimed at linking urbanites to natural areas deemed ecologically important, not with re-creating these natural areas within city boundaries. This leaves a subtle but clear delineation between what is considered "nature" and what is urban, leaving traditional nature/city boundaries intact.

The emphasis on preservation is also present in policy discourse on nature within city limits. Both neighbourhoods and urban parks or open space (the terms 'parks' and 'open space' are used interchangeably) are emphasized as stable assets that city-planning policy aims to preserve and protect, particularly with regard to maintaining the character, and thus, attractiveness and property values, of these areas (City of Toronto 2006d, 2.20, 2.21, 2.4, 2.5, 2.9). This is partly due to well-documented, strong neighbourhood resistance to infill development. It is also due to the recognized need to maintain greenspace, and in particular, the urban forest, as a means to combat urban environmental problems (City of Toronto 2006d, p. 3-23). Although there are some provisions for increasing the urban forest, the overall approach to nature in the city is again one of preservation and stability.

The place of nature(s) in Toronto planning documents is, thus, somewhat ambiguous. Although the city aims to connect urbanites with their natural heritage and encourage naturalized areas within the city, there still exists an underlying portrayal of Toronto's natural heritage as nature best separated, or protected, from damaging human activity. This parallels Anglo-American conceptions of wilderness, which tend to promote the separation of humans from nature in order to protect the latter (White 1995).

The Benefits of Nature in Toronto: Public Health, Public Good, and the Competitive City

The benefits associated with nature cited in Toronto's policy documents are numerous, but can be grouped under three main themes: public health, public good, and the competitive city. In Toronto's positioning of itself as a green city, all three are intimately linked:

> Our exceptional system of green spaces helps make Toronto a healthy and liveable City. The City's Green Space System, made up of parks and open spaces, the natural heritage system, and a variety of privately managed but publicly accessible spaces, is an integral part of our quality of life and social well-being. It provides opportunities for

> recreation, relaxation, and experiencing nature in peace and quiet, and contributes to Toronto's competitive advantage as a place to invest. (Official Plan, 3.2.3)

Following the environmental psychology literature, contact with nature is framed as restorative, with the potential to increase the psychological well-being of harried urbanites who can find peace, relaxation, and recreational opportunities in parks, ravines, and along the waterfront. Contact with nature is also seen as increasing social well-being, or public good. The use of nature through parks and recreational programs to "build social cohesion and soothe frazzled spirits" has been practiced in Toronto for over one hundred years (City of Toronto 2004b, p. 11), and is of particular importance in a multicultural and rapidly growing city. Public parks are also seen as providing important public spaces, which enhance the experience of place and provide experiential and educational opportunities (City of Toronto 2006d, 2.12, 3.19).

Third, Toronto's natural heritage and system of parks are seen to increase Toronto's competitive advantage in attracting both investment and skilled workers to the city. The preservation of ravines and parkland thus positions Toronto as progressive, healthy, and a good place to live. Nature also falls under Mayor David Miller's 'Clean and Beautiful' campaign, in which city beautification through flowers and park maintenance is linked with a commitment to the public realm that will help to attract skilled workers and investment (Miller 2007). What is not clear is how the goals of "tidiness" and "cleanness" fostered by the Clean and Beautiful campaign correspond to the ecological goals of the Department of Parks and Recreation, which aims to encourage naturalization and natural heritage preservation (City of Toronto 2004b, p. 23–24). As has been evidenced by public controversy over naturalization projects in Toronto, in which naturalized lawns have been dismissed as a "weedy eyesore" (Spears 2005), Miller's Clean and Beautiful program might be responding to older underlying public values that view "wild" nature in the city as unkempt, dirty, and not belonging in the city.

Nature(s) and its benefits, as portrayed in Toronto's planning policy documents, are, therefore, somewhat ambiguous. Although the support of natural heritage areas and naturalization, or "wild" nature, is encouraged to some extent by the city, this seems to be set against the goal of good nature in the city as clean, tidy, and groomed, a much more

traditional Anglo-American model for urban nature (Hough 2004). This ambiguity on what type of nature is desired and valued in the city, and where, influences not only Toronto's delineation of the city/nature boundary, but also its green-roof strategy, goals, and discourse.

Green Roofs and Toronto

While green roofs lack the symbolism and associated values of something as iconic as Toronto's forest, they are highly symbolic of both a new kind of green city and a revised relationship between nature and the city. The relative importance placed on their ecological benefits and role in the green city is also influenced by the context of a city's overall greening strategies and attitudes to nature. As such, in examining Toronto's green-roof strategy, I will be examining: a) the benefits associated with green roofs and how they fit into the larger urban greening strategy; and b) the policies and programs that have been put in place to encourage their adoption.

The Benefits of Green Roofs in the City: Quantifiable vs. Social Benefits

Although the social benefits of green roofs are recognized in Toronto's policy discourse, green roofs seem to be promoted mainly as innovative ecological urban solutions with little symbolic relationship to the system of parks, ravines, and natural heritage in the city. There is also a tension between official policy and unofficial practice, which might be due to the ambiguity of where and how green roofs are imagined to fit into Toronto's landscape, the benefits they bring, and for whom. Social and psychological benefits such as "adding more green to a built environment," "beautifying the city and creating more natural green spaces in urban areas," and providing passive (i.e., visual) recreational space (City of Toronto 2006b) are mentioned in both research commissioned by the city and in city documents. These public-good benefits are supported by some city policies, such as the 2006 Green Roof Grant Program, which subsidizes highly visible green roofs (City of Toronto 2006a) and Miller's Clean and Beautiful campaign. They also fit in with Toronto's desire to be a globally competitive city. Unofficially, the planning department has promoted green roofs to selected development projects experiencing community resistance to infill development (Loder and Peck 2004), arguing that green roofs provide a social benefit for the community comparable to the loss of visual amenity space. Officially, however, as discussed below, green roofs are not considered a public good, and this raises ambiguities about their role in Toronto's urban greening strategy.

Despite the mention of the social and health benefits of green roofs, the real focus of the City of Toronto has been on their quantifiable benefits of reductions in energy costs, stormwater overflow, and the urban heat island (City of Toronto 2006c). Toronto's estimated 1,700 premature deaths per year due to air pollution (City of Toronto 2004a) and ongoing watershed quality issues from stormwater management (City of Toronto 2004-2005), among other issues, means that the potential of green roofs to reduce current urban ecological problems has enabled them to be brought before city council for discussion in the first place. Notwithstanding this central framing of green roofs' ecological benefits, there has been little symbolic linkage of green roofs with Toronto's natural heritage, parks, or green corridors. They are only explicitly mentioned to be promoted in areas of change, infill development, and densification (City of Toronto 2006d, p. 3–28), and while there are practical reasons for this, it does leave the perception of green roofs ambiguous in terms of their symbolic value in Toronto's larger urban greening strategies. While this is understandable for a new form of greening, attaching symbolic meaning to a new urban greening project can greatly increase its chance of success, as we will see in examining Toronto's and Chicago's green-roof policies.

Policies and Tools to Implement Green Roofs in Toronto

The main mechanisms used by Toronto to encourage green roofs are leadership at City Hall, the Green Roof Grant Program, the Wet Weather Flow Master Plan (WWFMP), and the new 2007 Green Development Standard.

When comparing best-case practices among cities regarding green-roof implementation, a common thread is the need for municipalities to provide leadership in order to stimulate the development of a local green-roof market (Fisher et al. 1999). This is partially due to the cost of green roofs, which are about twice as expensive as conventional roofs (Peck 2001), and to the need to educate the public, train industry, align building permits, bylaws and other potential obstacles, and provide publicly accessible examples of successful green roofs. Under intense lobbying from green-roof advocates, Toronto took the initiative in 2000 to put a green roof on its city hall as a demonstration project to show their viability. As of 2007, Toronto has four public green roofs that the city maintains. There is little public awareness of most of them (Currie 2007), however, and the flagship green roof on City Hall has been criticized as ill-maintained and an eyesore by many green-roof

industry members. To publicize green roofs, the city maintains a green-roof section on its website with resources and materials, as well as maps of green roofs in Toronto. The city also initiated a Green Roof Grant program to subsidize costs for small commercial and residential projects (City of Toronto 2006b). However, discussions with those working in the green-roof industry found that almost none of their clients were aware of the grant program. Furthermore, industry experts have argued that the funding provided is inadequate to stimulate the local green-roof industry. In preliminary discussions with those working in proximity to green roofs, I also found little knowledge of the role of the city in green-roof promotion.

Despite the apparent public unfamiliarity with the city's role in green-roof promotion, Toronto does officially include green roofs as part of its urban greening strategy. In the city's stormwater-management plan and new Green Development Standard (City of Toronto 2007), green roofs are offered as one option to reduce the urban heat island effect, stormwater runoff, and building energy use (City of Toronto 2004-2005). However, because the city does not charge for stormwater runoff and has opted to encourage rather than require green development, both these policies are limited in their ability to encourage green-roof adoption. Interestingly, density bonusing — whereby developers are allowed to increase the density of their project in return for some public good the local government is trying to encourage, and which is often used by cities to encourage green-roof market development — is not an option in Toronto for encouraging green roofs. This is because green roofs are not officially considered a public good (Welsh 2007) despite the planning department's unofficial encouragement of them for infill developments (Welsh 2003).

This has interesting implications for the relationship of green roofs to nature, health, and the city in Toronto. Green roofs in Toronto seem caught between several discourses on nature, health, and public good. In their role as on-site management of stormwater and the urban heat island effect, green roofs are part of the city's green-city agenda, which is committed to green infrastructure, naturalization, and habitat preservation, and, thus, they contribute to the healthy city. The promotion of their social benefits, such as beautifying the city and providing passive recreation, links them with other forms of nature in the city, such as parks and ravines. They are also included, however, in the city's Clean and Beautiful agenda, which emphasizes tidiness and groomed parks, and whose values do not always coincide with

ecological benefits. While their placement in the city at sites of innovation and change might bode well for an attempt to blur the boundaries between what has traditionally been considered nature versus the city, it is not clear whether these sites are considered valuable, or even related, to the social and psychological benefits associated with parks and Toronto's natural heritage. Lastly, there is ambiguity regarding whether green roofs are, indeed, a public good. This leaves the role of green roofs in Toronto looking very good on paper, but ambiguous in their implementation and relationship to the city's urban greening strategy.

Chicago

Introduction

The City of Chicago is on the southwestern edge of Lake Michigan (see Figure 2) and has been known throughout much of its history as a booming industrial centre whose trade routes on the Chicago and Des Plaines rivers helped to transform the surrounding prairie plains into one of the breadbaskets of the United States (Cronon 1991). With a population of 2.8 million (US Census 2005) in the city itself and 9.4 million in the metropolitan area (Testa 2007), Chicago is a financial, business, and cultural hub of the Midwest and is ranked as an alpha city. Famous for its architecture, the birth of the stock market, the skyscraper, and a gritty industrialism that reversed the course of the Chicago River (City of Chicago 2007b), the city has long since erased most traces of the original prairie and Oakland savannah that covered the region (Gobster 2000). Like Toronto, Chicago's suburbs sprawl beyond its borders (Gorrie 2007). Chicago is also one of the most segregated cities in the U.S., with much of the city's poverty concentrated among blacks and Hispanics (Peck and Theodore 2001). Mayor Richard Daley's goal of being the 'greenest city' is thus a sharp departure from Chicago's traditional approach to nature. It should be noted that because Chicago does not have an equivalent to Toronto's Official Plan, analysis was based on interviews with selected public officials, thematic policy documents — such as the city's Environmental Action Agenda (2006), Stormwater Management Plan (2003), Chicago Standard (2007), and Landscape Ordinance (2000) — and on web-based municipal material. In examining the discourse around nature, the city, and green roofs in Chicago, the themes of urban revitalization and the competitive city, public health, and a re-thinking of the relationship between nature and the city are prominent.

Figure 2. Chicago
Source: http://chicagohotels.chidirect.com/z207/maps/chicago.gif

The Place of Nature(s) in Chicago: Watershed, Infrastructure, and Ecological Restoration

Chicago's mottos are "City Within a Garden" and "City that Works," and while both a park and a garden are cultivated forms of nature, a garden implies a much more direct sense of care, stewardship, and direction. This sense of intimate human-nature interaction is reflected to a large degree in how nature is presented in Chicago's policy and its place in the urban imagination. In examining how nature is framed, two themes emerge: first, nature as a watershed and as infrastructure essential to the city; and second, as referenced through naturalization projects. Both themes reveal a specific way of viewing nature and also situate it in reference to the city.

Unlike Toronto, there is little direct symbolic invocation of Chicago's immediate hinterland, except in terms of its waterways, and in particular, the Chicago River and Lake Michigan. In the myth-creating discourse about Chicago's origins and trajectory to greatness, Chicago's waterways are co-conspirators with human ingenuity in the creation of the great metropolis. They provide not only commerce, and, thus, wealth, but also health, safety, recreation, and experiences of nature in the city:

> Chicago's world-class status is owed largely to its position at the confluence of the Chicago River and Lake Michigan. These waterways signified transportation and trade to Chicago settlers and continue to attract millions of visitors to our city every year. Beyond the Lake Michigan shoreline, our water resources extend beyond, and beneath, the City… (they have) delivered drinking water and helped us manage stormwater...These resources are critical to our public health, safety, economy, and quality of life. They provide opportunities like boating, fishing, and swimming. Our waterways provide natural experiences in an urban setting. (Mayor Richard Daley, City of Chicago 2003)

Chicago's waterways are thus interwoven into a narrative of the creation, identity, and health of the city and its people, a symbol both of its greatness and of its indebtedness. They are the silent infrastructure that sustains the city and are essential to its continued health and success.

The other main way that nature is presented in the city is through the emphasis on naturalization and ecological restoration throughout the city's urban greening initiatives. Like Toronto, Chicago is revitalizing its waterfront and restoring habitat in ecologically sensitive areas (City of Chicago: Chicago Park District 2007a). In Chicago, however, the use of native vegetation as the best option for urban greening initiatives is a persistent theme across Chicago's urban environmental policy (City of Chicago: Planning and Development 2000; City of Chicago 2003; Eisenman 2004). Furthermore, current municipal policies have not only dramatically increased the amount of greenspace, replacing or covering up asphalt with vines, trees, grass, and native plantings (City of Chicago: Planning and Development 2000; City of Chicago: Department of the Environment 2007a), they also explicitly prefer native vegetation and see urban greening as expressing a new system of values that Daley and his administration are keen to promote. This new vision for the city argues that parking lots, garages, and expressways "should not be the dominant impression of a retail corridor or neighbourhood commercial district." (City of Chicago: Planning and Development 2000, p. 17, 25–26). This is supported by policy: parking garages are often mandated to be screened with vines (see Figure 3) and downtown areas with little greenery are required to plant and maintain trees of a certain size (City of Chicago: Planning and Development 2000).

While official policy discourses on urban greening projects do not highlight native vegetation as a symbolic link to long-lost prairie habi-

tat, its presence, it might be argued, is shifting the daily lived experience of urban landscape for Chicagoans:

> Although in no way the echo of Haussmann's Paris, the effects of these new boulevards on the texture of the city was no less stunning. The long slivers of golden prairie grass dividing those arterials provided dramatic visual relief and contrast to what were once landscapes of unrelenting asphalt. (Zimmerman 2007, p. 2)

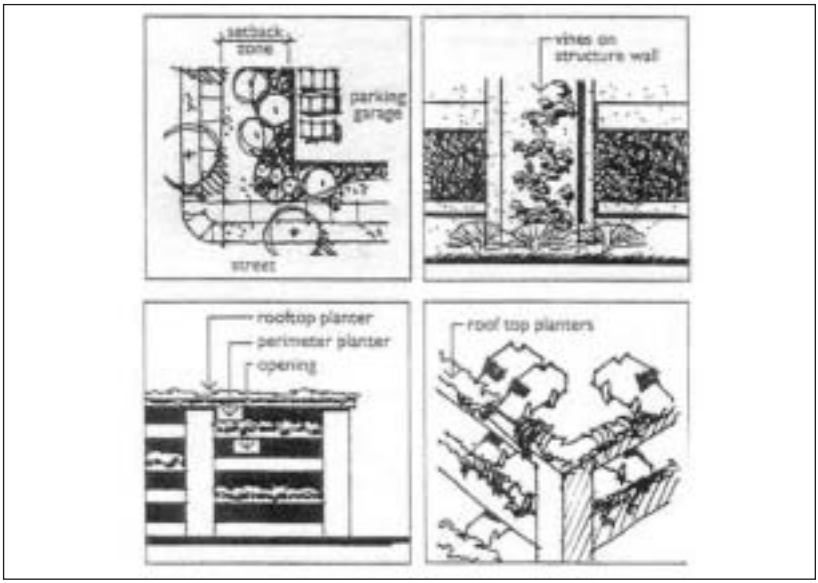


Figure 3. Urban greening requirements from Chicago's Landscape Ordinance Source: Chicago Landscape Ordinance (2000, p. 26)

What nature(s), therefore, emerge from Chicago's policy documents, and where is their imagined place? On the one hand, nature here is imagined as part of the narrative of industrialization and progress; the conquering of wild nature now subdued to a mutual working relationship and a realization of the limitations of the surrounding ecosystem. Although this nature both surrounds Chicago and bisects it, there is still a delineation between nature and non-nature, maintaining the traditional city/nature dualism. On the other hand, there seems to be a blurring of the traditional nature/city dualism in a shifting idea of the kind of nature that is appropriate in the city. Controlled, groomed parks and lawns are typical evocations of nature in narratives of modern cities that have been built upon its subjugation (Hough 2004). Daley's green-city vision is blurring this modern nature with a messy, shifting, pre-colonial prairie ecosystem.

Furthermore, the city is being redefined as the appropriate place for this nature, thus blurring the nature/city divide. In so doing, Daley's vision of the green city is challenging the idea of health and nature prevalent in modern North American cities since the Victorian sanitation movements.

The Benefits of Nature in Chicago: Public Good, Public Health, Safety, and Responsibility in the Competitive City

Chicago's policy documents discuss the benefits of nature in three main themes: a) public resource; b) public health and safety in the face of urban environmental problems; and c) urban revitalization and the beautiful city, in the context of competitiveness.

As seen in Daley's discussion of the Chicago River, nature, in Chicago's policy discourse, is portrayed as a public resource. This is particularly true when the nature under discussion is valued as habitat, or is undergoing ecological restoration (City of Chicago 2003; City of Chicago: Chicago Park District 2007a). Messy nature, however, has traditionally been associated with disease, ill health, vermin (Ashton 1992), and neglect (Spears 2005). To deal with this, the Daley administration has done two things. First, policy documents directly address potential public concerns about naturalization with regards to aesthetics and health. Documents on naturalization projects discuss the need for and benefits of controversial practices such as controlled burns (City of Chicago: Chicago Park District 2007b), while recommendations for native vegetation and naturalized landscaping (City of Chicago 2003, p. 16–17) portray native vegetation as aesthetically pleasing, more resilient, attractive to desirable bird and insect species, and safe for human health.

Second, "messy" nature is portrayed as safeguarding public health by cleaning waterways and cooling the city. Vegetation that reduces the urban heat island effect is especially emphasized, with Daley stressing that "plants and trees act like air conditioners and air filters." (City of Chicago: Department of the Environment 2006a). Daley's comments, and the tone of much of the landscape ordinance and green-roof policy, reflect the city's awareness of a strong linkage in the public mind between air quality, heat, and public health. In 1995, "a blend of extreme weather, political mismanagement, and abandonment of vulnerable city residents resulted in the loss of water, widespread power outages, thousands of hospitalizations, and 739 deaths in a devastating week." (Klinenberg 2002, 2005). Although Chicago is no stranger

to public-health catastrophes, the severity of the crisis and the political mismanagement of the situation have enabled Daley's linkages between a healthy nature and public health to carry a certain weight and urgency.

This fits in well with the third way by which nature is framed as benefiting the city, which is as part of urban revitalization and the beautiful city, in the context of global competitiveness. If nature protects public health, then the aggressive pursuit of a green city is not only responsible governance, but also ensures the city's continued competitiveness, attractiveness, and sustainability in its leadership:

> Chicago has become nationally known for its leadership in the environment… It improves public health; it beautifies the city; it enhances the quality of life; it saves money; and it leaves a legacy for future generations. (Mayor Daley, City of Chicago: Department of the Environment 2006b)

This not only challenges traditional conceptualizations of health, nature, and the city, but also links competitiveness, progress, and boldness with ecological values and "messy" nature. Nowhere is this more apparent than in the city's position on green roofs, their most famous example of Daley's new green vision for the city.

Green Roofs and Chicago

Although Chicago has embarked on many urban greening projects, the city is particularly famous for its green roofs: "When we planted our first rooftop garden on City Hall in 2000, it started a movement that is still going strong, six years later" (City of Chicago: Mayor's Office 2006). In examining the discourse surrounding green roofs in Chicago's policy documents, three main themes emerge. First, green roofs are positioned as part of Chicago's competitive edge and green transformation. With their high visual appeal, novelty, and radical blurring of the traditional nature/city boundaries, green roofs are a powerful symbol for a city looking to improve its image and transform itself from industrial city to green leader. "Chicago is like its architecture: bold, unconventional, and willing to take risks. And they work." (Daley 2004).

Second, green roofs are portrayed as an integral part of the city's response to Chicago's urban environmental problems, and, thus, are linked to public health, public good, responsibility, and innovation. Like Toronto, green roofs are framed in policy documents in terms of their ability to reduce the urban heat island effect, stormwater overflow, and, heating and cooling costs, and to improve air quality (City

of Chicago: Department of the Environment 2007b). Aggressively implementing green roofs is, thus, part of Chicago's overall urban greening strategy that positions the city as boldly safeguarding public and environmental health.

Where Chicago's framing differs is in its consistent focus on green roofs as a public social benefit and on their integration into the city's overall urban greening strategy as such. The city frequently cites literature on the psychological benefits of greenery to entice developers to include a green roof in areas that lack greenspace (Berkshire 2004). Green roofs are also positioned as a public benefit in their incorporation into green buildings, which are themselves argued to be a public good, or "good neighbour," in their reduced use of energy and resources (City of Chicago 2007a). In this way, green roofs are positioned as an essential, and very visible, part of Daley's leadership on the environment and public health.

Lastly, green roofs are positioned not only as something for corporations and green buildings downtown, but as roof gardens for residents (City of Chicago: Department of the Environment 2006a). This positioning of green roofs as the more recognizable and familiar roof garden is an astute way of popularizing green roofs for the residential market and linking them to other urban greening initiatives, such as sidewalk gardening, which are popular in Chicago.

Policies to Promote Green Roofs in Chicago: Leadership and Enforcement

The main policies used to promote green roofs in Chicago are municipal leadership, a comprehensive green building strategy, stormwater management plans, density bonusing, and power in the planning department to influence developments that are publicly funded or that work in collaboration with the planning department.

Chicago, and Mayor Daley in particular, have shown strong leadership in promoting green roofs. First, Chicago has deliberately chosen green roofs as a highly visible symbol of its commitment to becoming a green city. This choice of green roofs as a promotional tool is widely respected by other cities to promote the city as innovative and green (City of Toronto 2007). Second, the green roof on Chicago's city hall is award winning (see Figure 4) (American Society of Landscape Architects 2002), easily recognized, and highly promoted in all the city's green promotional material. Third, Chicago's aggressive goal to have all new city buildings designed to LEED (Leadership in Energy

and Environmental Design) gold by 2010 (City of Chicago 2006) and existing municipal stock retrofitted (City of Chicago 2007a) has given Chicago the highest number of LEED buildings in the U.S. (Zimmerman 2007). Because green roofs are often included as part of a green building, this promotes green-roof development and positions Chicago as a green leader. Chicago's promotion of LEED buildings as a public benefit also enables the city to use density bonusing as a planning option to encourage green roofs (Berkshire 2006).

Figure 4. Green roof on Chicago City Hall
Source: Earthpledge, 2005, Green Roofs: Ecological Design and Construction

Fourth, strong leadership has allowed Chicago to put teeth into some of its green-roof policies. Chicago, like Toronto, has included green roofs as one option to reduce stormwater runoff. Unlike Toronto, Chicago has passed legislation (in 2007) that requires large commercial and industrial properties to manage their stormwater on-site (City of Chicago: Department of Water Management 2007), thus giving teeth to their recommendations of green roofs as a stormwater-management option.

Chicago also has policies that mandate or encourage green roofs in areas of ecological need. Chicago's Green Roof Improvement Fund (GRIF) of $500,000 encourages companies to build green roofs downtown

and subsidizes individual projects up to $100,000 (City of Chicago: Department of the Environment 2006b). For public or planned developments in these areas (ones that need approval from the planning department and over which it has some control), the city has recommended, and in some cases, required, green roofs to be installed (City of Chicago: Department of the Environment 2006b). They are also working on a plan that will allow the planning department to negotiate the placement of green roofs in areas based on their ecological need — such as areas with poor drainage that are part of a river basin or areas with little present greenspace (Berkshire 2006). All of these programs have been immensely successful: at last count, there are over 300 million square feet of green roofs built or planned in Chicago on public or planned developments (Berkshire 2007), and Chicago's latest project boasts the largest green roof in the world (Metropolis Magazine 2006).

Where does this leave green roofs as part of Chicago's overall urban greening strategy? How do green roofs fit into the place of the city, the place of nature? Nature, in Chicago's policy documents, is framed as a co-conspirator of the city's great history, both encircling the city and projecting it. It is also framed as the infrastructure that ensures public health and that promotes the values of the new city: bold, environmentally progressive, and healthy. Its place is on top of, beside, and around existing relics of the old era that prioritized parking lots, pavement, and control of nature as a symbol of progress. Green roofs, in their symbolism and their deliberate shifting of the traditional nature/city boundary, are not only well suited to this vision of naturalization in the city, but have also become its symbolic figurehead. Furthermore, green roofs are integrated into the city's overall greening strategy and supported by policy. Thus, green roofs are indicative of the kind of values that Chicago promotes, which cover evidence of modernism with naturalization — a new ecological version of the City Beautiful (see Figure 5).

Toronto, Chicago, and Green Roofs: Symbolism, Politics, Power, and Health

Both Toronto and Chicago are promoting themselves as green-city leaders; both recognize and promote the benefits of nature for environmental and public health; and both cities are promoting green buildings and other environmental initiatives. Six years after adopting green-roof policies, however, Chicago is clearly much further ahead in promoting green roofs. There are several reasons for this, and these are

instructive to other cities wishing to implement urban greening policies. First, Toronto has much more "nature" to begin with: 17 per cent urban forest coverage compared to 13 per cent in Chicago (City of Chicago: Planning and Development 2000; City of Toronto 2004b). Furthermore, in the Anglo-American narrative on nature, forest carries with it a strong symbolism of wilderness, and this might psychologically be more present in the minds of Torontonians than the long-lost Oakland savannah surrounding Chicago is for Chicagoans. With urban sprawl rapidly eating up Toronto's hinterland, importance might simply be placed more on preservation of what already exists than on perceived "window treatments" such as green roofs. In this sense, the discourse around nature and the city in municipal documents can influence whether or not nature is valued mainly outside of city limits, such as the cottage country north of Toronto is, or also within the city, as seen in Chicago's focus on covering the city with naturalized greenery.

Figure 5. Chicago green roof website
Source: www.chicagogreenroofs.org

The different political contexts of Toronto and Chicago also strongly influence their differing levels of success in promoting green roofs. First, Daley has much more power than Miller. Daley can rearrange the Department of the Environment to his liking to promote green roofs, and is afraid of neither criticism nor of not getting reelected in

a city known for its nepotism. Although Daley has been accused of ignoring poorer neighbourhoods to beautify the city (Zimmerman 2007), these criticisms roll off the back of a mayor proudly described by Chicagoans as a "bully" (Gorrie 2007). Miller, who is conflict-adverse and hindered by a slow-moving bureaucracy resistant to change, would be unwilling, and unable, to push green roofs so aggressively. Second, Toronto's green-roof agenda was significantly slowed down by a change in mayor. The limited power for Toronto mayors means that it is unlikely that Toronto will see any of Chicago's boldness anytime soon.

The third factor influencing the difference between Chicago's and Toronto's progress on green roofs is the Chicago heat wave. Not only has this given weight and power to Daley's environmental initiatives, but the ensuing settlement with Commonwealth Edison, the large utility company whose power outage occurred during the heat wave, has funded both the city hall's green roof and subsequent green-roof initiatives (Berkshire 2006). Furthermore, due to amalgamation and cuts to the city's budget, Toronto's Parks and Recreation Services has only $2-million to maintain the city's parks and urban forest in comparison to Chicago's Park District's budget of $20-million (City of Toronto 2004b). Even if Toronto were to suddenly have an extra $20-million, there would be much debate over the money being used solely on parks and recreation, as opposed to, for example, on the city's ageing and increasingly inadequate public transit system or its lack of affordable housing.

What does this mean for cities attempting to adopt urban greening strategies as part of being a "green" city? In examining the case studies of Toronto and Chicago, cities both aiming to be green leaders, three things stand out. First, in an age of globally competitive cities, branding can have an enormous impact on the success of a city's image. Chicago's boldness in architecture and as a city is being transformed into a green city boldly pushing environmental initiatives and blurring the nature/city divide. Chicago still has many environmental problems and is still a dirty city dependent on coal-fired power (Gorrie 2007), yet it is now competing with very green cities such as Portland (Oregon) and Toronto. Green roofs, though they form but one part of an effective city-greening program, are highly symbolic, bold, and popular. Branding a city as supporting green roofs can, thus, be an effective means of turning a city's image around and developing

a groundswell of support for environmental initiatives, even in a city not traditionally seen as green.

Second, linking urban greening initiatives to public health, and in particular, making a link between naturalization and public health, can help to avoid public debate over which nature is appropriate in the city and which is not. This is particularly evident when dealing with "messy" nature, which happens to be the most ecologically beneficial: although Toronto suffers from poor air quality, there are still public concerns about allergies raised during naturalization projects and green-roof implementation. Reframing public health as working in tandem with naturalized nature and nature in traditionally urban places, like roofs, can blur the Victorian duality of the sanitized city versus dirty, uncontrollable, and messy nature, and help to move both ecological and public health forward.

Lastly, the particular power structure of a city is highly influential on how urban greening initiatives are both framed and implemented, if at all. Understanding the limitations and peculiarities of a city's power structure, and of its current framing of nature and its benefits, will enable a city to better understand how and where green roofs should fit into its urban greening program.

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Social Networks and Harm Reduction: The Influence of Social Capital on Substance-Use-Related Health Behaviours

Maritt Kirst

Abstract

Substance users such as injection-drug users and crack smokers are at risk for several health problems, including blood-borne-disease infections such as HIV, Hepatitis B and C, and overdose. Behaviours that contribute to health risk stem not only from an individual's knowledge and beliefs, but are also shaped by processes of influence and constraint operating within networks of social relationships. The analysis of users' social network relationships is, therefore, important to understanding users' engagement in drug use-related risk behaviours. Such an analysis produces knowledge of the social-contextual nature of risk decision-making that is useful to assist in breaking down barriers to risk reduction within drug-use settings. This paper discusses the utility of the social capital framework in the study of the health-risk and protective behaviours of marginalized drug users. The paper also explores how the findings of such research may assist with and potentially translate into improvement in harm-reduction services.

Introduction

Marginalized populations are typically susceptible to greater risk of morbidity, mortality, and lower quality of life due to their lower socio-economic status and limited access to environmental resources (Flaskerud and Winslow 1998). A lack of access to preventative and general health resources may lead to a preponderance of risk behaviours that can have a detrimental effect on health among these populations. In order to reduce health inequalities experienced by such populations, the social determinants of health must be considered

(Marmot 2005). As a result, a call has been made for research focusing on the social structural forces that contribute to the poor health and high level of risk behaviours of marginalized populations (Geronimus 2000). Health-risk behaviour stems not only from an individual's knowledge and beliefs, but is also shaped by processes of influence and constraint operating within networks of social relationships (Rhodes and Quirk 1998; Valente, Gallaher, and Mouttapa 2004). This highlights the importance of considering not only individual behaviours that contribute to risk, but influences that are exogenous to the individual, such as the social context in which such behaviours arise (Rhodes et al. 2005).

With respect to the marginalized population of drug users, many are aware of the health risks and harms associated with certain drug-use behaviours, but some users continue to engage in risky behaviours despite this knowledge (Lovell 2002; Erickson and Cheung 1999; Power et al. 1995; Magura et al. 1989). Since drug use often occurs as a hidden, yet social, activity, the micro-social environment in which it occurs influences related risk behaviours (Lovell 2002; Rhodes 2002; Hoffman, Su, and Pach 1997; Grund 1993). The analysis of users' social network relationships is, therefore, important in order to understand their engagement in drug use-related risk behaviours. Such a sociological analysis produces knowledge of the social-contextual nature of risk decision-making. This knowledge can subsequently assist in breaking down social context-related barriers to risk reduction, and facilitate the promotion of protective behaviours (Lovell 2002; Rhodes 2002; Weeks et al. 2002).

Researchers are now turning to the social context of drug use to explain why some users continue to engage in health-risk behaviours that contribute to high levels of drug use-related harm (Jackson et al. 2002; Lovell 2002; Hoffman, Su, and Pach 1997). In many Canadian cities, drug use-related harms involve a high prevalence of infectious disease, overdose experiences, and other drug use-related health problems, much of which is associated with injection-drug use[1] (Single 1999, 2000). Such a high prevalence of drug use-related problems creates costs to Canadian society. These costs include economic costs in the form of healthcare and law enforcement, as well as a broader public-health risk of morbidity and mortality related to infectious disease (Rehm et al. 2006; Single 2000).

Studies of the social context of drug use have found that aspects of social network structure, such as size, density, and location[2] (Friedman et al. 1999; Hoffman et al. 1997; Latkin et al. 1995a and b; Klovdahl et al. 1994; Neaigus et al. 1994), and social network resources, such as trust and reciprocity, information exchange, and norms and rules, can contribute to the risk of blood-borne-disease transmission and other health problems (Treloar and Abelson 2005; Weeks et al. 2002; Jackson et al. 2002; Kelley, Murphy, and Lune 2001; Friedman et al. 1998; Crisp, Barber, and Gilbertson 1997; Power et al. 1995; Zapka, Stoddard, and McCusker 1993; Zule 1992). However, many of the extant studies that have examined the influence of network structure and resources on drug use-related health behaviours have explored these two powerful dimensions of network relationships in isolation from each other, without incorporating a theoretical framework that effectively integrates them both. Furthermore, these studies have examined these network characteristics only among networks of *injection-drug users (IDU's)*. Other marginalized groups of drug users who are also at risk for infectious disease and overdose, such as crack smokers (CS's), are often excluded due to our limited research and knowledge concerning the risks associated with crack smoking. Studies have recently noted an increased prevalence of crack use among marginalized populations in various Canadian cities (Fischer et al. 2006). However, there is limited research on the prevalence of crack use-related risk and protective behaviours, as well as on the social mechanisms that might affect these behaviours.

Given such a lack of research on structure *and* resources embedded in social networks that can contribute to both risk and protective health behaviours among marginalized populations such as injection-drug users *and* crack users, this paper will discuss the utility of the social capital framework in the study of the health behaviours of such populations. The paper will also explore how the findings of such research may assist with and potentially translate into harm-reduction[3]-service improvement.

Risk Behaviours Associated with Injection-Drug Use and Crack Smoking

Injection-drug use-related risk behaviours, such as needle-sharing, syringe-mediated drug sharing[4], and other drug-use equipment-sharing (e.g., drug preparation receptacles like cookers and filters), are associated with an increased risk of blood-borne-disease infection such as HIV and Hepatitis B and C (Des Jarlais et al. 2003; Grund et

al. 1996; Koester, Booth, and Wiebel 1991). In many Canadian cities, the prevalence of such negative health outcomes related to drug use continues to be high, presenting significant individual and public-health problems (Single 2000). The prevalence of HIV infection among IDU's has been estimated to range from 1.2 per cent to 25 per cent, while estimates of Hepatitis B prevalence range from 20 to 50 per cent, and estimates of Hepatitis C prevalence range from 56 to 90 per cent among samples of IDU's in several Canadian cities (Health Canada 2004; Single 2000; Poulin, Single, and Fralick 1999).

While IDU's are at high risk for blood-borne disease infection and other health problems (e.g., skin abscess, endocarditis), CS's have also been found to be at risk for drug-use related harms (Clatts et al. 2002; Ward et al. 2000; Erickson and Cheung 1999; Faruque et al. 1996). Recent research has indicated that CS's often have open cuts and burns on their lips from smoking crack in heated glass or metal pipes, and that these cuts and burns may contribute to the risk of infectious-disease transmission through risky sex behaviours and pipe-sharing (Research Group on Drug Use 2001; Wong 2001; Ward et al. 2000; Ross et al. 1999; Porter, Bonilla, and Drucker 1997; Faruque et al. 1996). Research in this area has also found that the use of metal pipes results in more burns to the mouth than glass pipes, and that use of metal and plastic pipes is more harmful to the lungs than glass pipes, due to the inhalation of toxic fumes emitted when metal and plastic are heated (RDGU 2001; Wong 2001; Porter et al. 1997).

Consuming drugs in solitude can be considered a drug use-related risk behaviour because some IDU's inject drugs in excessive quantities and of unknown purity, thus increasing the risk of drug overdose and other adverse reactions (Broadhead et al. 2002; McGregor et al. 1998). The risk of fatal overdose is further magnified when the user injects drugs alone, without others to seek medical assistance if needed (Broadhead et al. 2002; McGregor et al. 1998). The same risks are relevant to crack use, wherein excessive use can lead to overdose symptoms such as blackouts and seizures, and the risk of myocardial infarction (Vasica and Tennant 2002; Pottieger et al. 1992).

