Disease Control in the New Millennium:
A Qualitative Inquiry on the Legitimate Use of Restrictive Measures

In an Era of Rights Consciousness

by

Cécile M. Bensimon

A thesis submitted in conformity with the requirements
for the degree of Doctor of Philosophy
Institute of Medical Science
University of Toronto
© Copyright by Cécile M. Bensimon 2009
Communicable Disease Control in the New Millenium: A qualitative inquiry on the legitimate use of restrictive measures in an era of rights consciousness

PhD/2009/Institute of Medical Science, University of Toronto

Background: When Canadian public health officials issued thousands of quarantine orders during the SARS outbreak in 2003, it raised difficult questions about the legitimacy and acceptability of restrictive measures to achieve public health goals. While public health interventions have traditionally been justified on utilitarian grounds, this project aims to establish an empirical basis to justify public health action. The objectives are: 1) Descriptive: To describe the views of members of society on the justifiability of using restrictive measures to achieve public health goals; 2) Analytic: To analyze the use of restrictive measures at the intersection of public health policy, human rights norms, and ethics; and 3) Normative: To situate public health ethics within a Habermasian model of communicative ethics that can serve as the basis of justification for the legitimate use of restrictive measures based on the intersubjective recognition of public health and human rights. Methods: Individual interviews were conducted with 62 participants, including 23 health care providers, 16 members of the public, 13 community and/or spiritual leaders from the Greater Toronto Area, as well as six public health officials and four health care regulators at the local, provincial, and federal levels of jurisdiction. Findings: Participant views were analyzed and organized into themes that revolve around the following concepts: 1) common good; 2) types of quarantine; 3) compliance; 4) reciprocity; 5) uncertainty; and 6) communication. Conclusions: Combining empirical research with conceptual scholarship, it is argued that the recognition of and commitment
to the common good by participants, which emerged as an overarching theme, provide justificatory power for the use of quarantine during communicable disease outbreaks. But to respect rights, while being committed to the common good, it is argued that we must move beyond the see-sawing between ostensibly competing requirements toward a conception that gives equal weight to public health and human rights; that is, both imperatives – the community and the individual – refer to one another without dissolving into one another. Following a Habermasian account of opening processes of decision-making to a moral-practical discourse, it is argued that public health ethics offers an important site for integrating his model of discourse ethics within public health deliberations to expand the scope of moral argumentation on--and ultimately to ground the justification of--the use of restrictive measures.
ACKNOWLEDGEMENTS

To Ross Upshur, my esteemed supervisor, for believing in me and showing me the way when I got lost in the labyrinth of this journey. Accepting to work with Ross was the single best decision I have made since I first entered the world of bioethics. In our intellectual quest to define the virtues of the “ideal bioethicist,” all too often we forget what it means to be that person. Ross epitomizes those virtues. One cannot ask for a better mentor. For this, my gratitude is really more than I can express.

To Barbara Secker and Solly Benatar, my trusted committee members, who never stopped encouraging me in small or large and always meaningful ways. Their support was invaluable. To Peter Singer and Doug Martin, with whom it all started, for giving me that first chance to prove myself. I wouldn’t be here if it wasn’t for them. To all my friends at the PCRU and the JCB who challenged me in myriad ways along the way.

To Cheryl Cline, my emotional wellspring, who endured the incessant ebb and flow of my emotions for so long. She rescued me from the abyss of despair too many times to count and invested so much of herself to weave with me, over and over, the fabric of faith one needs to sustain something like this.

To my nephews, Jacob, Jonathan, Joshua and Joseph and my nieces, Naomi and Liora, whose discoveries of the world which surrounds them gives true meaning to communicative action. To my little brothers, Michael and Emmanuel, who at some point were no longer boys and became men to whom I admiringly look up to.

To my parents, Benny and Yaffa, who made all this possible by instilling in me the love of learning and, greater yet, their extraordinary strength and indefatigable determination to never give up. This is for them. For that’s what this journey has been about.
# TABLE OF CONTENTS

CHAPTER 1: INTRODUCTORY REMARKS ......................................................................................................................... 1

CHAPTER 2: PROBLÉMATIQUE ........................................................................................................................................... 27
   A. INTRODUCTION ....................................................................................................................................................... 27
   B. BEYOND POSITIVISM: CRITICAL THEORY ........................................................................................................... 34
   C. BASIS FOR JUSTIFICATION OF PUBLIC HEALTH INTERVENTION: SCIENTIFIC LEGITIMACY? .................. 38
      1. Ethical Frameworks in Public Health .................................................................................................................. 38
      2. Ethics and Quarantine ......................................................................................................................................... 39
      3. Evidence and Effectiveness in Public Health Decision-making ........................................................................ 41
   D. BASIS FOR JUSTIFICATION OF PUBLIC HEALTH COERCIVE POWERS: LEGAL LEGITIMACY? .............. 44
   E. THE MODERN LIBERAL INDIVIDUAL: AN INCOMPLETE CONSTRUCT? ............................................................. 48
   F. TOWARDS MORAL LEGITIMACY: COMMUNICATIVE RATIONALITY .................................................................. 53

CHAPTER 3: BACKGROUND CONSIDERATIONS .............................................................................................................. 56
   A. THE INSTITUTIONALIZATION OF PUBLIC HEALTH: THE DOMINANCE OF DISEASE CONTROL .................. 57
      1. Quarantine .......................................................................................................................................................... 60
   B. THE INSTITUTIONALIZATION OF HUMAN RIGHTS: DISEASE CONTROL AND HUMAN RIGHTS ............... 68
      1. Human Rights ................................................................................................................................................... 70
      2. The Importance of Civil and Political Rights to Public Health Limits .......................................................... 71
      3. The Importance of Public Health to Economic, Social and Cultural Rights .................................................... 74
   C. THE HIV/AIDS DEBATE: BRINGING HUMAN RIGHTS TO BEAR ON PUBLIC HEALTH ............................ 79
   D. HIV/AIDS AND HUMAN RIGHTS: A SHIFT AWAY FROM PUBLIC HEALTH ..................................................... 83

CHAPTER 4: THEORETICAL CONSIDERATIONS ................................................................................................................ 87
   A. INTRODUCTION ....................................................................................................................................................... 87
   B. RETHINKING THE SYNTHESIS BETWEEN THE INDIVIDUAL AND THE COLLECTIVE ................................. 88
   C. THE HABERMASIAN PROJECT: BEYOND THE VERITIES OF POSITIVISM ......................................................... 91
      1. The Antinomie of Modernity ............................................................................................................................... 92
      2. The Anomie of the Public Sphere ....................................................................................................................... 96
   D. ESTABLISHING AND VINDICATING NORMS: THE CONDITIONS FOR UNDERSTANDING .................... 99
      1. The Theory of Communicative Rationality ......................................................................................................... 99
   E. INSTITUTIONALIZING AND ENFORCING NORMS: THE POSSIBILITY OF A LEGITIMATE ORDER .......... 105

CHAPTER 5: METHODS ................................................................................................................................................... 111
   A. INTRODUCTION ....................................................................................................................................................... 111
   B. CASE STUDY DESIGN .......................................................................................................................................... 111
   C. METHODS USED ................................................................................................................................................... 113
      1. Sampling and Recruitment .................................................................................................................................. 113
      2. Data Collection .................................................................................................................................................. 115
      3. Data Management ............................................................................................................................................ 116
      4. Data Analysis ................................................................................................................................................... 117
   D. ANALYTIC RIGOUR ............................................................................................................................................. 123
   E. ETHICS REVIEW .................................................................................................................................................... 128

CHAPTER 6: FINDINGS ..................................................................................................................................................... 129
   A. INTRODUCTION ....................................................................................................................................................... 129
   B. COMMON GOOD .................................................................................................................................................. 129
      1. The Duty to Comply .......................................................................................................................................... 129
      2. The Responsibility to the Community ................................................................................................................ 130
      3. The Role and Respect of Individual Rights ....................................................................................................... 132
   C. PERCEPTIONS OF EFFECTIVENESS .................................................................................................................... 136
      1. Effectiveness ........................................................................................................................................................ 137
      2. Restrictiveness ................................................................................................................................................... 143
CHAPTER 1: INTRODUCTORY REMARKS

I would not, therefore, waste time in debating a question [on quarantine], which, after the lapse of a century, cannot be decided.

– Tom Hancock, 1821, p. 236

Although…all other restraints on liberty…raise the issue of the state’s power to sacrifice an individual’s rights in order to protect the public, quarantine poses this question in its starkest context.

– Wendy E. Parmet, 1985-1986, p. 54

It is my contention that isolation and quarantine are both the simplest and most complex problems in public health practice.

– Lawrence Gostin, 2004, p. 85

In the aftermath of SARS and with an influenza pandemic on the horizon, the use of restrictive measures such as quarantine by public health authorities is back on the agenda of policy-makers and health care providers in a way that has not been seen since the turn of the century. First introduced as a means to control the infiltration of communicable diseases into local communities, systems of quarantine of yore were quasi-institutions commonly erected at seaports that saw thousands of people systematically quarantined at any one time. From the perspective of the scientific viability of communities, if not economic, there was little controversy about its use. Long before the notion of public health was formulated, both as a discipline and an institution, and even longer before the emphasis of security and protection embodied in the historic conception of the Welfare State entered our political consciousness, the use of quarantine was a fundamental pillar of what were essentially public health measures.¹

¹ The terms “quarantine” and “isolation” are often used interchangeably, but it is important to underscore that they actually point to different interventions. Stedman’s Medical Dictionary (1982) defines quarantine
By all accounts, it was the demands of communicable disease control that drove the development and (re)organization of health systems – so that by the time public health practice came to be known as such, quarantine was already viewed as a necessary and legitimate public health strategy. It is both one of the oldest tools of—and a precedent to—public health that, in bygone years, was viewed to be a microcosm of an implicit social contract where agency was defined as involving obligations—not rights. Quarantine drew its strength from the justificatory power of public health’s utilitarian pursuit.

For nearly half a century, however, when it appeared that communicable diseases were no longer a threat and bacteriology became a respected science, health authorities shifted to surveillance as an alternative to quarantine, fundamentally changing the nature of compulsory public health measures in communicable disease control. Not only was quarantine no longer the de facto intervention in the control of communicable diseases, it became no longer accepted as a valid public health strategy.² And so it was that quarantine was rendered antiquated and was hardly ever, if at all, considered an option—much less so invoked on a large scale than the way it was in February 2003, when the new infectious disease Severe Acute Respiratory Syndrome (SARS) emerged globally.³

---

² I recognize that public health includes environmental health, whereby animals and plants are regularly quarantined as a means to avoid introducing or spreading disease. For the purpose of this inquiry, however, I am limiting the scope of quarantine to human persons.

³ For a detailed description, see Rothstein et al., 2004.
In merely days, SARS would fundamentally challenge established public health practices and values, and become a public health matter “of international concern” (Plant, 2003, p. 14). Though it is believed that the disease first emerged in Southern China, it was first documented in Vietnam and later found to have spread mainly to Singapore, Taiwan and Canada. The spread of the disease on an international scale is significant: “By March 12, 55 cases of SARS were recognized, mainly in hospitals in Hong Kong, Singapore and Hanoi. A month later, there were more than 3,000 cases and 100 deaths in 20 countries worldwide. By May 8, 7,000 cases, and by June 11, almost 8,500 cases and more than 800 deaths had been reported to the WHO from 29 countries” (Lee, 2003, p. 274).

At the time that SARS was determined to be infectious, little was known about the disease, and preliminary research had yielded imprecise and uncertain data at best. Inadequate evidence and incomplete knowledge made decisions difficult to reach and even more difficult to ascertain with any degree of certainty. Within that context, public health authorities deemed it would be appropriate to invoke the precautionary principle – a principle that seeks to implement preventive measures to respond to (real or perceived) risks in the face of uncertainty (Resnick, 2003; Morris, 2000) – and turned to quarantine as a means to interrupt the spread of the disease. Every jurisdiction affected by SARS reached the same conclusion: The only viable measures to control the outbreak would be to rely on the centuries-old control measures used in epidemics before the age of bacteriology – isolation, contact-tracing and follow-up, quarantine, and travel.
restrictions.\textsuperscript{4} Quarantine measures used for SARS varied considerably by country (Rea et al., 2007). In the Greater Toronto Area (GTA), nearly 30,000 people found themselves in quarantine based on a home quarantine honour system, monitored almost exclusively by telephone by public health staff. Elsewhere, imposition of quarantine measures was more coercive: In most locations, those in quarantine were monitored by police, security firms or neighbourhood groups, which at times included home video-surveillance, and in some locations those identified at risk were relocated to central quarantine facilities (Rea et al., 2007; Lee et al., 2003; Lee, 2003; Pang et al., 2003).

Overall, quarantine was invoked on a scale unprecedented in several decades. At first glance, this did not seem to be controversial, even in Canada, a society where basic rights are genuinely respected and valued to such an extent that autonomy-limiting interventions are routinely challenged or contested.\textsuperscript{5} Nearly everyone in the GTA and the province of Ontario voluntarily complied with orders of quarantine (Rea et al., 2007), suggesting, it would appear, that voluntary and temporary relinquishment of liberty may not pose such a problem after all in a liberal democratic society like Canada.

The socio-political and ethical relevance of this phenomenon deserves further investigation. That people complied with quarantine or other restrictive measures during the SARS outbreak does not mean that the protection of rights or the acceptability of control measures were not in question. Presumptions of acceptance based on compliance, such as many observers have drawn since SARS, do not capture the reality that in modern societies compliance does not necessarily imply acceptance of legitimacy on the part of

\textsuperscript{4} Since the SARS outbreak, authorities have been much quicker to forcibly retain persons, as evidenced, for example, by the jailing of a teenager with active and contagious tuberculosis after he refused treatment at a hospital and said he planned to return to Mexico (Associated Press, 2007).

\textsuperscript{5} Interestingly, there was controversy surrounding this decision, mainly among those who can be considered “experts,” not among members of the public (see for example, Schabas, 2004).
those who are affected. Based on the empirical findings of this inquiry, drawing the conclusion that quarantine was accepted as justified based on spurious correlations (compliance equals acceptance) does not take account of the complexity of context, and fails to raise the underlying question of legitimacy. As I hope to show, a closer analysis reveals that the question of legitimacy is a highly problematic question for communicable disease control in an era of human rights.

The emergence and re-emergence of communicable diseases (see for example, Farmer, 1999; Fidler, 1997) – such as the SARS outbreaks, the Speaker case in the US, epidemics of MDR-TB (multi-drug resistance tuberculosis) and its newly-identified by-product, XDR-TB (extreme drug-resistant tuberculosis), for which they are as of yet no treatment options, the prospect of an influenza pandemic or bioterrorist attacks, the E. coli outbreak in Ontario, and dramatic public health emergencies such as the Asian Tsunami in 2004 and Hurricane Katrina in 2006 – has led to a new imperative to focus on the fundamental importance of public health policies (see for example, Allan, SM et al., 2007; Bloomberg, MR, 2007; Fidler et al., 2007; Singh et al., 2007; SARS Commission 2006; Homeland Security Council, 2006; World Health Organization, 2006a, 2006b; Markel, 2005; Basrur, SV et al., 2004; D’Cunha, C, 2004; Naylor, D et al., 2004; National Advisory Committee of SARS and Public Health, 2003; Expert Panel on SARS and Infectious Disease Control, 2003; Walkerton Commission, 2002; Gostin, 2000; Coker, 2001, 2000a; Gostin et al., 1999; Gebbie, 1994). As these crises have so dramatically highlighted, public health plays an instrumental role in providing the conditions necessary for people to be healthy and in shaping the development and outcome of communicable disease outbreaks or other emergencies. In particular, the
SARS outbreak and the Speaker case demonstrated that the exercise of quarantine powers raises fundamental issues about the use of restrictive measures, acting as a “gravitational pull” that brings up and connects broader political, governance, legal (Fidler et al., 2007, p. 616; see also Fidler, 2004) and ethical issues. In short, it raises deeper questions that underlie modern public health, which has led us to think about the role and nature of public health in modern society.

More broadly, the SARS crisis, along with other public health crises in Canada, such as the 2000 Walkerton E. coli outbreak and the inquiry that followed (Walkerton Commission, 2002), underscored the fundamentally political nature of public health, tied as it is to other domains of public policy (Robertson, 2006) and provided a magnifying glass through which to understand and analyze the crucial issues raised by cases such as these, notably the failings of modern public health. SARS revealed the vulnerabilities and weaknesses of a public health system that, concluded Justice Campbell, finds itself to be “unprepared, fragmented, poorly led, uncoordinated, inadequately resourced, professionally impoverished, and generally incapable of discharging its mandate” (SARS Commission, First Interim Report, 2006, p. 29). This very closely resembled the Institute of Medicine’s report on the state of public health in the US almost two decades earlier (Institute of Medicine, 1988). But more than that, it pointed towards an important gap in our understanding of public health and a fundamental failing with respect to the place it has been accorded in modern health systems. Set against the dominant biomedical (individualist) framework, public health interventions are no longer valued as legitimate

---

6 The Institute of Medicine’s 1988 report charged that the current state of public health signaled “great concern” and “some alarm” and that “a lack of leadership, tightly constrained resources, and limited vision were preventing the public health infrastructure of the nation from playing its proper role in protecting the public from disease and promoting a healthier nation” (Gebbie, 1994, p. 869; quoting the Institute of Medicine, 1988).
health initiatives, but rather “configured as the baffling intrusion of arbitrary [and paternalistic] authority” (Cottam, 2005, p. 1592), akin to Thatcher’s notion (or accusation) of the “Nanny State” (see for example, Colgrove, 2007; Harsanyi, 2007).

Over time, public health has been reduced to a technical and scientific epidemiological pursuit\(^7\) that lacks capacity, credibility and--most significantly--justificatory power to act on the authority of the common good.

If we go back to the last major debate on communicable disease control, when quarantine was resurrected from the historical annals of public health in the early 1980s during the HIV/AIDS debate, the prospect of using it quickly became an explosive issue that had little to do with underlying notions of good. When public attention and health officials turned to quarantine at the dawn of the crisis, some going as far as drafting regulations to respond to what was taken, like SARS, to be a matter of serious public concern, the renewed interest in quarantine spurred an intense and often passionate debate on the impact of the use of restrictive measures on the rights of victims or carriers of HIV/AIDS (see for example, Mann et al., 1994; Bayer and Fairchild-Carrino, 1993; Scheper-Hughes, 1993; Dubler et al., 1992; Kirp and Bayer, 1992; Sullivan and Field, 1988; Ford and Quam, 1987; Merritt, DJ, 1986a, 1986b; Fox, 1986; Macklin, R, 1986; Petersen, 1999, p. 116), underpinning public health discourse. As Petersen states, “the use of statistics to analyse public health problems from the 1820s onwards reflected the consolidation of the scientific understanding of society as an entity governed by norms and probabilities” (Petersen, 1999, p. 118, quoting Hacking, 1990). Statistics were used to measure the incidence of different diseases and to compare social groups and changes over time, providing the basis for a risk assessment of what were believed to be socially objective causes (see for example, Atenstaedt, RL, 2007; Foege, 2004; Petersen, 1999; Susser, 1998; Hacking, 1990; Rabinow, 1989, 1992). Mendelsohn reminds us: “It is easily forgotten that reform before bacteriology was not social reform but scientific reform, that is, rational reform in accordance with what were held to be the laws of hygiene (1995, p. 277). He adds: When public health reorganized around the bacteriological laboratory, [it] self-consciously gave up the ground of social reform” (1995, p. 268). As Mendelsohn suggests, the classic account of this shift in the American context is portrayed by Chapin, 1910.

---

\(^7\) This has been spurred in large part by broader shifts in conceptions of society, namely the dominant scientific conception of society as an entity “governed by underlying law-like universal mechanisms,” (Petersen, 1999, p. 116), underpinning public health discourse. As Petersen states, “the use of statistics to analyse public health problems from the 1820s onwards reflected the consolidation of the scientific understanding of society as an entity governed by norms and probabilities” (Petersen, 1999, p. 118, quoting Hacking, 1990). Statistics were used to measure the incidence of different diseases and to compare social groups and changes over time, providing the basis for a risk assessment of what were believed to be socially objective causes (see for example, Atenstaedt, RL, 2007; Foege, 2004; Petersen, 1999; Susser, 1998; Hacking, 1990; Rabinow, 1989, 1992). Mendelsohn reminds us: “It is easily forgotten that reform before bacteriology was not social reform but scientific reform, that is, rational reform in accordance with what were held to be the laws of hygiene (1995, p. 277). He adds: When public health reorganized around the bacteriological laboratory, [it] self-consciously gave up the ground of social reform” (1995, p. 268). As Mendelsohn suggests, the classic account of this shift in the American context is portrayed by Chapin, 1910.
Curran and Gostin, 1986; Gostin and Curran, 1986; Gostin, 1986; Beauchamp, DE, 1986; Grutsch and Robertson, 1986; Parmet, 1985-1986; Novick, 1985). Some forty years earlier, the human rights revolution had already left its footprint on public health practice by tracing a linkage between public health and human rights that aimed at balancing the exigencies of protection of public health against protection of individual rights (Nations Economic and Social Council on Economic, Social and Cultural Rights, Siracusa Principles United Nations, 1985). The aim of conceptualizing rights protections in relation to public health considerations was to formally sanction the imposition of restrictive measures under conditions of threat to public health. Public health was thus recognized as a legitimate pursuit in the context of what ultimately led to the legal institutionalization of rights.

But the HIV/AIDS debate would fundamentally question the purpose and boundaries of public health. The rights discourse moved away from the question of weighing rights against the public health and instead sought to align human rights principles with public health measures. Thereupon, the linkage was more substantive: Human rights activists and scholars alike challenged the prevailing view that human rights and public health are not fundamentally in conflict, but instead are complementary approaches to the common objective of addressing and advancing human well-being. Based on this logic, the protection of rights was seen as an effective public health strategy and, for this reason, it was thought that “public health endeavours should begin and end with a respect for human rights” (Murray, 1993, p. 1426). Human rights activists and scholars vehemently opposed the use of quarantine – terming such an approach “archaic doctrine” (Parmet, 1996) – and argued that it was unjustified on scientific, legal and
ethical grounds (Levine, 1986, p. 2). Pointing to the strength of – and perhaps faulting – the rights discourse, Scheper-Hughes expressed the view that “in the US the rights agenda already in place provoked a ‘hands off’ response so virulent we lost sight of the real threat” (1993, p. 967). Arguing that the logic of public health policy had been turned on its head (i.e., that rights considerations dictated public health policies), she recounted what Stephen Joseph, former Commissioner of Public Health for the City of New York, had told her in May 1993: “We came to think of AIDS as fundamentally a crisis in human rights that had some public health dimensions, rather than as a crisis in public health that had some important human rights dimensions” (1993, p. 967).

Over time, human rights came to be seen as central to the public health response, and most people accepted the new prevailing view that education was the best, and perhaps only, acceptable response (see for example, Lerner, 1999; Heymann et al., 1998; Asch et al., 1998; Efferen, 1997; Bayer and Dupuis, 1995; Asch et al., 1994; Dubler et al., 1992). The legacy of the HIV/AIDS debate was deeply significant: It pioneered a human rights approach to public health that championed the principle that human rights are the bedrock of legitimacy for public health practice. So great was the impact of the HIV/AIDS debate that most people believed that the newly formed marriage between public health and human rights would have broader implications for public health policy, and that future public health practice--especially in the context of communicable disease control--would embrace a human rights agenda. It seemed indubitable that “all future responses to communicable diseases would face human rights scrutiny” (Fidler, 2000, p. 198), especially in the United States where the rights discourse had gained a stronghold
in public health practice (see for example, New York City Tuberculosis Working Group, 1992).

So in the wake of the anthrax attacks, when the Centers for Disease Control and Prevention (CDC) drafted a state emergency powers act (Centers for Disease Control and Prevention, 2001) that promoted the use of traditional public health practices, such as the use of forced examination and quarantine, and gave public health “exceptionally broad powers” (Annas, 2002, p. 1338), while “short-circuiting due process” (Annas, 2002, p. 94), observers responded with disbelief at what they took to be a “regressive tendency” and a return to the “paternalistic pre-human rights days of nineteenth century” (Annas, 2002, p. 94; see also, Parmet and Mariner, 2001; Mariner, 2001). There was a new consensus among those who shared this view that “it was unnecessary and counterproductive to sacrifice basic human rights to respond to bioterrorism” (Annas, 2002, p. 94). Proponents of a human rights approach to public health restated the conclusions articulated during the HIV/AIDS debate, namely that human rights and public health are inextricably linked, and that appropriate safeguards had to be put in place in order to respect the rights of individuals during a public health emergency.

Perhaps because of the divisive nature of bioterrorism, and the wide media coverage it received, the public backlash against the policy response to the threat of potential attacks brought to the surface the persisting tension between human rights and public health more than any other coercive measures introduced for actual occurrences of disease since the HIV/AIDS debate. For example, laws passed in the early 1990s for the control of tuberculosis (TB) and multi-drug resistance tuberculosis (MDR-TB) which facilitated the involuntary detention of non-infectious persons had gone largely
unchallenged, even while the burden of proof had shifted from risks posed to public health to the likelihood of treatment compliance (Coker et al., 2007, p. 610). The unresolved conflict between public health and human rights became manifest again in the aftermath of SARS, when coordinated efforts were made to modernize public health laws and the system itself. It was in the shadow of these events that communicable diseases have contributed to a considerable shift in public consciousness with regards to the exigencies of disease control and the human rights impact of coercive public health policy instruments, such as quarantine and involuntary detention.

The increase in public health consciousness was evidenced by the staunch reaction provoked by the recent Speaker case and the high profile that the treatment of TB received (see for example, Boggio, 2008; Coker et al., 2007; Fidler et al., 2007; Markel et al., 2007a, 2007c; Brewer, 2007; Committee on Homeland Security, 2007; Swendiman and Jones, 2007) when an American citizen, diagnosed with MDR-TB, then XDR-TB, traveled to Europe against public health orders. The Speaker case closely mirrored the urgent and deeper dilemmas that confronted Canadian public health authorities during the SARS outbreak. It brought into focus the deep conflict between individual rights and public health protections in liberal democracies that have dominated the outpouring of literature in their aftermath. Both events reinforced three realities: 1) any linkage made between health and human rights has largely been to scrutinize, or even to reproach, the impact of (what are viewed to be detrimental) public health policies on human rights; 2) most attempts to place a priority on public health considerations over human rights have usually been met with opposition or have been contested; and 3) there have been few actual attempts to integrate human rights norms within public health
practice. In this light, it can be said that the linkage of human rights to public health has proved to be a fecund rhetorical device and theoretical concept, but has not had much impact on practice and, as Fidler observed, international law has not been shown to be an effective conduit for the principle that protecting human rights is an effective public health strategy (Fidler, 2000, p. 298). All in all, the human rights revolution was an important stepping stone in establishing a relationship between public health and human rights, and the HIV/AIDS debate gave us a platform to bring human rights to bear on public health. However institutions of human rights and public health remain today, as Tomasevski expressed at the cusp of the HIV/AIDS debate, “distant disciplines with little intercourse” (1992, p. 540).