There is a need for services that provide both IDU's and CS's with the means to reduce the risks distinctly associated with each type of use. Harm-reduction services have, thus far, been geared toward reducing health risks related to injection-drug use, and due to a prior lack of knowledge concerning risks associated with crack use, are only now

beginning to promote harm-reduction practices related to crack-smoking (Haydon and Fischer 2005). Furthermore, while peer-based harm-reduction services, which involve the use of trained drug users to educate their peers about harm-reduction practices, have been evaluated as effective in many cities in North America (Treloar and Abelson 2005; Wood et al. 2003; Latkin 1998; Coyle, Needle, and Normand 1998), they are largely focused on promoting harm-reduction among IDU's, and remain under-supported and under-funded by the Canadian government. I argue that, given the power of social relationships to influence and constrain individual behaviour, more needs to be known about social-relationship dynamics and resources at work within the social context in which injection-drug use and crack smoking occur. Once more is known, the dimensions of social capital that facilitate drug use-related risk-reduction can be better harnessed within peer-based harm-reduction services to ultimately improve their effectiveness and encourage various types of substance-using subgroups to engage in protective health behaviours.

An Integrative Framework: Social Capital Theory

Social capital theory has become popular in the study of social behaviours relating to employment, health, and crime (Cheung and Cheung 2003; Hagan and McCarthy 1997). Social capital is commonly defined as the resources embedded within social structures such as social networks or larger social structures (Lin, Cook, and Burt 2001; Portes 1998). When used or mobilized, such structurally embedded resources facilitate actions and provide returns in the form of individual or group-level benefits (Lin 2001; Portes 1998). Structural aspects and resources inherent in such social networks are, therefore, integral elements of social capital (Lin, Cook, and Burt 2001).

Social capital has been conceptualized in various ways (Lin, Fu, and Hsung 2001). Theoretically, social capital has been defined as a resource accessible at the individual or collective level (Macinko and Starfield 2001; Lin 2001; Putnam 2000). In the individual sense, social capital is viewed as a resource embedded in networks or communities obtained by individuals that, either intentionally or unintentionally, benefits their individual interests (Putnam 2000). Coleman's theory of social capital views the concept primarily as an individually beneficial resource. According to Coleman (1988), forms of social capital include structures of obligations, expectations and trustworthiness, information channels, and norms and sanctions

inherent in social relationships that facilitate members' actions. Coleman's (1988) structures of obligations, expectations, and trustworthiness refer to systems wherein network members are trusted and hold obligations to one another and, thus, reciprocate actions in the future. Information channels within social relations facilitate information flow between members, which, in turn, influences action. Norms and sanctions within social relationships facilitate and control action through the support and reward, or restriction of, particular actions (Coleman 1988).

Alternatively, at the collective level, social capital is conceptualized as a resource that, when used by individuals or groups, can benefit the broader collective or community (Putnam 2000). Bourdieu (1986) conceptualized social capital as stemming from individuals' association with a "credential" rich class, family, or other institutionalized network. He defined social capital as "…the aggregate of the actual or potential resources which are linked to possession of a durable network of more or less institutionalized resources of mutual acquaintance and recognition…which provides each of its members with the backing of the collectivity-owned capital, a 'credential' which entitles them to credit" (p. 249). Bourdieu's is a critical definition of social capital in that it discusses how such credentials are used by elite groups for benefit, but can also have detrimental effects through the exclusion of individuals who lack access to these credentials (Wakefield and Poland 2005).

Putnam's (2000) view of social capital can be considered a collective-based definition of the concept. Putnam (1993) defines social capital as "features of social organization" — such as social trust, norms of reciprocity, and civic engagement and volunteerism — that, at high levels, have the ability to improve the positive functioning of communities. He argues that civic engagement, which typically involves embeddedness in social networks, fosters social trust and reciprocity, and facilitates productivity, subsequently providing benefits to the collective. This collective definition is exemplified in Putnam's (2000) research on the decline of civic involvement in America in the last two decades. In his work *Bowling Alone*, Putnam (2000) argued, through review of survey data in the United States from the 1970s to the 1990s, that the U.S. is exhibiting a decline in social capital and social connectivity, manifested in decreased political, religious, and civic participation, workplace and informal social connections, and volunteering, reciprocity, honesty, and social trust, all of which, in turn, is

negatively affecting the health and democratic and social functioning of American society.

The concept of social capital can also be measured in multiple ways (Lin, Fu, and Hsung 2001). Research can measure *access* to social capital, involving the examination of the distribution of mobilized social resources. The use of social capital can be examined through the measurement of how social capital is harnessed by individuals and how it affects their well-being. Finally, both access and use of social capital can be measured through the examination of the processes through "…which embedded resources constrain and enable individual choices and actions" (Lin, Fu, and Hsung 2001, p. 59). While both access to and use of social capital are rarely studied together, inclusion of both dimensions of social capital is important as it speaks to the concepts' structural (access)- and agency (use)-related aspects (Lin, Fu, and Hsung 2001).

Critics of social capital theory (Muntaner 2004; Lynch et al. 2000) have viewed the concept as ill-defined and simply a fashionable re-packaging of the concepts of social support and social integration. However, social capital theory remains a popular and useful conceptual framework distinct from individual-level measures of social support or social integration (Lin, Cook, and Burt 2001). It is useful in that it integrates into one framework such micro- and macro-level sociological concepts as social support, social integration, social control, social networks, and social cohesion. This concept encompasses micro/relational and macro/collective social dynamics, and allows for the study of the influence of these dynamics on individual perceptions and behaviours (Lin 2001). The study of social capital allows the health researcher to move beyond the sole examination of individual-level predictors of risk-taking behaviour (Lovell 2002). Through analysis of the connections between relationships, resources, and the individuals embedded in networks, the social capital framework facilitates the exploration of how structure and agency contribute to, or protect against, risk (McCarthy, Hagan, and Martin 2002; Lovell 2002).

Research on the Relationship between Social Capital and Health Behaviours

A number of research studies have illustrated an important relationship between social networks, social capital, and behaviours related to health and drug use. Research that examines the relationship between

social capital and health outcomes has typically found that the presence of social capital through embeddedness in social networks or communities has a protective effect on health (Bolin et al. 2003; Crosby et al. 2003; Cattell 2001; Kawachi and Berkman 2000). Social capital affects health behaviour in the sense that individuals who are embedded in a network rich in positive support, well-placed trust, accurate information, and positive or functional norms, have resources that will facilitate positive action toward the achievement of particular outcomes (Lin 2001). For example, individuals experiencing health problems may receive useful informational, emotional, and financial support from members of their social network (Bolin et al. 2003) that assists them in maintaining or improving health. Furthermore, social capital in the form of social trust and membership in social organizations can discourage or regulate engagement in risky health behaviours such as drinking, smoking (Bolin et al. 2003), or unprotected sex (Crosby et al. 2003). These changes can result in lower risk of mortality (Kawachi, Kennedy, and Glass 1999).

To date, three studies have examined the influence of social capital on drug use-related health behaviours among the specific marginalized population of drug users. Lovell's (2002) study on the effect of network structure and types of capital on the injection practices of a sample of IDU's in France indicated that location in a two-core membership or a small, close-knit component of a larger social network of IDU's increases the likelihood of risky injection practices, and that there was a non-significant tendency for low social capital, in the form of low social integration, to increase the likelihood of risky injection. Based on her findings, Lovell (2002) advocated for interventions that build community social capital in order to reduce drug use-related harms and risks.

Cheung and Cheung (2003) examined the effect of social capital on the risk level of drug use post-addiction treatment among a sample of male former treatment clients in Hong Kong. They found that membership in a conventional social network provided positive social capital, in the form of tutelage on a conventional way of life, informal social control, and less perceived public discrimination, that increased the likelihood of reducing the riskiness of post-treatment drug use. Conversely, the researchers found that re-association with a drug-using network, post-treatment, led to negative social capital, in the form of tutelage on risky drug-use behaviour, lack of informal social control and bonds to non-drug-users, and high perceived public

discrimination, that decreased the likelihood of reducing the riskiness of post-treatment drug use.

In their sample of male and female IDU's in China, Choi, Cheung, and Chen (2006) compared the level of HIV risk behaviour (i.e., needle-sharing) by gender, and also explored the influence of five risk factors: lack of family support (social capital variable); having an IDU as primary sex partner (social capital variable); economic pressure; lack of access to methadone treatment; and age, by gender. They found differential effects of the social capital variables on HIV risk behaviour by gender. Family support was a predictor of increased HIV risk behaviour among males, while having an IDU as a primary sex partner was predictive of increased HIV risk behaviour among females.

A commentary by Erickson and Cheung (1999) argued that social capital is linked to harm reduction in the sense that drug users living in a community with high levels of social capital will be personally invested in maintaining this aspect of their community and will subsequently have the desire and resources to engage in more controlled and responsible drug use. Conversely, drug users in communities with low social capital may not have access to the resources that facilitate controlled use, potentially resulting in problematic drug-use patterns.

This research contributes important findings to our understanding of the relationship between social networks, social capital, and health risk. They have discussed how the presence of social capital can lower the likelihood that drug users will engage in risk-taking behaviour through such processes as social trust, social control, social learning, and social integration and support embedded in conventional networks.

Contributions of Health Research with Marginalized Populations from a Social Capital Perspective

Essentially, traditional social capital theory conceptualizes social capital as a metaphor for advantage (Burt 2001), and much research applying this theory has typically applied the concept as access to prestige and support through social networks. As a result of this conceptualization, a considerable amount of this research tends to neglect the exploration of *access* to or *use* of social capital among *marginalized* groups such as drug users. While the research studies mentioned above examine social capital among this population (Choi et al. 2006; Cheung and Cheung 2003; Lovell 2002), these studies are limited in

that they consider the conventional, non-drug-using social network as the main producer of social capital, and fail to examine the potential for the drug-use network to produce beneficial social capital (Friedman 2003; McCarthy, Hagan, and Martin 2002). While social relationships in the context of drug use can contribute to health-risk behaviours through processes of influence and constraint, these relationships can be similarly powerful in the promotion of protective health behaviours such as harm-reduction information-exchange, as well as the provision of norms and social support for safer drug-use activities. For example, studies of IDU's have revealed that some users exchange information about drug use-related health risks and harms and encourage others to engage in harm-reduction practices (Treloar and Abelson 2005; Kelley, Murphy, and Lune 2001; Latkin et al. 1995b; Power et al. 1995). It has been found that many illicit drug users are more likely to follow the protective advice of peers whom they trust, and that some networks establish rules of drug use that encourage risk reduction, for example, "no injecting" rules that discourage engagement in risky behaviours like needle-sharing by barring the injection of drugs altogether (Weeks et al. 2002; Kelley, Murphy, and Lune 2001; Power et al. 1995).

Thus, I argue that just as we promote the building of social capital for health improvement among the general population, we should also advocate for the building of social capital among marginalized populations. More specifically, the drug-use network has the potential to generate social capital that can contribute to such beneficial outcomes as drug use-related risk reduction, for example, a reduction in health-risk behaviours like drug-use equipment-sharing (Friedman 2003). However, more research exploring this potential among the drug-use network from a social capital framework is needed in order to understand how to better promote harm reduction at the social-network level. Through a consideration of the influence of social capital on both risk- and protective-health behaviours among marginalized populations, such research realistically recognizes and explores how social capital can have positive and negative outcomes for individuals. Such a consideration challenges the critique that much of social capital research overstates or promotes the view that social relationships have only positive implications for individual health and well-being (Wakefield and Poland 2005).

In order to effectively explore the potential for building social capital among marginalized populations such as drug users, a comprehensive

application of the social capital concept that considers various complexities of the construct is needed. I argue that this application should involve triangulation in measurement of social capital in multiple ways. Many research studies examining the influence of social capital on behaviour explore either access to or use of social capital, but rarely both in the same study (Lin 2001). Due to the conception that marginalized populations either possess low or no social capital, it is imperative that the level of access to social capital be established first, and then the use of these resources be examined further. Thus, both access to and use of social capital among drug users' networks and their influence on risky – and protective – health behaviours must be studied. Given the limited application of social capital measures in research with marginalized populations and the aforementioned assumptions about a lack of network resources among disadvantaged groups, traditional measures of social capital are not likely appropriate for measuring this aspect among such populations. These groups do not have access to the same types of prestigious resources as do more advantaged social groups (Wakefield and Poland 2005), and measures designed for research with more privileged groups will, therefore, be less effective at capturing access to the types of resources embedded in the networks of groups who are marginalized. An instrument that would be more appropriate at capturing and measuring access to and use of social capital among the drug-use network, and may be applicable to the study of networks of other marginalized populations, is greatly needed.

Various dimensions of social capital, including network structure and network resources, should be measured. Studies of social-network influences on the health behaviours of drug users have traditionally examined either structural or resource influences on risk behaviour, and few have sufficiently considered the influences of both of these important network characteristics within the same study. Furthermore, these various dimensions of social capital need to be examined through both quantitative and qualitative methods in order to provide the most comprehensive and in-depth analysis of how social capital affects health behaviour. In addition, contrary to much social capital research, which examines the strategic use of social capital for individual benefits (e.g., job attainment research), research needs to be conducted that advances our knowledge of the unintended use of social capital and its implications for health by marginalized populations.

Such a comprehensive application of the social capital concept not only addresses a gap in knowledge concerning social influences on the health of marginalized populations, but it also addresses another critique launched at extant research on social capital and health in general. The proposed examination of various complexities of the social capital concept through triangulation in its measurement expands on prior public-health research that has typically employed a narrow definition of social capital through a focus on the quantitative measurement of only one or two dimensions of social capital (Mitchell and Bossert 2007) (e.g., the application of the social capital concept as parental community attachment, contact with at least one employed individual, or neighbourhood perceptions of safety, as seen in Caughy, O'Campo, and Muntaner 2003; Lovell 2002; and Kawachi et al. 1999, respectively).

Conclusion

The inclusion of social capital theory is important to our understanding of the health-risk and protective behaviours of marginalized populations such as drug users. This theoretical framework facilitates an examination of social-network structural- and resource-related dynamics, such as trust, social support, and closeness, which may override individual risk knowledge and beliefs that encourage risk or which may promote protective responses. This understanding contributes to a knowledge base of how to reduce risks to health and well-being among marginalized groups. Social-network research that incorporates the social capital framework is thus a valuable tool to inform harm-reduction initiatives for injection-drug users (IDU's) and other types of drug users at risk (e.g., crack smokers) because this research has the capability to illustrate the effect of the social context of drug use on individual behaviour.

This type of research will be particularly instructive in improving the effectiveness, and subsequently, support for, peer-based harm-reduction services for drug users. These harm-reduction programs rely on social influence within drug users' networks to disseminate health-risk information that encourages the reduction and prevention of drug use-related harms. Peer workers are active drug users who are trained to educate their use-network members and other users on how to reduce risks to health within the social context of drug use (Latkin 1998; Power et al. 1995). These network-level programs have shown positive results with respect to reducing risks among IDU's (Treloar

and Abelson 2005; Lovell 2002; Kelley, Murphy, and Lune 2001; Coyle, Needle, and Normand 1998; Latkin 1998), and illustrate that network relationships can be harnessed in order to generate social capital, in the form of knowledge, information, solidarity, and norms, which is needed to reduce drug use-related harm (Treloar and Abelson 2005; Friedman et al. 1998). What is not clear from the evaluation research is how to mediate some of the negative influences that social relationships can have on the exchange of harm-reduction information in the context of drug use. For example, there is a body of research that illustrates that aspects of trust, reciprocity, and closeness in spousal or other strong social ties can contribute to risk behaviours such as drug-use equipment-sharing (Riehman et al. 2004; Bruneau et al. 2001; Neaigus et al. 1994). More research is greatly needed to discover and examine which forms of social capital are instrumental in reducing drug use-related harm, as opposed to increasing it, and which can be effectively incorporated into harm-reduction strategies such as peer-education programs.

However, what ultimately needs to occur in order to effectively reduce the harms and risks associated with injection-drug use and crack smoking, and improve the health of marginalized groups in general, is a fundamental change in the social-structural conditions negatively affecting the health of these populations (Wakefield and Poland 2005). Research must explore both structure and agency to identify how this change can be facilitated, and must isolate the broad ways in which social, psychological, economic, and political/legal factors create circumstances conducive to risk and harm, and which encourage drug users to act in a risky fashion (Lovell 2002; Bourgois 1995; Harrison 1992). This research will be an important means with which to convince policy-makers to expand social programs (e.g., harm-reduction services) that are key to building social capital among networks and communities that are affected by drug use-related risks, instead of limiting the reach of such programs.

Notes

1. Injection-drug use refers to the injection of opiates and/or cocaine into the body.

2. Network size refers to the number of individuals in a social network; network density refers to the degree to which individuals in a focal member's social network know one another; and location or centrality refers to the position of influence a focal member occupies in relation to his/her network members (Knoke and Kuklinski 1982).

3. Harm reduction is an approach to public-health policy that involves the prevention of harms related to drug use without requiring cessation of use (Centre for Addiction and Mental Health 2002). Examples of harm-reduction services include needle-exchange programs that provide injection-drug users with clean syringes and crack smokers with clean crack pipes; safer injection facilities that provide users with a safe and clean environment in which to inject their drugs; and addiction treatment programs that assist users in controlling and reducing their drug consumption, without requiring cessation of use.

4. Also referred to as frontloading or backloading, syringe-mediated drug-sharing is a risk behaviour whereby (opiate) drugs are mixed in one syringe and divided by loading another syringe into the back or front end of the main syringe and drawing the solution out. This behaviour contributes to the risk of infectious-disease transmission if the process involves used syringes.

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En Route to Participatory Health Evaluations: Local Women's Responses to AIDS in Africa and the Value of Participatory Interventions

Lauren Classen

Abstract

HIV/AIDS is hitting extremely high levels for women in sub-Saharan Africa. Prevention activities are still deemed crucial in the fight against HIV/AIDS. The primary preventative interventions have been education and services to encourage abstinence, faithfulness, and condom use (the ABC approach). This is based on an individual, rational decision-making model of risk reduction. An exploration of anthropological studies of women's own risk-reduction strategies in sub-Saharan Africa, however, shows the importance of social capital and the inadequacy of current public-health models that are more oriented toward individual decision-making. This paper advocates a "participatory philosophy" to HIV-transmission prevention initiatives, which encourages local assessment of needs, local solution development, participatory monitoring, evaluation, and assessment of project progress and impact. Doing so would not only help to achieve appropriate solutions to the local context; participatory methods themselves have been shown to build social networks and trust, both key factors in women's own HIV-prevention strategies

Introduction

The spread of HIV/AIDS in Africa continues to outstrip efforts to contain it, and is a growing concern, particularly for women, who now make up 75 per cent of the young people (15–24 years old) infected in sub-Saharan Africa (UNAIDS 2005a, 2004). Although still rare in health projects, mid-term and end-term project evaluations are gaining popularity in an effort to understand how projects can improve

their impact.[1] These evaluations, by seeking community input, have begun to heighten awareness of the complex socio-economic, socio-political, environmental, and cultural contexts in Africa that significantly influence the effectiveness of strategies for HIV/AIDS prevention (UNAIDS 2005a). Additionally, participatory tools[2] are increasingly incorporated into HIV-prevention initiatives to encourage the adoption of new risk avoidance mechanisms, as well as to improve "empowerment" and "gender equality," the public health ethos of the 21st century. However, anthropological studies on women's local responses to the disease show that women are more empowered at the outset than is often assumed by these initiatives. They also show that women use a number of locally appropriate risk avoidance mechanisms that differ significantly from those promoted by most public health interventions, despite increased attention to the socio-cultural factors affecting health and health-related decision-making. In particular, local methods tend to draw on social networks and collective action, sometimes referred to as social capital,[3] which contradict public health models that are more oriented toward individual decision-making. This gap indicates the need for heightened application of participatory approaches.

Participatory methods have generally been seen as "a fashionable and 'politically correct' frill to the more serious task of 'expert' quantitative and (more rarely) qualitative research" (Mayoux and Chambers 2005, p. 275). I argue that this is insufficient for understanding the diverse contexts of different communities and for promoting locally appropriate and, hence, sustainable prevention strategies. This paper advocates a "participatory philosophy" to project evaluation that goes beyond seeking community participation in terms of "compliance" with outsider interventions, and that encourages local assessment of needs, local solution development, participatory monitoring, and evaluation and assessment of project progress. Doing so would not only help to achieve appropriate solutions to the local context; participatory methods themselves have been shown to build social networks and trust, both key factors in local HIV-prevention strategies. Additionally, using a participatory philosophy would also help to resolve many of the challenges that render participatory initiatives rare.

The examples given in this paper span various African countries because there are still too little data on women's local responses to the disease to speak about one specific area. Being aware of the dangers of "totalizing" the African experience as homogeneous, this paper will

demonstrate the sheer diversity across African countries. It is intended that the lessons in this paper will help to reiterate this diversity and the role of participatory approaches in accommodating diverse needs and contexts.

Participatory Approaches

Policy agendas are shifting to encourage pro-poor development. The Primary Health Care (PHC) model adopted by the World Health Organization (WHO) with the Alma Ata Declaration in 1978 was a reflection of this (WHO 1978). The PHC model advocates accessible healthcare for the most vulnerable, and recognizes that good health is influenced not only by progress in biomedical technology and service delivery but also by "socio-economic conditions and individual and community choices" (Annett and Rifkin 1995, p. 1). In light of this, qualitative research methods were popularized for determining whom the most vulnerable people were, what their needs were, and what socio-economic variables influenced people's choices.

This reflects general trends in development theory, which are shifting from a positivist paradigm of top-down technology transfer to a more constructivist-based understanding of development as a social process (Douthwaite et al. 2003; Jackson and Kassam 1998). Constructivists view knowledge as actively assembled through interaction and dialogue and, thereby, having inherent social, cultural, environmental, economic, and political dimensions (Douthwaite et al. 2003; Jackson and Kassam 1998).[4] This has resulted in a proliferation of more integrated and *participatory* approaches to development. Participatory approaches attempt to break down power structures embedded in the conventional model of "development", seeking to understand local needs and develop appropriate solutions from an "insider" (local participant) perspective (Selener 1997; Chambers 1994; Uphoff, Esman, and Krishna 1998; de Koning and Martin 1996; McAllister and Vernooy 1999; McAllister 1999).

Participatory approaches are rooted in populist movements that sought new forms of "ideological hegemony" (Tan and Hardon 1998). These grew out of dissatisfaction on the part of social scientists with the concepts of 'development' and 'change,' questioning development strategies designed by the elite and mobilizing local people to challenge existing power regimes (Tan and Hardon 1998; Selener 1997; McAllister 1999; Freedman 1997). Brazilian philosopher Paulo Freire, who was committed to overturning unequal power relations in

research, introduced 'critical reflection' and 'committed co-investigation' in the 1970s, thereby playing a seminal role in the development of participatory approaches (Tan and Hardon 1998; Selener 1997; de Koning and Martin 1996). Today, the participatory philosophy is characterized by the absolution of the "clear-cut demarcation between 'researcher' and 'researched'; the conventional researcher becomes a 'facilitator' of the local research process" (Meyer 2000, p. 60).[5]

While participatory tools[6] were conventionally used for rapid assessments of rural development needs, and later, of community health needs (Chambers 1983; Annett and Rifkin 1995), they are increasingly said to be able to contribute to improving the project process (Fetterman 1994) for assessing project outcomes and impact (Mayoux and Chambers 2005) and for providing data relevant to local participants, researchers, and donors (Meyers 2000; Mayoux and Chambers 2005; McAllister and Vernooy 1999). These benefits have led to their application in a diverse range of health projects, including health-education interventions and nutrition initiatives (de Koning and Martin 1996).

A true commitment to a participatory philosophy is necessary to understand how challenges are prioritized and to develop appropriate risk-reduction mechanisms for HIV/AIDS. An examination of current HIV/AIDS risk-reduction strategies in Africa and of women's local responses to the disease captured in ethnographic and anthropological studies demonstrates a disjuncture and calls for truly collaborative approaches to be adopted in dealing with this epidemic. The challenges with participatory activities will be discussed with an eye to the difference between intermittent community participation in the project and community ownership of and involvement in every stage of the intervention process, and how this helps to overcome many of the challenges.

HIV/AIDS in Africa and Prevention of Transmission

"Urgent and sustained action is needed at all levels to increase access to HIV prevention and treatment services across Africa," Dr. Peter Piot, executive director of the Joint United Nations Programme on HIV/AIDS, announced at the 14th International Conference on AIDS (UNAIDS 2005a). Over 60 per cent of all people living with HIV globally (an estimated 25.8 million people) are in sub-Saharan Africa (UNAIDS 2005b), with an estimated 3.2 million new infections in 2005 (UNAIDS 2005b).

The concern is hitting extreme heights for women. Of those infected in sub-Saharan Africa in 2003, 57 per cent were women, and 75 per cent of young people infected were women or girls (UNAIDS 2004).[7] And these numbers are rising. Reported in the UNAIDS (2005) AIDS Epidemic Update for December 2005, in South Africa, HIV prevalence among all pregnant women has reached 29.5 per cent. The implications of this are profound. The International Food Policy Research Institute (IFPRI), in their 2005 report Looking Ahead: Long Term Prospects for Africa's Agricultural Development and Food Security, points out that women in Africa play a large role in agricultural food production. Thus, production can decline by 60 per cent in HIV-infected households, whether the woman herself is ill or is caring for the ill. Illness would interrupt the flow of food for consumption by the household and severely affect the entire family.[8]

Prevention activities are still deemed crucial in the fight against HIV/AIDS because there are numerous challenges to providing sustained antiretroviral treatment. The primary preventative interventions have been education and services to encourage abstinence, faithfulness, and condom use (the ABC approach), though new measures were encouraged by UNAIDS (2005b) in its December 2005 AIDS Epidemic Update. At the Society for Applied Anthropology meeting in Tampa in May 2007, Dr. Alexander Rödlach expanded this to the ACTB model (abstinence, condoms, testing, and be faithful). These approaches are based on the premise that the risk factors are well defined by biomedical science and prevention is simply a matter of rationally weighing the risks and making the 'right' choices about how to prevent the transmission of HIV/AIDS.

The theory is that risk perceptions, and the decisions associated with them, are made by rational actors independently weighing available options. The behaviour-change models are based on this theory — by providing information about the percentage of risk of contracting HIV, actors will make rational decisions about protective behaviour. However, over and over again, people appear to act irrationally. One theory behind this seemingly irrational behaviour is that gender equality and agency for marginalized people are required to enable individual 'rational decision-making,' in accordance with behaviour-change models. UNAIDS (2005b, p. 7) recognizes that "there is no single AIDS epidemic. Even within a country itself, epidemics can be extremely diverse. Therefore, prevention strategies need to address the diversity of epidemics." They point out that gender inequality, stigma,

and political, economic, and social marginalization are important variables influencing prevention strategies (UNAIDS 2005b). While Lock (1998) reminds us that women's agency in health decision-making is enmeshed in the social and political fabric of their lives, UNAIDS is encouraging new and innovative, but still very individualistic, preventative technologies, namely female condoms, male circumcision, microbicides, pre-exposure prophylaxis, and vaccines (UNAIDS 2005b). (I suppose this might make the acronym something like A, C, M, PPV, FC, T, B…). In a study to understand the more qualitative socio-economic and gender variables in HIV-transmission among women in sub-Saharan Africa, Greig and Koopman (2003) also found that at the individual level, condom use was positively correlated with women's negotiating power. An analysis of the variables affecting negotiating power indicated that this was highly influenced by economic independence (Greig and Koopman 2003). This led them to support the theory that "economic dependence compromises a woman's ability to negotiate safer sex" (p. 205). They recommended providing income opportunities for women to empower them to protect themselves against HIV through condom use (2003). Despite these recommendations fitting 'agency' into the behaviour-change model, they still focus specifically on the individual and are based on the same deductive risk-reduction theory, and will be largely ineffective in the fight against HIV/AIDS, as will become more evident through examination of the case studies below.

Anthropological studies indicate that even these *new* strategies (female condoms and empowerment) still largely overlook the local context and locally appropriate needs. Whereas UNAIDS determined that the 'female condom' "has not achieved its full potential in national programs because of its relatively high cost" (UNAIDS 2005, p. 16), several anthropological studies show different results. For example, a study in Malawi clearly indicates that condom use is simply unacceptable to married women and men for a number of reasons, including: a) married couples desire children and condom use can prevent pregnancy; and b) using a condom raises suspicion about infidelity (Schatz 2005). Therefore, the rejection of condoms by women in Malawi is not a question of a lack of 'empowerment' in women to ask their husbands to use a condom (even a female condom) because men are assumed to have more power than women. Men were also found to be as reluctant to raise the issue of condom use as women because in the context of marriage, this would raise concern about one's own behaviour (Schatz

2005). Heald (2006) found similar results in Botswana, where procreation is valued. She notes that due to labour migration, marriage age has been delayed, but the age at childbirth has not necessarily changed. Rather, "having children was [increasingly] seen as a step on the road to marriage: a proof of fertility" (Heald 2006, p. 34). Heald (2006) points out that "the condom message was initially developed for a population that practiced recreational and not procreat[ive] sex" (p. 34). These findings challenge Greig and Koopman's (2003) assertion that a lack of 'empowerment' prevented condom use in sub-Saharan Africa, rather than lack of appropriateness.

There is another problem with the recommendations put forth by Greig and Koopman (2003): even if gender inequality were the key factor preventing women from using condoms, the automatic assumption that economic independence is the best mechanism to empower women is problematic. In fact, in their study, Greig and Koopman (2003) included only women in the urban centre of Gaborone, while a secondary analysis indicated a "significant negative correlation between the Negotiating Power Scale and the Cultural Norms Scale . . . which suggests that those women who have greater negotiating power subscribe less to social norms of Twsana culture regarding gender roles in decision-making and sexuality" (p. 206). This means that it is unlikely that economic independence for women is culturally acceptable and that we do not know whether women, particularly rural women, desire economic independence. This would be as ridiculous as suggesting that Canadians should encourage dating among young children to inspire more long, saliva-exchanging kissing because the American Dental Association found a link between kissing and improved dental health.[9] This proposition would be considered preposterous. 'Empowerment,' though desirable for many reasons, can be as unreasonable in Africa as a blanket solution to HIV/AIDS transmission as a blanket-ABC approach.

Rather, looking at local women's responses to the disease helps to demonstrate what types of prevention interventions might be appropriate. The study by Schatz (2005) showed that despite their limited use of condoms, 75 per cent of married women in Malawi were 'very worried' about the threat of HIV/AIDS and do have effective local strategies for preventing the transmission of HIV. Some of these strategies were to: discuss the dangers of infidelity with their husbands, putting emphasis on preserving the family and the impact of HIV/AIDS on children; call on social networks to encourage their husbands' fidelity;

threaten divorce; and confront their husbands' girlfriends and discuss with them the threat that HIV poses to their family (Schatz 2005). Schoepf (1993) also found that in Zaire, the role of wife and mother provided opportunities for women to "cajole husbands into dialogue about the need for protecting parents and children" (p. 1405). As Schatz (2005) puts it, these behaviours are not consistent with the passive and disempowered notions of women as presented in the literature (also see Seidel and Vidal 1997).

Other studies on the prevention tactics among sex-trade workers reported similar findings; they indicate more complex reasons for engaging in sex-trade work than is assumed by WHO and UNAIDS empowerment strategies, and demonstrate that women have developed their own strategies to prevent the transmission of HIV. It is quite well documented by UNAIDS that women in sub-Saharan Africa are forced to engage in transactional sex, sometimes termed survival sex, to meet basic needs (Tawfik and Watkins 2007). Economic empowerment is seen to be the only reasonable solution. However, again, a study in rural Malawi found that women engage in transactional sex for a number of reasons, including money, but also for passion and revenge against unfaithful husbands. These women are not the "poor, powerless, and passionless" women that the World Health Organization and UNAIDS assume (Tawfik and Watkins 2007, p. 1090).

To prevent the transmission of HIV/AIDS, another study showed that sex-trade workers in Senegal drew heavily on their family and friend networks, threatening men with physical abuse if they refused to use a condom (Lewis-Renaud 1997). They also used tricks to prevent penile penetration by men without the men being aware (Lewis-Renaud 1997); for example, women would wear many layers of clothing to obstruct the view of men and use their thighs to simulate intercourse (Lewis-Renaud 1997). Other women also drew on local myths proclaiming that the devil would prey on naked victims to avoid oral sex (Lewis-Renaud 1997). These studies indicate women are not simply waiting for interventions to come and improve negotiation skills but are actively involved in creating and using locally appropriate mechanisms. A participatory approach to HIV prevention that incorporates these into plans for more effective strategies would be extremely valuable.

One thing that is clear from these case studies is that social capital, in the form of social networks and trust, is important to local prevention mechanisms. Social capital, according to sociologist James Coleman (in

Fukuyama 2002, p. 1), refers to "people's ability to work together in groups." Pretty and Ward (2001, p. 211) regard social capital as having four central aspects: a) relations of trust; b) reciprocity and exchanges; c) common rules, norms, and sanctions; and d) connectedness, networks, and groups. However, there is considerable debate on the best way to measure social capital, as is evident in the examples below.

Increasingly, social capital is seen to be an important variable in health outcomes. Boneham and Sixsmith (2006), in a qualitative study of elders in Britain, found that women associated a "culture of care" and social networks with an overall sense of well-being. Specifically, looking at nutrition, a recent study by De Silva and Harpham (2007) found a significant positive relationship between feelings of trust, reciprocity, and social harmony among mothers in Peru, Ethiopia, Vietnam, and India, and the nutrition of their children.

Additionally, studies are beginning to show a direct relationship between specific types of social capital and the prevention of HIV/AIDS. Campbell et al. (2002) found an association between membership in sports clubs and a lower prevalence of HIV infection among young men and women aged 15 to 24. Stoneburner and Low-Beer (2004) also report that the decline in population-level HIV in Uganda is strongly associated with social networks. "[P]ersonal channels predominated in communicating about AIDS" (Stoneburner and Low-Beer 2004, p. 716). These networks increased the chance that individuals had personal knowledge of someone with AIDS, which was associated with safer behaviour. Stoneburner and Low-Beer (2004, p. 716) call for a "better understanding of social elements that triggered the Ugandan response."

Not only does a participatory approach help to identify and strengthen these "social elements" of local responses to HIV, but social capital is also a direct outcome of engaging local people in the process of identifying needs and appropriate solutions. Probst (2002) and Guijt (1998) both found that participatory approaches play an important role in fostering a local sense of ownership over the participatory process, as well as promoting social cohesion, problem recognition, and group problem-solving skills. Participatory activities should be incorporated throughout the project to have this effect.

One of the main challenges to understanding the interaction between social capital and HIV-prevention strategies is the vagueness surrounding the concept. Critics argue that practitioners have turned

a blind eye to the complexities inherent in measuring social capital. They point out that there are often trade-offs for poor people engaging in collective action. Additionally, there is a dark side to social capital, whereby participation in community organization can serve to reproduce rather than challenge social inequalities (see Woolcock and Narayan 2000 and Cleaver 2005 for a comprehensive review). Portes (1998, in Whittaker and Banwell 2002) argues that "the point is approaching at which social capital comes to be applied to so many events and in so many different contexts as to lose distinct meaning."

Furthermore, although participatory approaches have been shown to increase collective action and social solidarity in some cases, there are many different approaches to participation. Also, there has not been a strong emphasis on the operationalization of participatory approaches, particularly with respect to developing positive forms of social capital in the literature (Oakley, Pratt and Clayton 1998; Mansuri and Rao 2004). Practitioners call for further qualitative research on social capital (Whittaker and Banwell 2002) and on the interaction between participation and social capital (Mansuri and Rao 2004).

The vagueness of 'participation' is an additional challenge.[10] Some feel that 'participation' has been reduced to mere rhetoric, "a way of talking about, not doing things" (Mosse 2001, p. 32; also see similar discussions in Cornwall et al. 1994; Rocheleau 1994). Rocheleau (1994, p. 4) argues that participatory development has succeeded only in "foster[ing] a kinder, gentler image of development-as-usual, which has been somewhat less than kind and gentle with many of the world's people over the past thirty years."

Participatory research is also sometimes accused of being 'unscientific,' and the results thought to be value-laden and more susceptible to biases than quantitative, survey research (Meyer 2000). As Cornwall et al. (1994) put it:

> [Participatory] methodologies provide means to produce knowledge, not discover it. . . knowledge is not something that can be revealed — it is produced through the interactions of people in particular situations. People actively interpret, rather than just describe, the outcomes of these interactions within their own frames of reference and according to their own assumptions and priorities (1994, p. 40).

Steckler and Linnan (2002) point out the challenge of proving validity, reliability, and generalizability of qualitative and participatory research. Much of the data gathered in participatory evaluations are

social and intangible in nature, resulting from a complex process of development, making it very difficult to validate a causal relationship between the participatory project process and the outcomes found in an evaluation (McAllister and Vernooy 1999). Because it tends to deal with small numbers of respondents, participatory research also suffers from the "stigma of the small n" (Mays and Pope 2000, p. 96), and the data gathered can be cumbersome and daunting.