While policy responses to the threat of bioterrorism pointed towards the fact that there is no actual human rights approach to public health (see for example, Ziskin and Harris, 2007; Annas, 2002a; Fidler, 2001), or even still, the Speaker case made us question whether this is feasible, diseases such as SARS and XDR-TB point towards another challenge: Even as a theoretical concept, the underlying rationale of the principle that the protection of rights contributes to the protection of public health holds little relevance for communicable diseases with different and more pervasive means of transmission than HIV/AIDS. Arguments against the use of restrictive measures for victims or carriers of HIV/AIDS drew much of their strength from the fact that HIV/AIDS is not analogous to diseases for which quarantine has traditionally been used, such as the plague, typhoid or cholera, or even tuberculosis (see for example, Bayer, 1991). Similarly, the dynamic nature of today’s emerging and re-emerging communicable diseases, such as SARS, pandemic influenza, or XDR-TB is not analogous to HIV/AIDS.
Thus, arguments against the use of restrictive measures for victims or carriers of HIV/AIDS may be irrelevant to the basic dilemmas posed by public health emergencies. The question of how to control communicable disease outbreaks in modern society was essentially taken out of the HIV/AIDS debate. In practical terms, public health has no modern precedent on which to base decisions for the use of quarantine. Until the causative agent of SARS was identified as a new type of coronavirus, public health decision-makers were operating under circumstances of relative ignorance, like that of public health authorities when the causes of communicable diseases were poorly understood before the advent of bacteriology.

However the society in which quarantine was invoked during SARS is fundamentally different than the world in which it was first conceived and enforced. Then, quarantine was deemed a societal good carrying a kind of moral clout that obligated individuals to abide by it. Today, society is underpinned by a mode of public thinking where rights are trumps, implying some sort of power against or freedom from autonomy-limiting measures. In other words, when quarantine was conceived, it was an obligation to abide by restrictive measures (Fidler, 1999, pp. 170-179). Today, citizens naturally presuppose, even if they comply, that they have the right not to adhere to autonomy-limiting measures (even though rights to liberty may be justifiably restricted to protect society).

This modern presupposition reflects the deeply-entrenched view in popular sovereignty that rights are fundamental – a view that can be described in Kymlicka’s terms as the development of a “rights consciousness” (Kymlicka, 2002, p. 7), in which
questions of rights are questions of basic morality. Briefly, rights consciousness developed from the liberal assumption that rights are prior to the (common) good and, from this, it follows that rights constitute the basis for determining the justifiability of public health interventions. In turn, assumptions about rights are reflected in the dominant understanding of health – i.e., clinical medicine or the biomedical framework, meaning that “the individual [is] the focal point of moral concern” (Beauchamp, 1999, p. 21), which leads to “reductionist, individualistic understandings of public health problems” (Wallack and Lawrence, 2005). The HIV/AIDS debate over health and human rights essentially reversed the linkage between rights and public health established in early human rights jurisprudence by shifting the focus from the imperative of weighing rights against public health considerations to weighing public health against rights protections (see for example, Coker, 2006, 2001b, 2000b; Martin, 2006; Harris and Martin, 2004; Gostin, 2000).

This was a subtle shift that had a powerful effect. First, it further reinforced the dichotomy between the dominant conception of (biomedical/individual) health and public

---

8 Kymlicka explains: “Since 1948, we have an international order that is premised on the idea of the inherent quality of human beings, both as individuals and as peoples. The international order has decisively repudiated older ideas of a racial or ethnic hierarchy, according to which some people were superior to others, and thereby had the right to rule over them. It is important to remember how radical these ideas of human equality are. Assumptions about a hierarchy of peoples were widely accepted throughout the West up until World War II, when Hitler’s fanatical and murderous policies discredited them. Indeed, the whole system of European colonialism was premised on the assumption of a hierarchy of peoples, and was the explicit basis of both domestic policies and international law throughout the nineteenth century and first half of the twentieth century. Today, however, we live in a world where the idea of human equality is unquestioned, at least officially. What matters here is not the change in international law per se, which has little impact on most people’s everyday lives. The real change has been in people’s consciousness. Members of historically subordinated groups today demand equality, and demand it as a right. They believe they are entitled to equality, and entitled to it now, not in some indefinite or millenarian future. This sort of rights-consciousness has become such a pervasive feature of modernity that we have trouble imagining that it did not always exist. But if we examine the historical records, we find that minorities in the past typically justified their claims, not by appeal to human rights or equality, but by appealing to the generosity of rulers in according ‘privileges,’ often in return for past loyalty and services. Today, by contrast, groups have a powerful sense of entitlement to equality as a basic human right, not as a favour or charity, and are angrily impatient with what they perceive as lingering manifestations of older hierarchies” (2002, pp. 7-8).
health that had begun at the turn of the century. Second, it shifted the discussion about health from providing the conditions necessary for people to be healthy for the sake of the common good to viewing it as a human, that is to say individual, right (or a human rights violation if conditions for [individual] good health are denied). Following from this evolution of the health and human rights discourse, implicit acceptance of the notion of public health is largely framed in terms of health as a right – something owed to individuals to enable them to develop and pursue their own conception of the good life (see for example, Meier, 2007; Donnelly J, 2003; Gruskin and Tarantola, 2002; Gruskin and Loff, 2002; Jacobson and Soliman, 2002; Torres, 2002; United Nations Economic and Social Council on Economic, Social and Cultural Rights Committee, 2000; Rodriguez-Garcia and Akhter, 2000; Toebes, BCA, 1999a, 1999b; Shinn, 1999; Bernier, 1994; VanderWal, 1990).

Clearly, we are still grappling with the question of how to align communicable disease control measures with human rights norms. Attempts to reconcile public health and human rights have foundered on the inability to establish a viable relationship between them. If anything, it has further exacerbated the inherent tension between, and the difficulty of reconciling, the need to protect individual rights and the need to protect public health. Thus practitioners and scholars alike are asking the same questions that surfaced at the dawn of the HIV/AIDS epidemic: “First, why should public health officials be concerned about burdening human rights? Second, to what extent is respect for human rights and dignity compatible with, or complementary to, public health goals?

---

9 Including pioneering work that preceded the HIV/AIDS debate: in bioethics (Beauchamp, 1989; Bayer et al., 1983), jurisprudence (Dworkin, 1978), and public health law (Burris, 1989; Gostin, 1991).
Finally, how can an optimal balance between public health goals and human rights be negotiated?” (Fidler, 2000, p. 283). In short, can human rights and public health coexist? This is a key question that will affect assumptions about the justifiability of the use of restrictive measures in future public health emergencies. Basically, rights consciousness necessarily calls into question the legitimacy of those acting against the norm – e.g. the imposition of public health coercive measures, which acts against what is taken as the norm. One thing is certain in this controversy: The justifiability of public health interventions rests upon claims that take rights into account. In this respect, rights consciousness thrusts the question of the legitimate use of restrictive measures onto centre stage. But scholarship has largely failed to address this question and, as a result of this failure, it has not addressed the role of legitimacy in determining the justificatory basis of public health interventions. Here we begin to probe how decisions are made during public health crises. Turning to the example of SARS, we are confronted with the problem of justification that emerges when there are no grounds on which the justifiability of public health interventions (that is to say, public health’s visions of the good) can be established.

Perhaps the greatest challenge facing health care providers and public health decision-makers at the outset of the SARS crisis was that decisions on how to contain the spread of the disease could not be arrived at systematically, in the sense now used within the context of the evidence-based health care movement, which assumes that science can uncover solid factual evidence--verifiable truths--to substantiate decisions. Public health publicly acknowledged the vulnerability of the system to uncertainty, and implicitly to unexpected change, and did not, indeed could not, conceal the fact that decisions were
being made against the backdrop of scientific and epidemiological uncertainty. Further exacerbating the uncertain nature of this new and seemingly virulent disease was the fact that every jurisdiction affected by SARS turned to quarantine, all the while quietly debating whether it would prove to be an effective means of intervention. Upshur recounts such concerns, noting that “despite controversies over quarantine, there is no clear or agreed-upon sense of what constitutes an effective quarantine” (Upshur, 2003). The debate over whether quarantine is effective persevered well after the SARS outbreak, with some asserting its effectiveness (Rea et al., 2007), while others continuing to challenge it (see for example, Dwosh et al., 2003; Schabas, 2003).

Invoking quarantine thus raises difficult questions about the justifiability of a restrictive intervention that may or may not be effective, while evidently infringing on human rights. From this lack of scientific evidence emerges a fundamental question about the basis of justification of public health interventions. Today, public health largely relies on statistical evidence and some implicit, though often unstated, notion of statistical causal association between interventions and effectiveness to make and justify their decisions. But clearly, they cannot, on these grounds alone, legitimately justify coercive measures when there is no or not enough evidence. On what grounds then, we must ask, can the use of restrictive measures be justified?

Although this is a fundamental question, it has hardly been addressed. The aftermath of SARS saw renewed calls to focus policy efforts on public health. There has been a flurry of activity at every level of government to take a hard look at the changing public health environment with the view of explicitly allowing restrictive measures and strengthening public health powers (see for example, Allan, SM et al., 2007; Bloomberg,
MR, 2007; Ziskin and Harris, 2007; SARS Commission 2006; Gross and Aoláin, 2006; Homeland Security Council, 2006; Committee on Measures to Enhance the Effectiveness of the CDC Quarantine Station Expansion Plan for U.S. Ports of Entry, 2006; World Health Organization, 2006a, 2006b; Basrur, SV et al., 2004; D’Cunha, C, 2004; Naylor, D et al., 2004; National Advisory Committee of SARS and Public Health, 2003; Expert Panel on SARS and Infectious Disease Control, 2003; Reich, 2003; Walkerton Commission, 2002; Miller et al., 2001; Centers for Disease Control and Prevention, 2001, 2002; US Congressional Research Service). Moreover, this resurgence of attention towards communicable disease control has inspired a burgeoning theoretical and empirical literature on public health governance, law, and ethics (see for example, Agwunobi, 2007; Aledort et al., 2007; Bloomberg, 2007; Coker, 2007, 2006; Fidler et al. 2007; Gostin, 2007; Swendiman and Jones, 2007; Markel, 2007a, 2007b, 2007c, 2006; Singh et al., 2007; Gostin and Powers, 2006; Gostin, 2006; Inglesby et al., 2006; Gostin, 2004; Greaves, 2004; Blendon et al., 2004; Abdullah et al., 2003; Barbera et al., 2001; Fidler, 2001).

It is my contention that this increased focus on public health, however, is moving in the wrong direction. Few have challenged assumptions that have proven to be problematic or shaped the discussion in ways that will have an impact. For the most part, practitioners and scholars continue to: Frame the health and human rights discourse in terms of the human rights impact of public health policies, squarely placing the burden of proof on public health; conceive of a public health/human rights linkage as a see-saw relationship that operates between competing or conflicting requirements; call for greater evidence-based decision-making, going as far as proposing “to introduce into the
language of ethics and rights the notion of evidence-based assessment of risk” (Cocker, 2007, p. 612) to make decisions about interventions; argue that we need scientific data to determine the validity of the causal relationship between the use of restrictive measures and the governance of communicable diseases; or focus, even from an ethical perspective at times, on the perceived instrumental value, that is to say the effectiveness, of public health interventions. All of the activity focusing on public health is only further entrenching the status quo – that is, the dominant--and grossly inadequate--positivist paradigm that marginalizes social dynamics (e.g. questions of ethics, values, norms, or interests) and assumes that it exists independently of the broader social context.10

Changes to public health laws, e.g. the Canadian Quarantine Act, the Ontario Health Protection and Promotion Act, or recommendations to develop robust guidelines, e.g. in the Campbell, Naylor and Walker reports, have ultimately only reinforced three existing problems: First, the assessment of the changes required has been left largely to “experts” without drawing on the knowledge and insight of citizens, thousands of whom were quarantined. Second, so-called modernized laws have not considered the relationship between public health and human rights, in spite of the modern imperative to account for rights. Third, there has been a renewed sense of purpose and urgency to develop more sophisticated models of scientific decision-making and further rely on legal

---

10 Positivism implies here that the practical (social reality) is reduced to, or eclipsed by, the technical, meaning that social processes, values, norms and interests (which are necessarily embedded in human inquiry) are separate from, and subordinate to, prevailing forms of scientific-technological rationality. It presupposes that only scientific knowledge is legitimate (because it recognizes no knowledge other than scientific knowledge) and that it produces facts that are value-free, devoid of value judgements. Based on this assumed neutrality (or in Habermasian terms, unproblematically assumed knowledge), it takes for granted, and thus cannot justify, its own claims. Under this view, political matters and policy decision-making are presented as technical problems that require expertise to evaluate and resolve, all but alienating, indeed rendering irrelevant, the social. What matters are questions that focus on the prediction and control of objectified processes, which are driven by “immutable natural laws and mechanisms” and exist independently of social reality.
mechanisms to justify and enforce coercive interventions, without appreciating the normativity inherent in modern scientism and legalism.

I agree that our recent experiences with communicable disease outbreaks have indeed given us a renewed sense of purpose and urgency but, I would like to argue:

1. In very different ways than is being considered, that is, based on:

   (i) The implications of the demonstration that quarantine is still a valid control strategy and the implications for an expanded application of quarantine authority;

   (ii) The public controversy over the justification for its continued existence;

   (iii) The evidence of the insufficiency of the scientific justification model.

2. And begins with very different assumptions:

   (i) We must redefine the dominant health and human rights discourse to mean something else: The rights discourse through which the relationship is framed has to move away from the narrow emphasis on the human rights impact of public health policies, move beyond the continuous see-sawing (or balancing or weighing or delineating) between the good and the right, and move towards a genuine synthesis;

   (ii) We must challenge the assumption that reliance on evidence alone, or greater reliance on evidence-based decision-making, has normative force or justificatory power; and we must make explicit that decisions about coercive interventions are framed with uncertainty in the absence of evidence of effectiveness or the lack of consensus about what constitutes an effective intervention;

   (iii) We must thematize how knowledge claims are constructed and broaden the process of construction to include those who are affected by policies, namely the community of citizens.

In essence, we must articulate a cogent argument justifying the use of restrictive measures that transcends 1) the dominant positivist paradigm of health that frames health considerations in individual terms rather than in population terms and 2) the dominant positivist (scientific and legal) systems of justification that provide a limited kind of
justificatory power to act against the norms established since the human rights revolution and reinforced the resulting development of a rights consciousness. Modern society implicitly holds two tacit beliefs that make it difficult, if not impossible, for public health to effectively manage an emergency, including a communicable disease outbreak, to wit: 1) individual rights are necessarily unchallengeable, and 2) public health measures are necessarily challengeable. That rights and the public good matter is not in question here; however rights ought not be viewed as some kind of uninterpreted given or self-evident tout court – if only to understand the full meaning and implications of why they matter.

Against these considerations, the purpose of this inquiry is to explore the concept of quarantine and, more generally, the role and nature of public health in modern society, with a view of inquiring into, and challenging assumptions about, the legitimate exercise of public health powers. My objective is to articulate an argument justifying the use of restrictive measures based upon quite a different justificatory model than the dominant scientific, that is to say positivist, system of justification. The poverty and inadequacy of the latter resides on three levels: It does not acknowledge the uncertainty of (scientific) evidence; it does not acknowledge the indeterminacy of laws upon which it relies for justification and enforcement; and it does not acknowledge that legitimacy requires compliance by those who are affected, the community of citizens, and compliance requires that justification proceed on terms that are acceptable to them.

When viewed together, the raising of these claims make explicit the normative underpinnings of public health practice and the shaky foundations on which it attempts to justify interventions. I believe that public health, or modern society more generally, can derive legitimacy only from a more fundamental justificatory model: That of moral
legitimacy. Following Habermas’ theory of communicative action, illuminating the normative content of public health practice and grounding the construction of (shared) norms requires that we move from a positivist system of justification to a justificatory model based on moral argumentation. In essence, moral argumentation as grounds for justification opens up the possibility of discursively redeeming criticisable validity claims (Habermas, 1996) and reaching an agreement on what is acceptable, what counts or what matters. In other words, justifying the use of restrictive measures based on moral argumentation about the legitimacy of normative (validity) claims generates the norms and values “worthy” of legitimation. The problem of grounding and justifying the normative foundation of, that is to say the fundamental norms that guide, modern society is therefore resolved both discursively and explicitly.

To do so requires that we restore what I fundamentally believe to be the intrinsic indissociability of the ethical and political nature of these questions to transcend the modern split between politics and ethics that has essentially individualized questions of the good, and to create the possibility for (re)articulating “publicly recognized models of exemplary life” that have been replaced in modern society with “the moral-political question of what are the just rules of social life that are equally good for everyone” (Habermas, 2003, pp. 279-280).¹¹ In view of what is now considered as a legitimate pluralism of worldviews, “modern philosophical ethics is no longer able to commend particular models for how to lead a good life” and questions of the good are confined to “what is good for me” or “how can I pursue a life of my own choosing” (Habermas, 2003, pp. 279-280). Raising the question of the legitimate use of restrictive measures,

---

¹¹ For an account of the relationship between politics and ethics in the context of bioethics, see Pellegrino (2006), who discusses the viability or desirability of opening bioethics to the “public square.”
however, necessarily re-inscribes questions of how to live a good life in the public (political) sphere, where the community of citizens interacts to reach an agreement about what is acceptable or what matters. A starting point for restoring the relationship between politics and ethics is the idea that thematizing political practice, tied as it is to questions of legitimacy of state intervention, is central to addressing the ethics of the use of restrictive measures. In other words, the foundational and practical claims of public health can only be carried out as political theory – understood in the classical sense of encompassing, not divorcing politics and ethics – and the search for justification can only be found within political theory.

One such perspective is offered by Habermas’ theory of communicative rationality, which weds philosophy to social theory and brings Kantian liberalism and communitarian critiques of liberalism into dialogue, providing an intersubjectivist conception of (political and individual) liberty tied to a strong sense of (political) community. In my view, situating public health in a model of communicative action holds the potential of successfully integrating public health with human rights by allowing us to foster a collective identity, that is, collectively constituted notions of the good relevant for communicable disease outbreaks and the use of restrictive measures, without compromising the inherent moral status of persons, even if, at times, rights are curtailed to achieve public health goals.

This is made possible because, on a Habermasian account, reason is embodied in speech, meaning that citizens enter into a practical discourse as rights-bearing individuals who aim to reach an understanding on shared norms. Thus communicative action is linked internally to the reason embodied in speech, and the aim of discourse is to
arrive at a rational consensus through the public use of reason. On this account, the private and public spheres are “co-original” (Habermas, 1996). This allows us to move beyond the see-sawing of ostensibly competing requirements towards a conception that gives equal weight to public health and human rights. Here it is no longer a question of what takes precedence or what is overarching (either the norm, i.e. rights are prior to the common good, or against the norm, i.e. the common good prevails over rights to achieve public health goals), because the viability of public health and human rights depend here on intersubjective recognition. That is, both imperatives – the community and the individual – refer to one another without dissolving into each other. Following a Habermasian account of opening processes of decision-making to a moral-practical discourse, I will further argue that public health ethics offers an important site for integrating his model of discourse ethics within public health deliberations to expand the scope of moral argumentation on--and ultimately to ground the justification of--the use of restrictive measures.

In Chapter 2, I discuss the central problématique of this inquiry as it relates to the basis for justification of restrictive public health intervention. I examine this question at the intersection of public health policy and practice, human rights (law) and ethics to explore what constitutes the legitimate use of restrictive measures in modern communicable disease outbreaks. I give an overview--and challenge assumptions--about the positivist rationality underpinning public health that relies on (positivist) scientific and legal models of legitimacy to justify decisions which, I argue, lack foundational justificatory power.
In Chapter 3, I give a historical overview of the institutionalization of public health and human rights with a view to conceptualizing their relationship and situating it against the backdrop of the prevalent health and human rights discourse. I argue that the latter ascribes greater moral authority to rights and consequently embraces a biomedical individualist conception of health that does not give sufficient consideration to broader questions of public health policy.

In Chapter 4, I outline theoretical considerations for determining what constitutes a justifiable claim and how we ought to conceptualize the relationship between public health and human rights to render them compatible. I propose a solution that I hope can be convincingly attempted through the lens of a Habermasian communication theory of society. This perspective provides both the theoretical underpinnings of this inquiry and a gateway to new considerations for public health practice and public health ethics.

In Chapter 5, I describe the qualitative methods that I have employed to address the research questions based, in part, on the 2003 SARS outbreak.

In Chapter 6, I outline the themes that emerged from the 62 interviews I conducted with members of the public, spiritual leaders, health care providers, public health officials and regulators of health care colleges, revolving around the following concepts: 1) common good, 2) effectiveness, 3) compliance, 4) reciprocity, 5) uncertainty, and 6) public deliberation.

In Chapter 7, I interpret the findings in terms of participants’ understandings of the relationship between public health and rights, as well as considerations relevant to public health decision-making and public health coercive powers. In my final analysis, I show how the findings are consonant with a Habermasian theory of communicative
action which provides, I believe, both the theoretical and empirical foundation to begin moving towards a model of legitimacy grounded in moral argumentation – or moral legitimacy.

By way of conclusion, I discuss the implications of this inquiry for public health practice.
CHAPTER 2:
PROBLÉMATIQUE

The object of this essay is to assert one very simple principle, as entitled to govern absolutely the dealings of society with the individual in the way of compulsion and control, whether the means used be physical force in the form of legal penalties, or the moral coercion of public opinion. That principle is, that the sole end for which mankind are warranted, individually or collectively in interfering with the liberty of action of any of their number, is self-protection. That the only purpose for which power can be rightfully exercised over any member of a civilized community, against his will, is to prevent harm to others. His own good, either physical or moral, is not a sufficient warrant. He cannot rightfully be compelled to do or forbear because it will be better for him to do so, because it will make him happier, because, in the opinions of others, to do so would be wise, or even right. These are good reasons for remonstrating with him, or reasoning with him, or persuading him, or entreating him, but not for compelling him, or visiting him with any evil, in case he do otherwise. To justify that, the conduct from which it is desired to deter him must be calculated to produce evil to someone else. The only part of the conduct of any one, for which he is amenable to society, is that which concerns others. In the part which merely concerns himself, his independence is, of right, absolute. Over himself, over his own body and mind, the individual is sovereign.

—John Stuart Mill, 1859, p. 13

Where technology is still unable to provide a solution to the spread of disease, people look to the law.

—Tomasevski, 1992, p. 543

A. INTRODUCTION

In this inquiry, I examine the ethics of using restrictive measures during modern communicable disease outbreaks, particularly in the context of the increasing intensification of rights (spurred in part by the broadening and recasting of the global discourse and declarations on rights—see for example, Gable, 2007; Soysal, 1996). The

---
12 Soysal explains: “This emphasis on rights is expressed through a codification of human rights as a world-level organizing principle in legal, scientific and popular conventions. As legitimized and celebrated by various international codes and laws, the discourse on human rights ascribes universal rights to the person, independent of membership status in a particular nation state. Even though they are frequently violated as a political practice, human rights increasingly constitute a world-level index of legitimate action and provide a hegemonic language for formulating claims to rights beyond national belonging” (Soysal, 1996, p. 19). This universal legitimization of rights has had major repercussions for the increasing recognition of the “new” health discourse on the right to health as a human right. Presupposing universality — such that a human right should be according to the philosophy it underlies — to the right to health appeal to international law as a sufficient claim to legitimacy. By doing so, however, these claims do not account for the fact that the materialization of rights are still vested in the state (Soysal, 1996, p. 21), meaning that the
relevance of this question can be appreciated by the fact that, as it stands, there are very few ethical or legal precedents in communicable disease control that reflect modern developments in constitutional and human rights jurisprudence to guide public health authorities. To be sure, there are examples of modern legal cases that have validated the exercise of restrictive public health powers. For example, the 1986 Supreme Court of Canada decision in *R. v. Oakes* sets out an analytical framework for determining when restrictions on constitutionally protected rights are justified. However there is an important caveat here. To a great extent, key constitutional decisions are predicated on individual judges’ unexpressed beliefs about how a law ought to be interpreted. As Heard argues:

> Even if [judges] agree that there has been an infringement, they then might determine whether this infringement is a “reasonable limitation” that can be “demonstrably justified in a free and democratic society” under Section 1 [of the Canadian Charter of Rights]. Although the Supreme Court has developed an analytic framework within which this determination can be made, considerable discretion remains to individual judges in applying this analysis.... Perhaps we need to reflect on the implications of the fact that Canada’s top jurists can hear the same arguments and read much the same material relating to a particular Charter claim, and yet come to opposite conclusions about that claim. One might pause to wonder what this means for the supposed “inalienability” of the rights enshrined in the Charter. But on a more immediate level, we need to consider just how important it may be which particular judges hear a Charter case. Does the likelihood of a Charter claim being accepted in the top court of the land depend upon *which judges happen to sit on the panel that deals with the case?*” (Heard, 1991, p. 294; emphasis mine).

That coercive public health interventions have successfully prevailed against legal challenges does not therefore, as some would argue, give them ethical legitimacy or

---

13 *R. v. Oakes* at 135-140.
grounding. At present, public health appeals to what I view as being flawed logic and an insufficient foundational structure to justify imposing autonomy-limiting measures:

1. Public health legislation relevant to communicable disease control was drafted before the legal institutionalization of rights (the codification of human rights norms), and therefore existing legislation cannot be said to be compatible with jurisprudence on rights. Yet the justifiability of public health interventions in modern society is inextricably tied to the respect of human rights. As evidenced during SARS and despite recent reforms, public health law is not equipped to confront the challenges posed by emergent communicable diseases. Moreover, it is paternalistic or largely punitive, supported by the assumed jurisdiction of the courts brooking no (or very little) refusal to cases brought forth by public health authorities.

2. The courts have historically accorded almost complete deference to public health decision-making to assess the justifiability of the infringement of protected rights, in effect making explicit what public health assumes and thereby creating a dynamic that feeds on itself: The courts rely on public health’s logic of (scientific) decision-making to render decisions about the validity of interventions, and public health relies on the courts to (legally) validate the use and enforcement of the measures it takes. The circularity of this justificatory argument is obvious: The prima facie validity attributed to the use and

---

14 Case in point: In a decision rendered by the US Supreme Court in the context of tuberculosis in School Board of Nassau County v. Arline, it postulated that courts “normally should defer to the reasonable medical judgments of public health officials” (School Board of Nassau County v. Arline, 1987, 480 U.S. 273 at 287).
enforcement of restrictive measures is taken as evidence of the validity of interventions.