Participatory methods, per se, cannot guarantee that power is shared equally. In fact, Tan and Hardon (1998, p. 3) argue that although power can be shared, it would be "sophistry" to claim that researcher and researched are equal. Mosse (1994) further points to the fact that farmers have sometimes taken 'local knowledge,' as it is condensed and authorized by the researchers and project staff, and manipulated it to serve their own interests in the project-planning stage or in other political or development arenas. Local knowledge and perspectives can, therefore, change significantly when packaged and authorized by researchers and then again when reinterpreted and put to use by the local community, and are susceptible to manipulation by local power inequalities. Open feedback to participants can also be very threatening:

> Democratic practice is not always a feature of healthcare settings. Care needs to be taken in undertaking democratic action research in such settings. An action researcher needs to be able to work across traditional boundaries (for example, between professionals, health and social care, and between hospitals and community care) and juggle different, sometimes competing, agendas (Meyer 2000, p. 62).

Participatory tools, therefore, rely heavily on researchers' and project staff's facilitation skills and require a high level of trust between the researcher and the researched (Mosse 1994; Meyers 2000; Annett and Rifkin 1995; de Koning and Martin 1996; Guijt 1998).

Incorporating the participatory approach as a philosophy, rather than a singular event or 'add-on,' makes it much less susceptible to these challenges. Engaging stakeholders in discussing and analyzing their research provides research triangulation, cross-checking the validity of the results (Mays and Pope 2000). Particular attention to capturing the needs and conditions of the most marginalized, in any context, and engaging them in reflection on these needs and appropriate solutions, also helps to ensure the generalizability of results. Furthermore, the added confidence and improved relationships of trust between researchers and participants gained during the participatory process

also help to ensure generalizability, reliability, and validity. Mayoux and Chambers (2005) found that since the early 1990s,

> …experiences of quantification using participatory methods have repeatedly shown how, when used well, participatory methods generate not only qualitative insights and but also quantitative data which are generally more accurate than those from conventional survey approaches and methods (p. 272).

They go on to show that:

> participatory methods can also be cost-effective by providing a better basis for targeting and by focusing more expensive forms of quantitative and qualitative investigation on issues and situations which need further investigation. . . Challenges for participatory approaches are not so much assuring rigour and reliability as ensuring that their mainstream use achieves their potential for enabling very poor women and men to have an equal voice in priorities and policies for pro-poor development (p. 272).

"It is participatory methods which should form the linking thread, involving not only rigorous use and statistical analysis of participatory tools, but also a participatory and pro-poor ethics underlining the whole assessment process" (p. 277). Mayoux and Chambers call for a "reversed paradigm" in which participatory approaches are mainstream, and more expensive quantitative surveys are saved for when they are really needed (2005).

Conclusion

HIV-prevention strategies increasingly recognize the complex sociocultural dimensions of the disease. Qualitative studies are becoming more popular in prevention initiatives. However, local input in these studies is still insufficient in influencing recommendations, which are most often based on the rhetoric of women's 'empowerment' and are still largely irrelevant to local needs. Anthropological studies show that local responses are very different from those promoted, even by recent public-health interventions that incorporate qualitative studies. The examples presented above show the importance of social capital and the present inadequacy of public-health models that are more oriented toward the individual decision-maker. This calls for more integrated approaches to understanding not only context diversity but also local risk-reduction mechanisms and, in particular, the relationship between participation, social capital, and HIV prevention. Initiatives that engage local people in every stage of the research

process are showing potential to highlight the nature of these interactions and to help build positive forms of social capital. The rareness of participatory initiatives reflects, in part, the challenges of ensuring representative, reliable, and quantifiable data from participatory activities and of turning local constructs of health into those appropriate for researchers and donors. However, evidence is mounting that a participatory philosophy that encourages local ownership over the research process can help both to validate the results and to improve communication between researchers and donors. The problem of HIV/AIDS in Africa is paramount and prevention still holds the most potential for slowing the spread of the disease. However, initiatives must incorporate participatory activities into every stage of the research process, from needs assessment to solution development and project evaluation, if there is any hope at effecting sustainable change in behaviour in order to prevent the spread of HIV.

Notes

1. There is considerable information on the value of project evaluations and assessments in health projects, and evidence that evaluations, participatory or not, remain rare in health-related research and interventions (Levinson et al. 1999). Levinson et al. (1999) refer to a study by the World Bank (Musgrove 1991, in Levinson et al. 1999) that found only 10 out of 97 feeding programs in Latin America had included an evaluation, and of these, only 3 had used "accepted evaluation procedures" (p. 159). Also see Patton (1997) and Hulme (2000) for a discussion of the different levels of evaluation and benefits to their application.

2. Also see Biggs and Farrington (1991),Tolley and Bentley (1996), and McAllister (1999) for various other approaches to differentiating participatory research.

3. 'Social capital,' referring to the benefits of relationships, or socializing with influential people, is often associated with Bourdieu (1986), but it became a mainstay in participatory development frameworks primarily as a result of Putnam's work (Putnam 1993, 1995). For Putnam, social capital is associated with participation in community organizations and encompasses features of social organization, including norms, trust, networks, and reciprocity.

4. De Koning and Martin (1996, p. 1) also note that "many factors, cultural, historical, socio-economic, and political, which are difficult to measure, have a crucial influence on the outcomes of interventions and efforts to improve the health of people," and prize participatory approaches for informing projects of these diverse contextual factors.

5. Participatory approaches first took popular hold in the field of development in association with *rural* development initiatives, largely owed to the work of Robert Chambers through the Institute of Development Studies in Sussex, England (Annett and Rifkin 1995). He developed the planning tool, 'rapid rural appraisal' (sometimes called 'rapid participatory appraisal'), intended as a fast and inexpensive way of assessing local needs and capturing the needs of the most vulnerable, who lived off the beaten track and were

often neglected by planners who preferred to stick to the paved roads (Annett and Rifkin 1995; Chambers 1989). Today, the value of local-stakeholder involvement in the planning, implementation, and assessment of *health* projects is also well documented. Participatory approaches are said to provide a way of overcoming the "theory-practice gap in clinic practice in which practitioners have to rely on their intuition and experience since traditional scientific knowledge, for example, the results of randomized controlled trials, frequently does not appear to fit the uniqueness of their situation" (Meyer 2000, p. 62). Similarly, de Koning and Martin (1996) note that participatory methods fill the gap between the biomedical interpretations of health and local constructs of health, improving communication between health workers and the community (also see Meyer 2000). Furthermore, stakeholder participation has been shown to foster in marginalized people "self-confidence," "pride," and "empowerment," and helps to incorporate local knowledge into the project processes, appropriating the project process to the local context and improving overall project impact (de Koning and Martin 1996, p. 4; Fetterman 1994). Fetterman (1994) refers to participatory evaluation as 'empowerment' evaluation. These benefits closely resemble those in the literature on rural development and stakeholder participation. (See Probst 2002; Guijt 1998; Hulme 2000; Davis-Case 1990; Oakley et al. 1998; McAllister and Vernooy 1999).

6. The methodological tools associated with the participatory approach focus on both group and individual activities designed to elicit knowledge and to empower and enable marginal groups and illiterate community members to share their opinions. Some of the most popular tools are: Group Discussions; Historical Mapping; Ranking, Rating, and Sorting; and Community Mapping. In order to be effective, the participatory approaches encourage a creative selection and application of each of these tools in a manner appropriate to the specific contexts (Rocheleau 1994; Cornwall et al. 1994).

7. Similarly, practitioners show that in southern Africa women comprise 55–60% of people with AIDS. (Lee 2004; Stein and Susser 2000).

8. There is some light at the end of the tunnel; data from Uganda indicates that the incidence of HIV-infection has declined over the past 10 years, usually attributed to changes in behaviour. However, UNAIDS (2005b) warns that this should be read with caution because in some areas of Uganda, such declines have been uneven and are not proving to be sustainable. The report advocates more research and revitalized prevention strategies in Uganda to try to sustain declines.

9. The American Dental Association has made the link between saliva and prevention of tooth decay. They have also shown that kissing increases the flow of saliva and, therefore, helps prevent tooth decay. http://www.ada.org/index.asp.

10. The broad span of activities and philosophies that 'participatory' encompasses today has led to much contestation over the term. 'Participatory' has become a catch-phrase for numerous activities and levels of local involvement in rural and health-related research and development processes. Some practitioners conceptualize the different forms of participatory in relation to the stage at which local participation is elicited. For instance, the most common participatory activities can be divided into needs assessments (Annett and Rifkin 1995), monitoring, evaluation (McAllister and Vernooy 1999), and impact assessments (Mayoux and Chambers 2005). It is also common to categorize participatory activities on a scale of local involvement in the project process. Cornwall (1996) identifies six levels of participation: co-option, compliance, consultation, cooperation, co-learning, and collective action.

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Underground Fieldwork with Kidney Sellers: Issues of Access and Methods

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Abstract

Underground fieldwork is quite challenging, especially when the research populations are involved in illegal activities. The issues of access and methods are particularly complicated in conducting underground fieldwork. This paper outlines how I gained access to a hidden population, particularly to 33 kidney sellers. It also explores how I employed a novel but effective and ethical methodology on organ commodification. By briefly outlining the current fieldworks on hidden populations, this paper not only contextualizes but also proposes to expand methodological approaches to underground fieldwork

> I did not tell the story to anybody, not even to my wife. How could I? Selling a kidney is the most humiliating thing a person can do. You are the only person whom I trusted. It took enormous courage to come and talk with you. I was worried, however very relieved after sharing it with you. (A kidney seller, following the interview)

Introduction

I faced tremendous difficulties in gaining access to people involved in organ commodification in Bangladesh. Very few participants wanted to disclose their identities and share their stories, largely because organ trade is illegal there, as it is in almost every other country in the world. The sellers' experiences were so humiliating that most of them did not disclose their actions to family members, not even to spouses or parents. Yet I was able to interview 33 sellers who had already each sold one of their kidneys. I also collected data from recipients, brokers, and health personnel to examine their experiences of the trade. By briefly outlining the current fieldworks with "hidden populations," I explore how I formulated my underground fieldwork, particularly access to the kidney sellers, and the employed methodology. Relevant issues such as risks, payments, and insider/outsider viewpoints are

also discussed. This detailed sketch of my methodology is significant in order to compare, formulate, and expand approaches to underground fieldwork.

Underground Fieldwork with Hidden Populations

"Hidden populations" are defined as groups of people who reside outside of mainstream society and who are often involved in clandestine activities (Watters and Biernacki, quoted in Singer 1999, p. 125). Their activities frequently go unrecorded and remain concealed due to illegality. It is, therefore, challenging to contact and conduct research with these populations. Despite these difficulties, underground fieldworks have been carried out on these populations because they reveal a deeper understanding of practices among invisible groups. Numerous studies on drug users, commercial sex workers, homosexuals, illegal migrants, and AIDS populations indicate various avenues for gaining access to and collecting data from underground fieldwork.

One of these classic underground fieldworks was carried out by ethnographer Laud Humphreys. Humphreys hung out in a public washroom where men would engage in sex with other men. He recorded their licence plate numbers and then obtained their home addresses from the Department of Motor Vehicles (1970). Similarly, Ralph Bolton participated in casual sex with gay men in order to study their private sexual practices in bars, saunas, restaurants, parks, tearooms, streets, and private rooms in Brussels (1992). Likewise, William Whyte established a rapport with Doc, a street-gang leader and key informant. Through this connection, Whyte was able to carry out interviews with impoverished inner-city Italian immigrants and their children, who were resistant to examination by outsiders (1955; Singer 1999). Also, Phillippe Bourgois gained access to a "hidden population" through addicts, thieves, and drug dealers to examine the selling of crack in New York City's Spanish Harlem (1995). Despite some ethical complexities and questions, these studies reveal possibilities for accessing concealed information about different enclaves of underground societies.

Underground fieldwork on "hidden populations" expanded in the 1990s as the spread of HIV/AIDS became an ethnographic focus. Much research was carried out on sexual practices and drug addictions. Underground fieldwork during this era also tended to focus on criminal activities such as trafficking of human bodies for the commercial sex industry and illegal migration. The expansion of this research

helped to provide diverse methodological directions for conducting underground fieldwork.

From the mid-1990s, a growing number of studies on organ commodification provides an opportunity to add new methodological insights and approaches to underground fieldwork. However, with the exceptions of Nancy Scheper-Hughes and Lawrence Cohen, researchers did not provide detailed elaborations on their methodologies. Scheper-Hughes (2004) addresses how she investigated covert and criminal behaviour and conducted 'undercover' research in numerous sites — from the impoverished shantytowns of the Third World to the privileged and technologically sophisticated medical centres of the First World. Her research team included graduate students, field assistants, human rights workers, documentary filmmakers, private detectives, political journalists, and "fixers," a class of paid research 'intermediaries' long used by documentary journalists. Her primary fieldwork method was open-ended key-informant interviews (often with the aid of local research assistants), followed by structured questionnaires (Scheper-Hughes 2004, p. 32–33, 64–65 and 67–68). The essential methodology of Scheper-Hughes's ethnography was "to follow the bodies," what George Marcus formerly described as "follow the things" (Scheper-Hughes 2004, p. 32; Marcus 1995, p. 107). In a critique of this approach, Andrew Walsh noted that following things leads followers away from the unique perspectives of the locals who experience things removed from them (2004, p. 226). How can we understand detailed local meanings of bodies when we are presented with fleeting glimpses of a vast number of research settings? Although Scheper-Hughes's research gives an overview of the organ trade globally, it does not delve deeply into how localized practices are played out in particular cultural contexts. For this reason, I do not follow her methods of a large-scale multi-sited ethnography but choose to focus on in-depth interviews with 33 kidney sellers.

There are some additional methodological concerns with Scheper-Hughes's research. She approached organ brokers as a potential kidney buyer, which raises an ethical question: Can researchers conceal their identities and introduce themselves as potential end-users to conduct underground fieldwork? Moreover, she collected data from organ brokers and other intermediaries via phone conversations using a pseudonym, but left unclear how informed consent was attained and ethics protocol was approved. Furthermore, she did not outline the detailed methodology employed by her research assistants, or address issues

such as the limitation of her distance fieldwork methods, the collaboration on the wide range of data, and the transactions, such as those between "fixers" and herself. Additionally, she delayed outlining her methodology until 2004, roughly ten years after her initial writings on organ commodification (Scheper-Hughes 1991, 1992, 1996a, 1996b, 1997, 1998, 2000, 2002a, 2002b, 2003 and 2004). By this time, I was already in the field and was, therefore, unable to assess her detailed methodology for organ commodification and consider them in relation to my own research.

Lawrence Cohen also provided a brief outline of the methodology he employed in the slum of Chennai in India (1999, p. 130–137 and 2002, p. 9). He briefly introduced and described interview subjects, kidney sellers, and his research assistant, as well as translator Felix Coutinho (formerly an organ broker but currently a social worker). However, Cohen did not outline why the kidney sellers contacted him and unfolded their stories or why Coutinho, the key informant, decided to support the research. He also did not address how the sellers contacted the patients or how their trade agreements were conducted. Nevertheless, both Scheper-Hughes and Cohen set out the most influential underground fieldwork methodology of organ commodification to date.

Outside of anthropology, medical doctor Madhav Goyal and three others conducted a survey among 305 kidney sellers in Chennai, India (2002, p. 1589–1593). They relied primarily on newspaper articles and transplant professionals to identify neighbourhoods where kidney sellers primarily resided in Chennai. Eight research assistants identified kidney sellers by going door to door in these neighbourhoods. They conducted snowball sampling and recorded each face-to-face interview on a questionnaire. However, they did not delineate how the research assistants approached kidney sellers, why they conducted interviews for only 20 minutes, what particular difficulties they experienced while collecting data, or why they verified the nephrectomy scars. In other words, their methodology was not explained in detail. Even if it had been, their door-knocking approach to finding kidney sellers would not have been useful for my research because Bangladeshi sellers reside in every part of the country and would not disclose their activities in this way.

The opaqueness of these methodologies suggests that conducting underground fieldwork, especially on criminal activities such as organ

commodification, is extremely questionable methodologically and ethically. How could the researcher gain access to "hidden populations" through a key informant, who is engaged in criminal activities and exploiting them? Can we only employ participant observation and depend mostly on interview techniques in underground fieldwork? What are the risks involved in conducting this fieldwork? How could we provide financial incentives for arranging and conducting interviews with "hidden populations"? How can we uphold informed consent and guarantee anonymity, since the research populations are vulnerable and engage in criminal activities?

Since there was no particular direction to follow, I could not formulate a methodological approach to organ commodification before going into the field. Based on previous fieldtrips to Bangladesh (preliminary fieldwork in August 2003 and distance fieldwork from December 2001 to March 2002), I realized it would be extremely difficult to locate research subjects, particularly kidney sellers. Yet I managed to gain access to 33 kidney sellers and create a novel but effective approach to underground fieldwork. The following section outlines a fascinating and detailed account of contacting "hidden populations" and the methods I used to conduct underground fieldwork on organ commodification.

Access to Kidney Sellers

Locating kidney sellers was the most arduous task in undertaking this research. In the first three months of a year-long fieldwork, all of my initial attempts were in vain. The turning point of my research came when I met a buyer, and through his arrangements, I was able to interview his kidney seller. Following this, I did not find any other sellers for some time. After trying all feasible means of locating sellers, I finally employed a broker as a key informant and a seller as a research assistant. Their help aided me in contacting and interviewing a total of 33 kidney sellers.

Going Nowhere

At the beginning of the fieldwork, I asked various Bangladeshi professionals for advice on locating kidney sellers. Suggestions included: i) contacting doctors and recipients in hospitals; ii) searching Bangladeshi newspapers for kidney advertisers; iii) locating potential kidney sellers whose stories are exposed in popular media; iv) meeting journalists and lawyers who investigate medical crime; and v)

finding slum dwellers and drug addicts who might serve as kidney sellers. In the following, I outline why I could not locate any kidney sellers via these approaches.

First, I attempted to uncover kidney sellers through health personnel involved in major kidney transplant centres in Bangladesh. In order to make contacts with medical specialists, I attended a conference on "The End State Renal Disease: A Global Issue," on October 9, 2004 in Dhaka. This gave me the opportunity to observe how Bangladeshi medical specialists approach issues of organ commodification. Local nephrologists and urologists used this venue to point out how the lack of infrastructure hinders the establishment of a successful kidney transplant program in the country. They claimed that kidney transplants from unrelated sellers are performed in other countries, but not in Bangladesh.

Through connections made at the conference, I was able to meet with the head of the Department of Nephrology, Bangabandhu Sheikh Mujib Medical University Hospital (BSMMUH), the major kidney transplant centre in Bangladesh, the following week. When I asked him if he could put me in contact with kidney sellers, he provided me with a copy of the Organ Transplant Act and stated that trading kidneys is "strictly illegal" and not performed in Bangladesh. At the end of the meeting, I asked for permission to conduct interviews at the hospital; he asked for a formal application outlining my research questions, methods of data collection, and institutional affiliation.

After several bureaucratic encounters, I finally obtained permission to conduct research at BSMMUH. The verbal consent did not give me access to kidney specialists, including nephrologists, urologists, or post-graduate trainees at BSMMUH. In most cases, their lack of availability could be attributed to their apparent busy schedules and to their aloofness. During brief discussions, they denied the existence of illegal organ transplant in Bangladesh. Surprisingly, I then noticed two advertisements (one on a wall next to the elevator and the other on the doctors' reading-room door) posted for selling kidneys at the Department of Nephrology and Urology at BSMMUH.[1] The kidney specialists declared that advertisements for selling kidneys are frequent in Bangladesh but all unrelated (and, therefore, illegal) transplants are performed outside of the country. A nephrologist told me that many of his patients were kidney recipients who have purchased kidneys from other Bangladeshis, had their surgeries in India, and

then returned to Bangladesh for post-operative care. I asked him if he could put me in touch with these recipients, but no meetings ever materialized as a result. Bangladeshi health professionals were reluctant to disclose the illegal kidney trade because many of them are beneficiaries of this trade.

With a fellow Bangladeshi anthropologist, I also visited the only private dialysis centre in Dhaka. He was acquainted with several employees there because his father-in-law had had kidney failure. We tried to locate a clerk who had previously offered to arrange the purchase of a kidney from a poor villager. Neither the clerk in question, nor any further information regarding this matter, was found at the dialysis centre. People were generally not enthusiastic to discuss organ commodification with an outsider researcher in healthcare settings, due to the illegality of the practice in Bangladesh.

Additionally, I directly approached the recipients of kidney transplants in further attempts to locate kidney sellers. I interviewed a few recipients currently admitted to BSMMUH for treatment of post-operative transplant complications. These recipients underscored the transplant experiences by pointing out inadequate organ establishments, poor healthcare services, high costs of dialysis and transplantation, and post-operative complexities. When asked where the donated kidney came from, recipients claimed to have obtained kidneys from family members, yet avoided disclosing the donors' identities. One particular recipient, after I gained his trust, disclosed that he had purchased a kidney from an undergraduate student enrolled in a college close to Dhaka. Although the recipient agreed to introduce me to the seller during their next meeting, he never called me back. I later visited the college but could not identify the seller because I had too little information about this large institution and was concerned about revealing his actions to authorities.

I also contacted kidney patients who were in the process of arranging transplantation. These potential recipients claimed that they were only considering related donors. One patient and her donor seemed unrelated but they both claimed to be family members. The patient enthusiastically produced official certificates verifying their relationship. I also approached family members of kidney recipients and of those needing kidney transplants. Most often, they revealed the donors' identities only vaguely. A father of a kidney recipient mentioned that during his son's transplant at BSMMUH, he met another

recipient who had purchased the kidney from a seller. I phoned the recipient in question after obtaining his contact number from his father.[2] The recipient did not want to disclose the kidney seller's identity to an unknown researcher, and then claimed to have obtained the kidney from a family member. Furthermore, he declared that he was no longer in touch with the donor and refused my request to meet with him. All of my efforts at contacting kidney sellers via health personnel and recipients had failed.

Second, in order to locate kidney sellers, I searched advertisements regularly posted in major Bengali newspapers.[3] As I had previously experienced in hospital settings, recipients were not keen to connect me with their donors/sellers; therefore, I only focused on the few advertisements from potential sellers.[4] I initially attempted to contact potential sellers over the phone because they resided throughout Bangladesh. Only six telephone numbers were in service and I did not successfully communicate with any of the sellers.[5] In one instance, a schoolteacher explained that his neighbour, a 29-year-old female village dweller who was in debt, had used his phone number for the newspaper posting on the sale of her kidney. He said that she had received phone calls from three potential buyers. Two of them had enquired about her blood group, which did not match with theirs; the other buyer did not call her back even though she borrowed money and went to Dhaka for tissue typing. In another instance, the sister of the advertiser picked up the phone and indicated that her brother had strangely not been in touch with the family for the last two months. She worriedly asked how I obtained his phone number. I did not want to mention the advertisement, so I abruptly disconnected the phone. In a third attempt, a person picked up the phone and mentioned that he had purchased his phone from a second-hand store. In a fourth effort, the person did not answer or return my numerous phone calls. Lastly, two others declared that they were unfamiliar with the persons I was trying to contact. I was unable to contact any potential sellers by phone.

I also attempted to locate potential sellers through the addresses some sellers provided in their ads. Unfortunately, I could not locate any of them since most of the addresses were not valid.[6] Some sellers used their friends' addresses, but their friends refused to put me in touch with the sellers because I was a researcher and not a potential buyer. I did not attempt to locate advertisers who used post office box numbers because I could not obtain their information from newspaper offices.

Third, I collected newspaper coverage of potential kidney sellers whose stories were sensational and widely publicized. I thought these stories might lead to kidney-selling networks in Bangladesh. The newspaper coverage showed interview locations, reasons for selling, and a brief context of commodification. As a result, in an eastern town close to Dhaka called Comilla, my research assistant contacted Minu Begum, a potential kidney seller whose story was widely covered in the daily newspaper *Prothom Alo* in August 2003. Minu became informally aware of the kidney-selling trade through one of her village neighbours and decided to post a newspaper ad because of her debts. She was not familiar with any particular brokers, sellers, or buyers who were currently involved in organ trade. I decided not to contact any of these potential sellers because they often do not sell their kidneys; rather, they receive donations from government officials after a wide circulation of newspaper coverage.

Fourth, I contacted journalists and lawyers who specialized in medical crime. I visited newspaper offices, talked to medical reporters, and searched library resources. This process did not prove successful in obtaining any useful information for locating kidney sellers. I also communicated with a lawyer who was conducting research on child-trafficking for a non-governmental organization. He referred to newspaper coverage that reported that Bangladeshi children were being smuggled to other countries for prostitution, camel jockeying, and organ harvesting (Khayer and Badal 2004). The lawyer could not validate his claim and the newspaper coverage seemed sensationalistic. Another lawyer was also solicited for information on locating kidney sellers. When I mentioned that a Bangladeshi court had tried to penalize an alleged gang for trafficking organs, he advised me to visit the court record room for archival research. Researching court records proved to be extremely time-consuming because records are seldom organized in Bangladesh. Regardless, I went once to the Dhaka magistrate's court and a record-room clerk there informed me that no cases had been filed related to the organ trade. Going through court records case-by-case would not have been a good use of my limited time.

Lastly, I chose not to contact slum dwellers and drug addicts, who may have been likely to be involved in selling kidneys. I realized that finding kidney sellers within this very broad group would be difficult and time-consuming. In conclusion, it was very frustrating not being able to locate a kidney seller in three months, despite these varied attempts.

The Turning Point

The turning point of my fieldwork came when a fellow anthropologist introduced me to Khairul Islam Chowdhury, a transplant recipient. Khairul had purchased a kidney from Montu Miah, a 32-year-old slum dweller who had sold his kidney in order to pay high business debts.[7] The operation was successfully performed in a renowned and expensive hospital in India in January 2004. After the operation, Khairul flew to Australia in order to obtain better healthcare and Montu travelled back to Dhaka to pay off his debt.

In the faculty lounge of Dhaka University, Khairul agreed to facilitate my research, largely because he appreciated the topic. For over three hours, he discussed the inadequacies of the kidney-transplant infrastructure and the poor provision of healthcare services in Bangladesh. He also described his transplant experience in India. At Khairul's request, we met again in a coffee shop the following week. In the seven hours that followed, he described the details of his pre-operative, operative, and post-operative experience. Khairul described how he began his search for a kidney by posting advertisements in three national Bengali newspapers. As a result, he was connected with approximately 90 potential sellers. Based on blood group and initial conversation, he selected about 30 sellers for tissue-typing examination. Of them, only six were selected based on their matching tissues. Because tissue typing is not always accurate in Bangladesh, Khairul, along with these six potential sellers, went to Calcutta, India to reexamine and verify the tissue-typing results again.[8] Khairul finally selected Montu Miah because their tissues matched well and he had demanded less for the exchange than the other sellers had.[9] I was finally able to explore a case in which kidneys were commodified in Bangladesh. For the first time, from this encounter, I was also going to gain access to a kidney seller because Khairul had agreed to connect me with Montu.

Arranging to meet with Montu was easy; Khairul had already informed him about my research. Montu wanted to discuss the issue in a concealed setting so we chose to carry out the interview at my apartment in Dhaka. In a conversation lasting over eight hours, Montu unfolded his experiences of selling his kidney. He underscored that finding a buyer is the most difficult job for a kidney seller because the tissues seldom matched. Montu sought a buyer for eight months, competed with other sellers, and finally managed to sell his kidney to Khairul.

He received $2,000 CDN for the kidney, plus three months' living expenses of $90 per month.[10] Almost all of his money was spent paying off his debt, which he had accumulated due to high and cumulative interest rates. He also managed to purchase a television and some clothing for his family. Montu was very fortunate that Khairul had kept his promise to arrange a clerical job for him at a medical college with a salary of $60 per month. However, he was eventually fired, and became a vendor earning as little as $25 per month. Nonetheless, compared to other sellers, Montu was very fortunate because Khairul kept his promises. Montu is now living without debt, but with only one kidney.

I tried to locate other sellers by applying the snowball-sampling method through Montu, but this did not prove to be productive. The sellers usually tried to conceal their true identities. In addition, their buyers often discouraged them from discussing their transactions in order to avoid ending up in jail. However, Montu did advise me to ask Khairul for addresses he might have had of other sellers who contacted him through the newspaper advertisements. Unfortunately, Khairul stated that he no longer retained the addresses of those potential sellers and that many sellers did not disclose their addresses. He also mentioned that the sellers did not have a telephone, so they used pay phones to contact him. Since I was desperate to find additional informants, Khairul insisted that I contact kidney brokers in order to locate kidney sellers. He provided the telephone number of Dalal Islam, a 34-year-old kidney broker from whom he had received three prospective sellers before his transplantation.

A New Tack

Contacting sellers through a broker could be ethically problematic and raised numerous questions. Can Dalal be a key informant when he is involved in illegal activities and potentially exploiting others? To what extent can he be involved in this research? Yet I had unsuccessfully examined all other possible ways of finding kidney sellers and was even considering changing the focus of my research. My research seemed only possible if I employed a broker as a key informant, as Whyte had done, to some extent, in his research. In the end, I decided to contact Dalal Islam.

Over the phone, I informed Dalal that I was a Bangladeshi citizen currently residing in Canada. When Dalal asked how I obtained his phone number, I referred to his client, kidney recipient Khairul. Initially, I

did not mention my study to Dalal, as my previous research had taught me that he might not be interested in discussing his business with a researcher. Instead, I mentioned that I wanted to meet in person to discuss kidneys in general. Dalal asked for my address and indicated that he would visit my apartment if he were in the neighbourhood. Eventually, one late morning, Dalal called me. Our conversation that morning was the major turning point of my research.

Both my insider and outsider perspectives played a significant role in dealing with Dalal. My identity as halify (half Bangladeshi and half Canadian) and my wife's distinctiveness as bedeshi (foreigner) played an essential role in gaining his trust.[11] My familiarity with local culture aided in determining my initial approach, and my fluency in Bengali provided an easy medium for sharing our thoughts without confusion. My wife's foreignness reassured Dalal that I was not an undercover policeman or journalist but a harmless researcher. Because my parents and Dalal were from the same part of Bangladesh, our regional affiliation may have been an important connection in ensuring his trust. My family's and friends' reputations, as well as my profession as a university lecturer in Bangladesh, could have influenced his support of the research. During our first conversation, I informed Dalal of my research and its progress since its initiation. At the end of our short meeting, Dalal admitted that he would be able to contact numerous kidney sellers but chose to think over the entire issue before notifying me of his decision.

Dalal eventually contacted me and agreed to facilitate the research. Exploring why Dalal chose to facilitate this research is a relevant question. It may have been that he considered his broker business secure because his clients included police officers, lawyers, and doctors, people who could resolve potential legal troubles should they arise. He may have also thought that this research would help to expand his business outside of Bangladesh (he persistently insisted I use his photo and name in publications). Dalal assumed that he would receive lofty monetary benefits even though I paid only for transportation and communication costs (on average $7) to locate kidney sellers. Nevertheless, it was a constant negotiation with Dalal: he would contact sellers in Dhaka but fabricate stories about their origins in order to overdraw the transportation costs. Dalal may have also facilitated my research in an attempt to help poor organ sellers whom he exploited.

Dalal's entry into the kidney trade began as a potential seller after he lost his job in the mid-1990s. After enduring economic hardship, he collected newspaper advertisements of kidney buyers. After several attempts, his tissues matched with a potential recipient's and he went to India for transplantation. He returned to Bangladesh, however, without selling his kidney because the potential recipient did not want to pay him in advance. During nearly a month of residing in a renowned hospital in southern India, Dalal met other Bangladeshis congregated in the hospital for kidney transplantations. Before departing, Dalal realized that if he could collect tissue-typing reports from kidney sellers as a business, it would be "handy for everybody," as he expressed it. Dalal approached Bangladeshi organ recipients in the hospital and proposed his idea. Five months after commencing his business, Dalal was able to match the tissues of his first clients, and their operations were successfully performed in India. Dalal mentioned that he received $200 CDN from the recipient and did not ask for any money from the seller, which is the typical "business policy" he continued to follow. At the time of the interview, Dalal claimed to have collected more than 500 tissue-typing reports from both recipients and sellers, and to have arranged 97 kidney transplantations that were performed in Bangladesh, India, Pakistan, Singapore, and Thailand.

At the end of the interview, Dalal and I outlined three possible approaches to locating kidney sellers: first, making phone calls to the sellers who were still linked with Dalal; second, seeking the sellers whose permanent addresses are accessible to Dalal; and, finally, contacting Dalal's recipients who are currently connected with their sellers. We decided that Dalal should approach them because they might not disclose their activities to an unknown researcher, as I had experienced before.

Dalal immediately made arrangements for me to meet Shahidul, a 30-year-old kidney seller who resided in Natore, a northwestern town in Bangladesh. Shahidul had sold his kidney to a Bangladeshi-born American citizen residing in New York. Their operations were performed in southern India in July 2003. By the end of December 2004, four months after I had begun my research, I had interviewed four more kidney sellers via Dalal. All of them were male and their ages ranged from 27 to 41. Their professions varied from barbers to street vendors to commercial artists. All of their recipients resided in Bangladesh, except for a female Bangladeshi immigrant who was living

in Italy. Three transplantations were performed in India and the other in Bangladesh, between November 2000 and March 2003. At this point I had interviewed six kidney sellers.

The Final Cut

The fieldwork also faced difficulties when Dalal decided to go on a business trip to India for two months.[12] Due to my limited time for the fieldwork, I insisted that he provide me with some kidney sellers' contact information. After several firm attempts, I collected about 30 contact addresses of recipients and sellers from him. Dalal asked to be paid for arranging interviews and providing contact addresses. He demanded a huge amount of money for transportation, telecommunication, and time spent. I carefully examined his bill and reduced it to about $25 for arranging interviews with five kidney sellers. I refused to offer any payment for providing contact addresses.

I eventually realized that Dalal provided me with only those addresses that were difficult to contact. I initially attempted to contact the sellers, even though they resided in remote parts of Bangladesh that were difficult to reach due to poor transportation. Some sellers' addresses were also incomplete, incorrect, or no longer in use. In addition, some of their telephone numbers were no longer valid. Nevertheless, I was successful in contacting a seller and scheduled an interview. Unfortunately, this seller did not appear at my apartment despite several attempts. Based on Dalal's contact addresses, I also contacted some recipients by phone. These recipients were concerned about my call and asked how I had obtained their phone numbers. The reference of Dalal was not enough for them to trust me.

I was stuck again. When I realized that a kidney seller might facilitate the trust between recipients, sellers, and myself, I employed Shahidul (the first interviewed seller from Dalal) as a research assistant. Shahidul had extensive knowledge of the kidney trade because he had gone to India twice: once to sell his kidney and then to accompany his brother for selling his kidney. He and I discussed ethical guidelines, upcoming workloads, and possible remuneration. Shahidul also requested that his contribution be gratefully acknowledged in the publication. With the support of Shahidul, I was able to interview seven more kidney sellers by the end of February 2005. Of these seven interviewees, only one seller was female, a 37-year-old divorced woman living with a son and a daughter, who sold fruits on the street of Mymensingh. The other sellers were male, between the

ages of 25 and 42, with diverse professional backgrounds, from farmers to butchers.

Based on Dalal's list, Shahidul and I deduced that most sellers resided in the northern part of Bangladesh. To locate sellers, Shahidul agreed to travel to Mymensingh, Natore, Dinajpur, Rajshahi, and Ishwardi, some of the northern towns in Bangladesh. When Shahidul met sellers in their homes, he invited them to go to a tea stall. At the beginning, Shahidul introduced himself as a kidney seller, then he outlined the research to them, and, finally, asked for interviews. Shahidul successfully gained most of the sellers' trust because he was a seller as well. At every meeting, Shahidul called me from his cell phone and I talked with the sellers. I clarified to them the research project and ethical principles, obtained their trust, and scheduled their interviews. Two sellers refused to meet with me and one seller scheduled an interview but did not appear on the agreed-upon day. Shahidul also approached several organ recipients residing in Dhaka; however, they did not reveal their sellers' identities. Only one recipient agreed to introduce his seller and obtained my phone number. He eventually contacted me and I was able to conduct an interview with his seller.

Interviews with 13 kidney sellers revealed that Tareque Azam Golam was the main broker for kidney trading in Bangladesh. Many Bangladeshi sellers went to Tareque and concurrently kept in touch with Dalal to maximize their chances of matching tissues with potential buyers. I obtained Tareque's telephone number from these interviewed sellers and called him in mid-February 2005. I mentioned to Tareque that I wanted to meet with him instead of talking over the phone in order to discuss kidneys. I still remember that early afternoon, walking in dark alleys in old Dhaka with my wife. She accompanied me because meeting with Tareque could have been dangerous. I also wanted to make clear to Tareque that I was not a local journalist hiding my identity in an attempt to reveal his illegal business. When we met, Tareque was accompanied by several men. My wife and I introduced ourselves, outlined the research, and guaranteed confidentiality. Tareque completely denied being involved in the illegal kidney trade. He warned us by mentioning that we were "playing with fire." Since we didn't have any power to challenge him, we requested that he call my phone or come to my home if he could support the research in any way. When we left his office, we felt very relieved to see Dhaka's city life. Tareque never did contact me; however, I was

constantly worried and felt on numerous occasions that somebody was following me. Despite this threat to my safety, I realized that it was important to interview Tareque's clients in order to obtain different insights on the kidney trade. I asked both Shahidul and Dalal about the possibility of contacting some of Tareque's clients. Shahidul met a few sellers who had sold their kidneys through Tareque during his and his brother's transplantations in India, and Dalal came across some of Tareque's clients through business. Based on Dalal's information, Shahidul attempted to contact a client of Tareque's who resided in Dhaka. After several attempts, Shahidul was able to contact the seller; however, he refused to discuss his selling experience to a researcher. It was a long time before I met some of the sellers who had sold their kidneys through Tareque, which I discuss shortly.