3. The paramount principle for public health decision-making, such as was reinforced in the Campbell Report (SARS Commission, 2006), is the precautionary principle – a principle grounded in the assumption that scientific data is available and that it can be easily interpreted to serve as a guidepost for decision-making – which does not take account of questions of either the good or the right (one could be precautionary without any concern for the common good or individual rights). Acting on precautionary grounds, often without firm scientific grounding, makes the nature, scope, and justification of the precautionary principle unclear and further entrenches the disestablishment of moral considerations inherent in practices of modern public health and law.

Based on this logic, there is a misguided assumption that the legal rationality underlying human rights and public health jurisprudence, as well as the scientific rationality underlying decisions about public health interventions, are in and of themselves valid. Yet how, and when, do we know that?

An analysis of this nature opens up two essential questions: 1) the first concerns the question of legitimacy in the use of restrictive measures against considerations of public health (the common good) and human rights (individual rights); and 2) the second concerns the question of legitimation (strategies for achieving legitimacy) of legitimacy claims. Any attempt to ascertain the conditions under which these questions are treated in dominant positivist conceptions of discourse and practice leaves us, however, with little
theoretical or empirical guidance on how legitimacy is--or ought to be--defined and how legitimation is--or ought to be--achieved. In fact it would not be far-fetched to say that these questions are seldom, if at all, treated as such. Instead they are taken as a given, concealing the normative ethical dimension of public health governance.

Decisions concerning, and implications on the use of, restrictive measures typically involve the analysis of scientific and legal facts that present moral dilemmas which are treated as matters of fact, rather than questions that require moral discernment and ethical reasoning. Tending towards scientific and legal instrumentality, which focus solely on the effectiveness of restrictive measures or the effectiveness of the laws that serve to enforce them, disregards any consideration of their normative ethical underpinnings and obstructs any authentic possibility to critique or rearticulate these. Further exacerbating this inadequate understanding of the normative ethical dimension of public health interventions, and the implications for the status of this normativity, is the fact that public health authorities are left to their own devices in making decisions of moral concern that are characterized by uncertainties associated with--and not easily resolved by--the very scientific-positivist rationality on which decisions are based.

We are left in a conundrum. What exactly do we fall back on to make decisions about the use and enforcement of restrictive measures? Are we bereft of a substantive foundation for their justification in the absence of evidence of their effectiveness, or the lack of consensus on what constitutes an effective quarantine (Gostin, 2006; World Health Organization, 2006a; Ferguson et al., 2005)? Given that laws are by nature vague or indeterminate, how do we legitimately make them more determinate? Who or what can render an authoritative interpretation of legal provisions? In cases where there is a
genuine claim on both sides, which side deserves precedence? How should we arbitrate among competing claims?

With so many questions, it seems necessary to investigate on what grounds public health authorities can justify their decision to implement restrictive measures. Hence the central question in consideration of restrictive measures is this: Given the significant uncertainties that characterize decisions made about restrictive interventions and the risks that public health policing powers pose to individual rights, on what grounds may they be justified?

This question underlies relevant considerations at the intersection of three disciplines that I propose to bring to bear on my analysis of the use of restrictive measures: Public health policy and practice, human rights, and ethics. Although this marriage of disciplines has been attempted to a degree in public health discourse and, more recently, in emerging scholarship in public health ethics, proposed frameworks or lines of argumentation fail to establish a viable theoretical relationship between public health and human rights that can be translated into practice. Correspondingly, they fall short of offering sufficient guidance to navigate through 1) the requirement of effectiveness of the intervention against the uncertainty of evidence, and 2) the compliance and enforcement of measures against the uncertainty of the law.

This is because scholarship and practice have not broken with or challenged underlying assumptions of dominant positivist (scientific and legal) systems of justification in public health discourse and practice, even though they have proven to be inadequate. As such, questions surrounding moral quandaries and scientific and legal uncertainties have not been made explicit in public health discourse and practice and thus
have gone largely unexamined in scholarship. I submit that this is no longer tenable. We need a system of justification that can make explicit the normative dimensions of public health governance and bring moral discernment and direction to questions of legitimacy and legitimation.

To this end, I aim to introduce a problématique – a complex set of interrelated issues that form the basis of this inquiry – into what constitutes the legitimate use of restrictive measures. By doing so, I will attempt to move towards the development of a model of legitimacy that serves to redress the weakness inherent in the normativity of the dominant models of scientific and legal legitimacy on which we wholly rely to make decisions in communicable disease outbreaks. But more than that, I will attempt to move towards a model of legitimacy that provides a substantive foundation for the scientific and legal justification of restrictive measures. To do so, I propose to critically explore the ways in which our historically and culturally shaped commitments to a particular kind of rationality – positivist rationality – construct systems of justification that are both insufficient and inadequate. I will also explore how our assumptions about the inherent validity of positivist rationality greatly obscure the moral quandaries raised by the use of restrictive measures. In order to transcend the paradigm divide that continues to persist, we must transcend the dominant positivist rationality within which public health and human rights currently operate and remain at odds. Public health and human rights cannot draw legitimacy from positivist rationality because it provides no basis, despite its claims of legitimacy, for acknowledging its own contingent and normative character, and it necessarily pits public health and human rights against one another, further reducing the legitimacy of public health considerations against the dominant rights paradigm.
It is from this starting point that I turn to my analysis of the problématique of the use of restrictive measures. My aim is to give an overview of the prevalence of positivist rationality in public health, with a view on emphasizing the existing lack of foundational justificatory power for restrictive interventions. Following this discussion, I will argue for a fundamental reconceptualisation in the relationship between public health and individual rights and, concomitantly, in the positivist (scientific and legal) systems of justification that underpin their claims of legitimacy based on the Habermasian notion of communicative rationality. Following a Habermasian account of opening processes of decision-making to a moral-practical discourse, I locate the possibility of integrating his model of discourse ethics, that is to say, a new understanding of legitimacy, in public health ethics in order to expand the scope of moral argumentation of public health deliberations on—and ultimately to ground the justification of—the use of restrictive measures. This is because the justificatory power of public health and human rights—and the foundation that underpins their relationship—derives, I contend, from a deeper structure, that of moral legitimacy.

B. BEYOND POSITIVISM: CRITICAL THEORY

As a first step towards addressing the problématique of the legitimate use of restrictive measures, we must restore the intrinsic indissociability of the ethical and political natures of this question. An understanding of political practice, tied as it is to the question of legitimacy of state intervention in modern society, is central to an understanding of the ethical issues raised by the use of restrictive measures, or more broadly, public health intervention. In other words, the foundational and practical claims of public health, I contend, may be carried out only as political theory, and the search for justification can
only be found within political theory, or more precisely, within a rationality that weds ethics to political theory. To that end, I propose to situate this inquiry within political theory, in particular critical social theory, and to introduce the Habermasian project of communicative action (1987) into the problématique in question.

The purpose of critical theory is two-fold: 1) To develop a critique of the status quo – *i.e.*, the prevailing (positivist) interpretations of what constitutes a rational society – to a new level of explicit questioning; and 2) to attempt to transform social reality in the hope of establishing a more just society that does not limit rationality to technical rationality and (legitimate) knowledge to scientific knowledge (Roderick, 1986). Furthermore, critical theory aims to adopt a critical stance towards the social phenomena it studies, with the aim of challenging its assumptions and remediying problems (or inequalities, or injustices, etc.). It draws normative conclusions or prescriptions that link directly to practical action, meaning that evaluation or observation of how something plays out in practice is integral to the process of analysis. What this means, at least on a Habermasian account, is that asking the question, “What is the philosophical rationale that would provide a basis for justification for the use of restrictive measures” – or more broadly, “What is the philosophical basis for legitimacy claims [or scientific knowledge, or knowledge acquisition, or reaching agreement, or the moral requirement for public health and human rights, etc.]” – is insufficient to allow for a complete analysis and understanding of what is required. For Habermas, the problem of justification is not a strictly philosophical question; indeed, it cannot be adequately answered from a philosophical perspective, since framing the question this way does not consider the social reality within which legitimacy is generated. That is, the social context, or
sociological considerations, remains unthematic in the background. Therefore, he argues, the basis for justification should be understood--and sought--against the background of its wider socio-political context because it allows for a broadening of the issues that warrant legitimacy.

Based on this logic, Habermas appeals to--mediates between--philosophy and social theory (what he calls a post-metaphysical justification) in order to look for the foundation and ground the critique of modern society. Against absolutist claims that Western rationality sows the seeds of its own destruction (see for example, Horkheimer and Adorno, 1972) or relativist claims that reject rationality altogether and argue that modernity is a historical stage coming to an end (see for example, Foucault, 1961), he attempts to articulate a way out – which for him is the development of a more rational society – that requires, he posits, the construction of a more differentiated and positive account of rationality, one that can be defended against the usurpation of scientific-technical rationality. He infuses critical theory with a “democratic impulse” (Bronner, 1994, p. 284) that reflexively seeks to both legitimize liberal democracy and function as a standard of critique (Bronner, 1994) against which the present society may be problematically thematised – and not taken as a given, such as positivism does. For Habermas, the basis for critique that creates the conditions to provide a foundation and a framework for the construction and justification of fundamental norms is communicative rationality (1987). The process of argumentation, he argues, is the essence of what I call moral legitimacy.

While I question what I understand to be the privileging of the liberal positivist model in modern society, I do not question, but rather embrace, like Habermas, the basic
tenets of liberal democracy, namely the universal right to equal liberties, respect for human dignity, and (arising from the project of the Enlightenment) reason as freedom. By arguing that we ought to transcend the dominant positivist rationality because it does not provide sufficient justificatory power to achieve public health goals in modern society does not mean that I am proposing that we ought to--it does not require that we--transcend rationality or liberalism altogether. In the Habermasian tradition, I argue that we ought to recast the dominant positivist rationality towards a broader understanding of rationality: Reason understood as communicative action, a kind of rationality firmly grounded in modern notions of autonomy. Indeed, the possibility for achieving moral legitimacy requires, I contend, that we retain, rather than reject, certain forms of autonomy. In this way, it is a fundamentally liberal view that does not reject or negate or denigrate the modern individual, but instead seeks to reconceive her in intersubjective terms to restore reflexivity and discourse, the public citizen and the public sphere.

I share the view of Elsthain, who speaks of the politics of displacement that has eliminated the notion of, and a role for, a public citizen and thus authentic democratic possibilities (1993). She “bemoans the loss of the public citizen” (1993, pp. 35-36) and calls for the return--a reconceptualisation--of the lost public citizen. This is precisely what Habermas does: He reconstitutes a public sphere in order to provide a democratic basis for a broader understanding of liberalism – political liberalism – where enfranchised (public) citizens use a communicatively generated (public) reason to construct collectively constituted notions of the good, without surrendering the (private) rights and liberties accorded to them in modernity. To do this, he makes both the private and public spheres a moral priority, without giving a privileged form of justification to either one. In
this way, Habermas presents a way out of the impasse by transcending the dominant positivist either/or paradigm that has us grappling with the inability to conceive of rights during a communicable disease outbreak while simultaneously satisfying the legitimacy conditions of using and enforcing coercive interventions.

I turn to modern public health to begin the discussion on my interpretation of this impasse.

C. BASIS FOR JUSTIFICATION OF PUBLIC HEALTH INTERVENTION: SCIENTIFIC LEGITIMACY?

1. Ethical Frameworks in Public Health

The impetus to articulate an ethics for public health was the recognition that it presents distinct ethical considerations, given its focus on population health (in contrast to clinical and research ethics’ primary focus on individuals – Dawson and Verweij, 2008; Dawson and Verweij, 2007; Holland, 2007; Anand, 2004; Roberts and Reich, 2002; Beauchamp and Steinbock, 1999). An ethical framework for public health could also provide public health authorities with a common vocabulary for the analysis of decisions that come into conflict with the principle of respect for autonomy that has traditionally been dominant in health care.15

Upshur (2002) proposes a public health ethics framework that identifies four principles – the harm principle, proportionality, reciprocity, and least restrictive measures – to guide public health intervention. In an article on the ethics of quarantine, he shows how the application of these four principles can provide the justification for the implementation of an autonomy-limiting strategy such as quarantine (2003). Other public

---

15 While clinical ethics and research ethics traditionally grew up in a highly individualistic framework with a privileging of the principle of respect for individual autonomy, it is important to underscore that there is now a greater diversity of approaches and a wider breadth of grounds upon which these have been made.
health scholars, such as Childress et al. (2002), Callahan and Jennings (2002), Kass (2001), and Roberts and Reich (2002) have also contributed frameworks of analysis that give priority to distinct ethical considerations in public health. In doing so, they identify dilemmas that range “from maximizing utility to preventing harm to distributing benefits fairly [to] identifying program goals, determining effectiveness, minimizing burdens, proportionality, and procedural justice” (Kass, 2004, p. 236). What is significant for the purpose of this analysis, however, is that these frameworks, almost unanimously, point to the importance of justifying a public health intervention on the basis of its effectiveness. Kass succinctly summarizes this view: “Programs that are coercive,” she argues, “should be implemented only in the face of clear public health need and good data demonstrating effectiveness” (Kass, 2001, p. 1780).

2. Ethics and Quarantine

In a similar vein, Barbera et al. (2001) examine the role of quarantine in the context of potential bioterrorist attacks in order to argue that large-scale quarantine should not be considered “a primary public health strategy in most imaginable circumstances” (p. 2711) because its effectiveness is questionable. Here they mean that there is no empirical evidence supporting the effectiveness of large-scale quarantine. That is, decision-makers must consider whether the implementation of large-scale quarantine has a “reasonable scientific chance of substantially diminishing the spread of the disease” (p. 2714), with the caveat that there is no valid (public health or scientific) justification to order quarantine in an outbreak where there is low or no person-to-person transmission of the disease.
Thus while Barbera et al. allow that public health authorities ought to be able to consider the use of quarantine for other diseases and thus, presumably, choose to invoke quarantine if it is deemed appropriate, they submit that authorities should seek or define “alternatives” to quarantine that “may have more scientific credibility” and that “may be more effective and more feasible” (p. 2716). Moreover, their conclusion that “with modern, in-depth understanding of specific diseases, [a] more specific and medically valid response [than quarantine] is [more] appropriate than that used in the era of poor scientific understanding that established the practice of quarantine” (p. 2716) suggests that quarantine is invalid as a modern public health intervention to achieve public health goals, and claims it is irrelevant in the light of scientific advances. Based on my interpretation of the article by Barbera et al., I can therefore conclude that they argue that if there is no definitive evidence of the effectiveness of an intervention, then it is neither feasible nor justifiable.

More recently, Aledort et al. (2007), though they affirm that “non-pharmaceutical public health interventions [are] vital in curtailing disease spread” (p. 209), nonetheless bemoan the “absence of a definite science base” and “dearth of evidence on the efficacy or effectiveness of most non-pharmaceutical interventions for influenza” (p. 209). To compensate for this gap, the authors elicited expert recommendation about their use with the caveat that, while the policy recommendations they present relied “heavily on expert judgment” (p. 208), decisions about non-pharmaceutical interventions could ultimately be informed--and validated only--by strong scientific evidence to determine their effectiveness. Furthermore, the authors report that experts concluded (within the constraints of the absence of evidence, we are reminded) that interventions “including
mask-use and other personal protective equipment for the general public, school and workplace closures early in an epidemic, and mandatory travel restrictions were rejected as likely to be ineffective, infeasible, or unacceptable to the public” (p. 208). Without firm scientific grounding, the authors do not find it necessary to provide a basis for this argument or how it was derived for that matter. In the final analysis, they call for the “pervasive…demand for scientific evidence” (p. 214) of the effectiveness of interventions, validated no less through randomized controlled trials, while contradictory in its appeal to expert judgement to investigate which interventions “experts believe are likely to be beneficial, feasible and widely acceptable in an influenza pandemic” (p. 218). Although it is unclear how Aledort et al. would reconcile a finding of effectiveness (or non-effectiveness) of an intervention with a finding of its non-acceptability (or acceptability), one thing is clear: According to their logic, much like Barbera et al., the effectiveness of an intervention is a necessary condition for public health to justifiably implement and enforce restrictive measures.

Is it feasible, however, to constrain action only if there is a lack of evidence of its effectiveness? Without definitive evidence of much of anything, as was the case during the SARS outbreak, could public health legitimately respond to an infectious disease outbreak in Barbera’s or Aledort’s view?

3. Evidence and Effectiveness in Public Health Decision-making

The uncertainty surrounding SARS created an epidemic of fear that spread with the disease, and an urgent sense to “discover” the “hard facts” about SARS. We expected, indeed demanded, that medical and epidemiological experts provide evidence-based truths about the disease and develop sophisticated measurements and risk calculations to
resolve any, and all, uncertainty (Lupton, 1995). This is because it has perhaps become a
given that the facts we gather to guide us in decision-making are grounded in the
assumption that (1) science determines the production of legitimate knowledge – \emph{i.e.,}
evidence – that directs the course and outcome of policy and decision processes; and (2)
scientific and technical experts are the only legitimate producers of knowledge. Leshner,
the chief executive officer of the American Association for the Advancement of Science
(AAAS), expresses this view succinctly, though reflexively: “Fundamentally, we sort of
believe that science can answer anything” (Leshner, 2008).

This model of evidence-based decision-making is now ascendant in public health
policy (see for example, Gard, 2004; Rychetnik, 2004; Upshur, 2003). The linkage of
evidence of effectiveness of an intervention to the justification of a public health action is
a given. For public health to restrict liberties, as Callahan observes, it must provide
“solidly based factual evidence” (Beauchamp and Steinbock, 1999, p. 21). In other
words, it must provide objective, scientific, and hard facts to validate decisions that
override autonomous decision-making. Indeed, the privileging of scientifically-measured
evidence as a means to guide policy and interventions in public health underlies the logic
of public health’s basic science – epidemiology – which seeks to gather relevant
contributors to disease, breaking these into quantifiable variables to map out the
probabilities of risk. As Lupton argues, referring to Gifford’s argument, the
epidemiological conceptualization of risk “describes[s] relationships which are objective,
depersonalized, quantitative, and reduces the causality of disease to a single factor or
combination of discrete factors whose effects may be traced in a cause-effect relationship
similar to the biomedical model” (Lupton, 1995, p. 84). Risk is conveyed in statistical
and abstract terms in order to render “propositions about general truths” (Ashcroft, 2004, p. 132) – truths that resolve uncertainties, it is believed.

Yet this conceptualization of evidence purports that epidemiological propositions are externally validated, paradoxically, outside of the social processes in which they occur. Findings about risk are regarded as objective statistical probabilities, as though it were, or could be, “a measured property” (Ashcroft, 2004, p. 132). However this obscures the contextual and (inter)subjective dimensions of public health science. Indeed, in epidemiological research, few people question–or even recognize--the subjective nature of risk calculations, e.g. how is risk defined? Whose judgement is to be considered in evaluating the acceptability of risk? Who should be involved in decisions about controlling risk? What constitutes adequate evidence used to measure risk (Lupton, 1995, p. 84)?

All of these questions point to the reality that evidence produced by epidemiological research, including clinical trials, cannot be divorced from the specific context from which they emerge – a context that is, I contend, inevitably historically limited. As Upshur outlines (Upshur, 2000), medical evidence has seven essential characteristics that underpin the contingent nature of evidence.16 Viewed this way, conclusions about effective treatments or interventions can therefore only be provisional. That is, something is believed to be true until there is better evidence available that will eventually lead to new truths. Under these conditions, the following questions emerge: In what sense are clinical and policy decisions about the effectiveness of a treatment or an intervention objective? What constitutes sufficient proof to update beliefs in light of new

16 The seven characteristics are: 1) provisional; 2) defeasible; 3) emergent; 4) incomplete; 5) constrained; 6) collective; and 7) asymmetric.
evidence? Or as Ashcroft puts it, “When should we regard a…proposition as proven?” (Ashcroft, 2004, p. 132). How, and on what grounds, do we establish that something is indeed effective, or ineffective, or no longer effective?

**D. BASIS FOR JUSTIFICATION OF PUBLIC HEALTH COERCIVE POWERS: LEGAL LEGITIMACY?**

Adding another layer of uncertainty, and further reinforcing the lack, or weakness, of a foundational structure to justify the use of restrictive interventions, is the fact that both the production and application of the law, in its current form, lack justificatory power.

Historically and conceptually, the emergence of positive law in modern society – *i.e.*, the differentiation of the law as an autonomous social sphere – occurred against the background of the centralization, and most importantly, the bureaucratization of politics, which was itself being progressively reduced, as Weber observed (1958), to technical imperatives and strategic activity. As such, modern law took shape “on the basis of merely empirical data regarding the means and effects of the decisions, not the values that inspire the goals” (Guibentif, 1996, p. 54; interpreting Habermas, 1964) at which they aim. This development epitomized the dominant positivist scientific model that suppressed, and eventually usurped, the traditional moral foundations of modern sociolegal conceptions (Guibentif, 1996; Peters, 1996).

Henceforth the production of law (lawmaking) shifted towards legal instrumentality, wherein law was divorced from its context and the uses of law were presented as the established authority for regulating society (Guibentif, 1996; Peters, 1996), even as it assumed to exist outside the social processes in which it was applied. Focusing, for example, on the effectiveness of both restrictive measures and the laws that serve to enforce their use disregards any consideration for their normative underpinnings,
and precludes the possibility of critiquing or reformulating them. Moreover, it suggests a sharp separation between the production of the law and the application of the law; or put another way, the elaboration of legal norms and the social uses of the law are held to be distinct.

Thus conceived, the law became disaffected, indeed autonomous, from those it represents: The community of citizens (Guibentif, 1996, p. 55; Habermas, 1973/1976). Within this context, Habermas succinctly explains, two closures occurred: 1) a dogmatic closure, wherein jurists consider themselves as the only legitimate producers of law and resolve indeterminacy in a “decisionistic” manner (i.e., based on arbitrary decisions by judges); and 2) a technocratic closure, wherein the foundations of political and legal decisions are no longer grounded in public debate, but in the empirical results of science that is run under state instructions (Guibentif, 1996, p. 55; interpreting Habermas, 1973/1976).

This dominant positivist understanding of the law presupposes that its normative foundation derives from political power, and that its legitimacy derives from a higher ranking (inherently rational) moral law that takes the form of formal properties (Weber, 1956). According to Weber, these properties are: 1) a system of legal norms, developed by professional jurists, that bring order to existing social norms; 2) a legislature that creates laws which are generally valid and formulated in the abstract; and 3) a judiciary and a government that are bound by these laws with regards to application and execution (Weber, 1956). Thus as Luhman later posited (1972), the legitimacy of the law is presumed to derive “positivistically,” meaning from existing law, eliminating the
question of normativity altogether (i.e., law is value-neutral) as well as the need for justification.

In this view, legality is legitimacy. The recent article by Boggio et al. that expresses the view that international law provides justification for enforcing compulsory measures against TB patients (who refuse to have diagnostic procedures, or who refuse to be monitored and treated once the disease is confirmed) is a case in point (2008). That is, coercive interventions are justified strictly on legal grounds. However we must look for justification beyond human rights currency.\(^\text{17}\) As Sumner observes:

[L]egal rights are the creatures of legal institutions, and especially of legislatures and courts. Since legal institutions and legal systems are themselves subject to assessment for the extent to which they respect basic rights, their pronouncements cannot provide an authoritative standard for authenticity for such rights. While reference to existing laws (or in the case of human rights, charter or bill of rights) might provide some specificity in relatively easy cases, it will fail us in precisely the cases for which we need a standard of authenticity. To the extent that some authoritative body interprets (abstract) rights or more generally laws as it sees fit, then these will remain indeterminate, indeed essentially contested. If the needed interpretation is provided by courts or other official bodies which have the authority to apply abstract rights to concrete cases, on what grounds are these legitimate? (Sumner, 1987, p. 6).

Positive law, as it is applied today, not only cannot justify its own principles, but does not address the question of--it assumes--the legitimacy of its coercive force and the mechanisms that embody that coercive force. However this cannot be taken for granted. While I support the view that modern law is a form of necessary coercion – what Habermas calls the facticity of lawmaking and law enforcement (1996) – it does not make it legitimate just by virtue of its existence. Such a posture says nothing about what constitutes valid law; it does not speak to the normativity implicit in the elaboration of

\(^{17}\) In support of this view, see, for example Benatar (2002), who argues this point in the context of global health.
legal norms, nor does it resolve the indeterminacy of laws themselves or their application – what Habermas calls the ambivalence of legal validity (1996). Hence grounding the legitimacy of the law in its formal properties – just because it exists – does not provide a sufficient claim to legitimacy. As Sumner explains, “Appeals to [legal instruments] cannot settle issues about moral rights because these merely codify the outcomes of political agreements or the decisions of particular institutions, and the existence of moral rights cannot be established either by such agreements or by such decisions” (1987, p. 7).

From here spring the questions: How do we establish, as Sumner puts it, a standard of authenticity of rights (1987, p. 11), and I would add, a standard of authenticity for the process of lawmaking? How do we ground the dichotomy between facticity of law and legal validity? How can norms be imposed and respected in order to guarantee the cohesion and stability of the social order, while at the same time being accepted as legitimate?

Questions deriving from scientific and legal uncertainties, which lie at the heart of public health governance, today remain largely unconsidered in both theory and practice.

Consider the following diagnostic:

Given the post-metaphysical thinking characterizing the modern condition, where ontological and theological background assumptions became more and more controversial, practical philosophy has gone on to sacrifice even its substantive content. For, in view of what is now considered as a legitimate pluralism of worldviews, modern philosophical ethics is no longer able to commend particular models for how to lead a good life and to hold them up as examples to follow. With Rawls we might say that in liberal societies everyone has the right to develop and pursue her own conception of the good life, or, more cautiously, of a life that is not misspent. Given this premise, ethics (in the Aristotelian sense of teaching how to live a good life) must confine itself to the more formal aspects of the basic question of who I am and would like to be, and of what is good for me in the long run. As an existential philosophy, ethics merely explains the conditions.

---

18 Habermas distinguishes, and weaves an inextricable web, between the facticity and validity of law by distinguishing between, while bringing together, the philosophy and the sociology of law.
and modalities of consciously or authentically leading one’s life. In the form of a
neo-Aristotelian hermeneutics, it investigates how people clarify their self-
understanding by appropriating traditions. And in the form of discourse ethics, it
traces the processes of argumentation that are necessary for attaining a clearer
view of one’s identity. Since Kant and Kierkegaard, the modern version of ethics
– in the classical sense of a guidance for how to live – have ceased to articulate
publicly recognized models of exemplary life; they have, instead, counseled
private individuals to opt for a specific form of reflection in order to lead
authentic lives of their own choosing. Once the classical alliance of ethics and
politics break down, genuinely modern forms of political and moral theory
develop with contractualism and Kantian deontology. They replace the existential
question of what is good for me or for us in the long run with the moral-political
question of what are the just rules of social life that are equally good for everyone.
Such norms are considered “just” if they are equally in everybody’s interest and
hence may be expected to have the consent of all rational subjects (Habermas,
2003, pp. 279-280).

In other words, we live in a highly individualized society that makes it difficult, if
not impossible, to weave broad understandings of the society that we want--or ought--to
live – in the Aristotelian sense of how to live a good life. So where does that leave us in
terms of the status of public health and the status of the justification of restrictive
intervention? As a first step towards answering this question, I will further probe the
underpinnings of scientific and legal rationality.

E. THE MODERN LIBERAL INDIVIDUAL: AN INCOMPLETE CONSTRUCT?
The privileging of positivist rationality in public health discourse and practice goes hand
in hand with the modern Cartesian conception of the self as an autonomous rational
subject set against a world of objects that it can rightfully appropriate and, through
appropriation, dominate. In other words, the rationality of technique and calculation that
came to prevail in society, and which underlies decision-making processes today, is
concomitant with the rationalization, and the primacy, of the individual. Inherent in this
rationalist understanding of human agency is that the modern individual is lifted out of a
“divinely-ordained place or function in the world” (Kymlicka, 1991, p. 186) and rendered sovereign by virtue of his capacity to govern himself through reason.

This conception of human agency is at the heart of liberalism, of the Enlightenment, an 18th century intellectual movement that redefined morality in secular terms and appealed to human reason as the fundamental principle of a new (private) morality. In doing so, it (re)created a new ideal for human relations via the social contract, introduced as an answer to, or a framework for answering, questions about the morality and legitimacy of obligations and duties, since they were no longer divinely-ordained. The social contract was thus posited as an agreement freely entered into by autonomous, independent individuals who are motivated by the desire to protect their natural rights and freedoms – rights that are, in turn, guaranteed by the “non-interference of the state in the concluding of private contracts” (Simon, 2004, p. 2). There is here a separation of the private and public spheres, which, like the social contract theory from which it derives, relegates the question of the moral life to the private realm. As such, the social contract acts as a foundation for moral life grounded in private experience, and it is defined by a moral good conceived in, and limited to, contractual and individualist terms.

Underpinning this framework is the dominant political philosophy rooted in Kantian liberalism, or implicit in Kant’s categorical imperative, which posits that individuals have an inherent moral standing. In Kant’s view, “every person, by the virtue of his or her humanity has an inherent dignity. All persons, as rational creatures with a capacity for moral autonomy, are entitled to respect, not only from others but from themselves as well” (Mappes and DeGrazia, 2000, pp. 18-19). According to Kant, the individual is an end in and of itself; it is a moral absolute. The Kantian individual, as
Sandel puts it, is an “unencumbered” self that exists prior to and independent of others, or purposes, or ends. “For the unencumbered self,” explains Sandel, “what matters above all, what is most essential to our personhood, are not the ends we choose but our capacity to choose them” (Sandel, 1984, pp. 85-86), which is guaranteed by the right to realize as many of their ends as possible.

At the heart of Kant’s vision is a theory of justice that claims that the right is prior to – and independent of – the good (Rawls, 1971; Kant, 1789, 1788, 1785). In what serves as the basis of Kantian morality and the individual, Kant argues that acts of private moral conscience are [willed] into a universalisable foundation for moral life. Society is thus governed by universal(isable) regulative principles, or an abstract universal, grounded in private experience – an abstract universal that does not, or more accurately that ought not, presuppose any particular conception of the good, but instead obeys the requirement of rights. For how these regulative principles are determined is not to maximize the general welfare, cultivate virtue, or promote the good, but rather to provide a framework within which citizens have the right to pursue their own values and ends. Given this logic, individual rights cannot be sacrificed for the sake of the general good. Any other arrangement, in Kant’s view, would fail to respect persons as being capable of choice; it would treat them as objects rather than subjects, as mere means rather than ends. As Simon interprets Kant’s formulation of the categorical imperative, it “represents the culmination of the liberal tradition in its insistence on the privatization of questions of morality” (Simon, 2004, p. 5), leading to, at least in practice, the culmination of the rationalist and individualist logic of the subject.19

19 It is important to note that mainstream interpretations of the Kantian individual are narrower in scope than Kant’s original formulation, that is to say intent, of the categorical imperative – for he does not
The legal institutionalization of rights was in many ways the realization of the Kantian project. The dominant human rights framework is essentially the embodiment of (a further deepening of) autonomous rationality and (a further entrenchment of) the universalizing logic of rights. It is the very avatar of the claim for the priority of the right over the good. In contrast, the use of restrictive measures, such as quarantine, essentially represents the very philosophical justification of public health practice to act on the basis of utility in order to maximize benefits for the sake of the general good. For at the heart of public health practices, there exists the classic utilitarian view that the utility value of interventions and policies is determined in proportion to their capacity to produce the greatest results for the greatest numbers. What is morally relevant in public health, and requires (moral) deliberation, are the consequences that public health measures will bring about. Hence the best strategy, according to this logic, is one that increases the general welfare to the greatest extent. In essence, the justificatory power of public health’s utilitarian pursuit of the good (and with it, the inevitable effect of restricting individual liberties) is at odds with the Kantian foundations of human rights principles, which do not presuppose any conception of the common good.

Thus, public health and human rights diverge on a fundamental level: In public health, the underlying rationality of the subject is conceived in terms of the principle of utility; in the human rights framework, it is premised on the principle of the inherent moral worth of persons. Despite the differences in the justifications of public health and human rights, however, they converge on another fundamental level: Neither system of conceptualize an atrophied hyper-individualist notion of the self, but rather a self among others in a “kingdom of ends” (Kant, 1785). As I will emphasize later, Habermas essentially recaptures a more complete understanding of the Kantian individual.
justification challenges, indeed takes for granted, the dominant notion of the liberal modern (i.e., autonomous rational) individual implicit in our practices and institutions.

Thus understood, what unites public health and human rights is as significant as what divides them. In this light, the puzzle of why their marriage has failed despite extraordinary efforts to render them compatible can be cast, I want to argue, in a different light.

It is true that the dominance of the individualist human rights framework has led to a further deepening of autonomous rationality and a further entrenchment of the universalizing logic of rights. It is also true that this has undermined the ability of the state (or public health as an organ of the state) to garner support for a common purpose and acceptance of the constraints on the pursuit of that goal. Part of the proposed answer to this problem has been to try to reconcile rights and public health – e.g. by making room for utilitarian pursuits within human rights norms or finding room for rights within a consequentialist framework (for example, a viable attempt of this has been made by Sumner [1987]). Thus instead of denying the existence and importance of rights, or of utilitarian pursuits, many scholars and practitioners alike have sought to rethink their assumed incompatibility.

However attempts to construct a relationship between public health and human rights have only further reinforced the separation between the individual and the collective that is so prevalent in modern discourse. The two perspectives are still presented as dichotomous and always follow an either/or paradigm. As White puts it, it always boils down to the fact that “either individual rights are given priority over collective autonomy, or collective autonomy is given priority over the individual”
(White, 1995, p. 12). In doing so, the viability of their relationship has foundered on the inability to resolve the tension between the good and the right.

In principle, attempts to reconcile rights and public health have been superficial at best. Any proposed answer amounts to establishing only a conceptual relationship between the two institutions, since no one has challenged the underlying assumptions on the authority or sovereignty of the modern individual. Herein lies the problem: Conceptualisations of this relationship assume a fundamentally modern positivist rationality. This limited scope, I believe, paralyses efforts to transcend the impasse we face.

F. TOWARDS MORAL LEGITIMACY: COMMUNICATIVE RATIONALITY

It is my contention that a way out of this impasse would be to move upwards to a more meta-theoretical debate on human agency by redefining assumptions about the modern individual, and in so doing to recast and reconceive the relationship between public health and human rights epistemologically. From this point of departure, we can elucidate a fundamental lacuna in the marriage of public health to human rights: Protecting collective autonomy (public health) without failing to embed individual autonomy (human rights) requires a paradigm shift in how we understand human agency – something that both modern public health and human rights discourses fail to do. The dominant Cartesian notion of human agency has had a profound impact on how we have constructed--or on our inability to construct--a sense of community or collective identity. To begin with a vision of what public health ought to be requires that we achieve a strong sense of community that supports a unified conception of the good life. To do this, I contend, requires that we recognize the intersubjectivity of the self. I hope to show that
forging a collective identity through intersubjectivity offers a way out of the current impasse.

Following a Habermasian account of moral argumentation, which embraces a broader kind of rationality based on argumentation, communicative action holds the potential for successfully integrating public health with human rights, for it provides the foundation to develop a genuine synthesis between the two by recognizing them as “co-original,” rather than as prior to one another. It also opens up the possibility of vindicating claims discursively; that is to say, justificatory power derives from a “discourse model of legitimacy” (Benhabib, 1992, p. 82), one that creates the conditions for moral legitimacy. Habermas, therefore, presents a way out of the impasse by transcending the dominant positivist either/or paradigm that has us grappling with the inability to conceive of rights during a communicable disease outbreak, and with simultaneously satisfying the legitimacy conditions through which to use and enforce coercive measures.

By constructing a participatory model of deliberation (or argumentation) to provide a foundation for legitimacy claims, communicative rationality opens up the possibility of treating questions hitherto unconsidered. The interplay of (ethical, social, legal, political) norms is implicit in every aspect of public health practice. Yet developments in modern public health, like modern law and science that underpin it, show a disconnect from its moral foundations. Tending toward instrumentality, questions revolve largely around the legal powers and duties of the state to ensure the conditions for people to be healthy (Gostin) without thematising what it bears. For Gostin, the classic question for public health jurisprudence is “the extent to which the state may
require its citizens to submit to restraint in order to interrupt the spread of communicable diseases” (Gostin, 1986, p. 80). Yet who decides this and by what authority? What values shape decisions, and upon what basis are decisions derived? A discourse model of legitimacy allows us to make explicit and tackle the normativity underpinning this classic question, and by doing so to articulate a new question in seeking an understanding of the extent to which citizens would agree to submit to restraint by the state in order to interrupt the spread of communicable diseases.

Underpinning this inquiry, in short, is the view that the legitimate justification for restrictive intervention is derived discursively. Hence I begin my inquiry into what constitutes the legitimate use of restrictive measures discursively; that is, I address the problem of justification through qualitative research methodologies.
CHAPTER 3:
BACKGROUND CONSIDERATIONS

I think the words “public health” convey a rather hazy and indefinite meaning to the man on the street, and if it were possible to rechristen our health departments as departments of preventive medicine.

– James Roberts, 1922, p. 807

There is an old motto that reads “Public Health is Public Wealth.”

– Stephen Smith, First President of the American Public Health Association, 1921, p. 10

In this chapter I give an outline of the background to: First, the emergence of public health, as both a discipline and an institution, which was largely driven by the demands of disease control; second, the emergence of the human rights revolution which led to the institutionalization of rights (or human rights norms) that spawned the first juncture between the demands of public health and the demands of individual rights. Further, I retrace the developmental trajectory of the relationship between public health and human rights from the HIV/AIDS debate, which brought human rights to bear on public health by articulating what for many are their intrinsic connections, to the health and human rights discourse, which had the effect of shifting away from public health towards a more individualistic conception of health.

This background discussion shows that attempts to reconcile public health and human rights have foundered on the inability to establish a viable relationship between them. Instead, these attempts have further exacerbated the inherent tension between what remains conceptually opposite poles. I conclude by sketching the current landscape, with a view to proposing a theoretical underpinning for critically redefining the relationship
between public health and human rights, and with that redefinition, providing the ground for the justifiability of using restrictive interventions without pitting them against rights.

A. THE INSTITUTIONALIZATION OF PUBLIC HEALTH: THE DOMINANCE OF DISEASE CONTROL

The *Dictionary of Bioethics* states that public health is the protection and promotion of the health and welfare of members of a society (Encyclopaedia of Bioethics, 2004, p. 2157). In its report entitled *The Future of Public Health*, the Institute of Medicine reiterated this point as such: “Public health is what we, as a society, do collectively to assure the conditions of people to be healthy”20 (Institute of Medicine, 1988, p. 19). As Gostin suggests, the richness of this definition can be “appreciated by examining its constituent parts” (Gostin, 2001, p. 122). He comments:

> The emphasis on cooperative and mutually shared obligations (“we, as a society”) reinforces the collective entities (e.g. governments and communities) take responsibility for healthy populations...there is a great deal individuals cannot do to secure their health; to overcome whatever these barriers may be, individuals need to organize, work together, and share their resources. Acting alone, people cannot achieve environmental protection, hygiene and sanitation, clean air and surface water, uncontaminated food and drinking water, safe roads and products, and control of communicable disease. Each of these collective goods, and many more, is achievable only by organized and sustained community activities (Gostin, 2001, p. 123; quoting Gostin, 2000b).

In turn, we can appreciate Gostin’s observations by understanding these in the historical context of public health’s emergence as a response to the problems (relating to food, water, sanitation, and disease) that were created by communal living in newly urbanized or urbanizing centres. Indeed, the rise of urban living led to a new (health and social) imperative: That of providing the conditions necessary for the development and sustainability of communities. At the time it was viewed not as the pursuit of the common

---

20 This definition is the most cited contemporary definition of public health.
well-being, as it would later be framed, but as “preventive medicine.” As towns and cities emerged, the responsibility for providing basic provisions for healthy living could no longer be left to individual or private business interests, and what essentially became public health measures began appearing throughout the 19th century (Encyclopaedia of Bioethics, 2004, p. 2157). These measures were strategically carried out by the state, which began taking responsibility for the prevention of disease through organized and sustained community activities.

For most of the 19th century, however, public health measures were enacted with limited coordination from local administrative structures, and were often conducted in a haphazard and arbitrary manner. Bryce explains that, upon Confederation in 1867 (when “the formative period of Canada was largely over, and the developmental period had begun” [Bryce, 1921, p. 61]), it became obvious to government officials that public health work, “if not crystallized into effective methods for organized action, [had] little meaning” (ibid., p. 65). A 1868 report by the Canadian Medical Association attests to this:

Here and there in Canada the municipalities have taken steps to remedy existing affairs; but their efforts are too partial in their action and too limited in their scope to be productive of any important advantages. A necessity therefore exists for the introduction by the government of a comprehensive system of sanitary laws, not so complete, perhaps, as those of the Mosaic code nor so severe in the punishment of any violation of them (Bryce, 1921, p. 62).

The recognition that public health required a more comprehensive system for civic sanitation, among other things, generated myriad initiatives that eventually shaped public health organization into a more systematic and integrated discipline. The progress of public health was largely attributed to, at least in Canada, the “remarkable results of modern preventive medicine,” and it was the application of such preventive measures,
argues Bryce, that “served greatly to advance public health work as an ordinary function
of government” (ibid., p. 64). Ultimately, this “evolution by progress from the simple to
the complex in health matters” (ibid., p. 62) led to the institutionalization of modern
public health as a vehicle of collective action that both creates and guarantees the
conditions necessary to a life in common.

The history of public health is intimately tied to the history of communicable
disease control (and quarantine as the first method used for the prevention and
containment of epidemics). Public health measures to control communicable diseases had
been instituted long before--and in fact significantly contributed to--the
institutionalization of public health. Since the prevention and treatment of disease was a
necessary presupposition to communal living, it is easy to see how that would be the
case. Before we could speak of a public health “system” in Canada, and approximately 50
years before the “Public Health Act of Ontario” was passed in 1884, the first quarantine
station for all ships arriving in Canada was established at Grosse Isle on the St. Lawrence
River (see O’Driscoll and Reynolds, 1988; Occhietti, 1988; O’Gallagher, 1984; Page,
1931; Montizambert, 1926), thereby instituting the essential features of an elaborate
quarantine system that endured until the end of the century (Bison, 1981, p. 90).

Reflecting on what Canada had accomplished in the 50 or so years since Confederation,
Bryce observed that in no field had such accomplishments been “more satisfactorily than
in that of public health” (Bryce, p. 62). By all accounts, it was the demands of
communicable disease control that drove the development and (re)organization of health
systems – so that by the time public health practice came to be known as such, quarantine
was already viewed as a necessary and legitimate public health strategy.
1. Quarantine

Historically speaking, the concept of quarantine precedes modern notions of public health by several centuries, at least. Concern over, and the practice of, isolating persons with communicable diseases and corresponding sanitary procedures can be traced back to the Old Testament (Rothstein et al., 2003, p. 17), where one can find detailed instructions in the Book of Leviticus and Numbers for the treatment of lepers. Other early recordings that urged the use of such formalized practices date as far back as Thucydides (c. 460-400 B.C.E.) and Hippocrates (c. 460-370 B.C.E.), as well as those of Galen of Pergamon (c. 130-200 B.C.E.). Medical historians report that one of the earliest uses of quarantine to control the movement of travelers from regions of the world where the plague was known to be spreading was enacted by the Byzantine emperor Justinian in 532 B.C.E., when he ordered that travelers and sailors be “cleansed” in special facilities before entering the city of Constantinople (Markel, 1997, p. 3; Rothstein et al., 2003, p. 17). Similar practices that were used over the succeeding centuries have been documented in particular in 7th century China and other parts of Asia, as well as in Europe during the Middle Ages.

The concept of quarantine (in Italian quarantina and quaranta giorni) was first construed in the 14th century by Italian officials, referring to a 40-day period during which ships entering the Port of Venice were required to remain in isolation before any person or merchandise was permitted ashore. In 1374 Venice enacted a 40-day quarantine regulation, and in 1403 it instituted the first formal system of quarantine, imposing the isolation and detention of all ships. This Venetian model held sway, and was reproduced

---

21 I owe much of the following overview to Howard Markel, who gives a rich account of the history of quarantine in Markel, 1997. I may have inadvertently borrowed ideas or phrases from his work without proper attribution. Nonetheless, I wish to underscore that I am indebted to him for this historical description, which is based largely on his original research.
around the globe, from the 14th through the 19th century, as the spread of epidemics only intensified due to the rise of international travel and commerce during the Renaissance and the following three centuries. As Markel observes, “from medieval times on, shutting the gates of a city or port to all those suspected of being ill and isolating those sick people discovered to have entered represented the best, and often the only, means available for stemming the tide of an epidemic” (Markel, 1997, p. 3). The practice of preventing entry of contagion into a city was also known as a *cordon sanitaire* (literally “sanitary cordons”) formed by a ring of armed soldiers guarding the gates of the city.\(^{22}\)

During the course of the 19th century, as communicable disease control became inextricably linked to public health organization, the rationale for quarantine was explicitly for the prevention and containment of epidemics. However contemporaneous health organizations were not yet systematic enough to effectively control the spread of epidemics—which only seemed to be proliferating, spanning from the plague to yellow fever and cholera by the mid-1800s. The devastating impact of these later epidemics galvanized international interest, especially by European nations with commercial or colonial interests, in establishing an international board of sanitary or quarantine control, leading, in 1851, to the first of a series of International Sanitary Conferences that continued for the better part of the 20th century (Markel, 1997, p. 4).

For decades, however, no meaningful consensus on international control of communicable diseases was reached, in large part, explain Rothstein et al., “because of the political bickering between European powers with competing interests in preserving or enlarging their commerce and trade with the Middle East and Asia” (Rothstein et al.,

---

\(^{22}\) The use of checkpoints for examining and disinfecting vehicles and persons crossing jurisdictions during SARS, especially in China, was referred by some as *cordons sanitaires* (Rothstein et al., 2003, p.129).
Yet as bacteriology became more and more accepted, and as major diseases such as typhoid and cholera were attributed to specific germs, delegates began to agree on rudimentary measures for containment and control by the 1890s. As a result, “substantive consensus on international sanitary and quarantine regulations began to emerge” (Stern and Markel, 2004, p. 1476; see also, World Health Forum, 1995; Bynum, 1993; Howard-Jones, 1974), leading to the signing of the first International Sanitary Convention at the Seventh Sanitary Conference in 1892. Notably, the Eleventh Sanitary Conference led to the establishment of the first permanent international health organization, the International Office of Public Hygiene (IOPH), which was a precursor to the World Health Organization, established as the world’s chief public health organization after World War II. This century-long focus on communicable diseases in international diplomacy and international law ultimately lead to the harmonization of national quarantine regulations, as well as the creation of an international communicable disease surveillance system instituting by the end of the 19th century, a rather sophisticated international system of quarantine.

By then, the maritime definition of quarantine had changed markedly from its medieval origins, no longer being based on the 40-day period of detention that held sway for several centuries. As the International Sanitary Conferences began to exert greater authority on international communicable disease control, and as bacteriology’s tenets began to dominate public health and medicine, the precise definition and length of quarantine began to vary widely, depending on the location and specificity of a particular disease and the understanding of physicians of that era.23 As Cumming observed in 1921,

---

23 In reality, Markel notes, the health officer could legally set the detention for any period of isolation he decreed, regardless of the opinions or theories of others (1997, p. 7).
quarantine was “carried out in accordance with the [local and individual physician’s] conception of the communicability of the disease” (1921, p. 119), even if that “conception” was not necessarily grounded in science. This differentiation of quarantine measures engendered, what Gensini et al. call, a “deep medicalization of quarantine” (2004, p. 260) during the late 19th century, meaning that there was a systematic integration of quarantine measures into medical practice. Supported by a well-developed system of medical inspection and detention, the treatment of those admitted to the isolation hospital at quarantine stations was largely supportive and no longer punitive, as had been the case when quarantine was first instituted. This trend towards a “medicalized” quarantine essentially served to reinforce the notion that it was a valid strategy for communicable disease control.

That being said, it is tempting to view the history of quarantine as one that was not without controversy from the distance of a century of events. Although it was indeed strengthened and reinforced as a viable method over time, there were widespread oppositions to quarantines throughout the 19th century, which eventually crystallized by the beginning of the 20th century as scientific and technological developments began reshaping the international health landscape. First and foremost, arguments against quarantine mainly focused on its nefarious impact on trade and property interests, leading many observers to argue against the questionable effectiveness of traditional quarantine measures. Hancock captured this line of thinking in 1821, arguing that:

Without being so secure a defence as is commonly imagined, quarantine establishments have been maintained with multiplied inconveniences and hardships; and that we are more indebted to chance than good management for our preservation; it’s high time we should know whether they be essential or not; whether they not be a mere form; and whether it would not be safer to dispense with them entirely, than to rely for security on burthensome regulations
defectively administered, which oppress whilst they deceive (Hancock, 1821, p. 237).

Later advances in new technologies of communication and transportation, which led to an exponential growth in international trade, put great pressure on medical authorities to limit quarantine regulations that were thought to burden its flow. In fact, Fidler notes that efforts undertaken to harmonize quarantine regulations were merely a strategy for reducing the burdens on European trade created by national disease control measures. The view that quarantine posed unnecessary and “vexatious” (Forster, 1832, p. 4) obstacles to commerce was further exacerbated by the wide spectrum of beliefs about the etiology of communicable diseases. Indeed, there was a long-standing and sometimes ferocious debate that played out for the better part of the 19th century between “germ theorists” (bacteriology) and “anti-contagionists” (see for example, Worboys, 2000; Kunitz, 1994; Rosenberg, 1992; Cunningham, 1992) who held that diseases were caused by constitutional changes in the atmosphere and environmental sources of filth. In support of this view, Forster wrote a book in 1832 whose objective was to expose the fallacy of the dangerous and absurd medicine of contagion, and to show that cholera and other epidemics depend on exciting causes, which are atmospherical, and over which quarantine and other measures of pretended defiance to the disease have no real control (Forster, 1832, p. 2).

As Markel remarks, “the notion that a tiny microbe might be the cause of a devastating epidemic was almost laughable to medical experts and the lay public” (Markel, 1997, p. 4). It was thought that “the most effectual stand” (Hancock, 1821, p. 244) to treat “Epidemic Disorders” was to “fight the predisponent causes by preparing the body against the disorder, by ventilating apartments, by removing filth and by adopting such fumigations and other correctives as experience has proved to be useful”
(Forster, 1832, p. 2). In other words, cleaning up the environment was believed to be the most, and perhaps, only effective method for preventing and controlling communicable diseases.

The fact that anti-contagionists professed that the origin of disease was caused by environmental factors which required remedial civic sanitation measures, however, did not mean that they were necessarily anti-quarantine. Indeed, throughout the early history of communicable disease control, quarantines were often devised even by those who did not believe in the existence of germs, but who used it more broadly and perversely, not to isolate a biological contaminant, but to isolate undesirable social groups (historically, the poor, the disenfranchised, and immigrants). Here Markel skilfully illustrates, through his exploration of the social, cultural, medical, and political issues surrounding the quarantine of East European Jewish immigrants during the typhus and cholera epidemics of New York City in 1892, that “one of the strongest leitmotifs in the history of epidemics and quarantines in the U.S. is the use of quarantine as a medical rationale to isolate and stigmatize social groups reviled for other reasons” (Markel, 1997, p. 4). Even though New York’s National Quarantine Act of 1893 warned against--and thus explicitly recognized the potential for--the conflation of epidemic disease and social scapegoating (“the elaboration of policies of isolation and quarantine to protect the public health should be a function separate from that of the control or restriction of immigration” [Markel, 1997, p. 190]), many felt that quarantine measures were not only arbitrary in the targeting of undesirable persons, but also interfered arbitrarily with civic liberties. As such, with the systematization of quarantine measures, there was a crystallization of the view that disease control had to be “tailored narrowly to public health needs so as not to
interfere arbitrarily with individual freedom” (Fidler, p. 170). Against this backdrop, opposition from people who believed that quarantines were used by the state for purposes other than disease control remained widespread.

It was in this context that formal claims against public health measures on the basis of (some notions of) individual liberty began appearing in the courts, planting the seeds of future constitutional challenges. Initially, however, arguments against quarantine focused on trade and property interests rather than on any serious concern for the rights of individuals.24 In the context of communicable disease control, there was both a limited definition of—and limited concern for—rights because individuals did not possess “a set of well-defined rights that could be weighed against conflicting social needs”25 (Merritt, 1986a, p. 4). Thus the courts’ invariable response was to “strongly endorse the power of the state and local governments to adopt stringent measures controlling disease” (ibid., p. 3). This was consistent with the prevailing view that systems of quarantine were a microcosm of the then-prevalent social contract, according to which individuals rights were subordinate to “the higher rights of the community” (Fox, 1986, p. 13), and that public health was “the highest law of the land” (ibid., p. 13). The protection of public health, and with it the implicit obligation to comply with control measures, thus continued to take precedence over rights – even in the United States, whose Constitution provided strong protections for individual liberties and civil and political rights.

24 Merritt notes that at the time “judges were particularly inclined to invalidate public health measures when they happened to interfere with business operations” (1986a, p. 5).