Dalal was back in town in early March 2005 and arranged for me to meet with nine more kidney sellers, all of whom were his clients. All sellers interviewed were male and resided in various parts of Bangladesh including Dhaka, Barisal, Khulna, Bagerhat, and Rajbari. Six sellers had gone to India for the surgery, while three of them had had the surgery performed at BSMMUH and BIRDEM (Bangladesh Institute of Research and Rehabilitation in Diabetes, Endocrine, and Metabolic Disorders, a World Health Organization collaborating centre) in Dhaka. Dalal was not satisfied with the amount of his previous payment for arranging the interviews and so we agreed to raise his fee to $8 from $5.

The research gained momentum when Shahidul bumped into Shamim Hossain, a 22-year-old undergraduate student at Dhaka College who had sold his kidney through Tareque. When I received Shahidul's phone call, I met with Shamim right away in front of the public library of Dhaka. We sat down at a tea stall and I convinced Shamim to meet with us again for an interview. In an interview lasting over nine hours, Shamim revealed how Tareque, a dodgy kidney broker, brutally exploited the kidney sellers. Tareque usually transported four or five sellers at a time to India, where they lived in a bachelor apartment that he continually rented for that purpose. He charged kidney recipients huge amounts of money and paid as little as possible to the sellers. Like other sellers, Shamim did not receive the entire payment that Tareque had promised. The sellers could not fight against Tareque because he was a rich businessman well-connected with powerful Bangladeshis. At the end of our meeting, Shamim mentioned that he might have the contact addresses of some sellers who had gone to

India with him. Although Shamim agreed to provide their contact information, he never picked up or returned my phone calls. He might have been terrified to talk against Tareque.

The other major turning point of this research came when Dalal introduced me to a 48-year-old transplant recipient who had also purchased a kidney through Tareque. I called the recipient, who revealed that he was still in touch with the seller, a 32-year-old rickshaw driver and day labourer residing in Bhairabbazar. Less than two weeks later, the recipient called me while visiting Dhaka. I talked with Dildar over the phone, outlined the research, and convinced him to proceed with an interview. Dildar described in detail his experience of selling his kidney through Tareque. Dildar was frustrated because he had not received full payment from Tareque even after he had called more than thirty times and visited his office about ten times. Both Dildar and Shamim, who had sold their kidneys through Tareque, narrated similar stories. Dildar also provided me with the contact information of four other kidney sellers with whom he had become friends while staying in Tareque's apartment in India, and easily arranged interviews with three of these sellers. These sellers revealed Tareque's murky business and the context of the kidney trade in Bangladesh. I was able to apply snowball sampling to Tareque's sellers since they had stayed together in the tiny bachelor apartment in India. After several failed attempts, I finally located and interviewed two female kidney sellers, Hawya Begum and Nazma Begum, sisters-in-law residing in Pirozpur. They outlined how their husbands had asked them to sell their kidneys in order to give them better economic stability. In all, I had interviewed 29 kidney sellers by May 2005.

I could have interviewed other sellers in the next months; however, I realized that the fieldwork was coming to an end: many of the sellers' stories resembled one another. Nevertheless, I interviewed three more sellers, as arranged by Dalal, since these sellers had gone to Pakistan, Singapore, and Thailand for the operations, and I thought their experiences may have been different and, therefore, informative. Their interviews revealed how wealthy Bangladeshis obtained kidney transplantations and care in various nations around the world. During one of the interviews, a seller compared his experiences in India and Thailand: he initially went to India for the operation but his recipient died and, as a result, he went to Thailand with another recipient. Lastly, via the brother of one of my research assistants, I interviewed a seller who had managed to sell his kidney

without a broker. I was exceptionally privileged to collect such rich narratives from 33 kidney sellers.

During the fieldwork, I also collected data from other relevant research populations. These include: recipients and their family members, potential organ buyers, possible sellers, kidney brokers, health personnel (including nephrologists, urologists, post-graduate trainees, nurses, and laboratory technicians), the president of the Kidney Patient Welfare Association, a member of the Bangladeshi Private Body Donation Group, journalists, documentary filmmakers, lawyers, social workers, university faculty, and students. These interviews provided insights and helped to situate the data collected from the sellers. Access to these research populations was quite simple, aside from a few exceptions. I was fearful when I went to interview a potential liver buyer in a hotel in downtown Dhaka. This potential buyer had posted a newspaper ad in the daily *Prothom Alo* on April 25, 2005, and after many calls, I finally arranged his interview by mentioning my desire to discuss the issue in person. He told me to meet him in the late evening at a major intersection in Dhaka. Before leaving, I informed my family and friends of our meeting place. As I was waiting, I called the buyer on his cell phone several times but nobody answered. I then received a phone call but when I answered, the person on the other end hung up. It was a trick so that the person could observe me and my activities. He eventually came forward and told me to come to the hotel for our discussion. Also, despite some insignificant difficulties, I successfully obtained data from a Bangladeshi woman who had posted a newspaper advertisement to sell her cornea; a Bangladeshi recipient who had collected money through art exhibitions and charities in order to purchase a kidney in Islamabad; a Canadian recipient who travelled from Ottawa to Dhaka to purchase the kidney of a poor rickshaw driver; and another Canadian who travelled to Islamabad to purchase a kidney for her mother. Through these various interviews with kidney sellers, buyers, brokers, and those involved with organ trafficking, I managed to gain access to this hidden population for conducting underground fieldwork.

Research Methodology

This section outlines how I collected data and applied ethical research standards during the course of my fieldwork. By sharing my experiences I hope to contribute to the formulation of a methodology for underground fieldwork. My fieldwork was based in Dhaka, the capital

and the largest metropolis of Bangladesh. Dhaka is the only city in the country where kidney transplants are performed and where organ commodification is concentrated. Bangladeshis travel from different parts of the country to Dhaka in order to obtain organ care at two established public and private kidney transplant units, public and private dialysis facilities, and many laboratory examination centres. Dhaka, therefore, became the centre of my research while my research assistants and I travelled to various parts of Bangladesh to locate kidney sellers and collect data. My fieldwork data, however, is still limited in its scope, considering the interviews were with a very small subset of the population. My research, therefore, cannot be representative of the rich social and cultural diversity of Bangladesh. In conclusion, the results of my study are both tentative and preliminary.

During my research, I was privileged to collect extremely hidden data, which amounted to 1500 pages of interview transcripts and diverse supporting documents. Interviews, participant observation, and case studies provided rich ethnographic data with which to explore and examine organ commodification in Bangladesh. Library research provided me with newspaper advertisements published in five Bengali dailies from 2000 to 2004. These advertisements were later used to analyze public discourses surrounding organ selling. Supporting documents — forged passports, notary certificates, government documents, laboratory examination reports, a personal diary of a kidney seller, letters from recipients to sellers, written trade agreements, a copy of the Organ Transplant Act, a Bengali kidney-selling film (*Shaheb*) and novel, *Rupar Palanka* (Ahmed 1999), and photographs of 33 kidney sellers — helped to enrich and situate the data.

Although various research methods were employed, interviews remained the key method of collecting data. In order to interview kidney sellers, it was imperative that I create a safe environment in which they felt comfortable. The location of interviews was significant, especially when people had to be secretive. The sellers preferred to meet with me away from their neighbourhoods in order to conceal their actions. Thus, I arranged to conduct all interviews in the living room of my apartment in Dhaka. Many sellers resided in different parts of Bangladesh and had to travel, on average, seven hours to Dhaka by bus or train. Sellers often would start their journeys late at night and Dalal, Shahidul, or I would pick them up the following morning. Since I had not met the sellers before, it was difficult for me to pick them up at their destinations. Upon arriving, sellers had to call me from a pay

phone so we could exchange descriptions of our appearance. These mornings often resembled scenes from movies where illegal goods are being exchanged. The busy mornings typically started with me having breakfast with the sellers. Most sellers then took a shower to feel comfortable after a long journey. In this phase, my function was to create a relaxed zone for the interview. The duration of the interviews lasted, on average, ten hours, though they varied from six to fourteen hours, and typically lasted until the evening. Usually, my wife prepared both lunch and dinner, which offered a half-hour break during the interview and a pleasant way to end the interview.[13] I then dropped the sellers off at a bus or train station.

At the beginning of each interview, I informed the research participants of the ethical guidelines from the Ethics Review Board at the University of Toronto. I clearly explained to them, verbally or in writing, the nature and scope of the research. Confidentiality, one of the key issues in conducting research with hidden populations, is especially important given that some participants may be involved in activities that are legally ambiguous or prohibited. Before conducting any interview, I discussed and evaluated with them the possible consequences of using their true identities. I then disguised features that could be used to identify individuals in field notes, transcripts, and publications. Pseudonyms are used in this research almost entirely. However, it must be recognized that there may be limits to confidentiality; that is, it can only be guaranteed to the extent permitted by law.

Before the interview, I also informed the participants that their participation was voluntary and they were free to withdraw their consent to be included in the study at any time. They could also ask that any part of the interview not be used. I then asked the participants to sign and date an informed-consent form to indicate their willingness to be included in this research. Interviewees were then given a copy of this form to keep for their records. I learned that written and signed informed-consent forms were of limited value in Bangladesh, especially with kidney sellers, recipients, and brokers, who must remain anonymous. Consent forms, therefore, aroused suspicions. At times, these forms were also inappropriate because few participants of this research were literate. As a result, I read an alternative informed-consent script to such respondents in order to provide them with information outlining the details of the research and the nature of their participation. I then asked for a verbal indication of their willingness

or lack of willingness to participate. Both the informed-consent form and script were provided and communicated in Bengali.

Unstructured, narrative-based interviews allowed me to establish a casual relationship with kidney sellers and provided them with the opportunity to talk. Most sellers would openly ask me questions related to kidney selling. My responsibility was to guide the conversation according to the purpose of the study. I attempted to develop an informal way of exchanging ideas whereby we were interviewing one another. Although no structured questionnaire was followed, a thematic arrangement was considered for the interviews. The thematic focus of the interviews can be divided into three sections.

First, the socio-economic conditions of the seller, including name, age, educational qualification, occupation, monthly income, gender, religion, marital status, and family size, were used to initiate conversation and to generate a preliminary rapport.

Second, the experiences of the kidney sellers were discussed in detail. This phase of the interviews began with me asking how and when participants became aware of kidney selling. The discussion was then expanded to a discussion of other issues, namely: the reason for selling kidneys; how they dealt with their family; how they connected with the network of commodifying kidneys; how much money they were promised and how much they received for the selling; how the money was spent; how they evaluate the financial and other benefits, versus the losses, of selling kidneys; the health consequences, if any, of pre-operative, operative, and post-operative kidney exchange that they experienced; the kind of relationship the sellers presently maintained with the patient; and whether they were familiar with legal aspects of kidney commodification. The sellers unfolded their stories and outlined their experiences in rich narratives.

Finally, the last stage of the interview commenced with a discussion on how and why human organs, especially kidneys, are widely exchanged in Bangladesh. It was followed by other inquiries, such as: who are the beneficiaries of commodifying organs; should organ exchange be regulated or banned; what are the ethical dilemmas of organ commodification; what is the role of the government of Bangladesh regarding this issue; why does a cadaveric organ donation program not exist in Bangladesh; what are the religious ideas and beliefs on the exchange of organs; and how is the body generally comprehended before and after the transplant surgery. In this stage, the

sellers engaged in the exploration of critical and theoretical issues related to organ commodification in Bangladesh.

At the end of the interviews, I asked for the sellers' permission to take their photograph. Most sellers were hesitant posing for pictures; however, I guaranteed that no photograph that could possibly identify them would be published without their consent. I also informed them that the purpose of these photographs was to recall, support, and validate the data. Some sellers agreed to have pictures that showed their faces published outside of Bangladesh. In all, I took six or seven different shots of each seller. The sellers were compensated with one day's salary, plus the cost of transportation, which varied between $10 and $20.[14]

I interviewed sellers individually, except for three who were accompanied by their husband, cousin, or friend. I only conducted one interview a day, except in one case where I had to interview two sellers because they visited Dhaka on the same day (the first interview was conducted from 7:30 a.m. to 2 p.m. and the other from 2 p.m. to 8 p.m.) Except for one seller, I was able to complete the interviews without any interruption. (This seller had to leave for an appointment during the middle of our discussion; however, he came back the following week to complete the interview.)

Recipients, their family members, doctors, and brokers also provided important data on kidney commodification. These relevant research populations were selected at random. I carried out their interviews at different locations (such as public and private transplant hospitals, dialysis centres, intensive care units, kidney wards, newspaper offices, universities, libraries, legal chambers, residential hotels, private offices, and personal dwellings where illegal kidney exchanges were performed, discussed, and debated). The length of these interviews varied greatly between one to ten hours. Interviews with these populations offered a wide range of data to cross-check sellers' information and situate the research.

In addition to interviews, I also used participant observation, the hallmark of ethnographic research, to collect data for this research. When I interviewed the sellers, I took note of their appearance, body language, tone of voice, and comments, which aided me in examining and cross-checking the data. I also spent a considerable amount of time conducting participant observation in transplant units and dialysis centres when doctors were on rounds, nurses were on duty, and post-graduate

trainees were on lunch. I 'hung out' in the nephrology departments when donors were lounging in the waiting room, patients were being prepped for surgeries, and their family members were cooking in the hospital kitchen. I was also able to observe Xerox stores where recipients photocopied false documents, and street corners where brokers approached potential recipients and made promises to find sellers. My participation and observations were recorded in field notes and later analyzed, and provided a valuable source of ethnographic data.

I also used case-study methods to support the research and cross-check the data. Three cases (one of recipient Khairul and seller Montu, another of recipient Moniruzzaman and seller Shamsul, and the last of recipient Momotaz and seller/donor Belal) were examined for a deeper understanding of the interactions between recipients and sellers. The recipients' and sellers' interviews were carried out and followed up separately.

Data recording is essential to fieldwork. Using a tape recorder, a common technique of documenting data, was not suitable for this research because the respondents were not comfortable with me recording their experiences. I did use a tape recorder during one interview with a seller, but this proved inefficient because he was not spontaneous and it took a long time to establish a rapport between us. Instead, all interviews were in the form of written scripts. Data storing is also particularly important due to the sensitive nature of the data collected. I keep fieldwork notes, informed consent forms, false and supporting documents, and photographs in a locked filing cabinet in a secure location in Canada. I also stored a copy of these documents in a safe place in Bangladesh. The materials of greatest risk, such as names and pictures of the respondents that could lead to identification, will be kept for a period of ten years, and then destroyed.

Conclusion

Every fieldwork is distinctive; however, all researchers strive to fully engage and participate with the population they study. This is not always possible, especially when the research subjects are concealed and involved in criminal activities. The major drawback of my fieldwork is that I could not do participant observation of the organ trade as I had originally planned; rather, I collected interview data of 33 sellers who recalled their experiences within Bangladesh's organ trade. It would have been remarkably informative if I could have followed a kidney seller and observed his/her actions during every stage of the selling process.

Employing participant observation, particularly with kidney sellers, is demanding. How much can one observe and participate in this illegal trade? Can we observe actions without participating? How can we understand actions based on the experiences? The level of difficulty in obtaining data on the kidney trade may partly explain why the study of kidney sellers is extremely rare, aside from short journalistic reports. My study is also limited in terms of gender representation: I interviewed 30 males but only 3 females. Being a male in a predominately Muslim society, I was absolutely fortunate to have been able to interview these female sellers. Thus, underground fieldwork is methodologically challenging. Despite some limitations, this research is unique because I did not apply a top-down approach, meaning that I did not follow the Western recipients to find their sellers. Rather, I successfully employed a bottom-up approach in order to locate their counterparts. I am also very pleased to offer the detailed experiences and the voices of 33 kidney sellers, which until now have been silent in the literature. As research on "hidden populations" is growing, my aim here is to outline how I contacted concealed groups and employed ethnographic methodology in an underground setting. This is the time to share, compare, and formulate directions to expand a more generalized methodology for underground fieldwork.

Notes

1. During the fieldwork, several advertisements for selling kidneys were posted at this hospital and all of them were removed shortly thereafter because of my presence.

2. Although the father promised to provide me with contact information of the kidney buyer over the phone, he never called me. My research assistant Sudipta went to Sylhet, about seven hours by train from Dhaka, only to obtain the phone number of the buyer in question.

3. With the invaluable help of three research assistants, Sami, Sudipta, and Sumon, who completed their Bachelor's degrees in anthropology from Shahjalal University of Science and Technology, Sylhet, Bangladesh (where I taught for almost three years), five national daily Bengali newspapers, namely, the *Ittefaq, Prothom-Alo, Jugantor, Janakantha and Inqilab*, published from 2000 to 2004, were examined. We covered the newspaper advertisements, reports, and articles by conducting archival research in Dhaka University Library, Public Library, and National Library in Dhaka, for almost two months. Babu, another research assistant and graduate in Computer Science from Khulna University, Bangladesh, helped us to scan the newspaper coverage.

4. Fifty ads to sell and 602 ads to buy kidneys had been posted in these five newspapers between 2000 and 2004.

5. Currently, mobile phones are widely used in Bangladesh. The SIM card (usually known as a 'chip') for connecting mobile phones was as cheap as $5. The potential sellers usually change their SIM's, so their numbers were changed a few months after posting the advertisements.

6. I asked family and friends to contact the advertisers because they were in every corner of Bangladesh. For example, my father attempted to contact a potential seller who resided in my hometown; however, he was informed that the person did not rent there any longer.

7. To conceal the respondents' identities, all the names used in the publication are pseudonyms. I am also careful in describing the interview location, relevant person, and any other factors that can reveal their identities.

8. Khairul, as well as others kidney recipients, mentioned that the HLA tissue-typing examination in Bangladesh is often not authentic. Most of them prefer to reexamine the results of the HLA test in India but cannot afford the expense of doing so.

9. During the interview, Khairul mentioned that Johra was "greedy" because she asked an outstanding amount of money for the kidney. It was difficult for him to select Montu over Johra; however, he opted for "needy" over "greedy," as he mentioned.

10. All the monetary values are presented in Canadian dollars.

11. I adopted the term *halify* from Lila Abu Lugod, with the familiarity of the debate of the insider and outsider viewpoints and its limitation.

12. Dalal accompanies recipients, who pay the fee, transportation, accommodation, and compensation of his income during the operation in India. He called them special clients and had, on average, two a year.

13. The seller, my wife, and I shared the food together, which is a pleasant way of interacting and ending the interview.

14.To pay the respondents is problematic. In graduate school, one of my professors argued that payment is necessary in many ethnographic studies to compensate for the time of the respondents, while another professor mentioned that any form of payment is unacceptable because the respondents could be biased. I became puzzled between the two opposing views. Goyal and others, who conducted a study on kidney sellers in India, noted that before the interview, participants were given 40 rupees (approximately $0.89) as compensation for their time and told that they could keep the money even if they did not want to answer any or all of the questions (Goyal et. al. 2002, p. 1590). In this study, it was essential to compensate transportation costs and one day's salary for the respondents.

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From Durham to Delhi: "Medical Tourism" and the Global Economy

Leigh Turner

Abstract

Health services are available for purchase through the global economy. Hip and knee replacements, ophthalmologic procedures, cosmetic surgery, cardiac care, and even organ transplants are all sold in the global health-services marketplace. Uninsured and under-insured Americans unable to afford healthcare in the United States fly to other countries for treatment. "Medical tourism" companies market "sun and surgery" packages to international hospitals in India, Singapore, Thailand, and other destinations. Just as automobile manufacturing and textile production have moved "offshore," patients are "outsourcing" themselves to facilities that use low labour costs to gain comparative advantage in the marketplace. Proponents of "medical tourism" argue that a global market in health services will promote consumer choice, foster competition among hospitals, reduce the cost of healthcare in the United States, and enable customers to purchase high-quality care at medical facilities around the world. Sceptics raise concerns about patient safety, information disclosure to patients, quality of care, and legal redress in instances where patients are harmed while receiving care at international hospitals. The emergence of a global market in health services will have profound consequences for health insurance, delivery of health services, patient-physician relationships, and the spread of medical consumerism.

Introduction

Medical brokerages and international hospitals marketing "medical tourism" first attracted customers by selling discount facelifts, tummy tucks, and other forms of cosmetic surgery. They targeted price-conscious customers wanting procedures not covered under health insurance plans. Typical advertising pitches featured "surf and surgery"

holidays in Thailand and "surgeon and safari" trips to South Africa. Although brokerages and destination hospitals still advertise cosmetic surgery "bargains," they now sell a wide array of services to much larger markets. "Medical tourism" is currently packaged as a solution to the high price of medical care in the United States and the lengthy treatment delays in countries with publicly funded healthcare. In Canada, the United Kingdom, and other countries with publicly funded healthcare, medical brokerages attract customers tired of waiting for hip and knee replacements, cataract surgery, or other procedures. Canadian businesses such as Speedy Surgery and Timely Medical Alternatives solicit clients willing to pay for expedited care. The United States provide a different and much broader client base for medical brokerages and international hospitals. The U.S. offers a large population of individuals searching for affordable healthcare.

Marketing campaigns promoting "medical tourism" try to link healthcare to adventure, relaxation, and holiday fun (Connell 2006). The reality of international health-related travel is quite different. Popularization of "medical tourism" is related to social inequalities, loss of employer-provided health insurance, and lack of access to affordable healthcare in the U.S., as well as to global inequalities that permit international hospitals to offer "bargain-priced" healthcare thanks to "cheap" local labour supplies. "Medical tourism" reveals the shape medicine takes when it is thoroughly subsumed within a global market economy.

Uninsured in America

In 2005, an estimated 44.8 million individuals in the United States lacked health insurance (Milstein and Smith 2006; Starr Sered and Fernandopulle 2005). In low-wage sectors of the U.S. workforce, over 75 per cent of employees decline health insurance (Milstein and Smith 2006). They cannot afford health insurance premiums; their earnings go to more immediate needs such as food and shelter.

The high cost of healthcare in the U.S. drives many low-income and middle-class Americans with serious health problems into bankruptcy (Himmelstein et al. 2005). Short of outright bankruptcy, medical debt is a growing problem for insured and uninsured Americans. Medical debt is a risk factor in being unable to gain access to treatment (O'Toole, Arbelaez, and Lawrence 2004; Seifert and Rukavina 2006). As medical bills accumulate, sick individuals lose access to doctors and hospitals. Denial of coverage on the basis of pre-existing

conditions means that even individuals who can afford to purchase health insurance are often unable to obtain the medical interventions they are most likely to need. Inclusion of coverage for these procedures can generate premiums exceeding $2,500 per month. High deductibles and co-payments mean that individuals with insurance sometimes cannot afford the medical care they require. In short, whether or not they have health insurance, low-income and middle-class Americans with limited finances are often unable to afford care at local institutions. They are forced to travel to regions where they can purchase affordable treatment.

Outsourcing Employment

The emergence of international supply chains, the Internet, global telecommunications, and interconnected economies has pulled jobs toward regions where workers are paid comparatively low wages (Blinder 2006). In the United States, this process first affected workers in manufacturing industries. It then spread through other sectors of the economy. The United States once had a huge textile industry. Most of those jobs moved to China, India, Mexico, and Thailand. "Back office" work that could be digitized and outsourced is now done in India. There, lawyers, computer programmers, accountants, information technology specialists, and call-centre employees earn far less than their American counterparts. Jobs related to the health-services industry are also outsourced. Medical transcriptions, accounting, case mix evaluation, client scheduling, and processing of insurance claims are all routinely outsourced by American clinics and hospitals.

Exploring how "offshoring" will alter America's social and economic fabric, Alan Blinder (2006) estimates that 30 to 40 million jobs in the U.S. could move to China, India, and other countries. From a global perspective, these jobs should improve the living standards of wherever they relocate. However, for Americans whose health insurance is connected to their workplace, offshoring of jobs will have profound consequences.

Employer-Provided Health Insurance

Health benefits constitute a major expenditure for American employers (Blumenthal 2006). To control costs and make themselves "globally competitive," American companies are cutting or eliminating employee health benefits (Foster and Mason 2006; Yi 2006). Executives threaten to move additional jobs offshore if unions do not

concede to reductions in employee benefits. Employees are faced with a choice: either they agree to wage concessions and benefit reductions or they suffer additional job losses. As jobs in America are outsourced to other countries, workers lose both income and health insurance. Replacement of long-term employees with temporary workers also reduces corporate expenditures on health benefits.

To obtain affordable health services, middle-class and low-income Americans lacking health insurance, paying out-of-pocket, or holding minimalist "min-med" plans "offshore" themselves by flying to regions where inexpensive health services are available for purchase (Kher 2006; Lancaster 2004; Rahi 2005; Roth 2006). Offshoring occurs at the level of individual patients seeking treatment. In addition, some companies now send employees to hospitals outside the United States.

With its large and growing population of uninsured Americans, underinsured Americans, and Americans struggling to pay rising health insurance premiums, the United States is a leading target market for hospitals seeking international customers. Medical brokerages are proliferating in the U.S. as Americans find they must travel to purchase affordable healthcare (Alsever 2006; Connell 2006).

Medical Tourism Brokerages

Medical brokerages play a crucial role in selling health services in a global market. They take clients from high-cost healthcare settings, arrange travel to less expensive healthcare facilities, and charge fees for coordinating transportation and treatment. The Internet, inexpensive telecommunications, and economy air travel all facilitate the sending of customers to destination hospitals offering low-budget healthcare (Carrera and Bridges 2006; Connell 2006). The packages that brokerages market have two major features. Clients must be healthy enough to travel; medical tourism companies do not sell emergency medical services. Also, customers need to see sufficient cost savings to justify the expense and inconvenience of travel (Mattoo and Rathindran 2006).

Leading medical brokerages in the United States include Planet Hospital, Global Choice Health Care, Med Journeys, and Med Retreat. Some agencies arrange travel to just one country. For example, IndUShealth coordinates travel to hospitals in India. More commonly, brokerages offer multiple travel destinations and a sliding scale of

prices for health services. Planet Hospital, a typical U.S. brokerage, sells packages to hospitals and clinics in Argentina, Belgium, Brazil, Costa Rica, El Salvador, India, Mexico, Panama, Singapore, Thailand, the United States, and Uruguay. At the peak of the price scale sit under-utilized hospitals in the United States. Customers able to afford mid-tier rates for treatment can purchase care at private hospitals in Singapore. Clients with limited financial resources typically select hospitals in India, Malaysia, Indonesia, or the Philippines.

Because the medical tourism industry is driven by international differences in the cost of health services, most company websites include charts and graphs comparing the cost of care at hospitals in various countries. Charts showing prices for orthopaedic procedures and cardiac surgery reveal significant price differences across countries. Prices in Thailand are often one-third to one-fifth the cost of treatment at U.S. hospitals. Many Indian hospitals charge one-tenth the price of procedures available at U.S. medical facilities. A coronary artery bypass graft that costs over $55,000 U.S. at hospitals in California can cost $5,000–$10,000 at hospitals in India (Milstein and Smith 2007).

Corporate Interest

U.S.-based medical brokerages first targeted individual clients seeking inexpensive healthcare. They solicited customers needing hip and knee replacements, dental work, spinal surgery, or coronary artery bypass grafts. Selling "retail" is a time-consuming and inefficient way to market health services. Brokerages now target small businesses, corporations, and health insurance companies in addition to pursuing individual clients (Foster and Mason 2006; Yi 2006). This strategy enables brokerages to significantly increase customer volume.

North Carolina's Blue Ridge Paper Products was the first American company to contract with a medical brokerage to arrange overseas medical care for an employee (Rai 2006). Carl Garrett, a technician at Blue Ridge, agreed to fly to India for surgery on his rotator cuff and gall bladder. In turn, Blue Ridge offered to cover Garrett's deductibles and travel expenses (saving him $20,000) and give him a share of whatever savings the company made by sending him to India for treatment. Just before Garrett was to leave for India, the United Steelworkers Union condemned the plan and the company cancelled the trip. Leo Gerard, president of United Steelworkers, argued that what began as the voluntary decision of one employee would become mandatory as companies routinely offshored employees for

inexpensive healthcare. Although Blue Ridge discontinued plans to outsource employee healthcare, other businesses now contract with medical brokerages and sell health insurance packages incorporating out-of-country treatment options. Such companies as GlobalChoice Health Care, Global Health Administrators, and United Group Programs all sell "global" health plans to corporate clients. In exchange for low premiums, these plans require out-of-country care for elective procedures.

Arnold Milstein and Mark Smith (2007) argue that small businesses are the "early adopters" as the corporate sector embraces the "offshoring" of healthcare for employees. They suggest that if liability issues are resolved, large corporations will incorporate outsourced healthcare into their benefit packages. Employees paying high premiums will be able to obtain elective surgical procedures at U.S. medical facilities. Low-budget plans will require travel to international hospitals offering inexpensive health services. The cost of health plans will vary depending on where health services are purchased.

Health Insurance Companies

Medical brokerages and international hospital chains are now trying to convince major American health insurance companies to sell plans covering "offshore" healthcare. For emergency care, customers will obtain treatment at local healthcare facilities. For elective services, customers will have to travel to international hospitals. Blue Cross and Blue Shield South Carolina — the Southern Blues, as they are called — now market such a health plan. Their customers can purchase "mini-med" health plans that include provision of health services at Bumrungrad International Hospital in Bangkok.

State Governments

Interest in reducing the cost of healthcare extends beyond the corporate sector to elected government officials. In 2006, Ray Canterbury, a delegate to the state legislature of West Virginia, proposed a House bill that would give financial incentives to West Virginia State employees willing to travel outside the United States for medical care (Searls 2006). If Canterbury's bill is passed, state employees will have the option of travelling to India or Thailand for elective healthcare. The bill proposes to cover all travel-related expenses, eliminate co-payments and deductibles, provide free transportation and accommodations for an accompanying family member or friend, include seven

supplementary sick days, and offer employees a share of whatever savings the state gains by arranging out-of-country care. Canterbury wants to increase competition and use outsourcing of patients to reduce prices at American hospitals. His proposal has considerable support in the West Virginia State Senate. Similar legislation is under review in Colorado.

Globalization of Health Services

How flying from Durham to Delhi or Charleston to Chennai for medical care came to seem like a sensible proposition is a complicated and rather circuitous story. The rising cost of health insurance premiums, job cuts, and loss of employer-provided health insurance are key features of this narrative. A detailed exploration of the emergence of a global market in health services would have to explore how American medicine and healthcare became such massive business enterprises, why healthcare in the U.S. is so expensive compared to other countries, how national economies interlocked to form a global economy, and how "biomedicine" (or "Western medicine") spread across the globe. Books such as *The Social Transformation of American Medicine* (Starr 1982) and *Sick* (Cohn 2007) describe how medicine in America came to be delivered through the market economy. Much less well-known is how international hospitals used the doctrine of comparative advantage to create a global market in health services. The origins of a global market in health services can be traced to the 1997 Asian financial crisis.

Bumrungrad

In 1997, Thailand's stock market fell 75 per cent and the value of Thailand's currency plummeted (Blustein 2001). Before July 2, 1997, it cost 25 Thai baht to buy one U.S. dollar. By January 1998 it cost 56 baht to purchase one U.S. dollar. Investor panic and economic turmoil rippled from Thailand to Indonesia, Malaysia, and South Korea. From there, it spread to Russia and Latin America.

Before its economy collapsed, Thailand experienced a rapid expansion of its middle-class population. The economic crisis erased the savings of Thailand's middle class and returned many citizens to poverty. With citizens unable to afford private healthcare, for-profit hospitals in Thailand lost their customer base. Many doctors and nurses left Thailand's private hospitals and found work at public medical facilities. During the crisis several Thai hospitals revised their marketing

strategies and began targeting patients in other countries. They solicited clients who could afford treatment and would bring foreign currency into the country. Bumrungrad Hospital, in particular, succeeded in attracting customers from Japan, Europe, the Middle East, and the U.S. Even when the financial crisis ended, Bumrungrad's managers continued expanding the hospital's international clientele. They used three strategies to pursue this aim (Talbot 2001).

Taking advantage of the devalued baht and the low value of salaries and property in Thailand, Bumrungrad executives undersold hospitals in Singapore. The marketing team placed ads in in-flight magazines, encouraged travellers on Thai Airways to apply frequent-flyer miles toward executive physical examinations, and offered discount packages for surgery and other procedures. Bumrungrad succeeded using a standard sales tactic — it beat its competitors on prices.

Next, Bumrungrad executives redesigned their hospital. They gave it the appearance and feel of a luxury hotel. They didn't just advertise private rooms; they marketed spacious private executive suites with wireless Internet access and widescreen televisions. They promised free limousine pick-up service at Bangkok's International Airport and complimentary visits from massage therapists. Bumrungrad executives selected the best restaurants in Bangkok and invited their chefs to bring upscale dining to the hospital. After a redesign of its atrium, Bumrungrad sported Au Bon Pain, Dairy Express, McDonald's, and Starbucks food outlets. These features had a powerful effect on lower-income and middle-income Americans visiting Bumrungrad. They discovered that by flying to Bangkok, they could afford posh "VIP" services reserved for only the wealthiest clients at private American hospitals. Bumrungrad's customers offered testimonials likening the hospital to a five-star hotel. After the television program *60 Minutes* aired a clip about the hospital, Bumrungrad was bombarded with over 3000 emails from Americans interested in receiving treatment there.

Lastly, Bumrungrad pushed a corporate philosophy promoting customer satisfaction (Talbot 2001). If a patient wanted surgery and hormone therapy to change from being male to female, Bumrungrad physicians did not introduce obstacles by making psychiatric evaluation a required part of the process. With this customer service ethic, Bumrungrad transformed itself from a small regional hospital into an international medical centre.

To executives at hospitals around the world, Bumrungrad demonstrated that given enough incentives, price-conscious patients would

travel in search of inexpensive healthcare. Surgery could be packaged with stays at ocean-front resorts, guided tours, and evening excursions to Bangkok's street markets and nightclub cabaret scene. Low-budget healthcare could be combined with the more traditional attractions of Thailand. Sun and surgery and hotels and hospitals could be fused to create "medical tourism." Bumrungrad International now provides care to over 435,000 international patients every year. According to Bumrungrad's marketing director, 58,000 of those patients are American. Hospital executives are building the Bumrungrad brand by constructing Bumrungrad Hospital Dubai in Dubai Healthcare City and establishing Bumrungrad International Philippines.

Private equity firms and pension funds, as well as hospital executives and senior government officials throughout Asia, noticed the increased flow of international patients flying to Bangkok for care. They grasped that hospitals situated in countries with low property values, low corporate taxes, low salaries for physicians, nurses, and other healthcare providers, advantageous currency exchange rates, and popular tourist destinations could attract customers from other nations. Hospital executives, government ministers, and investors in Singapore and India were particularly influenced by Bumrungrad's success in drawing international clients.

Medical Tourism as National Economic Strategy: The Singapore Example

Before Bumrungrad and its regional competitors in Bangkok and Phuket undercut their prices, hospitals in Singapore held the biggest share of the international patient market in Asia. Prior to the Asian financial crisis, hospitals in Singapore attracted wealthy clients from Bangladesh, Indonesia, Malaysia, the Philippines, and the Middle East. With the devaluation of the baht, Singapore's hospitals could not compete for clients on the basis of price. Hospital executives and government officials in Singapore decided they would forgo the discount surgery market. Singapore's leaders decided to boost research and development and build upon the country's strengths as a service economy. Government ministers and business leaders adopted strategies to transform the city-state into a regional "biomedical hub" (Cyranoski 2001; Gin 2005; Smaglik 2003). They marketed Singapore's hospitals as leading destinations for "well-heeled" international patients.

Hospital executives and government ministers in Singapore insist that with a population of just 4.4 million citizens, the city-state must draw

international patients to attract medical specialists, block the "brain drain" of healthcare providers, maximize institutional efficiencies, and promote economies of scale. According to Singapore's leaders, with increased volumes of international patients travelling to Singapore, hospital revenues will climb, specialization of medical practice will occur, healthcare providers will relocate to Singapore, costly medical equipment will become more affordable, and economic benefits will ripple through the city-state's economy (Chantarapitak 2006).

Singapore promotes medical tourism through its Singapore Medicine website. The portal provides links to Singapore's major hospital chains, specific hospitals and clinics, international patient centres, and lists of physicians. Singapore's medical tourism strategy is working. In 2000, Singapore attracted 150,000 international patients. In 2005, 374,000 "medical tourists" received care in Singapore (Yap 2006a, 2006b). Singapore wants to attract one million international patients every year by 2012. The Singapore Tourism Board estimates that regular tourists spend $144 U.S. per day whereas "medical tourists" spend an estimated $362 U.S. per day (Travel Smart-Asia Watch 2006).

Private hospital associations, government ministries, and tourism companies in other countries learned from Bumrungrad's success and from Singapore's coordinated national strategy. Hospitals in Hong Kong, Indonesia, Malaysia, the Philippines, South Korea, Taiwan, and Vietnam now all promote medical tourism. Countries such as Indonesia, Malaysia, and the Philippines have national "medical tourism" initiatives. Building upon the examples provided by Bumrungrad International and Singapore's hospital system, India is now the fastest-growing competitor in the global health-services market.

India

Private hospital chains such as Apollo, Fortis, Max Healthcare, and Wockhardt first promoted medical tourism to India. What started as the corporate initiatives of a few hospital chains soon became a national economic strategy; India now classifies care of international patients as an "export" product (Mudur 2003, 2004; Sengupta and Nundy 2005). Hospitals in India benefit from reduced tariffs on imported medical devices such as MRI machines and diagnostic imaging systems, low corporate taxes, substantial government investment in local transportation infrastructure and airport hubs, and special economic zoning laws. Provinces such as Goa and Kerala advertise regional medical tourism initiatives. Hospital management teams,

airline executives, private equity funds, venture capitalists, information technology firms, and tourism agencies all support India's national medical tourism initiative.