25 Conceptions of rights were limited to the notion of negative rights, according to which persons have the right to pursue their own ends insofar as it does not harm others. Berlin ably summarizes this conception of negative liberty: “Most modern liberals, at their most consistent, want a situation in which as many individuals as possible can realize as many of their ends as possible, without assessment of the value of these ends as such, save insofar as they may frustrate the purposes of others” (1969, p. 153).
The oft-cited case of *Jacobson v. Massachusetts* (1905), decided in 1905 by the U.S. Supreme Court, set an important precedent in recognizing that public health supersedes individual rights (in fact it laid the foundation for public health law in the U.S.) when Jacobson challenged the constitutionality of Massachusetts’ immunization law and refused to be vaccinated against smallpox. It was the first time that the United States Supreme Court considered an individual’s claim that a compulsory public health measures violated his “inherent right” to liberty. The fact that Jacobson’s case reached the Supreme Court indicates the recognition that individual rights were not completely irrelevant in public health. In so doing, it marked the beginning of a transition towards the recognition of rights in public health that would ultimately find meaningful expression. Yet while the U.S. Supreme Court agreed to consider Jacobson’s constitutional arguments against compulsory public health measures, it effectively rejected each of these arguments, ruling that the “liberty secured by the constitution of the United States to every person within its jurisdiction does not import an absolute right in each person to be, at all times and in all circumstances, wholly freed from restraint. There are manifold restraints to which every person is necessarily subject for the common good.” The Supreme Court affirmed the right of states to enforce public health measures as a legitimate use of public health’s police powers, clearly reinforcing that the protection of public health outweighed individual rights.

Thus in the early history of public health, state involvement was viewed as leading to positive consequences – in effect drawing on the strength of the justificatory power of public health’s utilitarian pursuit. Public health was a means to redress the fundamental problems caused by devastating health effects and the natural tendency of
private interests to fail to extend services to all segments of society (such as the poor). It was generally accepted that public health endeavours increased the general welfare, granting it a sort of privileged authority. As such, individuals had obligations, not rights, especially when it came to communicable disease control (Fidler, 1999, pp. 170-179). Even where formal claims of individual rights were made against public health measures, public health predominantly trumped individual rights (ibid.). Yet the notion that individual liberty invariably yields to public health risks would radically change.

B. THE INSTITUTIONALIZATION OF HUMAN RIGHTS: DISEASE CONTROL AND HUMAN RIGHTS

As scientific and technological developments began reshaping the international health landscape at the turn of the century, so did the view that individuals had obligations and not rights in public health. With the rise of bacteriology, health authorities were gradually coming to the conclusion that other methods of communicable disease control were better. By the mid 1920s, Canada had already begun shifting to surveillance as an alternative to quarantine (Bilson, 1981, p. 97), fundamentally changing the nature of compulsory public health measures in communicable disease control. Not long afterwards, Canada also began closing quarantine stations in favour of community hospitals, further reinforcing the notion that “elaborate quarantines were unnecessary” (Bilson, 1981, p. 98).

Quarantine was becoming less and less acceptable as a public health strategy by medical experts and the lay public; so was the broader role of public health, for that matter, which was increasingly viewed as paternalistic and intrusive. At least in the United States, this became manifest in the courts, which showed a greater willingness to challenge and invalidate public health measures, a trend that intensified by 1940, thus
completing the transition of replacing a negative view of individual rights with a positive concept. By applying this new definition of rights, the courts recognized that individuals retained a set of fixed rights that could, in some circumstances, legitimately override public health interests if it was deemed that the health risk was not sufficient to outweigh the burden on individual rights (Merritt, 1986a, p. 8). This repositioning represented a radical departure from the view that even constitutionally guaranteed rights must invariably yield to the demands of communicable disease control. More importantly, it paved the way for a paradigm shift in public health discourse and practice which recognized that individuals have rights within the context of public health.

However what really crystallized this shift was the advent of the human rights revolution, born in response to the horrific human rights abuses in the name of so-called scientific research programs, and the systematic genocide of millions of Eastern European Jews during the Holocaust. The disclosure and eventual reporting of the atrocities that took place in Nazi concentration camps galvanized a humanitarian movement that sought to create conditions that would prevent such atrocities in the future. It is reasonable to speak of a “revolution” in thinking about the impact that this movement had, as it ultimately led to the institutionalization of human rights norms in international law. While there is a long history behind human rights thinking, the human rights revolution effectively entrenched, that is to say it constitutionalised, the Kantian idea that all people necessarily possess equal and absolute rights that are inherent to them simply because they are human.

The institutionalization of human rights has had profound implications for society: The view that individual rights have independent, positive weights--and weights
of different value—fundamentally transformed the notion and status of rights in modern society, and in so doing it redefined the social contract between the state and the individual by reversing the public health tradition that emphasized individual duties and obligations rather than rights and freedoms. In turn, the explicit emphasis on human rights saw the entrenchment of two notions that had faint precursors in American jurisprudence and early British and Canadian sanitary reforms. First, it engendered greater scrutiny of public health measures that interfered with individual rights, and second, government responsibility for providing conditions conducive to public health was positively established (Fidler, 1999, pp. 170-179; see also Merritt, 1986). These developments made explicit the intersection of human rights and disease control, thereby weaving a new social fabric that explicitly recognized that “[v]irtually every measure of disease control has human rights implications” (Tomasevski et al., 1992, p. 539).

1. Human Rights

The specific rights that form the corpus of human rights law are listed in several key documents.26 Foremost is the Universal Declaration of Human Rights (UDHR) (see for example, Morsink, 1999), which along with the United Nations Charter (UN Charter), the International Covenant on Civil and Political Rights (ICCPR), and the International Covenant on Economic, Social and Cultural Rights (ICESCR), constitute what is often called the “International Bill of Human Rights.” The UDHR is considered to be the cornerstone of the human rights movement; it was drawn up to give a more specific definition of the rights and freedoms referred to in the UN Charter, as well as to set out

---

26 I owe much of the following overview to David Fidler and Sofia Gruskin. I may have inadvertently borrowed ideas or phrases from their work without proper attribution. Nonetheless, I wish to underscore that this description is based largely on their work.
the conditions in which states can legitimately restrict rights. Under the auspices of the United Nations, a large number of additional declarations, conventions, and human rights treaties echoing the spirit of the International Bill of Human Rights have been adopted at international and regional levels.\textsuperscript{27} As the Bill suggests, international human rights law consists of two sets of rights: 1) civil and political rights; and 2) economic, social and cultural rights.

Both sets of rights have implications for public health action: First, there is the recognition of the importance of civil and political rights to public health; and second, there is the recognition of the public health importance to economic, social, and cultural rights. The former was developed through instruments incorporating civil and political rights that delineated the legitimate use of public health powers that interfere with individual rights; the latter took shape in treaties addressing economic, social, and cultural rights that established government responsibility for providing conditions conducive to public health.

2. The Importance of Civil and Political Rights to Public Health Limits

Against the backdrop of the human rights framework, public health measures that infringed on individual rights would be subject to constitutional scrutiny through legal treaties that incorporated an expanded concept of rights. This expansion included civil and political rights, in particular the ICCPR and the ICESR, which further elaborate on the content set out in the UDHR. Of particular significance is the fact that all major treaties protecting civil and political rights also set out the conditions under which states can legitimately restrict these rights in order to protect the public health. By doing so,

\textsuperscript{27} For a detailed description, see Fidler, 2000, ch. 8.
they recognize that the protection of public health remains a legitimate reason to infringe upon *certain* rights,28 thus reinforcing the historical concept that public health legitimately outweighs burdens on individual rights, especially in the context of communicable disease control.

Even so, the recognition that it is legitimate to restrict civil and political rights for the protection of public health is balanced against the establishment of strict conditions, or procedural safeguards, for exercising public health powers when restricting such rights. In this way, explains Fidler, “the treaties demand more from governments seeking to restrict civil and political rights on public health grounds” (Fidler, 2000, p. 173).

Indeed, the establishment of conditions to basically discipline the exercise of public health marked a significant shift in thinking about rights in public health. Restrictions of individual rights are no longer taken for granted, but are instead viewed as a derogation from international human rights norms. More importantly, there exists absolute human rights norms from which no derogation is permitted, meaning that only *certain* rights can be restricted on public health grounds, placing considerable limitations on public health practice.

---

28 Fidler provides a succinct sketch of which rights have been placed under the obligation of public health needs. He summarizes: “Under the 1950 European Convention on Human Rights and Fundamental Freedoms (ECHR), persons may be deprived of the right to liberty ‘for the prevention of the spreading of communicable diseases’ (ECHR, art. 5(1)(e)). In addition, interference by a public authority for the protection of health in connection with the rights to privacy, freedom of religion, freedom of expression, and freedom of assembly is legitimate. Similarly, the 1966 International Covenant on Civil and Political Rights (ICCPR) recognizes protection of public health as a legitimate reason for restricting the rights of freedom of movement, freedom of religion, freedom of expression, right of peaceful assembly, and the right to freedom of association. Unlike the ECHR, the ICCPR does not provide that the right to liberty may be interfered with to prevent the spread of communicable diseases, but public health measures designed to prevent outbreaks that would restrict the right to liberty would probably meet the criteria of ‘established by law’ contained in Article 9(1) of the ICCPR. The 1969 American Convention on Human Rights (ACHR) also allows the rights to freedom of expression, peaceful assembly, freedom of association, and freedom of movement to be restricted for public health reasons” (Fidler, 2000, p. 173).
These limitations were incorporated in the Siracusa Principles (Siracusa Principles, 1984), which stipulate the specific conditions that have to be met in order to justify the implementation and enforcement of restrictive measures. According to these principles, the conditions are as follows: Restricting rights must be prescribed by law; must be applied in a non-discriminatory manner; must relate to a compelling public interest; must be necessary to achieve the compelling public interest; and must be the least restrictive measure possible to achieve the public interest. In addition to imposing conditions that apply to the limitation and derogation of civil and political rights, there are absolute, inalienable rights, also described in the Siracusa Principles as non-derogable rights (Siracusa Principles, Art. 58-60), which stipulate that under absolutely no circumstances may the right to life and the right not to be subject to torture or cruel, inhuman, or degrading treatment be restricted on public health grounds. The Siracusa Principles explicitly state that any limitation on these rights would be an egregious human rights violation, and in so doing would violate the fundamental conditions necessary to appeal to the Principles in order to legitimately implement restrictive measures. Finally, the Siracusa Principles laid the foundation for International Health Regulations, which emphasized that the use of restrictive measures must be proportionate to the health threat, and that measures taken must aim to prevent illness or injury and/or provide care to the ill or injured (Siracusa Principles, Art. 25-26).

In sum, treaties that incorporate civil and political rights establish both \textit{parameters} and a \textit{baseline} for public health action, in a sense creating a framework in which to limit public health powers. In effect, the human rights revolution radically changed the balance between public health and human rights, and while early public
health action was not met with resistance by the courts, limits to such action have now been deemed necessary. Yet more than that, medical advances and the explicit emphasis on human rights had led many to challenge the role and purpose of public health (and more broadly the welfare state). New discourses concerning the legitimacy of the state’s “paternalism” emerged, eventually undermining public health authority by characterizing it as such.

3. The Importance of Public Health to Economic, Social and Cultural Rights

At the same time, however, the second set of rights under international law (encompassing economic, social, and cultural rights) gives rise to a distinct set of human rights that require government intervention to satisfy those rights. Economic, social, and cultural rights include, among others, the right to the highest attainable standard of health, to non-discrimination, to work, to social security, to adequate food, to clothing and housing, and to education. As Fidler explains, economic, social and cultural (ESC) rights are often

...contrasted with civil and political rights through the observation that civil and political rights are negative rights, requiring the government to refrain from certain acts in their treatment of individuals, while ESC rights are positive rights, requiring governments to provide individuals with the conditions and resources necessary to satisfy those rights (Fidler, 2000, p. 299).

In fact these rights, which are embedded in the International Covenant on Economic, Social and Cultural Rights, emphasize the importance of governmental action and accountability in establishing policies and furnishing appropriate funding to develop, maintain, and deliver the conditions and resources necessary to provide, for example, an adequate standard of living to the community, housing, education, medical care and the
opportunity to share in the benefits of scientific and technological progress (Fidler, 2000, p. 301).

Historically, economic, social and cultural rights have been fraught with controversy (see for example, Gruskin and Tarantola, 2002; Fidler, 2000; Steiner and Alston, 1996; Craven, 1995). Indeed, the very (ideological and philosophical) origins of this set of rights have contributed to the polemic surrounding both their existence and status in international law. This is because ESC rights are thought to derive philosophically from the historic conception of the Welfare State that emerged in the late 19th and early 20th century, rights that would be later conceived in terms of “socialist” way of thinking. For reasons influenced by Cold War politics, these rights were artificially split into two treaties, with the United States championing civil and political rights, and the former Soviet Union championing those rights considered to be more economic, social and cultural in nature. As such, this division of rights and, more importantly, the association of ESC rights with socialist thinking during the Cold War, have contributed to their ideological and practical marginalization in international law and Western countries. Thus while ESC rights have been a part of international human rights instruments since the UDHR, many have claimed that civil and political rights sit atop the hierarchy of human rights in international law and are therefore more important. As Craven has argued, “[a]lthough within the UN there is now almost universal acceptance of the theoretical ‘indivisible and interdependent’ nature of the two sets of rights, the reality in practice is that economic, social and cultural rights remain largely ignored” (Craven, 1995, p. 9; as quoted in Fidler, 2000, p. 300).
Perhaps the most controversial ESC right is the human right to health. There are several reasons for this. First, the right to health “illustrates the indivisibility and interdependence of rights as they relate to health” (Gruskin and Tarantola, 2002, p. 7; see also Kirby, 1999; Toebes, 1999; Tomasevski, 1995; Leary, 1994). As Gruskin and Tarantola explain,

…rights relating to discrimination, autonomy, information, education and participation are an integral and indivisible part of the achievement of the highest attainable standard or health, just as the enjoyment of health is inseparable from that of other rights, whether categorized as civil and political, or economic, social and cultural in nature (Gruskin and Tarantola, 2002, p. 7).

As such, nearly every article of human rights treaties can be understood to have clear implications for health (Gruskin and Tarantola, 2002, p. 6). Second, government responsibility for health is codified in a number of international legal instruments. As such, the right to health is the principal framework for understanding governmental obligations under the right to health, which are, in fact, explicitly defined in the ICESCR. For these reasons, the right to health is highly relevant to public health, thus further entrenching the responsibility of government to provide conditions conducive to public health.

Although there have been significant problems in defining the scope of the right to health, as well as its implementation and enforcement under international law and public policy, the fact remains that one of the most fundamental characteristics of modern human rights was the claim to the human right to health. This claim was facilitated by the explicit recognition by the United Nations that health was “fundamental to the attainment of peace and security” (World Health Organization, 2000), leading delegates at a UN Conference in 1945 to concur that “a single global health organization should be founded
and recognized as an essential component of the postwar international system” (Stern and Markel, 2004, p. 1477; see also, Howard-Jones, 1981; Charles, 1968). To that end, the World Health Organization was formed to become the world’s prominent public health organization, replacing the IOPH. Upon its inauguration, the WHO adopted an expanded definition of health, conceived in terms of not just the prevention and treatment of disease, but also and more positively and broadly, in order to attain the highest standard of health, defined as a state of physical, mental and social health. Health was thus understood to encompass both the right to access to health care, as well as government responsibility to address and provide the underlying preconditions necessary for health. In doing so, the WHO linked its mission with concepts of fundamental human rights, proclaiming in its constitution that this broader concept of health, embodied in its objective to attain the highest standard of health, is “one of the fundamental rights of every human being” (World Health Organization, Constitution). By applying this new definition of rights, an explicit linkage was therefore made between the right to health and public health goals, thus recognizing the importance of the role of public health in securing economic, social and cultural rights, particularly the right to health. This creates an interesting paradox for public health: While strict conditions were established to rein in public health powers (that is, to limit the scope of government action by refraining from certain acts in their treatment of individuals), the right to health discourse emphasizes, paradoxically, the responsibility of government to provide conditions conducive to the public health in order to achieve the full realization of that right.

Hence the impact of bringing public health under the fold of international human rights law was significant. With the recognition of the importance of civil and political
rights to public health, it limited public health’s role to one of preventing disease. At the same time, it accepted the concept that the protection of public health constitutes legitimate grounds for limiting (civil and political) rights in international human rights law, while paradoxically reinforcing the role of public health in promoting health through the lens of economic, social and cultural rights. It also codified the obligations understood to encompass the underlying conditions conducive to public health, as well as access to health care.

The recognition that there is a linkage between human rights and communicable disease control, however, did not naturally lead to a human rights approach to public health. Generally thought to be fundamentally antagonistic, this first public health/human rights linkage continued to focus on the tension--and reinforced the dichotomy--between human rights’ focus on individual rights and public health’s focus on the collective well-being. Gruskin and Tarantola succinctly summarize the public health/human rights linkage by stating that “in practical terms, international human rights law is about defining what governments can do to us, cannot do to us, and should do for us” (Gruskin and Tarantola, 2002, p. 4). Yet the question of how to balance the positive duties of government (i.e., how and what governments should do in order to provide the conditions necessary for a healthy life) with the negative duties of government (i.e., not to engage in certain acts in order to protect the rights of individuals) remains unclear and essentially exists in tension. This dynamic played itself out during the HIV/AIDS debate when practitioners and scholars alike tried to apply international human rights law to HIV/AIDS. However as the emergence of HIV/AIDS showed, incorporating human
rights into public responses to epidemics was, to say the least, not easy (Tomasevski, 1992, p. 539).

Although the human rights movement left its footprint on public health discourse long before the emergence of HIV/AIDS, the intersection of public health and human rights had been limited to the distinct, though linked, roles of these disparate disciplines. Thus while “these two worlds had evolved along parallel but distinctly separate tracks,” as Gruskin and Tarantola note (2002, p. 1), the HIV/AIDS debate would explicitly link them together. Vehemently opposed to imposing restrictions on victims or carriers of the disease, prominent scholars and practitioners alike, led by Jonathan Mann, former director of the WHO’s Global Program on AIDS, appealed to human rights philosophical justification premised on individual liberty and autonomy in order to argue that human rights is a critical public health strategy; that is, that the promotion and protection of public health is inextricably connected to the promotion and protection of human rights (Mann et al., 1994; Mann, 1997; Mann et al., 1998; Bayer, 1989).

C. THE HIV/AIDS DEBATE: BRINGING HUMAN RIGHTS TO BEAR ON PUBLIC HEALTH
Growing concerns over the return (or the prospect of a return) to traditional restrictive public health interventions at the dawn of the HIV/AIDS epidemic had the effect of focusing attention on the intrinsic connections that exist between health and human rights, pioneering a human rights approach to public health that many say was “one of the most important and unanticipated outcomes of the first decade of the AIDS pandemic” (Mann, 1992, p. 537). Foremost, it was a catalyst for beginning to define some of the structural connections between health and human rights, with a view of protecting what
was thought to be most at stake in communicable disease control: The paramount value of human well-being and dignity.

In conceptual terms, Mann, Gostin, Gruskin et al. (1994) provide a compelling framework for understanding the linkage between public health and human rights by considering three relationships: The first focuses on the potential burden on human rights created by public health policies, programs, and practices; the second derives from the view that human rights violations have health impacts; and the third is that the protection and promotion of public health is inextricably linked to the protection and promotion of human rights (Mann et al., 1994; Mann, 1997).29

In practical terms, the HIV/AIDS debate sharpened the focus of the public health/human rights discourse by raising two interrelated issues: The lack of regard for modern notions of due process procedures in public health law, and the need to modernize the provisions of the International Health Regulations that guide public health measures, which had not been updated to incorporate human rights norms. This was because there had been no pressing circumstances that required attention, at least not since quarantine had been practically abandoned in favour of other, less restrictive public health measures such as surveillance during the dramatic decline in the incidence of communicable disease. And thus it was that HIV/AIDS “brought the human rights revolution to bear on public health” (Fidler, 1999, p. 198), for as Tomasevski noted, it was “the first worldwide epidemic to occur in the modern era of human rights” (Tomasevski et al., 1992, p. 538).

29 The international journal, Health and Human Rights, which claims to be “dedicated to studying the relationships between human rights and health,” has adopted as its mission the investigation of these three relationships, or intrinsic connections, first articulated by Mann et al. But it has dropped the word “public,” a subtle yet very significant change that I will discuss below.
In a briefing paper, the American Civil Liberties Union (ACLU) brought to attention the stark contrast of then and now:

General quarantine power (not specific to AIDS) exists in virtually every state’s law. The current issues as to isolation/quarantine concern both the proposal of new legislation and the existence of archaic powers in present public health statutes. Traditionally, such statutes gave state health officials wide-ranging and unchecked powers to undertake whatever measures were deemed necessary for the public health. Under such statutes, these public health authorities were explicitly (or implicitly) authorized to isolate infectious individuals as they saw fit, without regard to modern notions of due process (ACLU, *The Isolation or Quarantine of HIV-Infected Persons*, 1988).

Gostin and Lazzarini echoed this point. In a review of public health statutes in American states, they noted that most American legal and public health scholars found that “most state communicable disease statutes fail to ensure due process procedures for exercising public health powers” (Gostin and Lazzarini, 1997, p. 20). They concluded that even countries which respected civil and political rights had yet to reform public health laws to bring them into conformity with human rights norms. Moreover, International Health Regulations (IHR) on communicable disease control were limited to provisions for yellow fever, cholera and plague (Siracusa Principles, 1984). While some argued that the relevance to other communicable diseases could be found in the Regulations’ emphasis that the use of restrictive measures ought to be applied when it is “epidemiologically necessary,” just what that actually meant was unclear even in the context of yellow fever, cholera and plague.

Furthermore, there was a consensus by those who did not support the use of quarantine that the historical analogies between other communicable diseases and HIV/AIDS were totally inappropriate, since it was not the disease that posed an immediate public health threat – *i.e.*, there was no risk of transmission in casual and/or
daily contact. In this vein, it was concluded that quarantine would never be an appropriate public health strategy to deal with HIV/AIDS. It was further concluded that the use of other coercive and restrictive measures against carriers or victims of HIV/AIDS would have the opposite effect by discouraging people from seeking treatment and counselling. The National Academy of Sciences captured this line of thinking, stating that “coercive programs may not only be ineffectual, they may actually undermine individuals’ sense of responsibility for the community…[and would be] counterproductive in altering the course of the epidemic” (National Academy of Sciences, 1986, p. 126). For this reason, it was believed that a voluntaristic approach which respected the rights of individuals with HIV/AIDS would be more effective than the traditional compulsory infection control strategies (Gostin and Curran, 1986, p. 24; see also Bayer, 1991). “Respecting human rights,” stated Gostin and Lazzarini, “was the surest way to encourage people to participate in public health programs that offer testing, counselling, education, partner notification, and treatment” (1997, p. 538). As such, public health and human rights were conceived as a continuum wherein the protection and promotion of rights was critical to the protection and promotion of public health.

Bayer aptly summarizes the conclusions of the HIV/AIDS debate: “A simple dictum emerged: No public health policy that violated the rights of individuals could be effective in controlling the spread of HIV” (Bayer and Fairchild, 2004, p. 478). In turn, Mann et al. emphasized the importance of the dialogue between public health and human rights pioneered through the debate on HIV/AIDS, stating that the groundbreaking contribution of this era lies in the recognition of the applicability of international law to HIV/AIDS issues and in the attention this approach then generated to the linkages between other health issues and human rights – and therefore the ultimate responsibility and accountability of the state
under international law for issues relating to health and well-being (Gruskin and Tarantola, 2002, p. 1).

However the linkages between other health issues and human rights to which Bayer referred has generated, if anything, a shift away from public health towards a more individualistic interpretation of health, focusing on health policy and programmatic work, and on the (individual) right to health. Case in point, the World Health Organization “grounded its framing of a public health strategy in international [human rights] law” (Gruskin, 2004, p. 314), which is itself highly individualized.

D. HIV/AIDS AND HUMAN RIGHTS: A SHIFT AWAY FROM PUBLIC HEALTH

Beginning in the early 1990s, and gaining steady momentum since that time, there has been an explosion of conceptual, analytical, policy, and programmatic work on health and human rights, with an ascendant focus on rights. By the mid-1990s, the first concrete linkages of health and human rights were articulated in international consensus documents involving virtually all United Nations development agencies and programs (Gruskin and Tarantola, 2002, p. 2). Substantial resources have been increasingly channelled towards shaping policy and programmatic work that explicitly deal with the linkages. Research on the relationship or intrinsic connection between health and human rights continues to abound, including the development of frameworks on health and human rights, the development of human rights approaches to public health, the assessment of the human rights impact for the formulation and evaluation of health policies, and the assessment of the human rights standards of mandatory public health programs, to name just a few areas of research (see for example, Meier, 2007; Pogge, 2005; Donnelly J, 2003; Gruskin and Tarantola, 2002; Gruskin and Loff, 2002; Jacobson
Almost invariably, discourses on health and human rights, or the right to health, emphasize the human rights impact, that is to say the interference of public health policies with individual rights. This reinforces not only the presupposed dichotomy between the two poles (they exist only in opposition), but also the decision to choose one pole over the other, since it is assumed that one is always prior to the other (Freedman, 1995). Furthermore, discourses on health and human rights are framed in the dominant language of human rights (e.g. of responsibility and accountability) and within the context of biomedical considerations (e.g. the treatment of disease), further reinforcing the marginalization of public health considerations (see for example, Gable, 2007; Meier, 2007). Thus while the discourse on the right to health views public health as a necessary presupposition for fulfilling health rights, the very assumptions it takes for granted have the ironic effect of undermining public health, further reinforcing the dichotomy between health and public health begun at the turn of the century\(^30\) (Merritt, 1986). In sum, what underpins health and human rights discourses is a conception of health as viewed from a more limited and individualistic perspective. Based on this, there is no relationship between public health and rights to speak of. Moving away from the right to health discourse, and looking specifically towards the literature on modern communicable disease control illustrates that this relationship is still at odds.

\(^30\) Mendelsohn states: “Though the individual is no longer a standard of category of explanation for historians, it was the category for the new public health” (1995, p. 272; see also, Chapin, 1910; Hill, 1913; Ravenel, 1921; Winslow, 1923; Rosen, 1958; Cassedy, 1962).
The recent Speaker story is a case in point (see for example, Coker et al., 2007; Fidler et al., 2007; Markel et al., 2007a, 2007c; Parmet, 2007; Night, 2007; Brewer, 2007; Committee on Homeland Security, 2007; Swendiman and Jones, 2007). Scholars and practitioners alike grapple with what is still understood as the delicate balance between—and opposition of—the demands of individual rights and the demands of public health (see for example, Fairchild and Alkon, 2007; Fidler et al., 2007; Gostin, 2002; Rothstein, 2002). There is continuous see-sawing and there are still embittered debates about the importance of, or the problems related to, conceding or increasing public health powers or protecting or infringing upon individual rights. By all accounts, the relationship between public health and human rights continues to be framed in an either/or paradigm.