Selling Medical Tourism

Newspaper ads, special discounts, call centres, hospital websites, television commercials, billboards, classified ads, press releases, word-of-mouth marketing, and medical brokerages all draw patients to private hospitals seeking international clients.

Hospitals selling health services to international clients understand that many prospective clients are concerned about quality and safety of care in such countries as India and Thailand. Reservations about quality of health services available at international facilities are a major impediment to the emergence of a global market in health services. To address such fears, marketing to international customers uses various strategies to signal quality, competence, and "international" standards of care.

International Hospital Accreditation

The emergence of a global market in healthcare generated a need for an organization capable of assessing whether or not hospitals provide an "international" standard of care. Such a body had to possess widely recognized standards. Countries such as Thailand and India have national hospital accreditation bodies. However, hospitals wanting to proclaim themselves as "international" medical centres must be able to advertise that they meet "global" standards. An American company filled the gap by offering international accreditation.

The U.S.-based Joint Commission International (JCI) is now the overwhelmingly dominant organization in international accreditation of hospitals. JCI — the international offshoot of the U.S. Joint Commission on Accreditation of Healthcare Organizations — has accredited over one hundred hospitals outside the United States. To meet growing demand for international accreditation of hospitals in the Middle East and Asia, in 2006, JCI opened regional offices in Dubai and Singapore. JCI accreditation plays a crucial role in hospital marketing campaigns.

Physician Training

International hospital accreditation is supposed to certify quality of service provided by particular facilities. Just as JCI accreditation is

used to market hospitals, academic credentials are used to sell the skills of particular physicians. Degrees, fellowships at elite institutions, and U.S.-board certification are all used to promote the professionalism of physicians employed by international hospitals. Websites for hospitals in India and Thailand feature physicians trained in Australia, the United Kingdom, and the United States. The message to customers is that the physicians who will provide their care trained at the best institutions in the world. Hospitals seeking international patients encourage their physicians to obtain U.S. board certification. In the absence of global standards for medical education, U.S. board certification signals an international standard of training.

Building Brands

Around the world, certain universities and hospitals have an international reputation. Universities such as Harvard and Stanford are globally recognized academic "brands," just as Nike, Coca-Cola, and BMW are international corporate brands. Countries developing their health-services industry and promoting themselves as leading destination sites for international clients are encouraging brand-name academic institutions to build branch campuses and award prestigious degrees to local students. Duke University, in partnership with the National University of Singapore, runs a medical school in Singapore (Wagner 2006). Cornell University's Weill Cornell Medical College operates a medical school in Qatar. Harvard Medical International offers post-graduate training programs for healthcare professionals at Dubai Healthcare City.

The establishment of "North American" medical schools and satellite campuses in Asia and the Middle East serves multiple objectives. Many North American universities are developing initiatives in global health; satellite campuses enable them to expose students and faculty at their home institutions to other parts of the world. Construction of branch campuses also happens to be extremely lucrative for North American universities. Senior administrators of universities and medical centres in North America recognize that the fastest-growing markets for professional training are now in Asian nations. Duke University will receive over $350-million U.S. for establishing and running a medical school in Singapore (Wagner 2006). Satellite campuses generate significant revenue for brand-name universities. In turn, the training and credentials these programs offer will shape the global market for health services. Hospitals targeting international

patients will be able to advertise that their doctors and nurses are graduates of elite academic institutions. Staff members with degrees from such programs will bring instant cachet to hospitals targeting international clients.

Hospital Co-branding Exercises

Just as schools of medicine and nursing run by elite academic institutions are being built in Asia and the Middle East, hospitals in these regions are establishing partnerships with "brand name" medical centres. The Mayo Clinic is building a medical centre in Dubai. Johns Hopkins Medicine International is affiliated with India's Apollo Hospitals, and operates a clinic in Singapore. Harvard Medical International is part of Dubai Healthcare City, is affiliated with India's Wockhardt Hospital chain, and runs several hospitals in China.

Co-branding initiatives play major roles in international marketing campaigns. The "Harvard" name is on every Wockhardt hospital in India. Partnerships with elite organizations such as Harvard, Johns Hopkins, and the Mayo Clinic confer instant status and brand-name recognition. They act as customer magnets by addressing questions about quality of care and selling the promise of world-class treatment at prices well below rates in the United States.

Technology in the International Market for Patients

Just as international accreditation, training at elite institutions, and partnering with global "brands" are used to sell health services in the global market, symbols of advanced biomedical technologies convey the message that hospitals offer top-tier healthcare. Bangkok Hospital advertises itself as the only hospital in Thailand with a Gamma knife for neurosurgery. Apollo Hospitals promote their advanced diagnostic imaging suites. These icons of modern medical care enable hospitals to provide specialized services. They permit healthcare providers to perform procedures for which hospitals in the United States and other countries charge high rates. In addition, they project an image of hospitals in India, Singapore, and Thailand as participants in a global biomedical economy of advanced, specialized, and elite acute-care facilities. They provide powerful images for global marketing campaigns.

Globalization of Health Services

Private hospitals around the world want to attract customers from the United States and other countries. Medical brokerages profit whenever

they sell their services to clients. Many U.S. companies see outsourcing health services for employees as an effective way of cutting costs. Various parties have a clear economic interest in promoting the globalization of health services. Whatever the benefits of "offshoring" medical care, the establishment of a global market in health services will have profound consequences for patients, the practice of medicine, and the delivery of healthcare. Advantages of international health-related travel are widely advertised. In contrast, little consideration is given to how the globalization of health services will transform the practice of medicine, the experience of receiving care, and the organization of health systems.

Quality of Care and Patient Safety

International hospitals emphasize the high quality of care they offer. Advertisements commonly assert that destination hospitals meet or exceed standards for patient safety and quality of care in the U.S. Some hospitals draw attention to the many reports on medical error and adverse medical events at U.S. healthcare facilities. They use these findings to argue that U.S. patients will receive better, safer care if they leave the U.S. for treatment. In turn, U.S. organizations such as the American Medical Association and American Hospital Association express concerns about "medical tourism" and quality of care at international hospitals. The lack of comparative data from medical facilities around the world makes it impossible to assess patient safety and quality of care at leading destination sites for international patient travel. The Centres for Disease Control (CDC) have published reports about substandard care experienced by patients who underwent cosmetic surgery at clinics in the Dominican Republic and Venezuela (CDC 1998, 2004). Australia issued a travel advisory urging its citizens to avoid treatment at unlicensed cosmetic surgery clinics in Thailand. A website, www.bumrungraddeath.com/, accuses Bumrungrad International Hospital of providing negligent care to an American patient who died while receiving treatment there. Isolated reports raise concerns but do not lead to general conclusions.

While there are grounds for concern about quality of care and patient safety in the global health-services marketplace, there is no reliable evidence available to make broad characterizations about the quality of medical care around the world. With cosmetic surgery sometimes being performed by unlicensed practitioners at unaccredited facilities, cosmetic-surgery patients are perhaps at greatest risk when they travel

abroad for inexpensive treatment. Quality of care might be less of an issue at leading destination sites for medical tourism. These institutions have a powerful economic interest in providing high-quality health services. Of course, the profit imperative could also undermine quality of care with its pressure to minimize costs and maximize gains.

Patient safety is the most publicized concern in medical tourism. However, the most significant long-term consequences of a global market in health services are related to the global establishment of medicine as a market-driven business enterprise. Medical tourism represents the full integration of medicine with global capitalism. Ability to pay determines access to care; the more customers are prepared to pay the more services they can purchase.

From Covenant to Contract

Describing his father's pre-Depression-era medical practice in Flushing, New York, Lewis Thomas (1983) captures a period before American medicine was fully integrated into the market economy. In *The Youngest Science: Notes of a Medicine-Watcher*, Thomas describes a time of small-town physicians, the doctor's office being next to the living room in the family home, house calls, and an unstated sense of duty that included treating patients regardless of their ability to pay. Thomas sketches what medicine in America was like before the spread of managed care organizations, hospital marketing campaigns, and medical debt collection agencies. He captures the feel of doctoring before medicine was fully integrated into the market economy. Noting the often shaky financial status of his father's practice, Thomas writes:

> Very few of the patients paid promptly, and a good many never paid at all. Some sent in small checks, once every few months…These were the years everyone thinks of as the good times for the country, the ten years before the Great Depression. The town was prosperous, but the practice of medicine was accepted to be a chancy way to make a living, and nobody expected a doctor to get rich, least of all the doctors themselves. In the town where I grew up, there were two or three physicians whose families seemed rich, but the money was old family money, not income from practice; the rest of my father's colleagues lived from month to month on whatever cash their patients provided and did a lot of their work free; not that they wanted to or felt any conscious sense of charity, but because that was the way it was.

Sixty years after the era Thomas describes, William May (1983) used the phrase "the physician's covenant" to describe the moral bonds

connecting doctors to patients, making medicine more than just a service available for purchase in the marketplace. In *The Physician's Covenant: Images of the Healer in Medical Ethics*, May articulates an understanding of medicine in which ties between physicians and patients differ from the contracts governing economic transactions between buyers and sellers of goods or services. May describes powerful, quasi-religious bonds of trust and moral commitment connecting patients to physicians. For May, the intimacy of medicine, the involvement of doctors in the personal lives of their patients, the role of the physician in birth, the life course, and death, and the special moral obligations of doctors toward patients infuse the practice of medicine with moral gravitas and a sense of duty. For some contemporary doctors, the practice of medicine retains this dimension; being a doctor involves far more than just providing a service in exchange for remuneration. For other patients and physicians, the notion of medicine as "calling," "vocation," spiritual practice, or form of community service survives more as nostalgia for a dimly remembered past than as contemporary experience. In contrast to the 1920s, 21st-century American healthcare is delivered in a market-driven bureaucratized economy.

Managed care organizations control costs and carefully monitor the corporate bottom line. Investors in private hospital chains and clinics want managers to maximize their return on investment by reducing costs, increasing earnings, and providing treatment to paying customers. Hospitals maximize revenues by advertising for customers, marketing high-margin procedures, and refusing to cross-subsidize care for patients who cannot afford treatment. Focused "healthcare factories" specialize in doing shoulder operations or hernia repairs, and maximize profits by increasing patient volume and reducing time to complete procedures. Management teams bring efficiency-optimizing techniques from the factory floor to the hospital floor. Physicians sell their services to investor groups, pharmaceutical companies, and marketing firms (Saul and Anderson 2005; Topol and Blumenthal 2005). Private hospitals hire hotel managers to improve customer service. Hospital chains run much like other large corporations. Medicine, and more broadly, healthcare, is embedded within a larger service-oriented, bureaucratized, profit-driven market economy.

With the shift away from covenant-like relations to contracts between buyers and sellers, standard market mechanisms come into effect. Vendors try to maximize their economic returns using commonplace advertising techniques to increase market share. Hospitals compete for

patients and try to "build their brands" and control costs while maximizing revenues (Hudson 1999; Petromilli and Michalczyk 1999). In turn, customers want the best possible services at the lowest possible prices. With no special moral ties connecting patients to doctors, patients paying out-of-pocket for care comparison-shop and go where they can get the lowest prices on services. In a global economy in health services, the best prices for healthcare are typically not found at U.S. hospitals. Customers with limited financial resources are compelled to "offshore" themselves to get affordable treatment (Appleby and Schmit 2006; Foreman 2006; Garloch 2006; Kerr 2006). Given the high cost of healthcare at American medical facilities, price-conscious consumers travel from Durham to Delhi and from Boston to Bangalore to get the best deals for health services. Bound by moral covenants, patients and physicians are connected by ties that are not reducible to market transactions. Brought together through contractual relations, patients relate to doctors as buyers to sellers. The notion of a covenant, binding physicians to patients, makes little sense in an economic context in which patients select healthcare facilities on the basis of price, travel to countries to which they have no ties, receive services from physicians with whom they have no prior relationship, and then leave as soon as they receive the services they purchased. Buying medical interventions becomes much like buying other goods and services in the global marketplace. Locale loses much of its significance; medicine becomes "de-territorialized" as customers shop for the best returns on their expenditures.

The Customer Is Always Right

The integration of health services with the global marketplace is connected to a radical shift in the internal morality of medicine. In more traditional models of the patient-physician relationship, the ancient maxim Primum non nocere ("First, do no harm") is supposed to guide the practice of medicine. According to this norm, physicians must exercise clinical judgement when deciding whether or not a treatment is "medically indicted." In service-based market transactions, the guiding principle of business is, "The customer is always right." Clients, rather than vendors, should decide what they would purchase. Satisfying customer preferences played an important part in making Bumrungrad a leading destination for international patients. Such a philosophy, embedded as a core norm in the global delivery of health services, is reshaping the practice of

medicine. Satisfying customers' desires is different from respecting the internal morality of a profession guided by norms of beneficence, non-maleficence, and clinical judgements about what care is warranted. A global health-services market will enable some patients to obtain medical care that they could not afford to purchase in their local communities. However, it will also contribute to the spread of a consumerist ethos in which healthcare providers serve the needs of customers rather than respect medicine as a practice with internal standards.

Contracts and Caveat Emptor

In the United States, physicians have legal obligations to disclose risks, benefits, alternatives to treatment, and consequences of non-treatment. The concept of informed consent is, in part, based on this moral and legal duty. In the global marketplace, contracts tie customers to providers of health services. In marketplace transactions governed by contracts, vendors have obligations to purchasers but much greater emphasis is placed on the responsibility of buyers to exercise diligence when making purchases. Medical brokerages state that they merely "facilitate" or "coordinate" healthcare services; they assume no legal liability in the event of adverse events, medical error, negligence, or medical malpractice. Visitors to medical brokerage websites are told that customers choose where to obtain medical care, what procedures to purchase, and whom to select as physicians. Clients are told to "do their homework" before purchasing health services. Before customers sign contacts with medical brokerages they sign waiver-of-liability forms. These documents are designed to shield brokerages from legal action if their clients suffer harm when obtaining treatment abroad. Countries such as India, Malaysia, the Philippines, and Thailand are not known for strong regulatory or oversight mechanisms in the field of healthcare (Mudur 2004b). Physicians in these settings typically pay low rates for medical malpractice insurance. Plaintiffs rarely receive significant settlements even if malpractice or negligence is established. Although a global market in healthcare services exists, there is no accompanying transnational legal infrastructure governing the international sale of health services. "Buyer beware" accurately captures a global economy in which customers can purchase health services but often find they are unable to obtain redress when they are harmed while being treated.

Communication: Informed Consent and Selling Services

The profits to be gained from selling medical services in the global marketplace will have a profound effect on social interaction with customers. Medical brokerages are in the business of selling healthcare. Sales representatives at automobile dealerships do not encourage customers to try walking to work, riding a bicycle, or buying a subway pass before considering purchase of a vehicle. Medical brokerages are the car dealerships of the global health-services industry. They exist to sell health services in volume. They are not bound by a professional code of ethics or the traditional fiduciary duties of physicians. The profit imperative is likely to shape how they provide information to customers. To boost sales, brokers will be inclined to exaggerate benefits, minimize risks, leave alternatives to treatment unmentioned, and accommodate customers' preferences.

Medical brokerages and international hospitals want to sell their services. In marketplace transactions where medical brokers are not bound by professional codes of practice and where destination hospitals have made substantial financial investments to attract international clients, both medical tourism companies and international hospitals want to boost sales. Bonds of neighbourliness, duty, and community will not temper these market transactions. Business interests are likely to have a significant effect on what information is communicated to clients.

Global Privatization of Health Services

News media coverage of medical tourism commonly addresses risks related to obtaining treatment abroad. This orientation toward the interests of travelling patients overlooks how global privatization of health services undermines local access to healthcare. Private, for-profit hospitals in India, Thailand, and other nations sell services to foreign patients, expatriates, and local economic elites and sufficiently wealthy middle-class patients. They do not provide healthcare to local citizens with limited economic resources. Indeed, they maximize profits and offer better rates than many competitor hospitals by refusing to cross-subsidize care of low-income patients.

Privatization of health services in countries such as India and Thailand does not simply put healthcare beyond the reach of local patients. It also undermines publicly funded healthcare facilities. With higher salaries in private hospitals catering to medical tourists, public

healthcare facilities in Thailand and elsewhere have difficulty retaining healthcare providers. "Brain drain" occurs from publicly funded hospitals to private medical centres (Wibulpolprasert et al. 2004). As doctors and nurses leave public institutions, the differences between public hospitals and private institutions are magnified. Public hospitals become the healthcare destination of last resort even for low-income patients who cannot afford treatment at for-profit private hospitals. Promotion of medical tourism in such countries as India and Thailand is likely to undermine national efforts to improve health equity. For-profit hospitals in these countries maximize profits by ignoring the low-income populations that surround them.

The spread of privatized, for-profit health centres around the world benefits customers with the financial resources to purchase care. It risks harming low-income patients by hollowing out public healthcare facilities and undermining public access to affordable care. The rise of medical tourism is related to the global spread of a form of capitalism that tolerates striking inequalities in income and health.

Conclusion

The percentage of the U.S. population lacking health insurance is growing. Denial of claims, pre-exclusion criteria, high premiums, and co-payments further reduce access to care. As premiums for health insurance climb, jobs in manufacturing and service industries are moving to countries where labour costs are lower than those in the U.S. Employees who keep their jobs often must surrender health benefits in negotiation with company management.

At the top of the U.S. economic pyramid, the country's elite remains able to purchase healthcare at American medical facilities. Lower- and middle-income individuals increasingly struggle to afford the cost of healthcare in the U.S. Thoroughly enmeshed in the larger market economy, healthcare in the United States now takes the form of other service industries. It defers to customer preferences, is sold using standard marketing techniques, and is available for purchase to those consumers with sufficient economic resources. Older notions of the physician's covenant have little place in such a market-driven health-services industry. Secularized, stripped of any special meaning, diminished to just another service available for purchase in the marketplace, with personal ties to patients replaced by impersonal interactions inside large bureaucracies, hospitals must now compete for customers in the global health-services economy. Wealthy customers are still able

to afford healthcare in the United States. Lower- and middle-income Americans increasingly find themselves drawn to offshore hospitals offering health services at discount prices. With the physician's covenant but a faint memory, the age of global comparison-shopping for health services has arrived.

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"Our Women are Berehynia": (In)Authentic Femininity and Addiction in Western Ukraine

Maureen Murney

Abstract

Based on 13 months of ethnographic fieldwork in western Ukraine, this research explores the relationship between: i) discourses of 'normative' and 'deviant' behaviour; ii) health-seeking practices; and iii) the daily lived experiences of western Ukrainian women and men who are addicted to alcohol. In particular, this research illuminates the gendering of meanings and experiences regarding alcohol consumption, addiction, and treatment. For men, drinking is a marker of masculinity that is difficult to avoid. Problem drinking is interpreted as an understandable (if regrettable) response to a political-economic situation that is changing so rapidly that adaptation is difficult. For women, however, a difference is recognized between acceptable social suffering that provides laudable evidence of strength and endurance (e.g., coping with a husband's or son's addiction) and the unacceptable suffering of those who are themselves addicted. Women are expected to overcome their personal circumstances and embody the 'authentic' Ukrainian woman who protects her family and nation. Women who are addicted to alcohol, then, are seen to have consciously rejected the very essence of Ukrainian womanhood. These moral parameters not only affect perceptions of women's alcohol addiction but also constrain women's ability to "confess" and seek treatment.

Introduction

This paper is based on 13 months of ethnographic research in the western *oblasts* of L'viv and Ivano-Frankivsk, Ukraine; most of the fieldwork was carried out in the city of L'viv, a large urban centre with a population of about 800,000 people. I was there to explore the relationship between: i) discourses of 'normative' and 'deviant' behaviour; ii) health-seeking practices within and outside of official healthcare

institutions; and iii) the daily lived experiences of western Ukrainian women and men who are addicted to alcohol, especially mothers and women of reproductive age. Following a Master's program in which I studied the discourses surrounding fetal alcohol syndrome in North America, I came to Ukraine with an interest in the ways that stigma is used to circumscribe women's behaviour. I was also curious to return to the land of my maternal grandparents. What became apparent was that understanding cultural practices and meanings associated with drinking was anything but straightforward. For example, several months after my arrival, I was graciously invited to a friend's dinner party for Easter. The women each drank half a glass of wine while the men had a lot of vodka, then cognac. Laughing and joking, the men kept pushing me to drink the hard liquor. While I refused to gulp it back, they cheered with delight when I began sipping a shot of vodka. The women were quietly horrified. Throughout the evening, I watched the women acting as moral barometers for the men. They would whisper loudly into the men's ears when the men became too rambunctious. I began to realize the whispering was not only for the benefit of the men; it was so loud the women could witness one another's good behaviour.

Anthropologists have been studying drinking for decades; Ruth Bunzel published groundbreaking, comparative work on the relationship between alcohol consumption and culture in 1940. Following in the footsteps of many others, in this study, "the places and behaviours of drinking" are not "conceived as small ethnographic windows on more important structures and actions" (Wilson 2005, p. 3). Rather, I agree with Wilson that "drinking alcohol is an extremely important feature in the production and reproduction of ethnic, national, class, gender, and local community identities, not only today but also historically" (2005, p. 3). This region of the world has a long-standing relationship with alcohol. Indeed, Boris M. Segal begins his book, *The Drunken Society*, with the claim that "[c]ommunal intoxication was an important social custom among ancient Slavic tribes" (1990, p. 1). Segal adds: "[a]ccording to legend, the Varangian prince Vladimir, who reigned in the tenth century Kievan Rus [the predecessor state to Ukraine, Belarus, and Russia] and accepted Christianity in 988, had rejected Islam because the latter prohibited alcohol. 'Drinking is the joy of the Rusi,' declared Vladimir; 'we cannot do without it.'" (1990, p. 2). This part of the story was absent when Ukrainians regaled me with stories about how Volodymyr (Ukrainian for 'Vladimir') brought

religious salvation; perhaps this should not be surprising given the strong religious adherence in the western region of Ukraine.

While conducting this project there were three groups of people I interviewed and observed. The first group I categorize as my primary participants: those who *self-identify* as being addicted to alcohol. A great deal of debate has occurred over recent decades regarding the definitions of 'alcoholic,' 'heavy drinker,' 'addict,' and the like. By working with people who self-identify as addicted, I was able to avoid the epidemiological exercise of attempting to measure how much alcohol people consume; this was not the focus of the current research. In addition, working with those who self-identify fore-grounded substance users' *own perceptions*; as an anthropologist, I felt this was important. The second group of people I worked with can broadly be described as healthcare workers, and include physicians, nurses, social workers, sociologists, and psychologists. The third group consisted of people who were not overtly connected to addiction in any way; they provided me with general knowledge of cultural values and practices.

Unlike many other fields, in anthropology, the ethnographer is just as likely to study 'normal' as 'deviant,' 'excessive,' or 'problematic' drinking (Heath 1987). Worldwide, heavy drinking among men tends to be more prevalent than among women, and this is clearly also the case in Ukraine, so why did I focus on women? Certainly, this paper is *not* meant to add to a moral panic regarding women's drinking or any other practice. Rather, a major reason was this: if nationalism requires women to have "babies for the nation" because otherwise the nation will "die," and if this is especially prevalent in newly emerging states like Ukraine (Rubchak 1996, p. 328), then what might be the consequences for Ukrainian women who are addicted to alcohol? Here, then, I want to examine how specific moral parameters are being used to strictly define women's citizenship roles in western Ukraine, in ways that deeply affect women's addiction experiences. First, I will briefly describe the historical 'moment' in which I conducted my fieldwork. This will lead to my discussion of the relationship between gender, nationalism, stigma, and addiction. All names are pseudonyms unless otherwise indicated.

The Fieldwork 'Moment'

Ukraine is a former republic of the Soviet Union, and claimed independence in 1991. Less than a month after my arrival in October 2004, another political sea change swept the country. Viktor

Yanukovych was elected president, but these elections were largely regarded as fraudulent, with many people believing that Yanukovych's rival, Viktor Yushchenko, should have won. Ukrainians around the country responded by doing something that many assured me was fundamentally new — they protested. These protests became known as the Orange Revolution, orange being the colour that signified Yushchenko's campaign (I also heard the term 'Chestnut Revolution,' referring to the many chestnut trees lining the streets of Kyiv, the country's capital and the centre of the pro-democratic demonstrations).

If Yanukovych was seen to represent the "Russified" eastern side of the country, then Yushchenko represented the more "traditional," Ukrainian-speaking west. Yanukovych endorsed close economic and social ties with Russia and was openly supported by Russian president Vladimir Putin. Yushchenko, on the other hand, promoted democratic reforms and friendlier relations with the European Union. (Ukraine shares its western border with Poland, a member of the European Union.) Regarded as young and handsome, Yushchenko also represented an easier and wealthier future — he seemed to embody a glamour that was associated with capitalism. Yushchenko's dioxin poisoning and facial disfigurement, allegedly at the hands of a government official, were seen to threaten the promise of democratic reform, and only strengthened people's resolve to oust the pro-Russian government. When he became president, Yushchenko's approval rating was said to be 97 per cent in the L'viv region — or at least this was the figure bandied about over various kitchen tables, restaurant meals, and office discussions.

I had wanted to work in western Ukraine because this region has a long history of nationalism. So it was incredible luck that, just after my arrival, Ukrainians flooded the streets chanting *"Razom nas bahato! Nas ne podolaty!"*[1] ("Together we are many! We will not be overcome!") Immortalized in a popular song by the Ukrainian band Greenjolly, this became the mantra of the Orange Revolution. (I must admit to being less enthused when the chant became an inebriated howl at 2 a.m. outside my bedroom window, or when people drove up and down the streets at all hours, honking their horns and shouting "Yushchenko!" in loud, drunken voices.) Much was made in newspapers and personal conversations about the sobriety of the pro-democratic protesters and the inebriation of Yanukovych's more "Russified" supporters. Indeed, I often heard a similar comparison made about

drinking among Ukrainians and Russians, with Ukrainians claiming to be better mannered.

Figure 1. L'viv from the top of the Town Hall, looking toward Prospekt Svoboba (Independence Avenue) and the Opera House, August 2005.

Figure 2. A young man draped in a Ukrainian flag heads toward a protest in L'viv during the Orange Revolution, while orange ribbons, demonstrating support for Yushchenko, decorate the car behind him, February 2005.

Months later, when the fervour had died down, I met a young man who, along with his friends, refused to mark the end of World War II by celebrating Victory Day (May 9), claiming that this also marked the "beginning of the occupation" by Soviet forces. Still, the rhetoric about

the nationalists of western Ukraine being anti-Russian is often overblown. Almost half of my research participants preferred to speak Russian, the language they speak in their homes, as we sat together in cafés, church basements, or their kitchens, drinking tea and discussing their lives. Moreover, it would be a mistake to think that this region, or the people living here, has a perspective on or relationship with the Ukrainian nation and state that is unchanging over time. For my research participants, there were victories and disappointments, both of which occurred within broader personal, national, and state histories of economic, political, and emotional upheaval. By the end of my fieldwork year, those around me were expressing bitter disappointment that the Yushchenko government had not rectified problems of corruption and the low standard of living. Twenty-five-year-old Adriana exclaimed, "Ukrainian politics is all about personalities. They don't deal with our problems. It's an embarrassment." And 63-year-old Kalyna described another kind of "occupation," that of western capitalism and democracy. Shaking her head, she told me, "Years ago women wore beautiful coral necklaces and now they wear cell phones. [Women literally wear cell phones around their necks.] But capitalism isn't doing anything for me. This democracy isn't working. We should go back to socialism." For many, socialism offered a more stable economic existence. Especially among people who came of age before 1991, there is a nostalgia, a homesickness not for a different place but for a different time, when Soviet state practices afforded a more predictable life course. Fifty-two-year-old Tetyana told me, "When Ukraine became independent, it became worse, much worse. They opened people's eyes, but what's come of it? People live in poverty. Sometimes there isn't enough money to buy bread. It wasn't like this in the past. There was a stable job and a stable salary. And now what? There is no job, no money." On the other hand, while Kalyna maintained that "in the old days we always had money," 26-yearold Nadiya responded by claiming (after waiting until Kalyna was out of earshot), "Sure, before we had money but there was nothing in the shops. Now the shops are full but we have no money."

Gender, Addiction, and Social Transformation

I visited a polyclinic, a kind of out-patient clinic, to talk to physicians and nurses about addiction. These were front-line healthcare providers and I wanted to hear their perspectives. I sat next to one of two large desks in a spacious, windowed room on the first floor as

doctors, nurses, and patients scurried in and out from the hallway where people were waiting. Patients were having their blood drawn and describing their health problems while healthcare providers discussed other cases among themselves and sipped tea. I thought to myself, anonymity is not just absent but simply cannot be present here. Halena, the head nurse and a single mother, was augmenting her meagre government salary by selling smoked fish, arranging it on the newspaper strewn across her desk. (The fish was tasty.) She also sold men's cologne; about 30 or 40 bottles were neatly stacked in the cabinets at the side of the room. (These I declined.) When I asked if people thought of alcohol as a coping mechanism, Halena's retort was quick: "We're all struggling! Why should [alcoholics] be any different? The state should take away their children and send them to work camps. At least they'd be doing something useful." When I explained that I was particularly interested in women's addiction, Christina, a physician sitting next to me, sipped her tea, leaned toward me and explained, "When a man drinks it is bad, but when a woman drinks it affects the whole family."

There are two issues I would like to untangle in the remainder of my paper. First, *we're all suffering* economically, and secondly, with alcoholism we *really* suffer when a woman does the drinking. Alcohol is often explicitly linked with masculinity, and here I will draw upon two examples from popular culture to help illustrate this perception.

Figure 3. Billboard for Shustov Premium Vodka. Photograph provided by Victor Yashin, used with permission.

The billboard depicted in Figure 3 advertises Shustov Premium Vodka. Note the wings in the lower right, torn from the back of this fallen angel who treats his wounds with this Premium Vodka, his reward waiting in bed. Note also the text: *"Shustov Premium. Tradytsiina. Svoboda. Vyboru,"* or, in English, "Tradition. Independence. Choice." Two points are of particular interest here. First, tradition, independence, and choice are being linked to this vodka during the Orange Revolution, the struggle for democracy in Ukraine. Perhaps, then, this is a vodka for democratically minded men who can exert their independence while celebrating their "traditional" Ukrainian identity. Secondly, this is clearly not a drink for women, but for very male fallen angels. The women in the bed are not in sharp focus like the man. Instead, they recline in the distance; they are not important as active individuals, but merely symbolize the reward one presumably receives for drinking this vodka.

Figure 4. Antypolytsai lozenges, available at local pharmacies.

Similarly, the product shown in Figure 4 is a lozenge that purportedly masks the smell of alcohol and cigarettes. Given the name of the product, "Anti-police," perhaps the lozenge is meant to mask alcohol and cigarette consumption if one is stopped by a member of law enforcement. Yet the police are represented by a sexualized female, ready to perform her 'duties' with a smile, wearing a uniform that would inhibit strenuous labour. Hers is a sexual labour. Interestingly, across the

top of the box are the words *"Filosofiia zdrovoho zhittia"* or "Philosophy for a healthy life." Clearly, this product is not being marketed to women. With both the vodka and the lozenge, women are not expected to consume, but are offered to male consumers as sexual rewards for drinking behaviour.

How do such images reflect gendered assumptions regarding actual drinking behaviour? One of my research participants, 43-year-old Yulia, stated, "When I became addicted, every day I went to work, and I took a little bottle of vodka or beer. It was [she named the brand] and on the beer bottle it was written, 'Beer for real men' and I was thinking, oh, so what am I drinking? This beer for real men?" Later, when she began to attend Alcoholics Anonymous (AA) meetings, she found that "it was very hard for me to admit I'm an alcoholic myself because it's most associated with masculinity." On another day, as I walked down *Prospekt Svoboda* with Olha, a social worker, she said, "If we're talking about alcoholics, look at them." She pointed to a homeless person lying on the sidewalk. "We have a sick society. And women? I don't know if I can describe my feelings about that." Olha paused for several seconds. "I'm just so filled with disgust!" I asked Maria, a 33-year-old single mother and alcoholic, about the stigma that women experience. She explained, "The opinion is that if a woman drinks she will have sexual relations like a prostitute. One relative told me, 'You would sleep with a man for a piece of bread.'" Marko, another member of AA, claimed, "A Ukrainian woman from a good family will have half a glass of wine at Easter and another half at Christmas from the same bottle." The common rationalization, he said, is that "Ukrainian culture is a matriarchy. What would be forgiven for a man is long remembered for a woman."

What underlies this disgust that is almost unspeakable? Another incident provided some explanation. I was in another polyclinic asking questions about addiction among women when a female doctor reacted angrily. Pointing aggressively at me, she exclaimed, "Our women know better! They are mothers. They are religious. They are *Berehynia!" Berehynia* refers to a Ukrainian pagan goddess, a protector of the family hearth, who has, in recent years, been re-imagined as protector of the contemporary Ukrainian nation. She, along with the Christian Virgin Mary, is being referenced in print, on television, and in *everyday conversations* to define the role of women as protectors of both family and nation. Since Ukraine gained independence, the combined roles of wife and mother have been described as the most "nat-

ural" performance of femininity, and have been valorized as the central means for Ukrainian women to practice citizenship. Rubchak describes this construction of motherhood as a "God-given mission" to rebuild the nation, for women are to produce "saviours, that is to say the geniuses, philosophers, and military leaders of the nation. There is, of course, no thought of such outstanding individuals being female" (1996, p. 319). Pavlychko calls this "cult of the mother" a new kind of totalitarianism (1996, p. 307), because "a direct connection is established between restrictions of female activity — such as holding high public office, for example — and the process of state-building" (1996, p. 318). Despite the popularity of Yulia Tymoshenko, who was Yushchenko's first prime minister and who remains a major political figure, women's participation in the so-called public sphere is generally limited. For instance, women often work, but their work is not defined as career-related but rather as a practical and necessary way of protecting the economic well-being of the family. Though few can afford it, to be a mother who does not work outside the home is to be genuinely Ukrainian (Pavlychko 1996, p. 316). Notions of feminism, emancipation, and equality are "political dirty words" because the Soviets used these terms to describe their need for women to bear the so-called "double-burden," working outside the home while simultaneously maintaining responsibility for all domestic work (1996, p. 306). There is a widespread perception in Ukraine that "Soviet society contaminated and vulgarized the essence of masculinity and femininity" (Wanner 1998, p. 112); based on discussions with my participants, as well as an examination of books, journals, newspapers, and women's magazines, the valorization of this newer, more "natural" femininity appears to be occurring across Ukraine. If "gender and ethnic imagery are wound together as moral order in opposition to disorder," (McDonald 1994, p. 23), then women who are addicted are perceived to have abandoned their families, and by extension, their nation. They are seen to have consciously rejected the very essence of Ukrainian womanhood. They are no longer considered truly Ukrainian. Given the stigma associated with women's addiction — and this is a crucial point — women are reluctant to "confess" and seek treatment. Moreover, secrecy is crucial to decision-making regarding treatment choices.

I agree with Dragadze, who has written about gender roles and alcohol consumption in Georgia prior to 1989, that to describe women's abstinence as merely reflecting women's oppression is inadequate

(Dragadze 1994). Before and after 1989, women have derived a great deal of social status and authority through their domestic roles, status that would be lost if women drank heavily. Moreover, calls for women to 'return to the home' were being voiced in Russia even before the fall of the Soviet Union (Albanese 2006). Thus, social sanctions and stigma associated with alcoholism operate as an effective preventative measure for many women. And while Marko's claim about the half glasses of wine underscores an almost mythic abstinence, it does highlight the cultural stories that people tell about heavy drinking and the role of women. An article in a popular women's magazine, *Uspekhi i porazheniya (Successes and Defeats)*, includes a cautionary tale about a 24-year-old woman, "Iryna," who falls into moral and physical degradation, losing two jobs in one week due to her drinking. She loses one of those jobs, as a teacher, after sleeping with a 16-year-old student (interestingly, she would not have been found out had she bowed to her student's extortion; he was willing to conceal her misdeeds if she gave him an excellent mark). What is striking is the unbridled, inappropriate sexuality, reminiscent of Maria's statement about "having sexual relations like a prostitute."

Figure 5. A monument to Ukrainians in Kyiv stands next to a Soviet monument celebrating workers. While men may be Cossacks, statesmen and bandura players, the only role depicted for women is that of mother.

Urban women who came of age during the Soviet era were especially reluctant, it seemed to me, to drink more than half a glass of wine (or vodka imbued with herbs for medicinal purposes) in front of this foreign researcher.[2] While many of the women I interviewed came of age during the Soviet era, cautionary tales like Iryna's may indicate changing

attitudes toward alcohol among younger women and/or increasing discomfort about young women emulating "freedoms" perceived to be Western. Indeed, Webb et al.'s epidemiological study[3] of heavy alcohol use in Ukraine found that the likelihood of heavy alcohol use was higher for women aged 18 to 25. In contrast, heavy drinking was found to be more prevalent in men aged 26 to 54 (2005, p. 332). Ukrainian men's heavy drinking during middle age is consistent with findings in Russia and other post-socialist states, but stands in stark contrast to the situation in North America, where heavy drinking is thought to decline after age 25 with increasing responsibilities at work and at home (2005, p. 333).