The “default position” of mainstream discourses on modern communicable disease control has been to give prima facie justificatory power to rights, and to begin from the assumption that rights are prior to the good. To be sure, there has been a significant shift in focus in the literature towards public health requirements since the outbreak of SARS and the threat of bioterrorism (see for example, Allan, SM et al., 2007; Bloomberg, MR, 2007; Ziskin and Harris, 2007; SARS Commission 2006; Gross and Aoláin, 2006; Homeland Security Council, 2006; Committee on Measures to Enhance the Effectiveness of the CDC Quarantine Station Expansion Plan for U.S. Ports of Entry, 2006; World Health Organization, 2006a, 2006b; Basrur, SV et al., 2004; D’Cunha, C, 2004; Naylor, D et al., 2004; National Advisory Committee of SARS and Public Health, 2003; Expert Panel on SARS and Infectious Disease Control, 2003; Reich, 2003; Walkerton Commission, 2002; Miller et al., 2001). However the pendulum has essentially swung towards public health at the expense, at times, of human rights (see for
example, Centers for Disease Control and Prevention, 2001, 2002). Hence the tension between human rights and public health continues to persist, and the question of how to harmonize public health goals with human rights norms remains unclear. More than that, however, is the fact that a closer examination of the literature reveals that there seems to be lack a justificatory power to use restrictive measures in order to achieve public health goals. While analyses tend to fall on one side of the debate or the other, only when the case is made for public health to override rights does it spur opposition that could be avoided, I contend, if public health had justificatory power.

Petersen’s observation still rings true today: Modern citizens resist “top-down, parternalistic forms of intervention that are seen as characteristic of the period of sanitary reform” (Petersen, 1999, p. 119; see for example, Bracht, 1991; Bracht and Tsouros, 1990). This is because, I contend, we have failed to address the question of legitimacy in determining on what basis public health interventions are justified. We must acknowledge that legitimacy requires compliance by those who are affected, the community of citizens, and compliance requires that justification proceed on terms that are acceptable to them.
CHAPTER 4: THEORETICAL CONSIDERATIONS

At the age of 15 or 16, I sat before the radio and experienced what was being discussed before the Nuremberg Tribunal; when others, instead of being struck silent by the ghastliness, began to dispute the justice of the trial, procedural questions, and questions of jurisdictions, there was that first rupture, which still gapes. Certainly it is only because I was still sensitive and easily offended that I did not close myself to the fact of a collectively realized inhumanity in the same measure as the majority of my elders.

– Jürgen Habermas, 1983, p. 2

Social practice is the explanandum and not the explanans.

– Rick Roderick, on the Habermasian view, 1986, pp. 6-7

Theory now appears in a double guise: As false consciousness and as critique. In both respects, however, philosophy is embedded in the practice of a particular social context and remains dependent on it. While critical theory tries to uncover the context-dependency of a traditional theory that only imagined itself to be independent of any historical conditions, this critique becomes aware of its own social roots and becomes doubly reflexive: Gazing into the mirror of the historical context of its own genesis, it also discovers the addressee who can be spurred on to a liberating practice by means of the critical insights that the theory provides.

– Jürgen Habermas, 2003, p. 282

A. INTRODUCTION

I can locate two theoretical problems that must be addressed. Although they are interconnected, it is important to parse them out. Each question represents a strand in the knot of tensions and contradictions that are inherent to modern society. To reiterate, my problématique is to explore what constitutes the legitimate use of restrictive measures – i.e., on what grounds are restrictive measures legitimate in the context of the modern era of rights. I will examine this question in light of two theoretical considerations:

(1) What constitutes a justifiable claim?

To answer this question, I propose to examine it along these lines:

A. The problem of justifying claims = providing a foundation
B. Foundation = moral legitimacy
C. Moral legitimacy = establishment of shared norms
D. Shared norms = articulate a comprehensive concept of rationality that permits the establishment and vindication of norms
E. Comprehensive concept of rationality = communicative rationality
F. Communicative rationality = intersubjectivity through a community of inquirers

(2) What constitutes a viable ground for anchoring the linkage between public health and human rights?

To answer this question, I propose to examine it along these lines:

A. Positivist rationality = inadequate justificatory power to respect rights and public health considerations
B. More adequate model of legitimacy = moral legitimacy
C. Shared norms = articulate a comprehensive concept of rationality that permits the establishment and vindication of norms
D. Comprehensive concept of rationality = communicative rationality
F. Communicative rationality = intersubjectivity through a community of inquirers

B. RETHINKING THE SYNTHESIS BETWEEN THE INDIVIDUAL AND THE COLLECTIVE

The classic question in political sociology of the status of the community and the individual within modernity has long attracted critical attention. There are three distinct discourses that have emerged:

1. Those that lend themselves to analyses of the various dimensions of the erosion of the community or the public sphere (see for example, Lipovetsky, 1983; Giddens, 1990; Elsthain, 1993; Ferry, 1992);

2. Those that search for the foundations of modernity, with those that lament the effects of the dominance of (the increasingly alienating and antagonistic) individualism in modern society (see for example, Sandel, 1984; Renaud, 1989), and those that emphasise that there still exists communitarian roots in modern society (Taylor, 1992; Benhabib, 1992); and central to this inquiry
3. Those that have attempted to transcend the opposition and mediate the debate between liberal individualism and communitarianism or, more fundamentally, to create a new synthesis between the individual and the collective.31

Indeed, entire schools of thought have explored how the reconstitution of a new synthesis can possibly reintegrate the modern bifurcation of the individual with the collective. Despite various attempts, however, the question of how to do this has been almost invariably framed or interpreted as a dichotomy, meaning that any account ultimately gives precedence to one over the other, with the majority of accounts ultimately attributing a privileged and dominant status to the individual. Although it is beyond the scope of this inquiry to give a full account of these discourses and the expanded linkages that make them possible, there are viable accounts that deserve mention: Those which propose a reintegration through democracy (Gauchet, 1985), the political (Arendt, 1972), a return to the subject (Touraine, 1993), or citizenship (see for example, Skinner, 1998; Janoski, 1998; Dagger, 1997; Callan, 1997; Galston, 1991; Cairns and Williams, 1985). Like Habermasian critiques of modern society, these accounts are essentially democratic theories that seek to transcend the dominant liberal paradigm by reconstructing the notion of the public citizen and public sphere without surrendering the modern individual or the (liberal) notion of rights.

It is my contention, however, that Habermas’ project on communicative action is the most promising attempt at recomposition. As I hope to show in subsequent chapters, this is where the findings of this inquiry reside. Communicative action holds the

31 Other accounts that do not presuppose a split between the individual and the community, such as those of neo-Aristotelians, neo-Platonists, and neo-nominalists, among others (Dupre, 1993, p. 6), have essentially rearticulated a vision of change anchored in premodern premises. However this is neither desirable nor possible, first because for all intents and purposes such a reality simply no longer exists, and second because it does not accord an epistemological status to the individual. Consequently it cannot articulate a conception of the individual that ties in with the exigencies and ideals of the community – a question central to this inquiry.
potential, both theoretically and empirically, of successfully integrating public health and human rights because it provides a foundation for developing a genuine synthesis between them; this it does by recognizing them as co-original, not as prior to one another. Thus communicative action gives us a basis for justification by shifting the construction of norms (of what constitutes the good life) from the individual level (based on a citizen’s virtues, for example) to the intersubjective level of communication – or, viewed in another way, from the private sphere to the public sphere.

Moreover, Habermas examines not only how the establishment or vindication of shared norms is achieved through communicative action, but also how these norms can be legitimately institutionalized and enforced – all of which is precisely what is required for understanding and addressing the ethical issues raised during communicable disease outbreaks or other public health emergencies – through a discourse ethics of law. In other words, Habermas weaves the legal and political implications of his theory of communicative action by constructing an account whereby communicative action provides the foundation for legitimacy, or a legitimate order, through the medium of the law (1996).

In the following, I review Habermas’ project to construct the conditions for the possibility of understanding (the establishment and vindication of shared norms), and for the possibility of a legitimate order (the institutionalization and enforcement of norms). I then discuss how discourse ethics and a Habermasian conception of modern law reconceives the relationship between public health and human rights, setting the stage for a communicatively generated public health ethics (about the legitimacy of using restrictive measures).
C. THE HABERMASIAN PROJECT: BEYOND THE VERITIES OF POSITIVISM

Communitarian critiques of liberalism (see for example, Taylor, 1985; Walzer, 1983; Sandel, 1982; MacIntyre, 1981) and critical social theory share epistemological principles (Benhabib, 1992). Both reject highly individualistic liberal conceptions of human agency, which they view as deeply flawed and incoherent. The notion of an abstract, universalisable conception of an independent, autonomous, rational individual who enters freely into a social contract to protect his natural rights and freedom is, in their view, an impossible theoretical construct that presupposes an ahistorical, static, and atomistic conception of the self. That is, the individual, observe communitarians and critical theorists, “seems to spring *sui generis* from [itself] rather than being constructed through association with others” (Simon, 2001, p. 4). As Simon says of this view, “independent individuals and a political theory based on such conceptions cannot account for collectively constituted notions of the good” (Simon, 2001, p. 4). Communitarians and critical theorists argue that the idea of “unencumbered” selves engaging in individual acts of private moral conscience in order to establish a foundation for moral life presents an impoverished notion of morality and of community, and furthermore it cannot provide a view of the good life – for example, a view of what kind of society we want to be during a communicable outbreak.

While communitarians and critical theorists converge in calling for a reconceptualisation of collective conceptions of the good, how to achieve this is also where they diverge. According to communitarians, attempts to (re)construct a notion of community and defend a conception of the good life requires that we transcend liberalism altogether. In absolute contrast, Habermas, although he also rejects the notion of an unencumbered self, argues that the possibilities for this not only reside within liberalism,
but can take shape only through the medium of liberal democracy, since morally
defensible claims (about the good, for example) can only derive from an unfettered
political public sphere, which liberal democracy guarantees.

1. The Antinomie of Modernity

Habermas agreed with antecedent critical analyses of the concept of (Western) rationality
that prevailing forms of scientific-technological rationality had essentially usurped all
areas of social life (see for example, Weber 1958, Lukács, 1971, Marcuse, 1964,
Horkheimer and Adorno, 1972). What was perceived to be the instrumentalisation of
reason was thought to be inadequate, not comprehensive, and limited to its purely
instrumental functions, or as Marcuse put it, a “one-dimensional thought” (1964, pp.
143-157). In line with Marcuse, Habermas argued that the growth in the forces of
capitalist production – fuelled by scientific and technological progress, and instantiated in
every social process – had become the basic form of legitimation of the social system
(what he would later call the “colonisation of the life-world”), rendering freedom and
autonomy of the individual technically impossible. He deplored forms of domination,
both explicit and implicit, found in scientific-technological knowledge that both reduced
reason to a mere instrumental value and privileged, indeed legitimated only, technical
reason.

Yet unlike his predecessors, among them Marcuse (1964), Horkheimer and
Adorno (1972), who came to see the development of Western rationality as the

---

32 For a detailed discussion of the concept of reason developed by what became widely known as the
Frankfurt School of Critical Theory, see Arato and Gebhardt, 1978, pp. 390-396.

33 For example, the instrumentalisation of reason was seen in what was perceived to be the political and
administrative domination of social life through increasingly efficient and predictable techniques
characteristic of capitalist production.
totalisation of reification, domination and oppression,\textsuperscript{34} or Weber, who saw no possibility of escape from the “iron cage” of modern society (1958, pp. 180-183), Habermas believed that there were still kernels of freedom that clashed against, indeed resisted, elements of oppression and inhumanity. To him, the problem did not lie with “rationality as such, but rather, in the name of rationality, a specific form of unacknowledged domination” (Habermas, 1970, p. 82; as quoted in Roderick, 1986, p. 41).

Returning to the classical Aristotelian understanding of politics – \textit{i.e.}, that members of the \textit{polis} define the \textit{practical intentions} of forming a good and just society – Habermas argued that those practical intentions, which he saw in the unrealised promise of liberalism, had been eclipsed by what for him was the “scientisation of politics”\textsuperscript{35} and the concomitant decline in the public sphere. He would devote his life to articulating a way out\textsuperscript{36} – what for Habermas was the development of a more rational society – that

\textsuperscript{34} In the aftermath of the Nazi regime, what had been conceived as the dialectic of the enlightenment (its processes of domination \textit{and} of emancipation) turned negative and became a total critique of rationality, morphing into a critique of the very structure of Western reason. Ever so disillusioned, Horkheimer and Adorno claimed categorically that the pursuit of enlightened reason engendered, paradoxically and tragically, new--and more powerful--forms of irrationality and repression by becoming an end in itself (Roderick, 1986, p. 40). Adorno argued despairingly that the emancipatory potential of rationality and critique had been “dragged into the abyss…of a rationalized world gone mad” (Adorno, 1967, p. 34).

\textsuperscript{35} He reformulates the critique of instrumental reason to a critique of “scientism.” He explains: “Scientism means…that we no longer understand science as one form of possible knowledge, but rather identify knowledge with science” (Habermas, 1971, p. 4; as quoted in Roderick, 1986, p. 50). To do this, he brings into focus the relationship between scientism and positivism which, he laments, provides scientism with its sophisticated philosophical defense. That is, he challenges the dominant positivist view that attempts to reduce the theory of knowledge to the philosophy of science. The process of rationalization, and with it the rise of scientism, had given way to questions of methodology of the sciences, including the social sciences, and alienated, indeed rendered irrelevant, questions of practical philosophy (in the Aristotelian sense of the “practical intentions” of the \textit{polis} to form a good and just society). Henceforth inquiry into the conditions for the possibility of knowledge, as well as the meaning of knowledge itself, was muted. As Habermas states, “the meaning of knowledge itself became irrational – in the name of rigorous knowledge” (1971, preface and pp. 68-69).

\textsuperscript{36} That is, to strengthen two complexes of problems left unresolved by the critical theory of the earlier Frankfurt School: The problem of justifying the normative dimension of critical theory (to ground its critique of modern society), and the problem of establishing the relationship between theory and practice (the emancipatory practical intention to change society) (Roderick, 1986).
required the construction of a more differentiated rationality which could be defended against the usurpation of a single rationality, scientific-technical rationality.³⁷

To this end, he explicitly parsed out two separate spheres within social practice: Labour (purposive-rational) and interaction (communicative action). Broadly speaking, labour is the sphere in which human beings produce and reproduce their lives by transforming nature with the aid of technical rules and procedures, whereas interaction is the sphere in which human beings produce and reproduce their lives by communicating their needs and interests in the context of rule-governed institutions (Roderick, 1986, p. 7). Thus he drew an important distinction between the “technical interest” in the prediction and control of objectified processes (associated with the growth of the technical power of production), and the “practical interest” in “undistorted” communication in language (associated with the growth of rule-governed institutions, for example law).

He thus attempts to rescue from positivism what he deems to be fundamental to social life: The reflexive character of knowledge. In the positivist logic, knowledge is subsumed by a rationality specific to the natural sciences that assumes, as Apel observed, that “objective knowledge is possible without intersubjective understanding through communication being presupposed” (1972, p. 10). In other words, positivism presupposes unproblematically assumed knowledge – i.e., the very language upon which it rests, though intersubjectively constituted, is taken for granted in scientific knowledge. In

³⁷ He affirmed the Kantian view of the differentiation of reason into value spheres (of science, religion, morality and art) as both inherent and integral to progress within modernity. Rejecting this differentiation, he contended, basically amounted to abandoning the project of modernity. Instead he argued that each sphere has an equal right within its own sphere that can (or ought to) be supported by argumentation – i.e., by making claims with “good reasons” for their acceptance, thus ultimately appealing to the community of inquirers for justification.
essence, the monological nature of the latter does not encompass, and cannot successfully reduce social reality, to a technical interest. Moreover, the methodology of the sciences, viewed as value-free enterprises that produce knowledge (facts) which are devoid of value judgements, does not recognise, cannot even conceptualise, that knowledge is historically and socially rooted – that it is embedded in a social reality which is the product of past and culturally shared experiences. The social “scientist,” herself a social actor, is embedded in social processes and inextricably tied to values and interests from which she draws her knowledge. Yet from the standpoint of a scientific methodology, which presupposes neutrality, the social “scientist” draws on and produces unproblematically assumed knowledge of the social actors themselves. Habermas therefore maintains that “positivism is the denial of reflection” (1971, p. 68); it ignores the social processes, values, norms, and interests necessarily embedded in human inquiry. In short, he is concerned with unmasking the conditions for the possibility of knowledge(s).

To reach this point, he went through several stages of construction, which began as a political preoccupation with the unrealized promise of liberalism (to create conditions to protect the individual from arbitrary power, for example).38 It was in fact his commitment to democracy and democratisation that led him to what he came to see as the theoretical necessity of constructing a positive account of rationality. To this end, Habermas appeals to philosophy and social theory, conjoins them, bringing in dialogue American pragmatism and the analytic philosophy of language with questions of social theory, to transcend dominant--and largely unchallenged--positivist notions of social

38 Here it is worth noting that Habermas was the first member of the Frankfurt School to have grown up under a totalitarian regime and whose work was conceived against the backdrop of his postwar experience.
practice with a view to looking for the foundation and the critique of modern society. What he finds is communicative action. Put another way, the foundation of a critical social theory, Habermas argues, rests on a communicative rationality which serves as the basis for critique that creates the conditions to provide a foundation for the construction and justification of fundamental norms. This is rendered possible, Habermas tells us, because there is a profound continuity between language and the values embedded in the project of modernity that are revealed through communicative action.

From this basis, what counts as relevant, or justified, or moral, can be – as it ought to be – determined within the broader social context of practices and actions. Generally speaking, he wanted to secure the conditions of, and attempted to articulate the theoretical foundations for, the justification and legitimation of liberal democracy amid what he saw as an alarming legitimation crisis (Habermas, 1975). Put simply, Habermas’ political project has been “to secure criticism as a moral imperative” (Bronner, 1994, p. 287).

2. The Anomie of the Public Sphere

Thus it only makes sense that Habermas began his inquiries with an exploration of the notion of the public sphere – or what had become the anomie of the public sphere (Habermas, 1962) – wherein he argued that the reduction of the practical to the technical had effectively reduced the public sphere to the same logic of instrumental reason implicit in the state and the economy. In his earliest attempt to construct a more differentiated account of rationality (Habermas, 1963), he sought to defend the concept of the public sphere and the public sphere itself against usurpation by scientific-technological rationality.
He fundamentally believed that the public sphere is the arena in which civil liberties are applied, and that its viability is evidence of a democratic and legitimate order (Bronner, 1994, p. 286). Based on this premise, he would argue that only argumentation within a renewed public sphere could ultimately serve as the ground for the legitimation of liberal democracies and its attendant legitimacy and knowledge claims. The process of argumentation, he would attempt to show, provides a (democratic) basis that both reflects and reinforces the presuppositions underpinning political liberalism, which still – or perhaps especially for “a present just emerging from Nazism, still burdened by Stalin, and rife with neo-fascist impulses” (Bronner, 1994, p. 286) – held the emancipatory promise of the project of the enlightenment.

In agreement with Weber, he held, indeed decried, that the development of a capitalist economy, the commercialisation of the mass media, and the expanding influence of science and technology had deeply altered collective social life: It had led to a rationalised technocratic administrative apparatus that presented political matters as technical problems for experts, thus generating decisions from the top down rather than through the discursive engagement of citizens, which had been the raison d’être of the public sphere. Public opinion no longer derived from public criticism, or from the public itself for that matter, but was produced through the technical manipulation of the public, essentially eradicating or depoliticizing the public sphere. This made the repoliticization of the public sphere, Habermas believed, simultaneously imperative and impossible.

Against this backdrop, he claimed that such an inquiry could only begin from the standpoint of critical theory, infusing it with “a democratic impulse” (Bronner, 1994, p. 284) that reflexively sought to both legitimise liberal democracy and function as a
standard of critique against which the present society could be problematically thematised – and not taken as a given, which positivism does. For Habermas, the public sphere was the starting point for what would ultimately become a philosophical preoccupation with the role of discourse in advanced industrial society. Essentially, he sought to recapture reflexivity and restore the conditions for discourse.

From this starting point, his object of (re)construction turns to the philosophy of language as he seeks to embed a critical social theory of rationality in language. “The problem of language,” he states, “has today replaced the problem of consciousness” (1988, p. 190). Indeed, Habermas argues, the point of departure for a social theory that provides normative justification for a critical social theory and (re)establishes a relationship between theory and practice is found in the philosophy of language. Habermas’ investigation into the relevance of language for a critical social theory is predicated on the claim that “reaching understanding is the inherent telos of human speech” (1987, p. 287). Within this context, he attempts to answer the question: What are the conditions for the possibility of communicating and understanding? Or, putting it another way, what constitutes a rational dialogue? In this new direction, he wants to construct the conditions for the possibility of understanding, which he came to see as fundamental to the conditions for the possibility of knowledge.40

39 As Rasmussen explains, according to Habermas, “the linguistic taking-over of the process of reaching an understanding redeems philosophy from its commitments to a philosophy of the subject, while at the same time enabling philosophers to give an intersubjective account of rational action without getting mired in the 19th century problems of subjectivity” (1996, p. 22).

40 In rare accordance with anti-foundationalists (or post-modernists), Habermas concedes: “The unsettled ground of rationally motivated agreement among participants in argumentation is our only foundation – in questions of physics no less than in those of morality” (Habermas,1982, p. 238; as quoted in Roderick, 1986, p. 10). However against their claims that foundations for human inquiry can only be illusive, he argues that there are—and must be in order to avoid the kind of nihilistic relativism he repudiates—transcendental grounds for justification by providing a rationalist basis, or a normative foundation, for this process of argumentation. These foundations, he posits, can be found within the intersubjective workings of
For Habermas, the "linguistic turn" taken in the philosophy of language\textsuperscript{41} had to take another turn, a social turn. That way, social practice could not be taken for granted, as it is in positivism – \textit{i.e.}, it is treated as the explanans instead of the explanandum. A theory of language remains abstract and incomplete, Habermas explained, if it does not provide an adequate understanding of the social dimension of \textit{knowing} and \textit{doing}. In other words, the recognition and theorising of the intersubjectively shared structure of language, which was made explicit in the first linguistic turn, fell short of providing an adequate understanding of the use and role of language in modern society.

D. Establishing and Vindicating Norms: The Conditions for Understanding

1. The Theory of Communicative Rationality

To locate communicative action in modern society, Habermas moves beyond a formal (that is to say, philosophical) account of rationality in order to take account of the social embodiment and historical development of rationality. He employs an intersubjective framework, or what he would claim to be “a post-metaphysical perspective,” using as its referent a symbolically structured form of interaction in which reflexivity is constituted and norms are made; this he would call “the lifeworld.” From this post-metaphysical perspective, Habermas argues that the cognitive-instrumental approach to rationality is valid, but only partially so. He builds on his earlier distinction between labour and interaction by drawing a distinction between two concepts of rationality: 1) a cognitive-

---

\textsuperscript{41} Habermas’ own “linguistic turn” is very significant. He reconceives the first linguistic turn taken in Anglo-American philosophy that challenged the Cartesian concept of the individual consciousness (the solitary thinking subject) through its investigations of the intersubjectively shared structure of language. (For detailed accounts of the historical trajectory of the “linguistic turn,” see for example, Rorty, 1991; Toews, 1987.) Habermas further challenged the originary paradigm shift by recasting it within the larger social context to better account for the social dimension of language.
instrumental rationality that conducts action which aims at the successful realisation of privately defined goals (these action types are either instrumental, e.g. through labour, or strategic, e.g. in relations of domination); and 2) a communicative rationality that underlies action which aims at mutual understanding, conceived as a process of reaching agreement.

This distinction, drawn between strategic and communicative action, allows for criticism of and reflection on what had been taken for granted within a dominant positivist rationality: The uncoupling of the lifeworld from systems of purposive-rational action. For Habermas, this is not problematic in itself, first because it is characteristic of the differentiation of spheres in modern society\(^{42}\) and second because there is a synergistic--and necessary--relationship between these made possible by their very differentiation. That is, on one hand the lifeworld depends upon systems, both in terms of material production (the economy) and organisation (the state), while on the other hand the social system depends upon the lifeworld for the reproduction of socialised individuals and the establishment of legitimate norms. What is problematic, however, and what he wants to thematise, is that the historical evolution of the uncoupling of the lifeworld and systems has led to the subordination of the lifeworld to systems imperatives. In other words, instrumental action has “colonised the lifeworld” (Habermas, 1982, pp. 280-281) that ought to have been secured through communicative action oriented to mutual understanding. As Deflem explains,

\(^{42}\) Consistent with his defense of modernity, he argues here that it is precisely the differentiation of value spheres that makes possible the rationalisation of the lifeworld. That is, knowledge, norms (and orders), and modern forms of autonomy are dependent upon the level of the rationalisation of the lifeworlds. Through this rationalisation, Peters summarises, “world-views or systems of cultural categories have become differentiated and new levels of critical reflection, learning and discursive testing of inherited beliefs or normative orders are possible” – as long as the lifeworld remains “uncoupled from the mechanisms of system integration (the economy and the state) but not subordinated to it” (1996, p. 121).
...this twofold perspective indicates that societies have to secure the transmission of cultural values, legitimate norms and socialisation processes, and, in addition, they also have to efficiently manipulate and control their environment in terms of successful interventions.... These systems have in the course of history split off, or “uncoupled,” no longer on the basis of communicative action aimed at understanding, but in terms of the functionality of the steering media, money and power. Actions coordinated through these steering media relieve communicative action from difficulties in reaching consensus in complex societies characterised by a range of action alternatives and, therefore, a constant threat of dissent. Actions coordinated by the steering media of money and power differ from communicative action in that they aim at the successful (cognitive-instrumental) organisation of the production and exchange of goods on the basis of monetary profit (economy) and the formation of government to reach binding decisions in terms of bureaucratic efficiency (politics) (Deflem, 1996, pp. 4-5).

From the standpoint of a more differentiated conception of reason that uses communication as both a point of departure and a vehicle, Habermas affirms that the regenerative possibilities of rationality lie within its communicative element because language, or the linguistically mediated process of reaching an agreement, is inherently regenerative. It is only through language that social actors can coordinate their actions towards achieving mutual understanding (where communicative action “brings in mutual linguistic understanding as a mechanism of action coordination” [1996, p. 33]). Given that his linguistic turn is premised on the idea that the claims of rationality can be discovered in the linguistic telos of reaching an understanding, he articulates a critique of the subject (“an alternative way out of the philosophy of the subject” [Habermas, 1987]) that does not reject the modern/rational individual (and that continues to defend her inherent moral standing) but that recognizes her intersubjectivity within a “communication community” (Habermas, 1975). McCarthy explains: Habermas aims “to identify and clearly mark out a road indicated but not taken.” The determinate negation

43 The road indicated, but not taken, to which McCarthy refers is Habermas’ return to “those historical crossroads” of Hegelian, Nietzschean and Heideggerian philosophy on the subject, which also serve as a point of departure for post-modern/post-structuralist critiques of reason. He is in fact responding to radical
of subject-centered reason by reason understood as *communicative action*” (McCarthy, 1990, p. vii) – *i.e.*, rationality is rooted in the structure of the conversation itself (or, put another way, communicative action reveals the rational dimension of the conversation) that yields principles or norms legitimating social practices and institutions. Hence meaning is constructed *intersubjectively* (rather than by an isolated subject).