Why is the drinking pattern so different between women and men? This is a complex question. A very partial answer is that while the rules of conduct for men are also strictly enforced, these social rules advocate widespread drinking. One participant, Roman, pleaded, "What can I do? If someone has a birthday at work, or some other kind of celebration, there will be a bottle [of vodka], and I have to have some." When I asked what would happen if he didn't, he said, "I'll be ostracized." Being ostracized at work when it is already difficult to make ends meet is a dangerous prospect. Then again, so is the drinking. According to Popova et al. (2007), binge drinking is more common and is a norm among men in countries where vodka (as opposed to wine) is the preferred alcoholic beverage. It is important to differentiate between heavy drinking and problem drinking; despite high rates of heavy drinking, Webb et al. found that these appear to be normative — only 23.1 per cent of male and 11.2 per cent of female *heavy drinkers* met diagnostic criteria for an alcohol disorder (2005, p. 333). Nonetheless, binge drinking is linked to illness and premature death (Rajendram et al. 2006), an important concern given the falling population rates often lamented with the phrase, "Our nation is dying."

Still, when drinking becomes a problem among men it is met with a sympathy that women do not enjoy. This point is not only about gender but also about the political-economical situation. A common claim among my participants was that men drink because they are not as flexible as women, they less able to adopt or adapt to a changing "system of priorities and values." In other words, they are less capable of adapting to the new capitalism, especially if this means doing work with lesser authority and status. Women, on the other hand, are said to be more flexible. They are not expected to place their status or identity

in work outside the home, but rather, in being a mother and wife. They will work in the market or on farms, or transport goods across borders — low-status jobs that gain status when they are interpreted as providing support for a woman's family. A psychologist at the Narcology Hospital (an in-patient addiction treatment centre) claimed that women may become addicted while attempting to cope with low self-esteem, a lack of a sense of self-fulfilment, family problems (including domestic violence), and anxiety from social and economic pressures. Interviews with women who are addicted support this. Yet social suffering among women who are addicted is not met with sympathy because addicted women have not overcome their personal circumstances to embody the *Berehynia*. For women, then, alcohol addiction has become "an element of the performance and the evaluation of ethnic identification" (Room 2005a, p. 323), and in this region of Ukraine, symbolizes an abandonment of the nationalist project.

Conclusion

One of the most interesting findings in Webb et al.'s study was that national rates of heavy drinking in Ukraine were comparable to those in Russia. However, there was striking regional variation, with the highest rates in the southeast region, as opposed to the northern-central and western regions (2005, p. 333). The southeast region is heavily "Russified." This supports western Ukrainians' perception that Ukrainians drink less than their Russian counterparts. Perhaps cultural values and norms in the western regions are somewhat protective; more research is needed to compare regional findings.

A great deal of addiction research, including anthropological work, pays particular heed to "the impact of structures of social relationship, including unequal and oppressive social connections like interclass relations, on human action" (Singer 2006, p. 12). Indeed, it is generally assumed that the burden of suffering, from any ailment, including addiction, is disproportionately carried by those at the bottom of the socio-economic ladder. But what happens when, as Halena the head nurse said, "We're all suffering." What then makes alcoholics different from other people and from one another? The answer is hardly straightforward, but clearly, some suffer more than others. Here, I have not considered the enormous income gap between the billionaire oligarchs and the nurses selling smoked fish. Nor have I considered the myriad ways that the economic situation affects the quality of healthcare. (These are other papers entirely.) Rather, I am

attempting to grapple with the multiple structures, practices, and meanings that intersect to affect the lived experience of addiction in Ukraine — factors that are very different from those in North America and Western Europe.

This project takes a small step toward addressing calls for alcohol-related research in Eastern Europe given the high burden of disease (Rajendram et al. 2006), as well as research on stigmatization in different societies and environments (Room 2005b). In particular, this research illuminates the gendering of messages regarding alcohol consumption and treatment. For men, drinking is a marker of masculinity that is difficult to avoid. Moreover, it is interpreted as an understandable (if regrettable) response to a political-economic situation that is changing so quickly that adaptation is difficult. For women, however, a difference is recognized between acceptable social suffering, which provides laudable evidence of strength and endurance (e.g., coping with a husband's or son's addiction), and the unacceptable social suffering of those who have "fallen," who have not overcome their personal circumstances to embody the "authentic" Ukrainian woman who protects her family and nation. Women are deemed more difficult to treat for alcoholism; this is often ascribed to a weaker "organism," or in other words, a lesser physiological ability to "handle" alcohol. However, I argue that the stigma women face, which makes them reluctant to "confess" and seek treatment (whether at a Narcology Hospital, an AA group, or elsewhere), contributes significantly to women's burden of suffering, and should not be underestimated.

Notes

1. Transliterations from Ukrainian to English are based on the U.S. Library of Congress system.

2. A crucial factor in any ethnography is the ethnographer herself (or himself). Anthropologists have written volumes about objectivity, subjectivity, and reflexivity in ethnographic research. For my purposes here, suffice it to say that this research was unquestionably affected by my position as a woman, a feminist, a Westerner (who was presumed to be American and wealthy), a person of Ukrainian descent, a grand-daughter of "peasants," and an anthropologist (anthropology was associated by some with the study of folklore or with the relocation of villages during the Stalin era). I would especially like to note that a male ethnographer would not have been able to obtain some of the information that female participants generously shared with me. By the same token, I did not get the kind of data a male researcher would have gathered by "drinking with the boys."

3. It should be noted that this research was based on self-reporting, which may have led to under-reporting (Webb et al. 2005, p. 334). Nonetheless, Webb et al.'s study provides a compelling picture of heavy alcohol use in Ukraine, in no small part because it is not based on reports from Narcology Hospitals (in-patient addiction treatment centres) and Narcology Dispensaries (out-patient centres). While locally gathered statistics are useful, they do not include those who actively avoid the official healthcare system, an occurrence I found to be far from rare.

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Qualitative and Quantitative Analyses of Reproductive Change in Ethiopia: A Focus on Urban Areas and Urban-Rural Differences

Daniel Sahleyesus and Roderic P. Beaujot

Abstract

Fertility levels in most urban areas of Ethiopia have declined substantially in the face of low levels of socio-economic development. In contrast, rural fertility remains at high levels. Employing a combination of quantitative and qualitative research approaches, this study examines people's orientations toward reproduction, including the perceived benefits and associated costs of childbearing, and their attitudes concerning the changing reproductive behaviour in urban areas. It also examines the extent to which demographic, proximate, and socio-cultural factors can account for the urban-rural differences in fertility.

Qualitative data were obtained through in-depth interviews and focus-group discussions. It was observed that urban residents have reproductive goals that take into account costs and risks in the face of economic hardships, and a desire to achieve upward social mobility. Parents place emphasis on the well-being of a relatively smaller number of children and on attaining a certain level of investment in their own human capital, which is incompatible with large family size preferences. In addition, the findings suggest that induced abortion might have some role in regulating fertility in urban areas.

Data for the quantitative analysis came from the first Ethiopia Demographic and Health Survey (ETDHS). Life-table techniques were used to estimate the median ages at different parities and median durations between successive births, in urban and rural areas. A series of parametric hazard models were estimated to examine the effects of

theoretically relevant demographic, proximate, and socio-cultural covariates on the timing of births. Across all transitions, women who experienced child loss had faster transitions and, therefore, higher likelihood of subsequent births. Other covariates, such as union status, religion, and contraceptive use, were also observed to have significant effect on the timing of births and to play a larger role in urban areas. A major implication from these findings is that improving child survivorship is an important moderating factor in high fertility conditions, particularly in rural areas. The results also indicate that future studies are needed to conduct separate analyses of marital and non-marital fertility and examine the extent of induced abortion in urban areas.

Introduction

Like most sub-Saharan Africa countries, Ethiopia has only recently joined the global fertility transition. The country adopted a national population policy in 1993 that aimed to reduce the total fertility rate (TFR) from its 1990 level of 6.4 children per woman to 4.0 children per woman by 2015. Seven years after this policy was put in place, the 2000 ETDHS reported that the TFR was 5.9 children per woman. Findings from a recent survey show that the country's TFR continues to decline and, currently, it stands at 5.4 (Central Statistical Authority and ORC Macro 2006). Despite this, the level of fertility varies greatly between urban and rural areas: urban areas have a remarkably low fertility compared to rural areas. In 2000, the TFR in urban areas was 3.3, compared to 6.4 for rural areas (Central Statistical Authority and ORC Macro 2001). Currently, average numbers of children per woman for urban and rural areas are 2.4 and 6.0, respectively (Central Statistical Authority and ORC Macro 2006).

Although fertility differences between urban and rural areas have been observed invariably across populations, this study was motivated by three points. First, there is a difference of over three children per woman between urban and rural areas, which is a substantial difference compared to that of other countries. This phenomenon applies to only four other countries in sub-Saharan Africa: Burkina Faso, Tanzania, Togo, and Uganda, as indicated by their most recent demographic and health surveys (ORC Macro 2005). Second, some urban areas, such as Addis Ababa and Harar, have even achieved a below-replacement level of fertility. Third, although urban areas are better served with economic progress and social services, the overall social

and economic development of these centres does not parallel the level that is normally seen in the literature as necessary to bring about such a rapid decline in fertility.

Past studies on reproductive changes in Ethiopia examined fertility differentials largely on the basis of quantitative data. The gap between urban and rural fertility has also focused on the capital city, Addis Ababa (for example, Kinfu 2000, 2001; Sibanda et al. 2003). Studies that extend similar investigations to other urban centres of the country are scarce. In addition, the analysis of the impact of proximate, demographic, socio-economic, and cultural variables on the timing and spacing of births has important policy implications. In this context, this study raised the following key questions: What are the possible explanations for the faster decline of urban compared to rural fertility? What demographic, proximate, and socio-cultural variables are responsible for the differences in fertility levels between urban and rural areas?

Theoretical Considerations

This study makes use of explanations from various theoretical perspectives on fertility change. In 1890, Dumont (Spengler 1979) observed that it is the "social capillarity" principle that triggers fertility change. This hypothesis postulates that in an environment where people see opportunity for self-advancement but where success is not assured, as is the case in urban centres, modifying their fertility behaviour is a strategy to realize their aspirations. The idea that childbearing may hinder the realization of achievable goals during good times, or that it may cause the reversal of earlier achievements during periods of economic deceleration, is an important determinant of reproductive change (Casterline 2001). Coale (1973) observed that for reproductive change to take place, three preconditions must be fulfilled. Namely, couples must be "willing" to make change they think is legitimate (to control family size), "ready" to take advantage of smaller family size, and "able" to have access to contraceptives, which translates the readiness and willingness into action (see also Lesthaeghe and Vanderhoeft 2001).

The role of improved child survival in affecting fertility has also been extensively discussed in earlier, as well as in contemporary, studies of demographic transition (Notestein 1945; Davis 1963; Cleland 2001). For instance, Cleland (2001) argues that in the case of developing countries, a plausible explanation for fertility change comes from the

preceding large reduction in mortality. Another suggestion is to examine the causes and consequences of reproductive change by employing a unified framework that brings together socio-economic changes and changes in ideologies, attitudes, and the mechanisms of fertility decline (Caldwell 2001). In this respect, this qualitative study assesses: whether there are changes in the ideas and motivations of individuals regarding the benefits of smaller families; the use of family-planning methods; and the practice of induced abortion, which may have been associated with the urban fertility decline. The quantitative analysis tests the independent effects of socio-demographic and cultural variables on the timing of births.

Research Approach

This study sought to contribute to the understanding of the decline in fertility levels in urban and rural areas by employing both qualitative and quantitative research approaches. The qualitative approach aimed at identifying people's ideas and motivations in reproductive decision-making and related issues. The qualitative data were collected through fieldwork conducted during the months of May to August of 2004. In selecting individual participants for the qualitative study, background characteristics such as marital status, religion, ethnicity, education, and employment status were taken into account. Once potential interviewees were identified, the purpose was explained, along with the issues to be covered. Subjects were then asked if they would be willing to participate in the study. A total of 97 individuals from five major urban centres voluntarily participated in the study. The data collection strategies included in-depth individual interviews and focus-group discussions. All in-depth interviews and focus-group discussions were tape recorded and then translated into English and transcribed. The qualitative software package NVivo was used to organize and analyze the data. The qualitative study provides detailed narratives on how urban residents view reproduction, on the rationales given for reproductive decision-making, and on the views of urban residents regarding the nature of and change in urban areas. In addition, the qualitative research included information from both men and women, given the fact that men are an important component of the fertility process.

In addition to the qualitative approach, the study undertook a quantitative analysis of birth history data from the 2000 Ethiopian Demographic and Health Survey. Data were obtained from women

between the reproductive ages of 15 and 49. The focus of the quantitative analysis was to examine the relationship between a set of theoretically relevant covariates and the timing of births for urban and rural areas. The quantitative part of this study used two techniques of event-history analysis: life-table and parametric-hazard-model analyses. The use of parametric hazard models, which have not been much used in the analysis of fertility in Ethiopia in the past, proved useful for explaining the differences between urban and rural fertility.

The study also illustrates that, in studying reproductive behaviour, qualitative and quantitative approaches complement each other and much can be gained by combining the two.

Summary of Major Findings

The results from the qualitative study show that people referred to certain key values when they talk about the reasons for having children. Table 1 summarizes responses from one-to-one interviews.

Table 1. Percentage Distribution of One-to-One Interviewees, According to Their Responses to the Question "Why Do People Have Children?" by Sex

Attitude	Female	Male	Total
Reasons for having children*	**(N=29)**	**(N=31)**	**(N=60)**
To see oneself through children	48.3	45.2	46.7
Children provide joy	65.5	12.9	38.3
Support in old age	34.5	29.0	31.7
Follow the will of God	17.2	16.1	16.7
To continue the family tree	10.3	19.4	15.0
To have inheritor/heir	6.9	22.6	15.0
To have children is natural	13.8	12.9	13.3
Strengthen love between couple	20.7	6.5	13.3

** Question that allows multiple responses*

Both men and women interviewees observed that children provide economic benefits and other instrumental assistance. In addition, respondents suggested that having children awards psychological benefits to parents while interacting with children provides a source of happiness and warmth to the relationship between couples. Similar findings were obtained from focus-group discussion participants.

Respondents also argued that parents draw financial and emotional support from children, especially during old age. Continuing the family line, having heirs, and fulfilling God's will are all important dimensions related to having children, as the following interview excerpts substantiate:

> Why I wanted to have children is because they will support me in many ways, they will feed me, they will defend me, and if I can, I will educate them. (IDI-16, married woman, 35 years old)

> … to have a descendant, a successor. Children take care of parents in their old age. For myself, I will have someone who will take care of my funeral, be my namesake. (IDI-44, married man, 38 years old)

> When I get older, no one but my children will be there for me. So, having children is very important. It is also your child who inherits your property. (IDI-50, single woman, 19 years old)

Children are seen as especially important in their capacity to take care of parents during old age, including during the final hours of life, and even beyond this life. Having children helps to make sure parents are well cared for while alive; parents can die knowing that their funeral and related ceremonies will be properly handled. Like in many other countries, Ethiopian culture attaches great value to both birth and death. As a result, both events are highly celebrated. As parents are delighted to have children who provide them self-fulfilment and status in the community, they also like to have the peace of mind of having surviving children who would take care of their funeral ceremony and who will carry on their name. Having heirs and continuing the family line are more important to men, while cementing love within the couple and improving their acceptability to the husband's family are more important to women. Many female participants stated that the presence of children within marriage prevents divorce. The following transcript from a focus-group discussion conducted in Bahir Dar substantiates this idea:

> Moderator: Why do people want to have children?

> Respondent # 3: If couples don't have children, they won't have a warm marriage. The husband may divorce his wife if she does not give birth to a child.

> Respondent # 6: … If the wife does not give birth, the husband's family can disturb their peace. (FGD-4, women)

A similar notion was held by male focus-group discussion participants from the capital, Addis Ababa:

> Respondent # 5: … If you do not have a child, you won't be happy, however successful you are. Families without children are prone to divorce.
>
> Respondent # 6: Having children is a symptom of health. It is also a matter of satisfaction… (FGD-2, men)

This study shows that, for men, the instrumental aspects of the expected benefits from having children are most important. For women, the rewarding interaction, in the form of being happy and creating a warm relationship within marriage, are the most important elements. Psychological rewards such as *'to see one's eyes with one's own eyes'* or *'living through one's offspring'* are important motives for having children for both men and women.

While the attitudes toward childbearing are very positive, there are also constraints. These are especially visible through attitudes on family-size preferences, as Table 2 depicts.

A family of six or more children is defined as large by the majority of participants in the qualitative research, and about three-quarters disapproved of large family sizes. On the other hand, a family of two children is considered small. Rural residents, the less privileged, those with less education, and contraception non-users are seen as having large families. The significantly shorter transition time between births observed for rural women in the quantitative analysis further confirmed the results of the qualitative analysis (Table 3). Conversely, those who choose small family size are seen as better educated, having a higher standard of living, and wanting to pave the way for the success of their children by sending them to the best schools and investing more in their children.

It is observed that, on average, the ideal number of children for focus groups and for in-depth interview participants is slightly above three. This number is justified in various ways, but the primary reason was to ensure that enough resources are available for the proper care and education of young children. The other justifications for the ideal family size are to achieve desired sex composition of children and to take into account the uncertain child survivorship conditions. For instance, it was observed that having one child is risky, as demonstrated by the saying *"one child is for one day."* Since there is always a chance that the only child may not survive, respondents felt that there should be additional children. The effect of child survivorship on the timing of births was also clearly observed in the quantitative analysis.

Table 2. Percentage Distribution of One-to-One Interviewees, by Attitudes Towards Large and Small Family Sizes by Sex

Attitude	Female	Male	Total
Family size one considers large	**(N=29)**	**(N=31)**	**(N=60)**
2-3	7.1	6.5	6.8
4-5	32.1	48.4	40.7
6+	60.7	45.2	52.5
Who has large number of children?*	**(N=29)**	**(N=31)**	**(N=60)**
Low income and other disadvantaged groups	51.7	48.4	50.0
Those with no formal education	65.5	12.9	38.3
Highly religious people	34.5	29.0	31.7
Family planning non users	44.8	19.4	31.7
Those who don't understand what it takes to have and raise children	17.2	19.4	18.3
Rural residents	27.6	12.9	20.0
Those with traditional values and ideas	13.8	6.5	10.0
Rich people	10.3	9.7	10.0
Those in polygamous marriage/ have multiple sexual partners/women with no household decision making power	10.3	3.2	6.7
Attitude toward large families	**(N=29)**	**(N=24)**	**(N=54)**
Approval	3.4	12.5	7.5
Conditional approval	17.2	20.8	20.8
Disapproval	79.3	66.7	73.6
Small family size	**(N=25)**	**(N=26)**	**(N=51)**
1	12.0	23.1	17.6
2	48.0	30.8	39.2
3	8.0	30.8	19.6
4+	32.0	15.4	23.5
Who has small number of children?*	**(N=29)**	**(N=31)**	**(N=60)**
Family planning service users	27.6	22.6	25.0
Educated people	69.0	48.4	58.3
Those who balance between their resources and the number of children they want to have	20.7	3.2	11.7

** Questions that allow multiple responses*

Table 3. Time Ratios of Achieving Subsequent Births by Various Covariates, Ethiopia, 2000

	Age 10 to first birth		First to second birth		Second to third birth		Third to fourth birth	
	Model 1	**Model 2**	**Model 1**	**Model 2**	**Model 1**	**Model 2**	**Model 1**	**Model 2**
Age cohort								
35 Years and above[R]	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00
25- 34 years	0.99 (0.00)	0.99 (0.01)	1.02 (0.010)	1.02 (0.01)	1.02 (0.010)*	1.03 (0.01)**	1.07 (0.01)***	1.09 (0.02)***
15-24 years	0.99 (0.01)	0.98 (0.01)	1.06 (0.02)**	1.06 (0.02)**	1.13 (0.02)***	1.15 (0.03)***	1.17 (0.02)**	1.19 (0.06)***
Type of union								
Monogamous[R]	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00
Polygynous	1.02 (0.01)**	1.01 (0.01)	1.05 (0.02)**	1.09 (0.02)***	1.05 (0.02)**	1.10 (0.02)***	1.00 (0.02)**	1.05 (0.02)**
Formerly married	1.08 (0.01)***	1.08 (0.01)***	1.20 (0.02)***	1.19 (0.02)***	1.19 (0.02)***	1.18 (0.02)***	1.16 (0.02)***	1.15 (0.02)***
Never Married	3.18 (0.06)***	3.21 (0.06)***	2.46 (0.23)***	2.38 (0.21)***	1.98 (0.32)***	1.94 (0.31)***	3.91 (1.18)***	3.96 (1.17)***
Age at first Marriage								
16 years and under[R]	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00
17 years and above	1.52 (0.01)***	1.54 (0.01)***	0.97 (0.01)*	1.01 (0.01)	0.98 (0.02)	1.03 (0.02)*	0.99 (0.02)	1.03 (0.02)
Age at first birth								
18 years and under[R]			1.00	1.00	1.00	1.00	1.00	1.00
19 years and above			1.03 (0.01)*	1.02 (0.01)	1.00 (0.01)	1.00 (0.01)	1.01 (0.01)	1.01 (0.01)
CP initiated before 1st child								
No[R]	1.00	1.00	1.00	1.00				
Yes	1.26 (0.02)***	1.27 (0.02)***	1.44 (0.04)***	1.38 (0.04)***				
Place of residence								
Urban[R]	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00
Rural	1.02 (0.01)**	1.01 (0.01)	0.91 (0.01)***	0.94 (0.02)**	0.83 (0.01)***	0.87 (0.02)***	0.85 (0.01)***	0.88 (0.02)***
Survival status of previous child								
Alive[R]			1.00	1.00				
Dead			0.79 (0.01)***	0.79 (0.01)***				

Survival status of previous 2 children							
Both alive[R]				1.00	1.00		
1 alive 1 dead				0.90 (0.01)***	0.89 (0.01)***		
Both dead				0.77 (0.02)***	0.77 (0.02)***		
Survival status of previous 3 children							
All alive[R]						1.00	1.00
2 alive 1 dead						0.92 (0.02)***	0.92 (0.02)***
1 alive 2 dead						0.87 (0.02)***	0.87 (0.02)***
All dead						0.72 (0.03)***	0.73 (0.03)***
Education							
No education			1.00		1.00		1.00
Primary			1.02 (0.02)		1.01 (0.02)		1.05 (0.02)**
Secondary and higher			1.02 (0.02)		1.00 (0.02)		0.97 (0.02)
Relgion							
Orthodox Christian[R]			1.00		1.00		1.00
Protestant			1.05 (0.021)**		0.98 (0.02)**		1.06 (0.03)**
Muslim			0.91 (0.01)***		0.90 (0.01)***		0.92 (0.02)***
Traditional and Other			1.06 (0.04)		1.04 (0.04)		1.08 (0.05)*
Ethnicity							
Amhara[R]			1.00		1.00		1.00
Oromo			0.85 (0.01)***		0.87 (0.01)***		0.86 (0.02)***
Tigrawi			0.97 (0.02)		0.94 (0.02)**		1.02 (0.02)
Guragie			0.90 (0.02)**		0.84 (0.03)***		0.96 (0.04)
Somalie			0.73 (0.02)***		0.71 (0.02)***		0.75 (0.02)***
Affar			0.95 (0.03)		0.94 (0.03)		0.91 (0.03)**
Other			0.87 (0.02)***		0.88 (0.02)***		0.89 (0.02)***
Sample size	15364	15364	10139	10139	8378		8378
Number of failures	10139	10139	8311	8311	6703		6703
Negative log likelihood	6299.27	6237.99	8502.89	8364.18	7066.46		5643.71
Likelihood ratio Chi-square	7638.31	7760.88	841.65	1119.08	632.43		481.71
DF	8	19	10	21	21		22
Prob. Chi sq	0.000	0.000	0.000	0.000	0.000		0.000

Notes: R = Reference Category; Standard errors in brackets; Significance levels ***= 0.00; **=0.05; *=0.10

Across all transitions, women who experienced child loss have faster transitions and, hence, higher likelihood of a subsequent birth (Table 3). The transition time to the next birth is faster for those who experienced a recurrence of child death. This finding implies that improving child survivorship is an important issue in moderating high fertility conditions, particularly in rural areas.

In the qualitative study, particularly among focus groups, large families were identified with persons who adhere to strict religious values, particularly Muslims. The results of the quantitative analysis corroborate this finding (Table 3). Muslims consistently show faster transition to subsequent births and, hence, a higher likelihood of births, compared to women who belong to other religions. In the qualitative interviews, respondents repeatedly mentioned that Muslims take procreation as a serious religious duty and that the teachings of Islam encourage making sure that their religion is passed on to the next generation and that the tradition continues. In four of the focus groups, male as well as female participants strongly related large families with religious affiliation, particularly with those who follow Islam.

> Moderator: Who has large numbers of children?
>
> Respondent #2: Muslims tend to have more children as a religious duty. They often marry more than one wife and have more children.
>
> Respondent #6: It is a mechanism to make sure that their religion continues. That is why Muslims have more children.

In contrast, only a few in-depth interviewees associate Muslims with large families. For the majority of these respondents, it is not about being Muslim or not. As the following citations show, it is rather due to one's devout religious orientation. These individuals could be Muslim, Christian, or from any other faith, who consider procreation a blessing from God.

> People who have children are those who are blessed by God… those who are blessed to propagate their seed. (IDI-44, married man, 38 years old)
>
> People who have many children are blessed by God. This is what I say. (IDI-45, married man, 43 years old)

Other than the teachings of Islam, Muslims have higher likelihood of births due to their practice of polygyny, as some respondents in the qualitative study suggested. However, the results from the quantitative analysis contradict this particular notion. Overall, across all transi-

tions, women in polygynous unions have longer transition times to the next birth. These findings from the quantitative analysis favour the hypothesis that relates polygyny to lower fertility at the individual level (Garenne and Van De Walle 1989; Lardoux and Van De Walle 2003), often working through frequency of coital relationship, duration of post-partum abstinence, and husband's age.

Studying the family-size preferences of respondents, this study also looked into people's views toward not having any children at all. Childlessness is considered by almost all participants as an unfortunate situation. The burden of remaining childless is also harder on women, due to the society's cultural and traditional attitudes. At the same time, participants of this study did not favour having too many children without making sure that they are supported adequately and that one's self-advancement is guaranteed. In this regard, the study found that urban residents have strong views on the importance of reducing risk and uncertainty.

> People who have many children are less educated and those who have not taken into account their income. As a result, they end up having more children than they can support. Children need to be educated, fed, clothed, etc. If children are deprived of all these things, maybe parents are having them without considering how to take good care of them. (IDI-38, married woman, 25 years old)

While childbearing is accorded high value in the culture, making sure that enough resources are available per child is seen as part of reproductive decision-making. If the likelihood of a child's sound upbringing is uncertain, and parental self-fulfilment is jeopardized, respondents mostly proposed a "wait and see" strategy.

Another important factor in fertility decline is the use of modern contraception and the practice of induced abortion. The overwhelming majority of respondents in the qualitative interviews approve the use of contraceptives and about half of them were using them at the time of the study. The level of contraceptive use in a society undoubtedly reduces fertility. Similarly, in the quantitative analysis, the timing between first and second births is found to be longer for contraceptive users compared to non-users (Table 3). This pattern holds for both rural and urban areas, but the magnitude of the effect is larger for the latter.

With respect to the role of induced abortion in the fertility-decline process, about four out of five respondents and almost all focus-group participants suggested that induced abortion in urban areas is quite

common. Although the practice is illegal in Ethiopia, respondents confirmed that induced abortion is common, and some even reported that they had had abortions:

> Yes, it is common. I know other women who have gone through the procedure and it has also happened to me. People resort to abortion when they realize that they cannot raise the child properly. (IDI-04, married woman, 25 years old)

> Yes, abortion is common. Women resort to abortion because they fear exclusion from the community if they have a child outside of marriage. (FGD-3, women, Respondent # 1)

In an attempt to avoid embarrassment or ostracism by family and community members, unmarried women, in particular, will resort to induced abortion for handling an unplanned pregnancy. This suggests that, in urban areas, the role of abortion in regulating fertility cannot be discounted. However, the true extent of induced abortion in the society remains unknown, and quantitative information is lacking.

Among socio-cultural factors, ethnicity and the type of union were the most important in determining the timing of births (Table 3). The study revealed that *Oromos* and *Somalies* have shorter transition times across all transitions compared to *Amharas*. The adoption or *Gudifetcha* tradition, which is widely associated with the *Oromo* culture, might explain the higher rate of births among this ethnic group.

In explaining urban fertility decline, it is useful to start with the views of urban residents themselves. In general, the participants of the qualitative study stressed that the reproductive behaviour of urban residents has changed, and they suggested various reasons that may have led to the fertility transition in urban areas. Changing economic values and the cost of children are suggested as factors that contributed to this change:

> In urban areas, the cost of children is high. That is, children should have better education, and the high standard of living in urban areas doesn't encourage people to have more children. (IDI-36, married man, 27 years old)

Most underlined that the cost of living in urban areas has increased whereas their income has not. As a result, urban residents are experiencing economic hardship, which, in turn, is depicted as the motivating factor in altering their reproductive behaviour. The expected economic benefits that parents can draw from children in urban settings have also declined. In comparison, in rural Ethiopia, the

contribution of children to the family production and domestic chores is seen as remaining significant:

> …People in rural areas think that a child can benefit the family through contributing to the agricultural work … the standard of living in urban areas is high and the cost of rearing children is also high. So they are forced to have one or two children. (IDI-28, married woman, 25 years old)

Compared to parents from urban areas, rural parents expect much from their children in terms of care during old age. In the views of respondents from urban areas, these factors partly explain the high fertility attitudes still prevailing among rural people.

The other explanation for low fertility in urban areas, according to participants, is because urban residents are better informed, educated, and exposed to new ideas. The expansion of education, better mass media coverage, and other services in urban areas contribute to the diffusion and adoption of new ideas and practices, including family size limitation. Rising aspirations by parents and would-be-parents to benefit from the best products and services for themselves and their children also lead them to consider small family size as the best option. Most urban residents aspire to provide the best education, health, and other essential services to their children so that they can succeed in life. The study shows that the role of rising aspirations is affecting individuals' marriage and family-building decisions. To this effect, new forms of behaviour are surfacing in urban areas and residents are embracing them, even if these are sometimes against long-standing societal views. In this respect, individuals in urban areas are *willing* (Lesthaeghe and Vanderhoeft 2001; Coale 1973) to adopt new forms of behaviour, which they think are advantageous to them. Urban residents are attaching much emphasis to their own human-capital development and they have become individualistic in their mate selection and love life. Unlike earlier times, they are now free to choose their own spouse and they consider different factors to be important to family formation, including having a secure job, personal happiness, and drawing maximum satisfaction from the relationship. Thus, before making their final decision on marriage and family, they take their time to make sure that these issues are somehow addressed. As a result, age at marriage and age at first birth have increased in urban as compared to rural areas, as the qualitative study shows. Urban women marry one and a half years later compared to rural women (Central Statistical Authority and ORC Macro 2001).

Rural residents might be conscious of the deteriorating economic conditions that could possibly instigate change in their reproductive behaviour. However, the findings in this study imply that rural residents might lack the same level of *willingness* (Lesthaeghe and Vanderhoeft 2001; Coale 1973) to modify and legitimize new forms of reproductive behaviour, as have their urban counterparts. The following two excerpts support this claim:

> There might be economic problems both in rural and urban areas but rural dwellers do not consider children as an economic burden to the family, they love to have more children. (IDI-35, single woman, 19 years old)

> … Economic tribulations are observed in both rural and urban areas, but people in urban areas are willing to limit the number of children to correspond to their income and related resources. (IDI-56, married man, 37 years old)

Conclusion

The evidence presented in this study indicates that urban residents prefer smaller family sizes. This is, to a large extent, related to household economic hardship and to a desire to make use of services that enhance child quality (especially better schooling). People consider allocating higher per-capita resource per child as a strategy toward preparing their children in competitive urban environments. The proper education of children to enhance their future success has become important for urban residents. This is seen as easier to achieve with a smaller family size. Emphasis is placed on helping one's children to excel in life. In environments where social mobility is seen to be possible but not assured, the "social capillarity" principle, identified by Dumont (in Spengler 1979), would apply in motivating individuals to limit the size of their families. In effect, the findings from in-depth interviews and focus-group sessions support this "social capillarity" explanation. In order not to compromise their children's future and to maintain a decent standard of living, individuals emphasize balancing their family size with available resources. Contraception, and sometimes, induced abortion, are used as means to achieve these objectives.

To use the term from Watkins (2000), it can be concluded that a common "culture of reproduction," different from the one that existed a generation ago, is surfacing in urban areas. Respondents explained that they have observed a difference in the number of children people

now have and the number people used to have in the time of their parents and grandparents. Their own generation is mentioned as having smaller numbers of children compared to earlier generations. From the views of the majority of respondents, the reproduction model of the previous generation was based on the principle of "a child can grow in its own destiny." Accordingly, large family sizes were promoted through the norms and cultural ideals of the society. In terms of uncertainties and risks, this view is mostly concerned with child mortality. For rural residents, this model of reproduction may still be dominant.

On the other hand, urban residents are adopting a new model of reproduction that is aimed at achieving a higher standard of living and enhancing the social mobility of their children. At the same time, for the vast majority, children continue to have an immeasurable value. The basis of this alternative model is the principle of having children, but also making sure that social mobility is achievable for both children and parents. The ideal behind this model is "not too many nor too few children," as evidenced by the average ideal and expected numbers of children, which are 3.1 and 3.0, respectively, for the in-depth-interview participants of this study. Especially when it comes to getting married, there is the common view that one should be able to support a family and ensure that children have the necessary means for success. Respondents often expressed a "bottom line," meaning they wanted their children to do as well as, or preferably better than, themselves. Controlling the number of children is a means of achieving these goals.

Economic hardship alone, despite its importance, may not motivate people to alter their childbearing behaviour. At the same time, people are under pressure from societal norms and cultural values with regard to their reproductive decisions. Urban residents are well aware of fundamental economic, social, and institutional changes that have taken place in society. Major events that brought institutional change included war, famine, and drought. Drought and famine affected millions during the mid 1980s. The years following the famine years were characterized by certain demographic consequences such as lower fertility (Lindstorm and Berhanu 1999; Kidane 1985). People's aspirations have changed due to education and the perception of the possibility of positioning themselves in a better place in society. In addition, the revolutionary experience of the country brought changes to the way people view everyday life (Kinfu 1999, 2001). Women are encouraged to join and stay in schools, improving their position in the household. An individual's own effort is seen as a guarantor for success, and

knowledge of family-planning services has increased. All these factors have contributed to the modification of people's value systems.

These explanations for the lower urban fertility are supported by the findings from the quantitative analysis of the timing of transitions to the first four parities. In particular, these transitions are more delayed in urban areas, as is the age at first marriage. The various fertility differentials are typically stronger in urban areas. In particular, contraceptive usage is higher and has a stronger effect on the transition from first to second births. There is also a stronger differential between younger and older cohorts in the urban sample. The depressive effect of being never married, and, to a lesser extent, of being in a polygynous union, is stronger in urban areas. This also applies to the differentials by religion, with longer transition times for Protestants, at least for the second and fourth parities. By ethnicity, faster transition times are observed for *Oromos* (the largest ethnic group in the country) and *Somalies*.

Policy Issues

As this study shows, fertility differentials are stronger in urban areas compared to those in rural ones. We may ask what the implications of these findings are for those rural residents who may wish to follow the same path as their urban counterparts. In this respect, it is crucial to expand opportunities and choices in rural areas, which, in turn, requires political willingness and resource commitment. The expansion of education is particularly important. Introducing schools, and adopting models that would accommodate the needs of sub-populations in some rural places, is particularly important. For instance, in places where rural people's livelihood depends on pastoralism and they need to move from one place to another, tailoring the school season to their schedule and/or introducing mobile schools is a possible option. In the past, this practice has been tried by some non-profit groups; government policy makers can learn lessons from the experiences of these efforts.

The 1994 International Conference on Population and Development in Cairo also placed much emphasis on access to education, especially for girls, and the need to encourage them to take advantage of such opportunities. Girls' education, in general, is seen as a factor that contributes to the improved status of women in society. In the qualitative study, some women were observed to depend on childbearing to gain acceptance by their husbands' families and status in the community. It is also reported in the 2000 ETDHS that less-educated women were highly likely to justify wife-beating (a proxy measure for women's sta-

tus) for any reason. Thus, the role of education in addressing gender inequality, which has implications in reproductive decision-making and related issues, is an area that deserves the attention of policy makers.

Similarly, following the recommendations of Cairo, addressing reproductive health issues is an important area of policy concern. In this regard, adequate access to contraception, particularly for the rural population, is fundamental. The present study shows that contraceptive users have longer birth intervals, which have positive implications for maternal and child health. Again, policy makers can work to strengthen efforts pioneered by non-profit groups to expand voluntary family-planning services to rural areas through community-based reproductive-health services.

This study also shows that induced abortion in urban areas may have some role in fertility decline. This calls for further investigation on the extent of induced abortion in urban areas and its implications for women's reproductive health. For attitudinal change to occur, it is important that accurate information be available and that the public be educated on the social, health, and emotional implications of induced abortion. An organized effort will help women (particularly unmarried women) from being ostracized by the community in the event of unplanned pregnancy.

The strong relationship between child survivorship and fertility shown in this study implies the need to design an integrated program that addresses both fertility and mortality. It is crucial to design programs with the objective of increasing child survival. The current child-immunization programs and selected nutrition programs need to be further strengthened in scope and geographic coverage. This is crucial and it needs to be linked to programs on improving safe and accessible contraceptive methods.