By grounding rationality within the intersubjective structure of language, Habermas reconstructs notions of subjectivity and autonomy that are consistent with the intersubjective dimensions of individual autonomy and the situated character of social action. Thus understood, the individual is recast in an intersubjective paradigm of communicative action that enables citizens to construct a common good, while maintaining the rights and freedoms accorded to her in liberal society. Habermas thus seeks to establish a political process that can provide a unified view of the good life through a dialogue, or practical argumentation, while continuing to defend a deontological conception of liberty.44 Here Habermas attempts to show that “it *is* possible to combine respect for persons with the commitment to a norm of political truth internal to the deliberative process” (Bohman and Rehg, 1987). He is cognizant of, and fully supports, the view that the modern development of social and cultural diversity, or the pluralism of worldviews in modern society, cannot be replaced by a unitary conception of *the* collective good life. He equally maintains, however, that the pluralism of what he calls these life-worlds is nonetheless compatible with and capable of unity regarding fundamental shared norms. In this way, he restores and makes explicit the historical, critiques of subject-centered reason that reject rationality altogether and argue that modernity is a historical stage coming to an end. In what serves as the basis of critical theory, Habermas argues that modernity sows the seeds of its own critique and the “post-modern” thesis is instead a further articulation of that critique.44 Here we are reminded of Kant’s vision of a kingdom of ends and thus see in what way Habermas espouses a fundamentally Kantian view of the self.
social, and evolving nature of the construction and justification of norms, or more broadly, what he calls the political- and will-formation (practical argumentation that yields shared norms).

Habermas contends that it is necessary to juxtapose—and to mediate the tension between—what he calls facticity (strategic action) and validity (communicative action) that exist at the heart of modern society because validity claims come into play in all aspects of communication. In “performing speech acts,” “inquirers” inevitably raise four validity claims: 1) comprehensibility; the utterance is comprehensible, 2) truth; its propositional content is true, 3) rightness; it is appropriate, 4) sincerity; it is sincerely spoken (1987). Through the raising of validity claims, participants in the process of argumentation “thematise contested validity claims and attempt to vindicate or criticise them through arguments” (Habermas, 1987, p. 42; as quoted in Roderick, 1986, p. 114). By doing so, they establish intersubjective relations which make possible the socially binding recognition of these claims. The validity of agreements or norms is thus based on the intersubjective recognition of validity claims. Hence validity is at the heart of the process of reaching an understanding, and norms can receive validity only insofar as all potential participants in practical argumentation agree to them. Basically, Habermas observes, “the unavoidable claim of superiority of the enlighteners over those to be enlightened is a fiction…. [I]n a process of enlightenment there can be only participants…there is no privileged access to truth” (Habermas, 1973, pp. 33-40; as quoted in Roderick, 1986, p. 72). This logic of discourse has enormous practical implications: The notion of truth that it supports necessarily involves an analysis of the discursive justification of validity claims, i.e., an account of what constitutes a
“consensus” or “the truth of statements” or the “correctness of norms” – in short, of what constitutes a justified claim.

To that end, he argues in favour of a model of participatory democracy, what Benhabib calls a “discourse model of legitimacy” (1992, p. 82), that allows debate (about what counts or what is relevant) guided by the validity claims elucidated by Habermas. In such conversations, explains Benhabib:\footnote{Benhabib is referring here to Rawls’ notion of the “original position” (1971), a hypothetical situation where he asks us to imagine that all human beings gather before any of them are born, to determine what principles they would agree to. He argues that, since no one knows who or what he or she will be and hence, would not concede to an unacceptable outcome, they would choose principles of justice that do not presuppose any particular ends but that guarantee as much liberty as possible for all. Principles are thus chosen behind a veil of ignorance, i.e., from a position of equality, which guarantees that they are both impartially and rationally acceptable to all. Morality is here a matter of impartial deliberation, whereas for Habermas, it is one of practical argumentation.}

It is not necessary for [individuals] to define themselves independently either of the ends they cherish or of the constitute attachments which make them what they are. In entering practical discourses, individuals are not entering an “original position.” They are not being asked to define themselves in ways which are radically counterfactual to their everyday identities. This model of moral argumentation does not predefine the set of issues which can be legitimately raised in the conversation and neither does it proceed from an unencumbered concept of the self. In communicative ethics, individuals do not stand behind any “veil of ignorance” (Benhabib, 1992, p. 73).

For Habermas, the aim of argumentation is not to reach, or to proceed based on, an equitable adjudication of interests. It is the pursuit of the “best argument” and, for this reason, participants in a conversation (or “the communication community”) do not seek to discover some optimal solution or standard for ranking incommensurate values. Instead they seek to form a loosely defined consensus through which everyone affected by a decision is given the opportunity to participate, if only in theory. Only a rational consensus – rendered rational within a conversation reached by free and equal persons, and in a free and equal discussion (what he calls the ideal speech situation) that generates
the norms and values “worthy” of legitimation – can ground legitimacy claims. Like its precursor, the ideal speech situation, communicative rationality is not an attainable ideal, but rather a critical principle; it is the process of how disputes ought to be resolved, or the conditions under which consensus could be achieved. Thus conceived, communicative rationality is a model of moral argumentation for the possibility of grounding discursive claims under conditions of rational argumentation. Put another way, the possibility of grounding the claims raised in speech and action is precisely what constitutes their rationality.

What such conversations require, Habermas explains, is that “enfranchised citizens switch from the role of private legal subjects” by taking “the perspective of participants who are engaged in the [public] process of reaching understanding about the rules for their life in common” (1996, p. 461). In this sense, communicative action bridges the gap between individual liberty and collective political engagement. What this requires in turn, and is largely missing in (dominant) liberal institutions and practices, is a positive notion of the public citizen deliberating in a public sphere.46 And what this requires is that we reconstruct the conditions for the possibility of a legitimate order – a reconstruction necessary to move beyond the instrumental logic of positivism within which the conditions for a legitimate public discourse have been expunged.

E. INSTITUTIONALIZING AND ENFORCING NORMS: THE POSSIBILITY OF A LEGITIMATE ORDER

Here Habermas begins to delve into the quandary of modern political philosophy: How can norms be imposed and respected in order to guarantee the cohesion and stability of

46 According to Habermas, the role of citizen as active political participant has been reduced to the role of client of the state; the role of active producer reduced to passive consumer.
the social order, while at the same time appearing to be acceptable to those to whom norms are applied? Or as Habermas puts it: “How can the differentiated lifeworlds that are internally pluralized and disenchanted\textsuperscript{47} be socially integrated?” A classic dilemma: What constitutes legitimacy in a modern social order? Consistent with his view that philosophy alone cannot give an adequate answer, he argues that the “only way out of this predicament is for the actors themselves to reach an understanding about the normative regulation of strategic interactions” (Rasmussen, 1996, p. 27). From here the question arises: How can the realms of communicative action (validity) and strategic action (facticity) which have become separated and which are perceived to be incompatible, be integrated without dissolving one into the other? According to Habermas, amid the differentiation that occurred in modernity, the law emerged as a mode of integration stabilizing the gap between facticity and validity on account of the historical--and central--role it played in catalyzing social integration in modern society.

He therefore conceives the conditions for the possibility of a legitimate and cohesive order in terms of the law. That is, the socially integrative force of modern law is the democratic will-formation\textsuperscript{48} that “illuminates the original idea of self-constitution of a community of free and equal citizens” (1996, p. 474). What this means is that the law in

\textsuperscript{47} The term “the disenchantedment of the world” was first used by Weber (1958) to denote the removal of transcendence or the process of withdrawal of the divine that marked the origins of modernity (or the Enlightenment). He stated, “The fate of our times is characterised by rationalization and intellectualization and, above all, by the ‘disenchantment of the world’” (1958, p. 155). Modern thought disavowed all magical or religious ways as superstition or sacrilege, and relegated the divine to the supernatural; hence the dis-enchantment of the world.

\textsuperscript{48} To be sure, Habermas realizes that such an approach presupposes certain political forms of association that guarantee the possibility of critique and emancipation. By thematising communicative action in the elaboration of the law, he crystallizes the alliance between critical theory and liberal democracy that would make him known, at least in Germany, as the great exponent of political liberalism (Bronner, 1994, p. 284). To many, he fundamentally betrayed the Marxian driving force of the origins of critical theory. For Habermas, however, he is attempting to recapture what for him is the ethos of the Enlightenment. For that reason, he is unrepentant in what for him is the imperative not to make any concessions to either absolutism (what had become of critical theory after World War II) or relativism (post-modernism).
its capacity as a coercive instrument must be able to hold society together by enforcing laws, while the condition for the possibility of its coercive application is that it is valid (Rasmussen, 1996, p. 28). And put simply, in order to be valid, the law must derive its legitimacy from those to whom it is applied – “communicatively acting subjects, i.e., through the acceptability of validity claims” (1996, p. 110). As such, the law becomes the institutionalized domain of political- and will-formation.

In the dominant liberal view, the appropriate sphere of legal regulation is limited to private autonomy, meaning that it concerns itself only with private rights, which, for Habermas, attributes an exceedingly subjective character to rights. It presupposes that attributing autonomy to individuals is tantamount to guaranteeing only subjective rights – i.e., the classical rights to “life, liberty and property enshrined in ‘human rights’ and ‘an anonymous rule of law’ ” (Habermas, 1996, p. 141). According to Habermas, this view fails to embody other forms of autonomy, namely the political autonomy of citizens that derives from the democratic principle of popular sovereignty. It presupposes that public rights (rights to political participation) derive from basic or classical rights and liberties (human rights). By doing so, it concerns itself only with private autonomy, and democratic self-legislation finds itself in competition with human rights. This competitive dynamic, Habermas explains, “loses sight of the internal connection between private and civic autonomy, and thus loses sight of the democratic meaning of a legal community’s self-organisation” (Habermas, 1996, p. 491; as quoted in Rasmussen, 1996, p. 41), meaning that the dominant liberal model does not consider the subjects of law. That is, it leaves no room for enfranchised (public) citizens to exercise their public autonomy in reaching an understanding of their life in common (Rasmussen, 1996, pp. 39-42).
Within this logic, Habermas explains, modern law

…presents a Janus-face to its addressees: It leaves it up to them which of two possible approaches they want to take to the law. They can either consider legal norms merely as commands, in the sense of factual constraints on their personal scope for action, and take a strategic approach to the calculable consequences of possible rule violations; or they can take a performative attitude in which they view norms as valid precepts and comply ‘out of respect for the law.’ A legal norm has validity whenever the state guarantees two things at once: On the one hand, the state ensures average compliance, compelled by sanctions if necessary; on the other hand, it guarantees the institutional preconditions for the legitimate genesis of the norm itself, so that it is always at least possible to comply out of respect for the law (Jürgen Habermas 1996, p. 136).

This is a crucial point: In order for citizens to accept the law as valid, they must be able to understand themselves as authors of the law to which they are also subject as addressees. In order to be both authors and addressees – that is, in order to legally institutionalize collectively constituted norms – citizens participate in the process of the production of law as autonomous legal persons, who appear in the dual form of private and public autonomy (Rasmussen, 1996, pp. 28-39). To be both authors and addresses, we cannot draw legitimacy from moral self-determination (according to which each person obeys only those norms that she considers binding to her own impartial judgement), but from the self-determination of citizens:

The exercise of legal autonomy divides into the public use of communicative liberties and the private use of individual liberties. This differentiation is explained by the positivity of a law that stems from the collectively binding decisions of lawmaking (and law-applying) agencies. Hence conceptually it requires at least a provisional separation between authors who make (and apply) valid law and addresses who are subject to law (Jürgen Habermas 1996, p. 139).

The very forms of communication that make it possible to make valid claims require

…the creation of the status of possible legal persons, i.e., of persons who belong to a voluntary association of bearers of actionable individual rights. Without this guarantee of private autonomy, something like positive law cannot exist at all.
Consequently, without classical rights that secure the private autonomy of legal persons, there is also no medium for legally institutionalizing those conditions under which citizens can first make use of their civic autonomy (Jürgen Habermas 1996, p. 142).

This means that the establishment of laws, or more broadly norms, implies the guarantee of individual liberties – basic rights – which are implicit in every democratic legal-political order. This does not mean, however, that human rights take precedence or are originary. The specific content of these rights becomes legitimate only as a product of deliberative political processes. Put another way, rights must be completed through communicative and participatory processes. This way, as Rasmussen explains, “the substance of human rights is written into the very discursive shape of the process of reaching an understanding which derives autonomy intersubjectively” (Rasmussen, 1996, p. 29). Private and public autonomy are “co-original” (Habermas, 1996).

Hence the universal right to equal liberties (conceived as human rights) allows the undertaking of the establishment of positive law (political rights), not because it precedes the process of lawmaking, but because it is written into the very discursive process of lawmaking – i.e., the deliberative process of political opinion- and will-formation to achieve collectively binding decisions in the medium of law. Without it, there can be no unfettered political public sphere; that is, there can be no communication community. Yet while the discourse principle presupposes such a community, it is not a precondition to—nor does it ground—political participation because it remains indeterminate until it is tested, indeed completed, through deliberation. Rather than ascribing a greater role to agency, where individuals use their communicative liberties to enter into a contract with a view to pursuing their own values and interests, the deliberative paradigm is constitutive of an intersubjectively-exercised civic autonomy wherein citizens use their
communicative liberties for the purpose of the public use of reason, meaning with an orientation towards the common.
CHAPTER 5:
METHODS

To make progress in our job, we need to give full and comparative attention to the not-yets, the didn’t-quite-make-it, the not quite respectable, the unremarked, and the openly "anti" goings-on in our society.

– Everett Cherrington Hughes, 1984, p. 53

A. INTRODUCTION

This chapter describes the methods I employ to address the research questions, as well as the rationale for selecting those methods. The primary purposes of this inquiry are three-fold:

1. Descriptive: To describe the views of members of society on the justifiability of using restrictive measures to achieve public health goals;

2. Analytic: To analyze the use of restrictive measures at the intersection of public health policy, human rights norms and ethics;

3. Normative: To situate public health ethics within a Habermasian framework of communicative ethics that can serve as the basis of justification for the legitimate use of restrictive measures.

B. CASE STUDY DESIGN

My motivation for choosing a single case study design is that the 2003 SARS outbreak is a unique case that presents a unique opportunity to explore the many questions and issues it raised. As I discussed, when public health decision-makers implemented a system of quarantine at the dawn of the SARS outbreak in Toronto, it raised difficult (legal, political, ethical, moral, and philosophical) questions about the legitimacy and acceptability of using restrictive measures in an era of human rights. More generally, it revealed the vulnerabilities and weaknesses of our public health system that could hardly, at the time, withstand the extraordinary pressures levied against it during the 2003 SARS
outbreak. Yet as this crisis illustrated, public health plays an integral role in the control of communicable diseases. SARS thus represents a unique opportunity to explore the concept of quarantine in modern society, the legitimate exercise of public health powers in an era of human rights, and the role and nature of public health.

There are several reasons why a case study is an appropriate design for the purposes of this inquiry. Case studies are a structured yet flexible approach that are used to describe individuals, institutions, actions, etc. (Lincoln and Guba, 1985, 2000; Yin, 1994). As Stake points out, a “case study is not a methodological choice, but a choice of what is to be studied” (2000, p. 435). In his description of the different types of case studies, he explains that the choice of which case to study depends on the purpose of the study. In the context of this inquiry, the 2003 SARS outbreak is used as an instrumental case study (Stake, p. 437). Contrary to an intrinsic case study that focuses on the study of the case itself, an instrumental case study serves as both an anchor and vehicle for exploring broader questions:

I call it instrumental case study if a particular case is examined mainly to provide insight into an issue or to redraw a generalization. The case is of secondary interest, it plays a supportive role, and it facilitates our understanding of something else (Stake, 2000], p. 437).

That is, rather than having an intrinsic interest in the case itself, I am interested in both the singularity of the case and how it operates within its multiple contexts. First, it allows me to explore lay and expert perspectives that are specific to their experiences, and to gather views from a retrospective and point of analysis informed by people who were involved and/or affected by the SARS outbreak in Canada. Further, it allows for an in-depth and nuanced analysis of the broader processes and forces surrounding the SARS outbreak, which also means that the empirical findings of this inquiry would be relevant
in the context of other communicable disease outbreaks and could contribute to the preparedness and management of future outbreaks.

An instrumental case study design is consistent with critical theory-informed qualitative research that seeks to understand and change the broader social context. But more than that, it facilitates the interpretive process by bringing “the concrete, the parts, the particular into focus, in a manner that grounds them contextually in a larger understanding of the social forces, the whole, the abstract (the general)” (Kincheloe and McLaren, 2000, p. 287). Ultimately, an instrumental case study design is used with the aim of giving normative issues a particular context that shapes how we think about them, and which provides empirical insights that can advance our understanding of substantive issues related to the legitimate use of restrictive measures. It can also surface unexamined assumptions about the role and place of public health in modern society.

C. METHODS USED
In this section, I will describe the research methods used to gather the views of members of society in relation to the research questions. I will describe the design (sampling and recruitment), data collection, data management, and data analysis.

1. Sampling and Recruitment

1a. Sampling
The study was largely undertaken in the Greater Toronto Area (GTA), a large, multicultural urban centre that was significantly and widely impacted by the SARS outbreak. Other Canadian cities were included, namely Vancouver, Edmonton, Ottawa and Montreal, in order to collect the views of those who were either directly or indirectly affected by the SARS outbreak outside of the GTA. In an effort to gather multiple views
and perspectives, I conducted qualitative personal interviews (by telephone or face-to-face) with the following five groups: Health care providers, members of the public, public health officials, regulators of health care provider colleges, and spiritual leaders. I targeted these participant groups in order to capture diverse perspectives on the justifiability of using restrictive measures during communicable disease outbreaks. All interviews were held between October 2004 and June 2005.

The final list of interviewees – obtained via purposive sampling, snowball sampling, and theoretical sampling – consisted of 67 participants from the following constituencies:

- Twenty-six health care providers: Thirteen nurses, seven physicians, six other health care providers (three social workers, one paramedic, one radiation technologist, one respiratory therapist).
- Sixteen members of the public, half of whom were quarantined.
- Fourteen spiritual leaders: Eight Christian participants from five denominations (Baptist, Catholic, Lutheran, Protestant and United Church), two Jewish participants (orthodox rabbis), two Buddhist participants (one Thai monk and one Buddhist academic reverend), one Muslim participant, and one Punjabi Sikh participant.
- Six public health officials.
- Six regulators of health care provider colleges.

To be eligible for the study, participants had to be able to communicate in English, identify with one of the five targeted constituencies, and have the capacity to provide informed consent.

1b. Recruitment

Potential participants were recruited by way of several channels. All participants were recruited via advertising in the Metro Toronto newspaper (a free daily newspaper distributed primarily to Toronto-area commuters on public transit; see Appendix 1). Health care providers were recruited via advertising in the Hospital News (Canada’s
health care newspaper, published monthly and made available in distribution racks placed in high traffic areas in hospitals and related institutions across the country, and also available by subscription; see Appendix 2). Spiritual leaders were recruited according to their religious/spiritual/community affiliation, with particular attention paid to inviting all major groups in Canada.

Participants responding to newspaper ads contacted me either by telephone or email. I answered any questions and determined eligibility for the study. In all other cases, I approached potential participants either by telephone or by email to formally invite them in the study (Appendices 3-6). Following initial contact, I followed up twice with those who did not respond. All participants provided informed consent (either in writing or verbally) in advance of their participation (Appendix 7). Before obtaining consent, I reviewed the purpose of the study, potential harms and benefits and confidentiality considerations, and reminded participants that they were free to withdraw from the study at any time or refuse to answer any question.

2. Data Collection

Data was collected through in-depth, semi-structured interviews using an interview guide (Appendix 8) that was first developed by identifying domains of inquiry from a literature review, as well as by way of discussions among the research team (involved in the larger study). By using open-ended questions, I sought to capture participants’ views and experiences without imposing any a priori categories that could potentially narrow the breadth of inquiry. Broadly speaking, participants were asked to share their views on the use of restrictive measures during the SARS outbreak and/or communicable disease outbreaks in general, whether and when they would support the implementation of a
quarantine system, what was of concern to them during an outbreak, and how they felt about the use of restrictive surveillance measures (such as electronic bracelets or cameras in the home). After participants expressed their initial views, I probed for clarification and explored new themes as they arose.

Throughout the course of each interview, participants were encouraged to raise issues or describe experiences that were important to them and/or that I had not specifically addressed. As successive interviews revealed new themes, I modified my questions to allow for further exploration of these new ideas. Furthermore, I made decisions about data collection concurrently with data analysis as the study proceeded, and interviews were continued until saturation was reached; that is, until no new concepts emerged from successive interviews (Morse, 1995). I conducted interviews either in person or by telephone, each lasting between 40-75 minutes.

The use of multiple sources of data is a key aspect of a case study design. Data triangulation (the use of a variety of data sources in a study) is used to corroborate the empirical data in an effort to, as Yin explains, develop “converging lines of inquiry” (Yin, 2003, p. 98). To achieve this, I conducted interviews with key informants and members of the public.

3. Data Management

Data management consisted of (what I call) field notes and contact summaries. I drafted field notes to summarize conversations that were not recorded – conversations that often yielded rich data – at the conclusion of every interview. I also developed contact summaries (Miles and Huberman, 1994, pp. 51-54) for every participant. These summaries included the code I assigned to every participant in order to maintain
confidentiality, the date of the interview, the participant’s name and contact information, and any issues or concerns that arose. My field notes and the contact summaries allowed me to start thinking about the data by writing down overall impressions of the interviews and key emergent ideas. Both sources informed further data collection and analysis in the development of codes and categories derived from the transcribed text and, on a more practical level, helped me manage the growing body of data that I was acquiring as the study proceeded.

All interviews were either audio- or digitally-recorded and transcribed verbatim by two hired transcribers. I verified the accuracy of the transcriptions by reviewing and editing them. I also clarified any inaudible passages in the transcripts while listening to the audiotapes. Like the field notes and contact summaries, the verification of transcripts is also a ripe opportunity to begin doing a preliminary analysis.

4. Data Analysis

My general strategy for analyzing the data that I gathered was based on a hermeneutic process of data interpretation. Before discussing what it means in practical terms to analyze a case hermeneutically, it may be useful to briefly describe what such a strategy is not. In the matrix of qualitative inquiry strategies and methods of analyzing qualitative empirical data, perhaps the most common approach, and one that is contrary to a hermeneutically-informed analysis, is a grounded theory approach (Strauss and Corbin, 1990). This aims to discover data-induced hypotheses by identifying and developing concepts into categories that are ultimately linked into theoretical models. Thus theory has no role to play in data analysis, but instead emerges from the data. As Ryan and Bernard explain, it is “an iterative process by which the analyst becomes more and more
‘grounded’ in the data and develops increasingly richer concepts and models of how the phenomenon being studied really works” (2000, p. 783). This is conventionally represented by way of “concept maps” (Kearney et al., 1995; Miles and Huberman, 1994, pp. 134-137). Another common method of analysis is the realist approach, which seeks to draw out the “facts” that are (believed to be) nested in the data. It is based on the assumption that it is possible, even desirable, to access or discover some underlying reality “behind” the data; that is, to treat participants’ accounts as facts that represent a “true picture of reality” (Silverman, 1993, 2000), or as events that reveal an external reality. Put another way, the realist approach aims to theorize the world “in terms of the impact of (objective) social structures upon (subjective) dispositions” (Silverman, 2000, p. 824).

More recently, the narrative approach (Holstein and Gubrium, 1995, 1997), inspired by post-modern thought, has been offered as an alternative path to data analysis. In line with Richardson’s premise that “participation in a culture includes participation in the narratives of that culture, a general understanding of the stock of meanings and their relationships to each other” (Richardson, 1990, p. 24), the narrative approach treats interviews as a form of narration and is centrally concerned with participants’ “cultural stories” or “personal tales” (Silverman, 2000, p. 824). Rather than being viewed as giving direct access to an underlying reality or to experience itself, interview data is treated “as actively constructed narratives involving activities that themselves demand analysis,” and as such, allowing for the possibility that people do not necessarily attach single meanings to their experiences but multiple meanings (Silverman, 2000, p. 824). By treating interviews as narratives, understandings of “reality” are viewed as an ongoing, ever-
changing process based on the perspectives of participants and the context from which these perspectives are drawn.

The post-modern understanding of, and approach to, interview data and data analysis share some similarities with a hermeneutic understanding in that they both focus on the content and the context of what participants are saying. In contrast to the decontextualisation of data sought by many conventional methods of analysis, post-modern and hermeneutic analytical approaches think about what participants’ accounts mean in relation to the broader context within which these narratives or conversations take place. They focus attention not only on how people see things, but on how, why, and in what context people do things. They also share the common view that there can be multiple legitimate meanings.

Yet while the narrative approach aims to structure meaning through narratives, and while other methods of analysis aim to, for example, categorise or condense the meaning of what has been said, a hermeneutic process aims to interpret meaning (Kvale, 1996, p. 187). While analysis and interpretation is often used interchangeably in qualitative research, a hermeneutic process goes beyond analyzing, or interpreting, the apparent meanings of a text. It seeks a more deliberative and deeper interpretation of texts (Kvale, 1996, p. 193), with the aim of recontextualising what is said within a broader frame of reference, either within a conceptual or theoretical context. Kvale explains the relevance of hermeneutics to interview research:

Hermeneutics is doubly relevant to interview research. Because the interview, like the hermeneutic principles of interpretation of texts, is a conversation about the lived world, with the oral discourse transformed into texts to be interpreted, a hermeneutic approach is relevant to interview research, first by elucidating the dialogue producing the interview texts to be interpreted, and then by clarifying the
subsequent process of interpreting the interview texts produced, which may again be conceived as a dialogue or a conversation with the text (Kvale, 1996, p. 46).

In practical terms, I analyzed the data that I gathered according to six analytic tactics inspired by analyses of hermeneutic interpretation (see for example, Radnitzky, 1970). Broadly speaking, these tactics can be understood as methodological steps that represent, not a series of discrete steps that follow a linear progression, but a dialectical mode of analysis insofar as they constantly act upon each other to maintain a dynamic process of analysis and ultimately, knowledge production. This way, it is possible to capture the complex intersections of overlapping and often conflicting conceptual categories.