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"Right" and Wrongs: What Utility for the Right to Health in Reforming Trade Rules on Medicines

Lisa Forman

Abstract

This paper explores the restrictive impact of trade rules on access to medicines and the potential contribution of the human right to health to mitigating these restrictions. It argues that the human right to health offers a powerful mechanism for achieving trade reform with regard to medicines, and explores this right's growing legal and normative force, illustrated in both global jurisprudence and significant changes ensuing from the AIDS medicines struggle. This exploration is guided by the analytical framework of international legal compliance theories and by the strategic guidance these theories offer for realizing this right's transformative potential.

Introduction

There is considerable international concern about the impact of trade rules on access to medicines and a related move to mitigate the restrictive impact of these rules through considerations of social welfare and human rights concerns. This working paper argues that the human right to health offers a powerful mechanism for achieving trade reform with regard to medicines, a claim that seems largely counter-intuitive given that the right to health remains highly contested terrain. In this paper, I argue, however, that this right has a growing legal and normative force, illustrated in both global jurisprudence and significant changes ensuing from the AIDS medicines struggle. Theoretical accounts of why states comply with law provide a useful framework for this analysis and offer important strategic guidance for realizing this right's potential. The paper will proceed by illustrating how trade rules influence access to medicines by: expanding on why the right to

health may be a powerful tool for opposing these restrictions; exploring the contribution of international legal compliance theories to this analysis; discussing experience around AIDS medicines; and concluding with thoughts about the implications of the theoretical and experiential analysis for reforming trade rules.

TRIPS, Patents, and Impact on Access to Affordable Medicines

The World Trade Organization's (WTO) Agreement on Trade-Related Aspects of Intellectual Property Rights (TRIPS) was introduced 13 years ago when the WTO was formed, as part of the package of agreements all acceding countries must implement. TRIPS globalized pharmaceutical patents for the first time, requiring all WTO members to provide 20-year, exclusive patent protection on pharmaceuticals (TRIPS, articles 28.1.a and b). This was an unprecedented legal requirement in many countries that had not patented drugs or had far less stringent patent rules for medicines. For example, before TRIPS, over 40 countries did not patent drugs; many (like India) only patented processes and not products, and many others had patents for less than 20 years (WHO 2001, p. 3; Bartelt 2003, p. 285). TRIPS does permit limits to patents in order to enable governments to meet public-health needs, including (but not limited to) parallel imports (whereby countries import cheaper patented medicines) and compulsory licensing (whereby countries manufacture or import generics under strict conditions) (TRIPS, articles 6 and 31). The use of these mechanisms, however, has been highly contested and constrained by corporate and government pressures through litigation and unilateral trade sanctions, and countries are also being persuaded and coerced into adopting far stronger intellectual rules in bilateral and regional free trade agreements (FTA) that extend TRIPS restrictions even further (Forman 2006a, p. 135; 2006b, p. 190).

The primary impact of TRIPS is to drive up drug prices in countries introducing drug patents, since patents give patent holders the exclusive right to sell their medicines for particular periods, thereby excluding the price-reducing impact of generic competition (Abbott 2002, p. 5; Correa 2002, p. 262; Bloche 2002, p. 838). However, TRIPS is also restricting access to generic alternatives globally by phasing out the generic manufacture of patented medicines unless done under TRIPS exceptions such as compulsory licensing. This restriction strongly affects countries dependent on generic exports. While TRIPS was

amended in 2005 to allow export of medicines produced under licence under strict conditions, this provision has never been used, including by Canada, despite the country's implementation of legislation to enable such exports (WTO General Council 2003).

This is not to suggest that access to medicines is primarily determined by drug prices, nor that drug prices are only influenced by patents. Several factors, in addition to patents, inflate drug prices, including transport and storage costs, import tariffs and taxes, procurement practices, and dispensing fees (Henry and Lexchin 2002, p. 1590). Moreover, as WHO indicates, affordable pricing is only one determinant of access to medicines (the other three primary variables are rational use of medicines, the existence of adequate infrastructures, and sustainable financing) (WHO 2004, p. 24). Nonetheless, as the previous paragraph indicates, patents are a primary factor in determining price. When patents expire and generic entry occurs, drug prices fall sharply (Scherer 2000, p. 1322-1324), coming much closer to marginal production costs (Caves et al. 1991). Moreover, the influence of pricing is disproportionate in poor countries, where the majority of individual drug expenditure is out-of-pocket (Velasquez et al. 1998) and medicine procurement is often the greatest public expenditure on health (WHO 2004, p. 14). Pricing can also influence the availability of sustainable financing both within and outside a state, since a very expensive drug is not likely to be purchased in any great quantity, or at all, by poor governments, or to receive international funding. These effects were illustrated by the absence of public-sector or international financing of AIDS medicines until their prices were greatly reduced, and by the decision of international organizations to treat malaria using chloroquine despite its growing inefficacy, rather than artemesinin, a far more effective and expensive drug. The impact of pricing on public- and international-sector financing of medicines underscores the notion that drug prices may keep medicines for priority and common diseases such as cancer and diabetes well out of reach of those who need them most. Thus, while a multiplicity of variables determines access to medicines, price may constitute the most significant obstacle, particularly in limited-resource settings.

Questions about drug prices are closely linked to various arguments about the necessity of patenting. In this light, it is notable that there is growing consensus that TRIPS serves no innovation purpose in poor countries, so much so that the WHO's Commission on Intellectual Property Rights explicitly recognizes that in poor countries, "patents

are not a relevant factor or effective in stimulating research and development and bringing new products to market" (WHO 2006, p. 34). If patents in poor countries are not necessary to sustain the innovation of new medicines, this raises valid questions about the justifications for requiring them, particularly considering the human costs of limited drug access in poor countries.

The Power of Rights

The human right to health proposes a considerably different picture of government duties on medicines, one that significantly re-prioritizes public needs for medicines. The provision of essential medicines is seen to place on governments a core duty that cannot be traded for private property interests or for domestic economic growth. This right may, therefore, provide a means of achieving a more public-health-oriented formulation, implementation, and interpretation of trade rules by domestic courts, governments, and the WTO alike, and perhaps even a mechanism to assist efforts to eradicate or amend the TRIPS agreement itself. However, these are strong claims for a right often criticized as indeterminate and lacking universality and enforceability, and for a body of law widely perceived to be ineffective (Shand Watson 1999; Kennedy 2002). Yet, while critics who dispute the universality and efficacy of rights may touch on some truths about their weaknesses, the right to health and international law may, nonetheless, hold a transformative, albeit contingent, legal and moral power.

To some extent, this power is implicit in the tremendous growth of the international human rights system itself. Over the past sixty years, human rights have exploded into existence in international law and have been expanded in more than one hundred human rights instruments and countless UN resolutions, declarations, conferences, and programs of action. A large international human rights system has developed at the UN, as have regional systems in Africa, Europe, and the Americas. There has been a similar growth in constitutionalism over this time period: since 1945, about 50 per cent of UN members (92 countries) have introduced forms of rights into their constitutional systems, with enforceable rights a recurrent feature (Klug 2000, p. 12).

The growing legal force of the right to health in international and domestic law is eroding perceptions that this right lacks legality, determinacy, and enforceability. The right to health is now extensively codified in international and regional instruments, as Figure 1 indicates.

Many of these instruments are now extremely widely ratified: as of mid-2006, 99 per cent of all countries (192) have ratified the Children's Rights Convention (CRC); 94 per cent (183) have ratified the Convention on the Elimination of Discrimination Against Women (CEDAW); 88 per cent (170) have ratified the Convention on the Elimination of Racial Discrimination (CERD); and 79 per cent (153) have ratified the Covenant on Economic, Social, and Cultural Rights (CESCR) (UN Office of the High Commissioner for Human Rights 2006). Expert interpretations have considerably advanced the understanding of the scope of individual entitlements under this right — and the correlative duties it places on states — with access to medicines articulated as a core duty that cannot be limited due to resource constraints (UNCESCR 2000, paras. 42–43). Health rights are also increasingly entrenched domestically, appearing in two-thirds of all constitutions (Kinney and Clark 2004, p. 287). The right to health is also increasingly being enforced domestically, including through civil rights to life and equality (e.g., *Paschim Banga Khet* 1996; *Eldridge* 1997) and as a direct justiciable right (e.g., *Minister of Health* 2002; *Viceconti* 1998; *Cruz Bermudez* 1999). There is also a growing jurisprudence in which access to medicines has been successfully claimed under human rights protections (Hogerzeil et al. 2006, p. 306), with the implementation of these decisions, in certain cases, leading to considerable public-health benefits. For example, after the 2002 Minister of Health decision in South Africa, which held that government was bound to ensure access to services to prevent mother-to-child transmission of AIDS as part of their constitutional duties under the right to obtain healthcare services, the government implemented a national program in over 80 per cent of government clinics. This decision also laid the groundwork for a national AIDS treatment program, which was announced in 2003. By October 2006, approximately 165,000–175,000 people were obtaining antiretrovirals through this program (South African Ministry of Health 2007; International Treatment Preparedness Coalition 2006, p. 45).

The Normative Force of Rights

The force of the right to health is not constituted only by its technical legal standing in any given country, and the remainder of this working paper will focus on the more normative power of rights and law. This is to directly address one of the most common perceptions about international law and, in particular, international human rights law, which

is that while it promotes beautiful rhetorical aspirations, since it lacks a central enforcement body, a world police, and a world court, it is weak, unenforceable, and largely ineffective (Watson 1999). There is certainly some truth to these criticisms — human rights law has been shockingly ineffective in preventing even egregious gross violations. This failure is powerfully illustrated by persistent genocide since the Second World War, including in Cambodia, Rwanda, and currently, Sudan. There can be little doubt that ratification of international treaties is no guarantee of their fulfilment.

Figure 1: International and regional instruments containing the right to health

- Universal Declaration of Human Rights, 1948, article 25
- Constitution of the World Health Organization, 1946, article 12
- International Covenant on Economic, Social, and Cultural Rights, 1966, article 12
- International Convention on the Rights of the Child, 1989, article 24(1)
- International Convention on the Elimination of Racial Discrimination, 1965, article 5(e)(iv)
- Convention on the Elimination of All Forms of Discrimination Against Women, 1979, articles 11(1)(f) and 12
- International Convention on the Protection of the Rights of All Migrant Workers and Members of Their Families, 1990, article 28
- The European Social Charter, 1961, article 11
- African Charter on Human and People's Rights, 1981, article 16
- Additional Protocol to the American Convention on Human Rights in the Area of Economic, Social, and Cultural Rights (Protocol of San Salvador) (1988, article 10)

However, critiques of the efficacy of international law often fail to recognize the more transformative ways in which human rights have entered our collective consciousness, not simply as commitments in law, but as ideas and collective understandings with the potential to transform basic social and political priorities and shift real-world outcomes. As Martha Minow suggests, this is to recognize that civilization advances when what is commonly perceived as misfortune becomes considered injustice instead (Harvard Law School Human Rights Program 1995, p. 30). Ideas can considerably alter what is considered appropriate and legitimate, and certainly, the demise of slavery, apartheid, and colonialism, as well as the extension of

women's suffrage, provide powerful examples of how ideas can produce real-world changes.

Slavery, in particular, provides a fascinating illustration of the power of ideas and norms to shift our collective understandings. Until two hundred years ago, the dominant socio-political perspective on slavery was that it was a legitimate form of property and labour, and it was only through the assiduous efforts of a global abolitionist movement that slavery was abolished. This outcome was remarkable because for as long as human history had been recorded, so had instances of slavery. Today, there is not a single country in the world where slavery is not outlawed, and the dominant perception is that it is an evil practice and a shocking violation of human rights.[1] This shift reflects one of the most covertly transformative aspects of human rights, which is its core idea that all persons, irrespective of their race, geographical location, gender, or sexual orientation, is possessed of inherent human dignity and equal worth, and that this value places reasonable limits on economic interests and property claims, as well as on domestic and global governance.

This is not to suggest that ideas alone can produce transformative outcomes. Certainly, what is common to slavery, women's suffrage, and anti-colonialism is that these changes were accompanied and enabled by extensive social action (see, for example, Rajagopal 2003a, p. 401). This relationship is reflected in the recognition of international legal theorists that social movements are central not just to advancing rights claims but to creating them (Rajagopal 2003a and b; Baxi 2002; De Sousa Santos 2002; Risse-Kappen 1995). In this conception, subaltern legal and political struggles are increasingly understood to hold a rights-'creationist' (Baxi 2002, p. 101) and -'jurisgenerative' (Siegel 2004) potential that may drive the development of international law from below. This is a critical contingency for the force of rights that I will explore below.

A fundamental component of the force of rights lies in their nature, not simply as morality but as law. This is to recognize the normative function of law itself, which is, in large part, central to socio-political regulation. Consider, for example, how intimately concepts such as the rule-of-law are linked to conceptions of good governance, and how the existence of law itself is linked to order. In this view, the absence of law is seen as lawlessness and the breeding ground for *"Lord of the Flies"*-like predations (Golding 1954). Law, as a language

for rights claims, may hook into these meanings, so that advancing claims based on international law can add considerably to their perceived legitimacy, appropriateness and, indeed, necessity.

This is not to suggest that all law provides effective or appropriate rules: law is as easily an instrument for repression as it is for emancipation. However, whatever its tenor, law provides the rules on which societies are premised and may, therefore, provide an important source of socio-political power, as well as an important site of resistance. This power is perversely illustrated by the effective adoption of rights-talk and international law by corporations to advance the global protection of their interests: indeed, TRIPS itself is recognized as a victory of corporate lobbying advanced via the industry's extraordinary economic power, which enables them to prescribe self-serving laws and policies (Sell 2003, p. 5–6; Weissman 1996).

If rights can counter this one-sided participation in law and policy formation on medicines, and enable marginalized and subaltern groups without economic power to influence policy and law, they may provide social power and empowerment, as well as the promise of political accountability. Certainly, courts play an important role in empowering rights, since in legal forums, judges can either give teeth to the substantive justice potential of rights or reduce them to formal rules that entrench the status quo. No amount of prescriptive rules can eradicate this penumbra of uncertainty (Hart 1961). Thus, the legal force of these rights may be contingent on judicial willingness to give them force and effect, and achieving this force may be difficult, given ideological objections to health rights that persist in some jurisdictions.

Therefore, I am not advocating rights as guarantees of justice. Rights are inherently indeterminate, and their application to various problems must be worked afresh in contexts that textual formulations are likely to address only abstractly. Yet, while they are not guarantees of justice, they may well ensure systemic trends towards justice, and in the case of health, they may ensure a commitment to equity in health policy, free from contingent politics. Patricia Williams puts this point very well, and suggests that rights are to law as conscious commitments are to the psyche, a metaphor that suggests both the strengths of rights and conscious commitments, as well as their potential weaknesses (Williams 1992, p. 159). This is apparent, for example, in how few individual conscious commitments (e.g., New Year's resolutions) translate into concrete action and tangible outcomes. The implication

is that, like us, governments may need some external assistance and added incentives to fulfill their conscious commitments.

The Discursive Force of Rights

I propose that part of the normative power of rights lies in their potential to reconfigure what we consider to be appropriate and, indeed, what we consider to be right and wrong. Consider, for example, the intimate interconnection between rights and 'right:' what we understand to be right is not just what we consider appropriate, but also what we consider to be correct and true. To this extent, using the language of rights may overlap beliefs and truths in ways not consciously obvious. This overlap is apparent in the multiple meanings of the word "belief," which does not simply refer to what should be ("I believe in rights"), but also to what "is" ("I believe in God; I don't believe in fairies.")

Michel Foucault has powerfully advanced the idea that truth may be both shifting and contingent, arguing that 'truth' is not inherent, but is "a thing of this world … and that [e]ach society has its regime of truth, its "general politics" of truth — that is, the types of discourses it accepts and makes function as true" (Faubion 1994, p. 131). Thus, Foucalt argues, truth is not "the ensemble of truths to be discovered and accepted," but rather:

> …the ensemble of rules according to which the true and false are separated and specific effect of power attached to the true, it being understood also that it's not a matter of a battle 'on behalf' of the truth but of a battle about the status of truth and the economic and political role it plays (Faubion 1994, p. 132).

To this extent, rights may hold the potential to shift collective conceptions, not simply of what is appropriate, but also of what is true. This effect is apparent in the starkly opposing and competing paradigms of truth relating to trade rules, patents, and AIDS medicines. Until recently, the dominant paradigm, and one vigorously promoted by companies and their supporters, was that TRIPS did not permit limitations of patents; that patents could not be limited in any way without destroying the medical innovation system; that poverty, not patents and prices, determined access to medicines (IFPMA 2000, p. 14; Rozek and Berkowitz 1998); that access to medicines in poor countries was, in any event, irremediable (Mallett, in CIPR 2002); that African healthcare systems were inadequate for the complex and expensive task of monitoring the efficacy of complicated antiretroviral

(ARV) therapies; and that Africans were, in any event, too ignorant to adhere to complicated ARV routines (Donnelly 2001). These arguments considerably influenced how the feasibility and wisdom of providing AIDS medicines in Africa were seen, and how the moral and legal duties were perceived to flow (or not flow) from this 'truth.'

International Legal Compliance Theories: Why and How Do Rights Work?

My argument proposes a far broader conception of rights and law than legality alone. This analysis is considerably assisted by international legal compliance (ILC) theories, which provide competing explanations for how international law may influence state behaviour. Rather than debating whether rights and international law do, in fact, work, these theories instead explore how they work. There are two main camps of ILC theories. Rational choice theorists, such as realists and institutionalists, are sceptical that international norms have direct causal effects, and argue that states only comply if doing so furthers self-interested goals like enhanced power or reputational benefits (Hathaway 2002, p. 1944). The central insight of these schools is that countries weigh the costs and benefits of compliance and act accordingly (Guzman 2002, p. 1823). Interestingly, costs are not just those produced from legal enforcement through courts or treaty penalties, but can come from mechanisms such as negative public opinion or economic sanctions — indeed, any threatened action that offsets the benefits of non-compliance (Downs 1998, p. 321). This is an important insight in relation to the right to health, suggesting that rights and rights strategies can be coercively 'enforced,' even in the absence of law and legal mechanisms.

Normative theorists posit, on the other hand, that norms have a direct causal impact on state behaviour (Keohane 1997, p. 487). They argue that it is virtually impossible to achieve high levels of compliance over time through coercion (Young 1994, p. 134), and that states comply with international law because they are moral agents and it is a normative system. The normative theorists propose that states *internalize* international norms through a variety of mechanisms, either because of "an iterative process of discourse" (Chayes and Chayes 1995, p. 25); a transnational legal process (Koh 1997); or because rights reconstitute the identities and interests of social and political agents and, hence, their actions (Checkel 1998, p. 324). Both the rational choice and normative schools provide valuable insights for assessing how rights may

hold either a coercive or persuasive force with regard to medicines and trade rules. These schools provide not mutually exclusive, but complementary, explanations (Koh 1997, p. 2649). Certainly, when it comes to medicines, states may act both out of self-interest and because they have, to some extent, internalized human rights norms (Checkel 1997, p. 475). In any event, it is perhaps less relevant to work out which of coercion or persuasion is the superior process than to assess when either mechanism will apply (Checkel 1997, p. 475).

Normative Emergence, Cascades, and Internalization

Considerable guidance, in this respect, emerges from various theoretical models that focus on process-oriented explanations of how norms emerge, influence actors, and become internalized through mixtures of persuasion and coercion (Koh 1997; Finnemore and Sikkink 1998; Risse et al. 1999). Each model displays several commonalities and describes a similar process whereby norms are either persuasively or coercively advanced by norm entrepreneurs and transnational networks, leading to the emergence of new rules and their internalization when they are adopted as collective understandings. Moreover, each model identifies transnational actors, either in the form of activist networks or norm entrepreneurs, as key to the emergence of new norms, either through persuasion or public pressure. The remainder of this paper focuses exclusively on the process model advanced by Martha Finnemore and Kathryn Sikkink, which provides a framework that appears to explain the changes that have occurred around AIDS medicines.

Finnemore and Sikkink argue that "norms evolve in a patterned 'life cycle' and that different behavioural logics dominate different segments of the life cycle" (1998, p. 888). This life cycle is composed of a three-stage process of norm emergence, norm acceptance and cascade, and finally, norm internalization (Finnemore and Sikkink 1998, p. 895). They argue that what moves an emerging norm into acceptance is when a threshold or tipping point is reached and "a critical mass of relevant state actors adopt [it]" (1998, p. 895). Finnemore and Sikkink indicate that the notion of a tipping point is a pattern independently found in many other disciplines exploring social norms, including American legal theory, sociological research, and international relations theory (1998, p. 895). A similar idea is advanced in the book of the same title by Malcolm Gladwell, which describes how social epidemics of ideas and behaviour occur, and tip from a small

group of people into the general population (Gladwell 2000). Gladwell argues that things can happen all at once and that little changes can make a huge difference.

In Finnemore and Sikkink's model, at the first stage, norms emerge through persuasion by norm entrepreneurs who reframe state and public perceptions. They are successful when the "new frames resonate with broader public understandings and are adopted as new ways of talking about and understanding issues" (1998, p. 897). The tipping point comes when a critical mass adopts the norm, leading to the second stage, when norms cascade through combined coercion and persuasion. The final stage of normative internalization occurs when norms "acquire a taken-for-granted quality and are no longer a matter of broad public debate." Finnemore and Sikkink suggest that completion of the life cycle is "not an inevitable process" and that "[m]any emergent norms fail to reach a tipping point." (1998, p. 895). Certainly, the internalization of norms is not a static process and may become supplanted by other norms undergoing the same process.

The Example of AIDS Medicines

Finnemore and Sikkink's model appears to explain the changes that have occurred around AIDS medicines globally, and the role played, in particular, by the Pharmaceutical Manufacturers Association (PMA) case in South Africa in 2001. This case seemed to facilitate a tipping point for the emergence of a human right to AIDS medicines and to act as a catalyst for broader legal and political changes around AIDS medicines. In this respect, the struggles for AIDS medicines can be seen as an iconic rights experience that, like the U.S. civil rights movement and struggles for women's suffrage, offer important guidance about the kinds of coercive pressure and normative persuasion that could alter trade restrictions. This experience suggests that the right to health may be used to ensure broader access to medicines and also provides a roadmap showing how rights may be used to mitigate trade restrictions more generally.

Seven years ago, the picture of AIDS medicines was bleak. The drugs cost approximately $15,000 U.S. a year. WHO and UNAIDS's official position was that given the high drug costs and the need for effective prevention, treatment was not a wise use of resources in poorer countries (WHO and UNAIDS 1998, p. 13). This shadowed a broader policy consensus that cost-effectiveness demanded a brutal triage in which prevention of HIV/AIDS was considered a higher priority than

treatment, an ethically questionable choice in a gross pandemic that had already infected almost 28 million people in sub-Saharan Africa. As a result, there was no international funding for developing countries to purchase drugs, and companies gave extremely limited price concessions. The idea that poor people in Africa should receive expensive state-of-the-art AIDS drugs was viewed as naïve and unrealistic, and arguments for lower-priced medicines were viewed as proposing an unacceptable violation of corporate patents and international trade rules. Generally, access to these drugs in developing countries was around 5 per cent of HIV-positive persons, and in sub-Saharan Africa, the vast epicentre of the global pandemic, access was considerably under 1 per cent.

Yet millions of people were dying from AIDS in sub-Saharan Africa every year, at the same time that antiretroviral medicines had begun to slash AIDS-related illness and death in the West and transform the very nature of the disease. To those on the frontlines of the pandemic, this lack of access primarily on the basis of price did not seem logical, appropriate, or ethically defensible. Rather, it seemed to be a shocking prioritization of property interests over the health and welfare needs of much of the African continent, in service of nothing other than profit — a global crisis not just of health but also of morality. A dramatic global battle for AIDS medicines ensued, coalescing around moral arguments and human rights claims for medicines and mass actions by social networks of health and human rights activists. This battle challenged drug pricing, legal interpretations of TRIPS, and corporate contestation of TRIPS flexibilities.

The tipping point of this struggle appeared to come in 2001 in the PMA case in South Africa. Between 1997 and 2001, the U.S. and 40 pharmaceutical companies used trade pressures and litigation to prevent the South African government from passing legislation to gain access to affordable medicines. South Africa, then, as now, had one of the world's largest HIV epidemics. Industry claimed that the legislation (and the parallel importing it authorized) breached the TRIPS agreement and South Africa's constitutional property protection. It also argued that the proposed act threatened industry's incentive to innovate new medicines. The litigation and its implications for access attracted very unflattering media attention, partly generated by domestic and international protests. In 2000, the U.S. withdrew its trade pressures after Al Gore was embarrassed by AIDS advocates during his election campaign. However, the pharmaceutical companies

went to court in South Africa. In April 2001, South African treatment advocates joined the government's case, and in detailed affidavits, set out to show the weakness of corporate arguments about the TRIPS legality of the legislation and the research- and development-based necessity of opposing the legislation. South Africa's constitutional framework considerably assisted activist claims, particularly because it entrenches a justiciable right of access to healthcare services and has rules on the limitation of rights that demand strong justifications for any restrictions of core dignity and life interests (Republic of South Africa Constitution 1996, sections 27(1) and 36). Using this framework, activists brought human rights arguments drawn from international and domestic law, arguing that the right to health provided constitutional authority for the legislation itself, and was a legal interest that should be prioritized over corporate property rights. Activists also presented extensive empirical research that undercut corporate claims about the cost of R&D and its link to innovation, as well as very moving personal testimony from people unable to buy medicines to illustrate the human costs of the litigation.

Activists organized an extraordinary level of public action concurrent with the case. On the day the case began, an international day of action was held with demonstrations in 30 cities across the world. A petition opposing the litigation signed by 250 organizations from 35 countries was published in *Business Day*, a national South African newspaper. The international aid group *Médecins Sans Frontières* initiated an international petition that collected 250,000 signatures and persuaded the European Union and Dutch governments to pass resolutions calling for the case to be dropped, followed by the German and French governments (McGreal 2001). The World Health Organization not only stated its support for South Africa's defence of the litigation, but also provided legal assistance (Agence France Presse 2001). In the days before the hearing, Nelson Mandela, the former South African president, criticized the pharmaceutical companies for charging exorbitant prices on AIDS drugs, attracting considerable media attention (Denny 2001). This confluence of activism and media coverage attracted an extraordinary amount of global censure against the corporations, which recognized that they had far more to lose through reputational damage than through any outcomes to which the *Medicines Act* could possibly lead. In April 2001, the pharmaceutical companies withdrew their case. The litigation and surrounding media furor precipitated a discernable shift in how the appropriateness of

TRIPS and patents in poor countries came to be seen. Even conservative publications such as the *Washington Post* and *Time Magazine* began to question the legitimacy of corporate action to protect patents in developing countries, and, indeed, of the intellectual property system itself (Washington Post 2001; Karon, in Time World 2001).

Closely following the conclusion of the PMA case, what looks like a norm cascade began, with a sharp upsurge at the UN in international statements on treatment as a human right and on state obligations to provide ARV (UN Commission on Human Rights 2001a, 2001b, 2001c, 2002, 2003; UN Committee on Economic, Social, and Cultural Rights 2001; UN Office of the High Commissioner for Human Rights and UNAIDS 2002). This process moved later that year to the World Trade Organization in a Declaration on TRIPS and Public Health, issued at the Doha Ministerial Conference. This declaration articulated that WTO members had the right to protect public health and to promote access to medicines for all, and to do so using TRIPS flexibilities such as compulsory licensing and parallel imports (WTO 2001). These rhetorical commitments were matched by considerable policy and price shifts. As a result of the combination of pressure, concessions, and the availability of generic alternatives from India (which was not yet bound by TRIPS), drug prices in many low-income countries dropped from $15,000 U.S. to $148–$549 U.S. per annum (WHO and UNAIDS 2006, p. 30). Global funding mechanisms were created, such as the Global Fund to Fight HIV/AIDS, Tuberculosis, and Malaria, the American President's Emergency Plan for AIDS Relief (PEPFAR), and the World Bank Multi-Country HIV/AIDS Program for Africa. In 2002, the WHO adopted the activist goal of placing three million people on ARV and, in late 2005, shifted upwards to the goal of achieving universal access to treatment by 2010, a goal similarly adopted by the UN General Assembly and by the G8 as part of a comprehensive plan of assistance for Africa (United Nations General Assembly 2005, para. 57d; WHO 2006, Gleneagles Summit, 2005). In six years, access to ARV in sub-Saharan Africa increased from under 1 per cent to current levels of 28 per cent (WHO, UNAIDS and UNICEF 2007, p. 5).

Implications for Rights and Trade

The AIDS medicines struggle and the PMA case suggest that rights-based discourse, litigation, and action have played significant roles in shifting policy, price, and perception around AIDS medicines. In the

PMA case, discursive arguments and empirical evidence in the litigation, accompanied by mass action and media attention, ensured growing reputational damage for the industry. Without this coercive pressure, the companies are unlikely to have withdrawn the litigation. However, the PMA case also illustrates how social action and rights discourse persuaded a global collective of the legitimacy of the rights claim for medicines and of the immorality of the corporate positions. This not only assured the collective disapproval that became so important to ensuring the corporate withdrawal of its litigation, but also ensured a far broader global acceptance of the rights claim and a shift in perspectives on the moral necessity of AIDS medicines in Africa. The combined force of persuasion and coercion appears to have initiated a process of normative emergence, tipping, and cascade, providing empirical evidence of Finnemore and Sikkink's theoretical model. In the gap that opened up, competing truths about the remediable nature of inaccessible AIDS medicines came to the fore.

To return to the WHO framework on access to medicines, in which price is only one of four claimed factors, it is notable that the primary changes precipitating the steep rise in access to AIDS medicines were economic. This correlation suggests that factors like infrastructure (and poverty) are less a bar to access than is commonly believed, and that political willingness to address other access factors may be fundamentally linked to removing financial barriers. This is to suggest that addressing economic (price) factors may facilitate action on all other access fronts. The AIDS medicines experience further suggests that the multiplicity of variables influencing inaccessible medicines requires multiple strategies, including ensuring the affordability of medicines, rather than simply advancing poverty reduction as the solution, as company representatives have argued (Sykes 2002, p. 214–218). Nonetheless, the figures themselves express caution: at 28 per cent access, over two-thirds of people in need remain without access. The need to address other political and infrastructural constraints remains.

In the aftermath of PMA and ongoing treatment activism, other arguments have shifted: TRIPS clearly permits exceptions to its patent rules; international consensus is building that patents in poor countries serve no innovation function; and experience suggests that adherence to ARV among Africans is proving higher than among North Americans (Mills et al. 2006). There is no basis, however, for triumphalism. While the gains are significant, they remain limited; TRIPS has only been altered through a miniscule and complex amendment with unproven

utility. The carve-out of permissible restrictions of TRIPS rights is, however, limited to AIDS and Africa; health needs in other countries and for other drugs are still seen as illegitimate limitations of patent rights. For example, in 2006, the Thai government issued compulsory licenses on two antiretroviral drugs sold by Merck and Abbott and on a heart medication sold by Bristol Meyers Squibb. Abbott responded by announcing that it would no longer register new drugs for sale in Thailand. In addition, the U.S. government threatened trade sanctions, citing weakened respect for patents. Litigation and trade pressures on these fronts persist and stringent patent protection is still sought through bilateral and regional free trade agreements.

Returning to the process explanations of normative influence, these outcomes seem to suggest there have been an emergence and cascade of a right to medicines, though not necessarily yet, the broader internalization of this right that the theoretical process models suggest is the end point of this process. While the gains on AIDS medicines are limited, they can be seen as tactical concessions indicating that a process of normative diffusion and compliance has begun (Risse, Roppe, and Sikkink 1999, p. 20). There is, however, nothing inevitable about the completion of the process and much remains to be done if trade rules more attentive to medicine needs are to be achieved.

AIDS and international legal compliance theories provide a strategic roadmap for advancing this process, so that access to medicines as a human right starts to assume a 'taken for granted' quality in politics, law, and public opinion. In this context, collective disapprobation of actions that limit access to medicines may become more likely, and political and legal acceptance of limiting patents in the service of access to medicines may follow. To achieve this, trade considerations should become inextricably linked to rights in political considerations and legal adjudication. Violations of the TRIPS agreement should be adjudicated not on TRIPS's own terms, but against a broader international law framework in which rights are increasingly accepted as providing competing obligations. Potential strategies include advancing international law argument and reasoning at the WTO's Dispute Resolutions Panel and Appellate Body (through *amicus curiae* interventions or through more direct commentary of panel decisions) and influencing policy makers by advancing a rights framework for assessing the legitimacy of TRIPS and any other bilateral or multilateral treaties affecting intellectual property rights.

Rights and international law, therefore, offer a legal, political, and moral force that can be harnessed in order to alter existing interpretations and implementation of TRIPS, and to shift political and social understandings of right and wrong around medicines and trade, so that TRIPS is increasingly assessed against a rights backdrop, and the health needs of the poor are more appropriately prioritized against private property interests.

Note

1. Certainly, there are important caveats to the force of the abolition of slavery. The first is that illegal slavery persists and may involve larger numbers of people than previous centuries of legal slavery. This mostly applies to migrant labourers and women and children in the global sex trafficking industry. Second, there is a form of legal economic slavery permitted in the form of lesser legal rights in many countries for migrant domestic, agricultural, and temporary workers.

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Benefit Sharing and the Privatization of Medical Research

Ron A. Bouchard

Abstract

Medical research has undergone a profound transformation over the last two decades, particularly in jurisdictions where technology transfer and commercialization of innovative products are considered a vital element of national science and technology (S&T) policy. As part of this transformation, governments have moved away from their traditional gate-keeping roles in medical research, licensure and product regulation, adopting instead a stance where public health considerations and economic activity resulting from commercialization of research are equally embraced. While S&T policies have undoubtedly helped underpin economic growth in certain nations, questions are beginning to emerge over whether the benefits of an increasingly privatized medical research enterprise are being equitably distributed amongst the various public and private actors responsible for generating, capitalizing and consuming the products of medical research. Here, I contend that distribution of the benefits of commercialization are skewed towards for-profit entities and against the public interest, and that a legitimate and economically efficient solution to this imbalance includes levying compulsory government royalty fees on successful commercial products that were made possible by public contributions.

Introduction

The nature of federally-funded medical research has undergone a profound transformation over the last three decades (Bouchard 2007a). Initiatives have emanated from all major public and private spheres of most liberal democratic states, including political, economic, legal, regulatory, industrial and public welfare sectors. Governments have begun to explicitly move away from their traditional gate-keeping

roles, adopting instead a stance where both public health considerations and economic activity resulting from commercialization of innovative research are advocated equally. Tensions between these competing objectives can be seen in the missions and mandates of every major federal public health and granting agency in Canada, the United States, the European Union and other jurisdictions where technology transfer and commercialization are considered a vital element of national science and technology (S&T) policy[1]. Increased emphasis on industrial partnerships in medical research and the move away from a precautionary[2] to risk management[3] stance in drug regulation are but two examples of the new hybrid commercialization regime.

While it is generally accepted that S&T policies have provided substantial fuel for the economic engines of many developed nations over the last century (Bozeman and Sarewitz 2005; Dosi, Marenho and Pasquali 2006; Arrow 1962; Landes 1969), questions are beginning to emerge over whether the benefits of an increasingly privatized medical research enterprise are being equitably distributed amongst the various public and private actors responsible for product development. Indeed, the full impact of recent legislation and policy aimed at enhancing technology transfer and commercialization has not been fully appreciated until now, as it has only recently become apparent that inequalities in the distribution of benefits derived from privatized research may require some rethinking in order to avoid policy failure (Bozeman 2002). In this article, I contend that the distribution of the benefits of commercialization are skewed towards for-profit entities such as universities and private firms and against the public interest, and that a legitimate and economically efficient solution to this imbalance includes levying compulsory government royalty fees on successful commercial products that were made possible by public contributions.

The Privatization of Medical Research

As is now well known, in the early 1980s a number of legislative initiatives were undertaken by the United States Congress allowing patenting and technology transfer by universities[4], leading to swift changes in the commercial orientation of scientists and their parent institutions (Culliton 1982). This was accompanied by the storied *Diamond v. Chakrabarty* decision[5], which broadened the category of patentable subject matter to include "anything under the sun made by man". Along with consolidation of patent appeals before a single

appellate court referred to as the Federal Circuit and restructuring of the United States Patent & Trademark Office (PTO) as a fee for service organization (Jaffe and Lerner 2004), this spurred an explosion in patenting by medical researchers and, according to at least one patent scholar (Jasanoff 2002), spawned the global biotechnology revolution.

Beginning in the 1990s, however, a second and more subtle wave of privatization occurred under the twin banners of translational research[6] and public-private partnerships (de Bettingnes and Ross 2004). The rationale was that medical research was seen to be increasingly complex, global, and interdisciplinary, in turn requiring an expanded base of people, infrastructure and resources to translate basic research into commercial products. Public private partnerships formed a central component of Elias Zerhouni's (2003) roadmap on taking over the National Institutes of Health (NIH) in 2003, which was mirrored by the Food and Drug Administration's (FDA) 2004 Critical Path Initiative to bolster biomedical pipelines (Ratner 2006; Buckman, Huang and Murphy 2007). In 2002, Alan Bernstein, President of the Canadian Institutes for Health Research (CIHR), made commercialization and public private partnerships a central component of the new agency's mandate (Bernstein 2003). Indeed, legislation establishing the agency[7] legally mandates public private partnerships as part of the nation's commercialization strategy.

Finally, and even less appreciated than the movement towards public private partnerships, a third front of privatization has quietly advanced represented by the ever-increasing influence of industry on the legal and regulatory requirements for clinical trials and drug approval. Notably, this has included expansion of patent rights and the intrusion of patent protection into regulations controlling drug approval via so-called "linkage regulations" in the United States[8] and Canada[9], which tie drug approval to patent protection for the resulting marketed products[10], as well as the growth of data, market and pediatric exclusivity rights through expansion of international trade agreements such as the World Trade Organization's (WTO) Agreement on Trade-Related Aspects of Intellectual Property Rights (TRIPS). A second and related factor is the shift in these same nations from a licensing regime for biomedical products focused (to varying degrees) on the precautionary principle to one where risk management and risk-benefit considerations are central. It is no coincidence that the same firms and industry lobbying groups that were central to the evolution of the public private partnerships model and linkage regulation regime are also those

considered "clients" and "partners" by federal food and drug agencies following their switch to a fee-for-service model.

Intellectual Property and Regulatory Rights

Each of the privatization "waves" was undertaken by federal governments as part of a larger economic project to enhance domestic competitiveness with other nations seen to be capitalizing more effectively on their S&T bases (Pavitt 1996; Sampat 2006; Stokes 1997). For example, large efforts were made in the post-war years by Vannevar Bush and his contemporaries to bolster research coffers and provide scientists with independence and self-policing responsibilities. The debates leading up to the passage of Bayh Dole differed in the sense that the emphasis was on enhancing the pipeline of "practical uses" of basic research via technology transfer, commercialization and industry partnering. To some degree, analogous debates were ongoing in the United Kingdom, Germany, France and Japan, to name just a few nations taking note of America's powerful S&T base (Pavitt 1996; Sampat 2006; Stokes 1997). Strong domestic and international intellectual property and regulatory rights were viewed as central to this endeavor (Kitch 1977; Merges and Nelson 1994; Jaffe and Lerner 2004) and broad patent, license and regulatory rights were instituted by several important federal agencies in the United States, including Congress, the PTO, NIH, FDA, Federal Circuit, United Stated Supreme Court, and Federal Department of Justice (Lunney 2001). The United States also played a major part in setting the global threshold for expanded patent and regulatory rights through international trade agreements such as TRIPS and the North American Free Trade Agreement (NAFTA), the latter of which is responsible for repeal of Canada's compulsory licensing regime in favour of the NOC Regulations. A similar pattern of support for broad domestic intellectual property and regulatory rights has played out in Canada over the last twenty years, supported by policies, legislation and regulation pertaining to the scope and nature of funding for medical research and product licensure originating from Industry Canada, Health Canada, the Treasury Board, and the Privy Council (Bouchard 2007a; Lemmens and Bouchard 2007a). Together, this basket of legal, regulatory, policy, economic and political initiatives enabling the three waves has been referred to jointly as the "industrialization" (Ravetz 1971; Prager and Omenn 1980; Culliton 1982) or "privatization" (Bouchard and Lemmens 2007) of medical research.

Increased emphasis by federal funding agencies on commercialization and strong intellectual property and regulatory rights in the context of privatized medicine has not been without opposition. Chief among the issues raised is the growing frustration amongst some scientists and the public that industry has gained control of government purse strings, S&T policies and intellectual property practice (Tyers et al. 2005; Kondro 2005). Concerns such as these date back at least to the Bush-Kilgore debates leading up to Bayh Dole (Sampat 2006; Stokes 1997). One of the more serious criticisms is that a fundamental policy emphasis on commercialization may lead to ghettoization of research lacking in commercial potential, including the possible demise of true public interest science (Krimsky 2003). To paraphrase Martone (1998), once the marketplace has exclusive rights over the funding, development and licensure of biomedical products it can redefine the human person standards that create demand for products the market can itself develop[11]. This is not a trivial concern. As noted by Art Carty (2003), then Science Advisor to the Canadian Prime Minister, one quarter of the entire federal research budget in 2005 was composed of "co-funded" grants (federal grants aimed at commercialization that require matching industry or other funds). A recent study of biomedical researchers in the United States found that about 20% held industry funding, 22% had applied for a patent within the past two years and 25% participated in a "business activity", defined as participating in negotiations of intellectual property rights, constructing a business plan, spinning out a firm, or accrual of licensing revenue (Walsh, Cho and Cohen 2005). Thus, it is hardly surprising that in FY 2002, US universities brought in approximately $1B in licensing royalties, filed 6,500 patent applications, executed 3,700 licenses and created over 400 startups (AUTMLS 2003; Triggle 2005). The industrialization of publicly funded biomedical research is entirely in keeping with the growing nexus between patent law and regulatory law governing the sale and consumption of pharmaceutical products in Canada, the United States and the European Union (Lexchin 2005; Bouchard 2007c), whereby the traditional government "gatekeeper" role in safeguarding public health and safety is being challenged by the reach of national innovation agenda policies (Eisenberg 2003).

Benefit Sharing: Distributive Grounds for Reallocation

In addition to setting national research agendas, a second major concern relating to an increased emphasis on technology transfer is over

the distribution of risks and benefits arising from commercialization of publicly funded biomedical research. In other words, are the benefits of publicly funded medical research distributed equitably amongst the various public and private actors responsible for its production, construction and use (Latour 1987; Jasanoff 2004)? Public "inputs" to clinical product development include clinical trial participation, provision of tissue samples, tissue and organ donation, provision of genomic, proteomic and other "omic" information, and general taxation tied to public health, as well as philanthropy and other donations for cause-specific medical research.

For purposes of this article[12], "commercialization" refers to commercial development of biomedical products for sale to the public developed in whole or part using tissues, data, information or other resources contributed by the public. "Benefit" means a good contributing to the well-being or value of individuals, communities and firms. "Benefit sharing" refers to balancing creation of biomedical products using public resources with equitable sharing of benefits derived from those products via monetary and non-monetary vehicles. Note that this definition extends beyond the mere provision of monopoly-priced products in the marketplace to both tangible and intangible benefits of medical research.

Benefit sharing has received increased attention lately, largely in the context of genetic research. However, the notion that the benefits of medical research should be shared equitably can be legitimately extended to cover all medical research, owing simply to the evolution of clinical science itself from a relatively communitarian activity aimed at the global public good to an increasingly commercial one. The alternative is "benefit hoarding", whereby the benefits of a policy designed to provide aid to the general public are captured asymmetrically by a subset of the population. Under such conditions, policy failure is said to occur (Bozeman 2002; Bozeman and Sarewitz 2005; Dosi, Marenho and Pasquali 2006). For the purpose of the present discussion, benefit hoarding would refer to the asymmetric capturing of benefits from publicly-funded medical research by the private or public sector.

As described by Bozeman and Sarewitz (2005), policy failure occurs when neither the market nor public sector provides needed goods and services required to achieve core public values or when public values are not reflected in social relations. This approach differs from a pure market failure approach in that it requires of government something

more than a focus on achieving market efficiency. It accords with the view that needed goods are not and should not be freely tradable commodities when deemed to be a socially recognized need (Walzer 1983). In the present context, the public values at stake are first, an equitable distribution or allocation of the benefits of publicly-funded medical research and second, reasonable access by the public to affordable medical therapies funded by the public purse. Obviously, the strength of this argument will vary from jurisdiction to jurisdiction, depending on the emphasis on free market economy and how strongly regulated are the generation, licensure and marketing of medical products. Even so, as discussed in greater detail below, most liberal democracies recognize that the state has a significant role in promoting equitable access to needed social goods, based in part on the notion that egalitarian justice requires market forces to be restricted in some capacity in order to promote their distribution. This idea, referred to by Walzer (1983) as "complex equality"[13], is particularly relevant to the issue of public health given that clinical research, patenting, licensing and marketing of biomedical products are strongly regulated in most developed nations and because biomedical products are generally derived from publicly funded research aimed at the global common good (Dickersin and Rennie 2003; ICMJE 2004, 2005, 2007; Sim et al. 2006).

The question of benefit sharing is a timely one for scientific, political and economic leaders, as the changing face of medical research is being accompanied by a similar shift in public expectations with regard to the results of this research, due in some measure to controversies relating to the safety and efficacy of marketed drugs. While it is true that much innovation in clinical research would not occur in the absence of some form of government or public subsidy, the question remains as to whether the distribution of benefits from publicly funded research is so skewed to the private sector so as to attract policies based on the principal of reciprocity.

Indeed, one issue common to almost all public opinion surveys over the last decade is that the public depend strongly on government to protect their best interests, including avoiding undue influence by industry. As discussed in detail later, concerns of this nature encompass mission creep (also referred to as monopoly or regulatory creep) whereby government agencies are captured by the industries they regulate (Boldrin and Levine 2005), a concern that has been expressed specifically in the context of federally-funded medical research (Johns,

Barnes and Florenicio 2003; Lemmens 2004) and regulatory approval of the resulting commercial products (Lemmens and Bouchard 2007a).

Tension between Public and Private Interests in Commercialization

A major premise of this article is that public and private interests in the commercialization of medical research are at odds with one another to a certain degree. The "private interest" in biomedical commercialization is, for the most part, said to be aimed at efficient wealth maximization for stakeholders (Heller and Eisenberg 1998; Dosi, Marenho and Pasquali 2006). Under market failure theory (Bozeman and Sarewitz 2005; Dosi, Marenho and Pasquali 2006), even where the results of publicly funded research retain some aspects of a public good through a relatively restricted intellectual commons (Bouchard 2007a), the output of such research cannot be a free good, since private firms (or technology transfer offices) must intervene in order to transform basic knowledge into applied knowledge, the latter of which constitutes patentable subject matter as well as marketable products (Pavitt 1996). By contrast, the "public interest" in medical research is traditionally focused on issues relating to public health and well-being independent (though not exclusively so) of transaction costs. An argument typically advanced in this regard (Berg 2001; Phua 2004; Bovenberg 2005; Dhanda 2005; Triggle 2005) is that individuals consent to participate in clinical trials and donate money, tissues and organs (before and after death) generally for the public good, even if sometimes that good is in relation to discrete patient populations. Indeed, the public good nature of medical research was the primary ground offered by the medical community in favour of mandatory clinical trial registration (Lemmens and Bouchard 2007b), and donations of this nature often yield large repositories of biological samples and data ultimately intended to benefit humankind in general as well as more discrete patient advocacy groups or genetically diverse communities. The results in either case are inevitably deemed to be for the public good, and 'solidarity' considerations of this nature permeate the mandates and mission statements of both the NIH and CIHR (Bouchard 2007a).

As discussed elsewhere (Bouchard 2007a), tensions between public and private interests in commercialization are real in the sense that large-scale increases in the budgets of the NIH and CIHR over the last

decade or so were premised on the promise of health benefits for the public, even though healthcare became increasingly unaffordable to a larger swath of the public and the public returns on health research remain difficult to document empirically (Bozeman and Sarewitz 2005; Dosi, Marenho and Pasquali 2006; Pavitt 1996). Nevertheless, there is strong historical evidence (Stokes 1997; Sampat 2006; Rosenberg and Nelson 1994) to the effect that universities and research institutes were never pure "ivory towers" of so-called basic research, and that there has been a strong interplay of public and private interests in the medical research enterprise with the aim of solving practical problems faced by society. With this and Bozeman's (2002) theory of public policy failure in mind (Bozeman and Sarewitz 2005), we therefore cannot say with certainty that public and private interests in commercialization are *inherently* and *irretrievably* in conflict. We are in a position, however, to say that public and private interests in commercialization do meaningfully conflict with one another *to the degree* that the benefits of commercialization are skewed or "hoarded" by one of the enterprise partners thus giving rise to conditions of policy failure.

Distribution of Benefits Is Asymmetric

The financial benefits for firms and their university partners resulting from enhanced privatization efforts have been substantial (Bouchard 2007c). In 2004 alone, licensing revenue by United States universities amounted to $1.4B and combined revenues for spinout firm venture capital funding, IPO and M&A activity was $47B. This was accompanied by record profitability in the pharmaceutical industry, which reaped a 300-500% increase in revenues beyond those for median Fortune 500 firms from 1980 to 2000. Indeed, in 2002, profits by the top 10 drug firms exceeded that for the remaining 490 firms combined. Earnings have been realized in the context of reduced tax burdens compared to other industries (Public Citizen's Congress Watch 2001) and a decrease in drug approval times, and hence cumulative transaction costs, over the same time period (Bouchard 2007a). Moreover, consumption of products by the public has skyrocketed over this time period, with no slowing in growth in the foreseeable future. The market for biomedical products is therefore substantial and growing.

Intensification of efforts to commercialize the products of medical research has been accompanied by strong and wide-ranging shifts in norms within the medical community. Scientific values and practices

pertaining to clinical research have evolved away from traditional Mertonian norms (universalism, communalism, disinterestedness, skepticism) towards profit-seeking norms (secrecy, withholding, intellectual property, profit, delayed disclosure) to accommodate the increased focus on commercialization (Eisenberg 1987; Rai 1999; Bouchard 2007b). The shift in norms relating to practitioners of medical research has been paralleled by strong organizational adaptations by senior administrators of universities, local and regional governments and technology clusters in order to obtain as great a piece of the commercialization pie as possible[14].

Increased profitability and prosperity enjoyed by firms is not, however, enjoyed equally by all strata of society. This is true notwithstanding the rhetoric of governments regarding projections of enhanced prosperity and productivity presumably arising from enhanced product development activities. What empirical research there is has shown that measurable national spillovers resulting from a general science and technology focus have been difficult, if not impossible, to quantify let alone spillovers from enhanced medical knowledge translation and technology transfer per se (Pavitt 1996; Mazzoleni and Nelson 1998). While it has long been understood that significant income and drug access "gaps" exist in developing nations (Reich 2000), it is becoming increasingly clear that serious gaps in personal and household income, pensions, inheritance and access to affordable health care and essential medications exist in developed nations, including those with strong GDPs per capita and high growth rates (World Bank 2005). It is also well established that inequalities in income of this nature translate to inequalities in access to affordable health care, and that this gap occurs across a wide spectrum of social democracies (Bouchard 2007c; Canadian Council on Social Development 2001; United States Census Bureau 2006). In fact, when income and access data are tracked on the same timeline as the evolution of the three privatization waves noted above, it is clear that gaps have widened considerably notwithstanding opposing trends in profits made by firms, universities and researchers and notwithstanding the importance of free market principles (for example, Gini Index values are similar in Canada, the United States, Germany, France, United Kingdom and the Netherlands notwithstanding the differing roles of the market and social welfare programs in these nations).

Attention to benefit sharing is warranted by the sheer value brought by publicly funded research to firm drug development[15]. For example,

the majority of studies cited in United States patent applications are from university, government and other public institutions (Gerth and Stolberg 2000; Angell 2004). More important, however, is the fact that the vast majority of drugs identified by government health agencies, public interest groups and firms themselves as the most medically and commercially significant in the years since World War II were developed via publicly funded research (Love 1996; Cockburn and Henderson 1997; December 1998; Gerth and Stolberg 2000; National Institutes of Health, 2000; Public Citizen's Congress Watch 2001; Baker and Chatani 2002). The data also demonstrate that publicly funded research is responsible for the riskiest and most costly research, with firm entry largely after identification of a marketable target. For example, one NIH study revealed that public research was responsible for development of the five best-selling drugs of 1995, each of which had sales in excess of $1B per year. 85% of the research on the compounds was done at public institutions. Importantly, the NIH determined that public research is responsible for the riskiest and most costly research, with firm entry only after identification of a marketable target. Publicly funded researchers contributed by discovering basic phenomena and concepts, developing new techniques and assays, and participating in clinical applications of the drugs. Similarly, an MIT study of the 21 most important drugs introduced from 1965 to 1992 demonstrated that public funds were used to discover and develop 14 of the 21 compounds, and an investigation by the *Boston Globe* demonstrated that public research funds were involved in 45 of the 50 best-selling drugs in the United States from 1992 to 1997. Finally, a study by the Center for Study of Responsive Law demonstrated that the United States government funded clinical trials and other research for 34 of the 37 cancer drugs approved for marking in the United States between 1955 and 1992, and that half of all FDA "priority drugs" approved for marketing between 1987 and 1991 had benefited from a significant federal government role in funding research on the drug. The study also showed that government focuses its research investments on drugs which represent largest gains in therapeutic value and which treat the most severe illnesses.

While data such as those discussed above do not, and can not, make quantitative statements about just exactly what fraction of the resulting products were funded by the public purse, they do illustrate clearly that a significant proportion of the funds and risk necessary to underwrite strong firm innovation and product development are

derived using public resources. Consequently, there seems to be little question that publicly funded research remains the major source of risk-intensive innovative biomedical products notwithstanding shifting patterns in public and private research funding (United States National Science Board 2006). As the privatization of medical research moves forward, the distinction between public and private contributions will become harder to determine owing to the legal nature of public private partnerships and the effect thereof on disclosure of confidential financial information. Experience has shown that this will almost certainly benefit private firms far more than the public when it comes time to assess the relative research and development contributions of each partner to actual product development (United States Congress 1993).

Questions regarding reallocation must be undertaken in light of the fact that the public contributes a wide array of resources to medical product development under conditions of substantial risk, including that of permanent disability and death. This is true of no other sector of the economy, including other subsidized technology-heavy sectors such as information and computer technology, aerospace, natural resources and transportation. Public inputs to medical product development include voluntary clinical trial participation, the provision of cells, tissues and organs, the provision of genomic, proteomic and other "omic" information, philanthropy and other donations targeted to specific aspects of medical research, general taxation tied in some, but not all, jurisdictions to a public health system, and finally contributions to the general intellectual commons, in which the ever diminishing scientific commons is embedded (Heller and Eisenberg 1998; Nelson 2003).

A claim to equitable compensation can also be seen to arise from the ashes of several well-publicized cases[16] in which tissues and genetic information contributed by the public were leveraged by publicly funded researchers to develop patentable and profitable inventions. Together, these cases stand for the proposition that patients currently have no legal rights in *(a)* cells, tissues, organs or "omic" information once removed from donor bodies by consent, *(b)* patented cell lines, tissues or other products derived from *(a)*, or *(c)* profits made by researchers, universities or firms from *(b)*. The same is true of clinical trial data and drugs derived therefrom, which are owned by drug companies and their shareholders. An important aspect of the case law is that the fulcrum leveraged by the courts in each case was the

intellectual property rights attaching to research activities engaged in by researchers, universities and firms. While plaintiffs in one case[17] succeeded based on a finding of unjust enrichment, it is highly unlikely this finding will be extended to the public generally, based on the court's decision that the plaintiffs were so involved in research and development activity that they were essentially inventors. The result of this is that the public have no general legal rights in tissues removed from their bodies, knowledge obtained from use of this tissue or clinical trial participation, or profits made from the resulting patentable inventions.

Finally, there are a number of ethical grounds on which to make a legitimate claim for benefit sharing. Historically public contributions towards medical product development were made in a spirit of altruism or solidarity (Berg 2001; Bovenberg 2005). The public, by participating in clinical trials and donating tissue and genetic information, were said to extend their moral rights in personhood and property for the common good. However, it is entirely reasonable to speculate that the ethical grounds on which voluntary participation proceeds has evolved along with privatization of medical research and the ever-increasing costs of the resulting monopoly products. Given the serious nature of risks borne by the public in light of the privatization of medical research, one might argue that for-profit entities have accrued a duty to compensate the public equitably for their efforts and risks, and that the public has a particularized expectation of an equitable share in the benefits of research embedded within the informed consent process (Simm 2005). This is consistent with the claim by Glasgow (2001) of how, in light of the profitability of the pharmaceutical industry over the last 30 years and the range of inputs to product development by the NIH and other public agencies, it is difficult to characterize an industry that is consistently the most profitable as "risky". In the same vein, Berg (2001) has claimed that persons, firms or nations should not profit unduly from someone else's resources without paying equitably for them. In other words, because for-profit entities receive many tangible and intangible resources for free from patient volunteers, because these resources are provided for the common good and with the expectation of access to affordable medical care, and because pharmaceutical and biotechnology firms have become among the most profitable in the world in the last three decades, it is reasonable to conclude that the ethics and altruism traditionally associated with medical research have evolved along side

the privatization of medical research, and that some form of benefit sharing can be a legitimate answer to the problem of asymmetric benefit distribution. Distributive arguments of this nature would be particularly strong in jurisdictions such as Canada with publicly funded health care and medical research systems aimed at the common good and where medical research and product licensure are heavily regulated on behalf of the public.

The High Level View: Democracy Matters

Two further considerations relevant to the discussion thus far are the distributive metric for access to essential medication and therapies (United Nations 1976; UNESCO 1997; Human Genome Organization Ethics Committee 2000) and the norm in liberal democracies that needed goods such as biomedical products are not, indeed should not, be freely tradable commodities when deemed to be a socially recognized need (Walzer 1983). The latter point is particularly relevant to the issue of public health given that clinical research, patenting, licensing and marketing of biomedical products are strongly regulated in most developed nations and because biomedical products are generally derived from publicly funded research aimed at the global common good. Indeed, all liberal democracies recognize that the state has some role to play in promoting equitable access to needed social goods. Moreover, there are social determinants of health that may have no or, at least, less of a *direct* nexus (or causal relationship) with the economy, including considerations such as morbidity and quality of life, how and why we value physical but also emotional and spiritual health and well-being, and being a good public citizen as opposed to a mere consumer. According to Walzer (1983), egalitarian justice in a system of complex equality requires that goods be distributed contextually, according to their practicable social meanings (e.g., not just relative to the economy), and that no one good or class of goods be allowed to dominate distribution of all goods or even goods in other spheres of society, most notably those in the public health and/or social welfare spheres. While conflict between spheres is inevitable, an important limitation on the free commercialization of goods is that the market is merely one zone of democratic society not the whole of it. In this model, market forces can be legitimately submitted to restrictions in order to promote the equitable distribution of needed goods.

The notion of egalitarian justice has critical ramifications for the privatization of medical research. At varying points in the twentieth

century, governments in most liberal democratic states accepted the principle that biomedical products and health care in general are needed goods and that under certain conditions (old age, disability, poverty, etc.) market forces can and should be preempted by the needs of the welfare state (Walzer 1983). In particular, the state frowns on exchanges of desperation whereby people are forced to bargain without adequate resources for the very means of life. However, as noted above, this is precisely the condition in which great swaths of the public in developed as well as developing nations find themselves. Furthermore, various international and national human rights and related documents recognize either directly or indirectly through the right to life and physical integrity that access to health care is a human right. This provides a further basis for the claim that health care products ought not to be distributed solely on the basis of market criteria alone (Leary 1994; Kinney 2001). Thus, particularly in jurisdictions which have embraced some degree of public healthcare, distributive reallocation of asymmetric benefits is justified on political grounds.

Distributive reallocation would go some way to alleviate concerns, expressed both outside and inside government, over mission creep (Lemmens and Bouchard 2007a). As government increasingly relies on private funding and consults with the private sector over a growing number of issues relevant to the research, commercialization, licensure and marketing of biomedical products, it will be imperative to maintain not only the integrity of government-industry relations, but also to be seen to be doing so publicly. To this end, it has been suggested (Gagnon 2006a; Gagnon 2006b) that the failure of standard economic models to account for dramatic structural and economic transformations in the global pharmaceutical industry over the last two decades compared with other leading sectors lends itself to the conclusion that proactive industries are gaining ground on competitors by transforming socio-economic institutions and actors to increase strategic control over industry, government and the public. Regulatory creep is a particular concern in Canada given that the deregulation agenda is moving forward under the banner of Smart Regulations and other biomedical product-specific policy directives (Lemmens and Bouchard 2007a). From this, one might conclude that distributive reallocation of benefits based on political grounds may take on a certain exigency in proportion to the degree that public private partnerships and other forms of government-industry partnering enhance, or are seen by the public to enhance, the political influence

and market power of firms over competing spheres to the detriment of the public.

Suggested Vehicle for Distributive Reallocation

There is precedent for fiscal reallocation in international benefit sharing instruments, including allocation of a percentage of net profits to support national health care infrastructure (Human Genome Organization Ethics Committee 2000) by means of trust funds, licenses (Secretariat of the Convention on Biological Diversity 2002) or a general innovation tax (Bovenberg 2005). A more focused and historically relevant[18] alternative may be a compulsory government royalty (CGR) on technologies commercialized using the public purse (Bouchard 2007a). Indeed, a "recoupment" provision was originally contained in the Bayh Dole legislation only to be removed just prior to being signed into law by President Carter over concerns relating to the administrating agency, form, and costs to firms (Sampat 2006). All three of these concerns are mitigated if not obviated by three decades of successful university-firm contracting and commercialization efforts. Moreover, as demonstrated by the $206B settlement between United States Attorneys General and Big Tobacco in 1998 (Bouchard 2007a; Wilson 1999), public agencies have not shied away from recovering public health costs from firms when they see fit and have proved adept at successfully reinvesting these funds to finance public health research, primary care and other relevant public health programs.

A CGR has the advantage of a clear and direct structural (legal), functional (economic) and institutional (administrative) nexus between the scope of public input to product development and the scope of benefits derived from this input. Unlike a tax, which levies past, present and future innovation, a CGR yields a royalty stream only on past innovative activity undertaken by public agents and assumed by firms relative to the commercialized product at issue. As such, it offsets the effective "excise tax" levied by firms on products arising from strong patent protection and resulting monopoly pricing (Baker and Chatani 2002), as well as the associated deadweight loss on national economies. The latter issue is particularly relevant to a royalty mechanism grounded in distributive concerns, as the dead weight loss associated with biomedical monopolies is considerably larger than that calculated for other "subsidized" industries. It is estimated to be equivalent to the amount spent by firms on product research and development (Baker 2004), even assuming that the widely criticized

$800M to $1.5B in research and development costs per drug proposed by DiMasi (DiMasi 2000; DiMasi 2001; DiMasi et al. 2003) and colleagues is correct. For example, Baker (2004) has calculated that the average increase in price for pharmaceuticals resulting from patent protection beyond marginal cost is approximately 400%, with the gap in many cases exceeding 1000% marginal cost. This can be compared with a gap of 30% associated with the largest comparable steel tariffs. To give a broader context, the magnitude of the deadweight loss owing to patent monopolies on biomedical products ranged from 0.1 to 0.5% of GDP, depending on market elasticity. As noted by Baker (2004), these losses are minimally an order of magnitude larger than efficiency losses typically addressed with economic policies. Losses of this nature might be expected to be either produced or at least maintained in jurisdictions such as Canada and the United States, where linkage regulations allow for "evergreening" of drug products long after patent protection on the new chemical entity has expired[19]. Under such conditions, the Supreme Court of Canada has recognized that for-profit firms and other entities are poorly incented to engage in truly innovative activity, opting instead to add "bells and whistles" to existing products in order to allow for continued monopoly pricing[20].

Royalty revenue could be used primarily to ensure equality of access to essential medications and health care, with surplus funds used to address public health concerns and facilitate clinical trials and innovative commercialization efforts for traditional small or niche markets where few firms currently operate. It could also provide an additional source of funding for clinical research and be used to promote independent regulatory review of biomedical products once they enter the regulatory approval process. The terms and conditions of a CGR could easily parallel those in traditional license agreements between universities and firms and be either standard or negotiated. Negotiated terms may have the advantage of stimulating early adoption of innovative technologies, thus facilitating economic efficiency in the innovation process. Importantly, the proposed model is aligned with and works to mitigate the tension in the mandates of major public health agencies to protect public health while simultaneously stimulating the economy through medical research. As such, it operates to balance public and private interests in the privatization of innovative research and thus ensures taxpayers' interests in securing an appropriate return on federally funded research are protected (National Institutes of Health 2001).

A CGR would also satisfy various legal grounds said to underpin equitable benefit sharing in the case law and international instruments (Human Genome Organization Ethics Committee 2000): the ground of compensatory justice is satisfied in that the public receives compensation in proportion to its direct contributions to product development; the requirement of procedural justice is satisfied in that administrative procedures for gathering and distributing royalties would under law be required to be fair, impartial and inclusive; and the requirement of distributive justice would be satisfied through an equitable allocation of benefits. As noted in *Greenberg*,[21] to cut the public out of profits subsidized by them is equivalent to unjust enrichment based on the principles of justice, equity and good conscience. The proposed CGR would also comport with the "global public good" model whereby efficient health funding is aimed at promoting truly public health issues (Reich 2002). Members of the public contributing resources to product development do so largely for reasons of solidarity and the common good by extending the moral rights in personhood and property to firms (Pullman and Latus 2003).

Conclusion

There is little question that substantial benefits accrue to society from publicly-funded biomedical research. It is questionable, however, whether these benefits are distributed equitably between the parties responsible for generating, capitalizing and consuming the products of this research. I submit that the benefits from publicly funded research are not equitably distributed amongst public and private interests, and that there are several grounds on which to base a claim by the public for a direct economic interest in profits realized from commercialization of publicly funded biomedical research.

The degree to which governments participate in the distributive reallocation process however will depend on answers to a series of deeply existential questions for the public health branch of national governments. Is the primary function of the agency to protect the public? Is it to stimulate the economy through health research commercialization? If both, where does the balance lie on the scale of public to private concerns? The answer to this third question will dictate the direction of future privatization efforts, whether and how benefits from privatized research should be equitably distributed, as well as the degree of risk assumed by the public should governments vacate their traditional consumer protection role in favour of economic development. It

will also determine the degree to which agencies become dependent on industry for the development and implementation of regulatory policy. This may be a particularly poignant concern for governments such as those of Canada, the United Kingdom, France and other similarly situated jurisdictions which lack the cultural, fiscal and human resources necessary to underpin a more arm's length litigious relationship between government and industry such as that in the United States (Wiktorowicz 2003).

Under controlled circumstances, there is no reason why governments in nations with well developed S&T policies and programs cannot harness the commercial interests of industry to achieve improvements in public health in a manner that is consistent with the principles of complex equality. Public private partnerships are particularly valuable in circumstances involving large transaction costs associated with truly novel biomedical inventions aimed at the global public good. However, a combination of self-interest and anxiety in the face of globalization has led to wide swings of the pendulum of S&T policy in recent years, with argument for expansive and pro-competitive intellectual property rights on one hand and abolition of intellectual property rights in favour of an open source model on the other. Neither position is likely to be balanced or workable over the long term, as both skew too far to private or public interests.

If governments are truly shifting emphasis away from a primary focus on public health protection towards equally facilitating the economy on the back of public health research, then a solution more in the manner of a middle or "third way"[22] will be necessary to protect not only the interests of industry, universities and other for-profit entities, but to also represent the interests of the public, for whom government is an agent. A benefit sharing scheme typified by the proposed CGR model may be a step in the right direction.

Notes

1. The approach taken in this work is focussed on neither economics, law, politics nor ethics per se, but rather encompasses all social determinants of health relevant to S&T policy in a liberal democracy such as Canada, where both market and non-market principles (such as the fundamental importance of social welfare, human rights and a public health system) contribute to peace order and good governance.

2. The term precautionary principle refers to Galen's injunction to "first, do no harm" (*Primum non nocere*): Claudius Galenus of Pergamum (131-201 CE). In public health debates its use refers to notion that when an activity, such as drug approval, raises a

threat of harm to human health, precautionary measures should be undertaken even if some aspects of the cause and effect relationships have not yet been scientifically established. Independent of the definition, the principle is widely agreed to comprise three elements: the presence of scientific uncertainty, a significant threat of harm, and a set of possible precautionary actions to avoid such harm. Proponents tend to view the principle as a proactive and anticipatory approach to human health, while detractors see it more as an unscientific approach which impairs economic and technological development based on unfounded fears.

3. Based on probabilities of the occurrence of harm, calculated using (largely) deterministic statistical approaches and methods. For further discussion of the movement from a precautionary to risk management approach in drug regulation, see Lemmens and Bouchard (2007a), Section VI.E.

4. *Bayh-Dole Act 1980*, codified and amended as 35 USC §§ 200-212 (1994); *Stevenson-Wydler Technology Innovation Act. 1980*, codified and amended as 15 USC §§ 3701-3712 (2000); *Federal Technology Transfer Act 1986*, codified and amended as *15 USC §§ 1501-1534 (1986)*

5. Diamond v. Chakrabarty 447 US 303. 1980

6. Food and Drug Administration Critical Path White Paper. Innovation or Stagnation (updated 2007) describing translational research as "multidisciplinary scientific efforts" directed at "accelerating therapy development" (i.e., moving basic discoveries into the clinic more efficiently). See also Elias Zerhouni (2003) describing translational research as "lab to bedside" research, also commonly known as "bench to bedside" research.

7. Canadian Institutes of Health Research Act. 2006, RSC. c. 6.

8. *Drug Price Competition and Patent Restoration Act 1984*, codified as amended at 21 USC § 355 (2000) (Hereinafter, "Hatch Waxman")

9. *Patented Medicines (Notice of Compliance) Regulations*, SOR/93-133 (Hereinafter, "NOC Regulations")

10. For discussion of linkage regulation in the context of the pharmaceutical and biotechnology industries, see Eisenberg (1996, 2003) and Bouchard (2007 b, c).

11. See also Caufield (2003).

12. Definitions adapted from the Human Genome Organization (HUGO) Ethics Committee Statement on Benefit-sharing (2000) (Hereinafter, "HUGO 2000").

13. See Walzer (1983), discussing the theory of "complex equality", which claims the standard of just equality is not a discrete material or moral good, but rather one that is distributed according to its particular social meaning. Hence, no good (private knowledge; patented or marketed products) is allowed to dominate or distort the distribution of other goods in the same sphere or goods in other spheres (affordable health care or medical products). Egalitarian justice is a normative moral standard as opposed to a universal Platonic standard in the form of a universalized abstraction.

14. The vast majority of universities have made substantial adaptive accommodations in order to maximize profits, including establishment of adaptive administrative routines and policies, technology transfer offices, and spinout firms. As noted by Argyres and Liebeskind (1988), these organizational adaptations are in conflict with the long-standing philosophical and cultural championing by universities and certain federal

policy-makers of intellectual independence through maintenance of the commons, most obviously the "Mertonian norms" of universalism, communalism and disinterestedness, even if such policies are now acknowledged to be against the public interest. In fact, recent work in the area appears to extend the proposal by Argyres and Liebeskind (1998) by conflating the two issues together. For example, in the work of Litan, Mitchell and Reedy (2007), technology transfer and commercialization are seen as entrenched and beneficial norms within the university community to the inherent benefit of society which should be strongly supported by focusing on greater volume of commercialization activities rather than on return on investment considerations by relevant technology transfer offices.

15. Criticism aimed at relatively narrow analytical focus on patenting and funding patterns in the United States is mitigated by historical AUTM reports, which conflate data from Canada and the United States, the lack of strong empirical data from other jurisdictions, the prevalence of American biomedical goods and services in the global market, similarities in FDA and Health Canada and NIH and CIHR missions and programs pertaining to technology transfer and commercialization, and the ever-growing convergence in S&T policy, case law, PTO practice, patent legislation and drug regulation in most developed nations (or the desire on the part of "outsider" nations to emulate the U.S. S&T "basket").

16. *Moore v. Regents of the University of California*. 793 F.2d 479 (Cal.) 1990, 490; *Greenberg v. Miami Children's Hospital Research Institute, Inc*. 264 F. Supp. 2nd 1064 (SD Fal). 2003; *Washington University v. Catalona* 2006

17. *Greenberg v. Miami Children's Hospital Research Institute, Inc*. 264 F. Supp. 2nd 1064 (SD Fal). 2003

18. See Bouchard (2007a), Section IV.B. for a detailed discussion of previous efforts at "recoupment" and other vehicles identified by Congress and the public as equitable means of distributive reallocation of benefits in the context of Bayh Dole.

19. "Evergreening" refers to undue extension of the statutory monopoly attached to drug products by means of listing on the patent register multiple patents with obvious or uninventive modifications. Under such circumstances, the patentee prolongs its monopoly beyond what the public has agreed to pay: *Whirlpool Corp. v. Camco Inc.* [2000] 2 SCR 1067, at para. 37; *Bristol-Myers Squibb Co. v. Canada (Attorney General)* [2005] 1 SCC 26, at 66; *AstraZeneca Canada Inc. v. Canada (Minister of Health)* 2006 SCC 49, at 39. According to the Romanow Report: "A particular concern with current pharmaceutical industry practice is the process of "evergreening," where manufacturers of brand name drugs make variations to existing drugs in order to extend their patent coverage. This delays the ability of generic manufacturers to develop cheaper products for the marketplace and it is a questionable outcome of Canada's patent law" (Commission on the Future of Healthcare in Canada 2002; pp. 208-209, 253).

20. *AstraZeneca Canada Inc. v. Canada (Minister of Health)* 2006 SCC 49, at 39

21. *Greenberg v. Miami Children's Hospital Research Institute, Inc*. 264 F. Supp. 2nd 1064 (SD Fal). 2003.

22. The "middle way" has received considerable attention over the years from philosophers as a path to balance and wisdom: As noted by Plato for example, "If we disregard due proportion by giving anything what is too much for it; too much canvas to a boat, too much nutriment to a body, too much authority to a soul, the consequence is always shipwreck." Similarly, Aristotle wrote that "the psychology of the soul and its virtues"

is based on the "golden mean", or the desirable middle between the two extremes of excess and deficiency. Finally, Mainonides states "If a man finds that his nature tends or is disposed to one of these extremes, he should turn back and improve, so as to walk in the way of good people, which is the right way. The right way is the mean in each group of dispositions common to humanity; namely, that disposition which is equally distant from the two extremes in its class, not being nearer to the one than to the other."

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