The first step is the constant back-and-forth process between the parts and the whole, a movement inherent in the hermeneutical circle. Parts of a text (or transcript) are interpreted in relation to the whole text, and the whole text in relation to the parts. Using the whole text as a starting point, and based on a general understanding of its content, its parts are interpreted and the interpretations that stems from it are related to the totality. This in turn prompts new interpretations of the whole text, which are again related to the different parts of the text, and so on. As such, I began my analysis of a transcript by reading it a few times to get a general sense of its content. Following that first reading, I returned to certain themes or expressions in order to shed light on their meaning and, out of these interpretations, generated a new collective meaning. This in turn suffused a new meaning to the different themes and concepts I had identified in light of the deepened understanding of the text, and so on. For every transcript, I went through multiple iterative cycles (circular movement of analysis) of data interpretation. I identified
emergent patterns and clustered and partitioned themes, moving back and forth between patterns and themes in order to understand the meaning of one in relation to the other.

This tactic is analogous to what Gubrium and Holstein call “analytic bracketing” (Gubrium and Holstein, 1998), a process of analysis that entails focusing on a particular issue or situation, while temporarily deferring – bracketing – the analysis of other issues with the aim of returning to the interview and focusing on other issues, as well as to extend and deepen the meaning of the themes already identified. Rather than analyze each interview line-by-line or under the rubric of each question, as is the case in more traditional methods of analysis such as content analysis, the back and forth process allows for an analysis of the interview in parts (focusing on certain particular issues), and in its coherence and diversity (relating the meaning of these issues to the collective meaning).

The second tactic posits that the circularity of interpretation allows for the surfacing of contradictions, inconsistencies, or paradoxes in order to bring to light implicit assumptions and what they exclude. In my analysis, I noted contradictions and worked through competing explanations within and across transcripts in order to give meaning to what would otherwise be an inchoate string of views and experiences, while continuing to make explicit contradictions or points of contention. In this way, the process of interpretation focuses on both what is said and what is not said.

The third tactic is to “test” the different interpretations of the parts against the collective meaning of the text, as well as against other texts by the same author. Practically speaking, this entailed making contrasts and comparisons between interpretations of parts of an interview and the global meaning of individual interviews, and doing the same between interviews. If there was an incongruity between my
interpretation of the parts and the global meaning of the individual interview, I followed up with the participant to seek further clarification on their statements or views.

The fourth tactic is the autonomy of the text, implying that the text or themes within a text should be understood on the basis of its own frame of reference, that is, to seek an understanding of what the text conveys about a theme. For analysing interviews, this meant that I interpreted the content of an interview based upon what I knew of the participant’s circumstances (lifeworld) with respect to their experience during SARS (e.g. whether they were quarantined or not) in order to garner an understanding of the autonomous meaning of individual accounts.

The fifth tactic pertains to knowledge about the theme itself, allowing for the possibility of going beyond what is directly said and recontextualising it in a specific conceptual or theoretical context (“to work out structures and relations of meaning not immediately apparent in a text” [Kvale, 1996, p. 201]). An integral level of analysis of the interview process and this inquiry in general was to gain an extensive knowledge of the case in focus and the issues it raised, a step that preceded and guided the conduct of the interview itself. From a hermeneutic standpoint, this is especially important in order to discern differentiations, distinctions and nuances of meanings within and between interviews, as well as the different contexts into which these meanings could enter.

The sixth tactic posits that a text presupposes assumptions of meaning and structure (given that it is set within the broader socio-economic and political contexts within which it was written). Likewise, interpretations emerging from the hermeneutic process are necessarily embedded within the social world and cannot be conceptualized (and cannot actually make sense) outside of it. What matters is that the interpreter of a
text recognizes and brings these presuppositions into relief so that she can begin to understand the limitations of her context and how it may orient her interpretations, or how it permits the dialogical transformation of presuppositions. In practice, I grappled with, examined, and made explicit the theoretical commitments or pre-conceived notions that I brought into the interview process and subsequent interpretation of it. This was done in order to take into account the role that I played in orienting the interview by how I formulated my questions, and by how it influenced my interpretation of the interviews. It is important to note here that this is not necessarily analogous to an interviewer who asks leading questions that predetermines the answers. Instead, in a hermeneutic process of interpretation, the interviewer is a co-creator of the interview that she interprets insofar as the interview itself emerges from the same process as its interpretation, and her questions codetermines, rather than predetermines, what meanings will be found.

The seventh tactic asserts that the process of interpretation requires creativity and insight, for the interpretation goes beyond what is apparent in the text, or what is directly said, by constructing new and deeper meanings and conceiving of different structures or developing relations in the text. Correspondingly, I identified thematic categories and recurring patterns, negotiated their relationships in order to refine and expand interpretations and reach further levels of abstraction across the interviews, and recast my interpretations within a broader context.

D. ANALYTIC RIGOUR

Although a hermeneutic mode of understanding allows for a plurality of interpretations, this does not mean, as Ricoeur argues (1971), that all interpretations are equal or legitimate. Kvale discusses the validation of multiple interpretations, and more generally
critical qualitative research, in three ways: Checking, questions and theorizing. First, 
checking is a reflexive process that entails critically appraising one’s own findings, 
building-in controls to offset partial or biased understandings (in the sense of pre-
understandings) that could prevent a thorough analysis or reasoned judgement, and 
making explicit the personal theoretical commitments and assumptions that one brings to 
the study. Miles and Huberman (1994) describe procedural tactics that can enhance the 
process of checking, tactics such as

...checking for representativeness and for researcher effects, triangulating, 
weighing the evidence, checking the meaning of outliers, using extreme cases, 
following up on surprises, looking for negative evidence, ruling out spurious 
relations, seeking feedback from participants and exploring competing 
explanations (Miles and Huberman, 1994, p. 263; quoted in Kvale, p. 242).

Runyan (1981) discusses more substantive tactics to negotiate the validity of 
multiple interpretations, including checking for empirical evidence for and against an 
interpretation, examining the theoretical coherence, and critically evaluating and 
comparing the relative plausibility of the different interpretations (Kvale, 1996, pp. 242-
243).

The second method of validation, questioning, involves asking different kinds of 
questions in order to focus attention on not just the whats - i.e., what is occurring, but 
also the whys and hows of the interview process and data - i.e., the contexts, particular 
situations, nuances and so on. The hermeneutic primacy of the question (recognizing that 
different questions lead to different meanings) demands not only that the interpreter 
makes explicit her assumptions that enter into the question, but also draws a distinction 
and makes explicit the purpose of the interpretation – e.g. Is the purpose of the 
interpretation to discern the participant’s intended meaning, or does it concern the
meaning the text has for the interpreter? More specifically, what is the purpose of analyzing a transcript: Is it to attain an understanding of the participant’s views and experiences during the SARS outbreak in terms of quarantine restrictions, or is it to develop, through the participant’s views on the use of restrictive measures during the outbreak, a broader interpretation of the justifiability of using restrictive measures to achieve public health goals?

Thirdly, theorizing requires that the researcher (interpreter) examines the theoretical questions inherent in the generation and interpretation of data. The aim and practice of interpreting human action (what others are saying, doing, and thinking) in order to generate knowledge, I believe, is necessarily framed in the context of theoretical concerns or beliefs, and therefore necessarily generates questions as to the nature of the investigation. Theorizing also requires presenting the explicit formulation of the research questions and the rationale for, and context of, interpretations to justify one’s perspectival interpretations. As Kvale explains:

> If the principle of a legitimate plurality of interpretations through interview analyses is accepted, it becomes meaningless to pose strict requirements of interpreter consensus. What then matters is to formulate explicitly the evidence and arguments that enter into an interpretation, so that the interpretation can be tested by other readers (Kvale, 1996, p. 211).

Because this inquiry challenges the privileging of positivistic science in public health, it seems a propos here to pre-empt (positivist) claims that critical qualitative research methods based on a case study design lacks rigour and does not generate sufficient data to yield scientific “generalizability,” or that findings are not “valid” or “reliable” (Thompson, 2005, p. 58; Yin, 2003, p. 10). It is important to underscore that dominant notions of generalizability and validity are based upon positivist
epistemological assumptions of truth and knowledge as absolute and objective referents –
standards of measurement that are neither legitimate nor relevant for qualitative inquiries.
The idea of an objective reality against which knowledge is to be measured is
incompatible with other forms of generalizability (analytic, inductive, etc.) or other
concepts of validity (pragmatic, communicative, etc.) that are relevant to qualitative
research. It is important therefore to conceptualise concepts of generalizability and
validity in ways appropriate to qualitative research or, more broadly-speaking, to
interpretive modes of inquiry (Morse, 2007; Kvale, 1995; Polkinghorne, 1983; Wilson,
1983).

For example, the nature of purposive sampling in qualitative research enables us
to evaluate the theoretical representiveness of participants to conduct an analysis or
develop a conceptual framework, not that is quantitatively or demographically
representative, but rather that is “representative for meaning” – i.e., that “represents the
phenomena” (Morse, 2007, p. 148). Generalizability here is thus conceptualized and
achieved through the development of meaning. Similarly, validity is not determined by
way of the “falsification” or “verification” of claims, which presupposes that knowledge
(and knowledge production) is “a mirror or reality” (Thompson, 2005, p. 51) or derives
from “uninterpreted, hard facts” (Bernstein, 1978, p. 111, emphasis mine). Rather,
validity or validation is, as Thompson puts it, “inherently interpretive,” and it is achieved
through defensible knowledge claims (Thompson, 2005, p. 52), which are themselves
constructed through dialogue. As Thompson explains, in this conception, “the ways in
which humans assign meaning is dependent on interpretation and negotiation. It is here
that dialogue becomes very important” (Thompson, 2005, p. 52). “Truth is constructed
through dialogue; valid knowledge claims emerge as conflicting interpretations and action possibilities are discussed and negotiated among members of a community” (Kvale, 1995, p. 23; as cited by Thompson, 2005, p. 52). In a hermeneutical approach that emphasises the contextuality of knowledge and the interpretive nature of knowledge production, there is an inherent tension between generalizability and validity with contextualization. However it is precisely this dialectical process – the question-answer dialectic in the process of interpretation and the particular-general dialectic in the movement of recontextualisation – that allows us to draw deepened and richer meanings and understandings. In this sense validity is communicative – which forms the basis of this inquiry.

Quite simply, as Morse aptly puts it: “If you have developed your concepts well, they should be recognizable in other places, in other groups, and in other situations” (Morse, 2007, p. 148). As Kvale states (1996, pp. 229-252), there are pragmatic approaches to validating interpretations that show that:

The complexities of validating qualitative research need not be due to an inherent weakness in qualitative methods, but may on the contrary rest on their extraordinary power to picture and to question the complexity of the social reality investigated (Kvale, p. 244).

I will attempt to show in the subsequent analysis that my research is directly applicable to the current debate on pandemic influenza preparedness and other newly emerging communicable diseases, such as XDR-TB. While the case in focus is the particular SARS experience in Toronto, discussions with participants revolved around communicable disease outbreaks in general. Furthermore, I conducted my research against the backdrop of the threat of an influenza pandemic, and this prospect (and the wide media coverage surrounding it) informed participants’ views. Moreover, many
participants drew on their past experiences during outbreaks of polio, tuberculosis, and malaria. As such, I believe that this inquiry would hold for other scenarios, thus making its findings both valid and meaningful.

E. Ethics Review

Institutional ethics approval was received from the Health Sciences I Research Ethics Board at the University of Toronto (Appendix 9).
CHAPTER 6:
FINDINGS

A. INTRODUCTION
In this chapter, I will present the results of an analysis that I conducted based upon data from the 67 interviews. I identified six main themes that characterize views from members of the public, health care providers, public health officials, and regulators of health care colleges regarding the use and justifiability of restrictive measures. These themes revolve around the following concepts: 1) common good, 2) types of quarantine, 3) compliance, 4) reciprocity, 5) uncertainty, and 6) communication. Collectively, these six themes can best be understood in terms of a set of interrelated concepts that provide a justificatory framework empirically-based grounding public health action. This framework serves to legitimize and justify, from a deliberative standpoint, the implementation and enforcement of quarantine to achieve public health goals.

B. COMMON GOOD
Common good encompasses three factors: 1) the duty to comply; 2) the responsibility to the community; and 3) the role and respect of individual rights.

1. The Duty to Comply
Virtually all participants felt that the use of quarantine during communicable disease outbreaks is justified through appeal to the common good. Moreover, there was a general agreement that not only is quarantine justified in the context of communicable disease outbreaks, but more pointedly, it is a (civic) duty or an obligation to adhere to an order of quarantine in virtue of the common good.
As such, it was felt that it is imperative that individual follow the prescribed guidelines once quarantine is in effect. One physician encapsulated a preponderant view when he said:

> People have a duty to comply. It’s part and parcel of following the rules of society – in the same way that I have an obligation not to drive through red lights and not to speed on the highway and not to do things that put other people at risk, even if I have some good reason why I need to do that.

Others drew similar analogies between the duty to comply with quarantine and the civic responsibility to obey laws or rules of society:

> Following the rules of society means that there are some things that I do even though they are inconvenient or disruptive [to me] because it’s necessary to maintain order.

Or, as another participant said:

> If there needs to be – if everybody is required to be quarantined if they are deemed infectious, just like if everybody is required to come for an immunization and so on – by all means, let us comply with those in order that we maintain order and the maximum health for every individual in our society.

On the other hand, one public health official, who did not experience SARS first-hand, argued that treating quarantine as a civic duty is tied into its acceptance. In other words, he questioned whether someone could understand quarantine to be a civic duty if they did not support its actual implementation:

> I think there’s a civic duty here but you’ve also got to be convinced that what is being done is the correct thing. And I think that’s where I would have struggled had I been visiting my grandmother in a Toronto hospital somewhere, and then as a result of that been placed in quarantine. Knowing what I do as – I’m trained as a virologist – know what I do, and my feeling is that quarantine went out decades ago as a control measure of disease – I would have been, I would have really struggled with what was my civic duty to conform to a practice that I did not really subscribe to.

2. The Responsibility to the Community

Just as laws serve to establish and maintain a social order in the public interest, most thought that the duty to comply with quarantine is for the sake of the common good or, as one participant put it, compliance is our responsibility to the greater community. In the
course of describing how they feel about quarantine, a great deal of participants referred to its use as one that serves the “greater good,” “protects the public,” and “benefits society.”

A member of the public, who was herself in home quarantine during the SARS outbreak in Toronto, captured this thought, stating that:

First there is individual liberty and then there is the common good, or the protection of others. In the case of a disease outbreak, I think that individual liberty has to be sacrificed for the common good of society and the health of society as a whole.

The idea that individuals ought to accept sacrifices for a common good was shared by nearly all the participants interviewed. One physician stated:

I think in our society, at least in Canadian society, we realize and accept that in some situations the rights of the many outweigh the rights of the few.

Another member of the public concurred:

The quarantining or isolation of people for the protection of other people is a necessary piece of our society…. There are circumstances in which we need to impose restrictions on people for the benefit of society as a whole.

For many spiritual leaders, the use and respect of quarantine is not only justified in virtue of the common good but also, more broadly and positively, there is a “duty to promote” the common good. Viewed this way, they felt that the use of quarantine satisfies the goals of social justice (or a just society), rendering it an essential part of the common good (and in one instance, quarantine was thought to be a common good) and a healthy community:

We’re called to be good citizens, as well as people of faith – to be salt and light, and part of being “salt” is to work for the eradication of poverty and for the health and dignity of all. Quarantine would be part of that.

The willingness of participants to support efforts to control communicable disease outbreaks, coupled with the view that such efforts are not only justified for the sake of the
common good but also serve to promote it, may explain why very few participants
questioned the use of quarantine. Indeed, the large majority of those interviewed
expressed the view that it is a necessary--and remains a valid--tool for communicable
disease control. One participant concluded that:

I don’t think that there’s any question that certain restrictive measures, such as quarantine, must be
taken [during communicable disease outbreaks].

Reflecting on the decision to invoke quarantine during the SARS outbreak in
Toronto, a member of the public agreed:

I don’t think that there were other options. And I’m not exactly certain whether I want to say that
quarantine should be an absolutely last measure…. But I think that certainly it’s a valid tool that
public health has at its disposal.

3. The Role and Respect of Individual Rights

3a. Justifiable Infringement of Individual Rights

Most participants linked the notion of the common good with the notion of individual
rights when considering the use of quarantine; that is, most of them thought of the
common good and individual rights as inextricably tied to one another insofar as one
always has to be thought about against the other. Yet almost invariably, it was thought
that the common good justifiably prevailed over rights in public health emergencies.

Many participants were in fact categorical about the need to use restrictive measures to
protect the public health in the context of communicable disease outbreaks, in spite of the
inescapable infringement of individual rights.

A nurse, who worked in a SARS ward, stated categorically:

I see it as black and white. I think it’s an instance where personal freedom just needs to go on the
back burner for a little bit.

A spiritual leader concurred:
As an individual, I have to give up my individual rights and my autonomy for the better of the society.

Another spiritual leader, who in turn gave positive weight to individual rights, stating that the question of how to resolve the tension between individual rights and the rights of the collective is “situational,” also concluded that in times of communicable disease outbreaks, the common good takes unequivocal precedence. Invoking a liberal argument to justify the use of restrictive measures, he pondered:

There always comes a time when the rights of the individual versus the rights of the collective come into play – this is not a particularly religious argument; it’s more philosophical than it is a faith argument. I’m all for the rights of the individual – that every individual has dignity and needs to be treated with justice and fairness and no discrimination. However, I don’t believe that I have the right – by demanding my rights – to foist harm on somebody else. The rights of the individual are limited by the rights of others. Of course, the dilemma is when my individual rights conflict with the rights of the collective; how we resolve that becomes situational. But on the topic of infectious diseases, it seems to me that the rights of the collective, or of society, supersede the rights of the individual.

The fact that practically everyone agreed with him does not mean, however, that participants were not concerned about the rights of individuals in the context of communicable disease control.

3b. Balancing the Common Good and Individual Rights

Very few participants thought that the notion and respect of individual rights during communicable disease outbreaks ought to be dismissed or made irrelevant while committing to efforts promoting the common good. While the majority of participants disputed neither the use of quarantine during communicable disease outbreaks nor the decision to implement it during the SARS outbreak, there was a broader spectrum of views regarding the place that ought to be accorded to individual rights during communicable disease outbreaks.
As one nurse put it, the role and place of individual rights in these circumstances “depends on which moral side of the coin you take.” Suggesting that some people did not adhere to quarantine because it was their right not to, he continued somewhat bewildered:

During SARS, I found it hard to believe that some people were not adhering to their quarantine and were very public about that. Again, I think it gets back to your interpretation of rights. These individuals felt that their rights were being violated and as a result of that, they weren’t going to adhere to quarantine. For me, if I felt confident that somehow I was at risk and perhaps going to put other people at risk, I think I do have an obligation or a duty to respect the greater community.

So while a great deal of participants thought that the demands of communicable disease control justify putting individual rights on the “back burner,” other participants felt that it is crucial to balance individual rights with the collective interest even under circumstances that compel immediate action, especially with respect to those who place a higher value on rights and felt that their rights were violated during the SARS outbreak.

One nurse raised the question of how to ensure that the rights of individuals are maintained amid conflicting needs and rights during emergencies, thus pointing out the importance of balancing rights during quarantine. He wondered:

Who is responsible for ensuring that the rights of individuals are maintained? … And how do you balance rights within quarantine? I think that’s where some of the ethical conflicts arise: The rights of the health care provider versus the rights of the patient versus the rights of the organization versus the rights of the community…. It is of utmost importance to balance these rights.

One participant echoed this thought, stating bluntly:

Everyone knows the problem: You have to balance the good of the whole against the good of the individual.

3c. Justifiable Infringement on Some Rights

The notion that individual right remains a valid concept in the context of communicable disease control led to another interesting point. Many participants cautioned that only certain rights could be legitimately limited, meaning that quarantine, as one physician put
it, is only justifiable “as long as certain basic human rights are preserved.” Similarly, a health care provider underscored that people

…definitely have a right, for sure; they have a right for example to not be quarantined. However, if it’s a medical illness that could: One, cause them death or serious harm; and two, cause others serious harm and death, then I feel that those rights need to be compromised – if it comes to an illness that calls for control measures in order to avoid severe medical problems or death. Apart from that, I think peoples’ rights have to be carefully monitored and protected, and it is extremely serious if they’re contravened.

When asked if he was concerned about the rights of individuals during a public health emergency, a member of the public answered emphatically, “No, one hundred percent not” for in his view those in quarantine “still have their rights.” In other words, even though imposing quarantine is “a breach of some civil rights, or human rights,” it does not change the nature of these rights or cancel them out altogether. Thus while quarantine infringed upon some rights, what mattered is that the existence or the bearing of rights was not in question. For those who emphasized this view, there was a qualitative difference between what it means to compromise some rights, which was the case during the SARS outbreak, and what it means to repudiate rights altogether, which is the case under many authoritarian regimes.

Regardless of the views that participants held on the place accorded to individual rights in the context of communicable disease control, the large majority of participants, even those who were not particularly concerned about individual rights, understood the use of quarantine as being both limited in time and in scope precisely out of concern for individual human rights. Many participants did not feel that quarantine is controversial or particularly problematic because, as one nurse put it:

We’re not talking about permanent quarantine; we’re talking about a limited amount of time.
Emphasizing the idea that certain rights must be preserved, another participant explained:

As long as certain basic human rights are preserved, and there is an understanding that these are temporary measures, in our society we realize and accept that in some situations the rights of the many outweigh the rights of the few.

In turn, a public health official also emphasized the idea that quarantine should not—and, most importantly in his view, does not--violate all or most rights. He stated somewhat authoritatively:

You would obviously be abrogating the rights of those people in that small village to travel. But you would not be abrogating their rights to get medical treatment or to get access to vaccines or to have food on the table or to know what was going on or to know why they were placed under a quarantine order. You’re limiting their right to travel freely, and that’s only one right out of a whole array of rights.

Thus while some participants emphasized that only certain rights could be legitimately limited, others emphasized that quarantine only infringes upon certain rights anyway.

3d. Building in Safeguards

Closely related to the idea that only certain rights can be legitimately limited is the idea that safeguards must be established for those who are affected by quarantine measures, precisely in order to protect their rights.

One public health official maintained:

Of course there is always an appeal mechanism to individuals. It would be really interesting to research how many have successfully appealed [public health mandatory] orders. Very few people bother. Most people are intimidated so they just follow what they’re told. It would be crucial during an outbreak, where mandatory quarantine orders are being handed out, to strengthen appeal mechanisms.

C. PERCEPTIONS OF EFFECTIVENESS

As reported above, the use of quarantine was for the most part uncontested. Where there was wide disagreement, however, was regarding the effectiveness and appropriate use of
various types of quarantine with respect to their restrictiveness. Participants held dramatically different views on the appropriateness and effectiveness of different models of quarantine (work, home, institution-based, designated institutions). Recognizing that it is not a monolithic concept, most participants distinguished between the various definitions and applications of quarantine, often questioning whether the different models implemented during the SARS outbreak were either appropriate or effective. Here virtually everyone supported the use of quarantine, though very few agreed with the actual models put in place during the SARS outbreak.

While most granted legitimacy to what they perceived to be the most effective intervention, which at times was understood to be the most restrictive intervention, many struggled between legitimizing an intervention based on its effectiveness while negotiating its ethicality based on its restrictiveness. Some thought that an intervention was legitimate regardless of its restrictiveness if it was deemed to be effective, while many thought that legitimacy was satisfied if the least restrictive measure possible was used. This led to a rich and at times paradoxical debate as to which system is best suited or most desirable to control the spread of communicable diseases.

1. Effectiveness

Prefacing his comment by underlining--and reinforcing the prevalent view--that the question is not whether restrictive measures must be taken, one public health official said that what is at issue is how to reconcile substantially divergent views on which quarantine measure to take:

It’s the extent to which [quarantine measures] are implemented, and just exactly what those measures are – that is where, I think, differences of professional opinion may lie.
However the differences of opinion regarding which and how to implement restrictive measures were not limited to “professional” opinions. Virtually all those interviewed expressed a view as to which type of quarantine they felt was either appropriate or effective.

1a. On Work Quarantine

A number of participants challenged the underlying logic of work quarantine, arguing that it is both ineffective and untenable. They wondered how quarantine can be just that – quarantine – when health care providers traveled from home to work. The very notion of work quarantine seemed to irk many people who argued that it is “completely ineffective” and “illogical.”

A hospital chaplain, who was herself on work quarantine, discussed the many challenges she faced during that time as she and others often made “compromises” to manage her everyday life, usually to do things, she argued, that are taken for granted, such as stopping at the gas station to fill up. Many others gave examples of daily activities they were not “allowed” to do but felt that they “had to” do in order to “get by.” In their view, this rendered their (work) quarantine ineffective and the general concept inoperative.

Echoing this view, one nurse explained that most people struggled with work quarantines, many of whom thought that those affected by SARS should have been able to stay home, instead of going to work:

There was a lot of debate on whether [work quarantine] was really quarantine. People were allowed to go to work, but they were quarantined while they were not at work. … But if they were exposed or in contact with patients with SARS, shouldn’t they just be at home? People really felt that if you were on quarantine, you should be at home and not be allowed to come in and care for people.
Another nurse reinforced this view, arguing that work quarantine was untenable in the light of the “casualization of the work force,” which has created the need for—and increased the number of—nurses holding multiple jobs over the last few years. This presented serious challenges to health care professionals working in more than one institution, especially when they found themselves on work quarantine in one of the institutions, inevitably causing tension in their other workplace(s).

Giving an example of situations in which health care providers worked in more than one institution, another nurse added:

There was a lot of discussion here about whether work quarantine is feasible because we had people that worked in other places as well as here. If there’s been exposure at another place but not here, what does that mean for us who work here? They shouldn’t have been allowed to work here or anywhere for that matter. I didn’t think work quarantine was really the right thing for some of our professionals. It caused a lot of anxiety and stress for all of us – for those that weren’t on work quarantine and for those that were on work quarantine.

Here she captured a prevalent theme, where individuals tried to “adapt” guidelines to circumvent or overcome the problems caused by work quarantine:

The guidelines were coming from public health so we were taking our direction from them, but we tried to work around them a little bit. So if somebody was on work quarantine, we tried to encourage them to stay at home and cover the units with other people that weren’t on quarantine. It helped reduce the stress of people who were really worried, especially those people that worked in four or five different places and two or three of them were heavy with SARS patients; they were worried about not only coming to work with our patients, but about themselves and their colleagues.

The general consensus thus appeared to be that the concept of work quarantine is a contradiction in terms. Most importantly, participants felt that it is difficult, if not impossible, to effectively implement such a system.

For one health care provider, the imposition of work quarantine raised more fundamental issues about the nature of the profession itself. He said:

I felt that the work quarantine was wrong. I really thought that if you were quarantined, you should have been quarantined at home and been compensated for being at home. When you sign up as a health care professional, you don’t sign up for this kind of intrusion into your private life. If it happens again, I think they’re going to have some big trouble. I think that hospital
administrations and EMS administrations and paramedics are going to have some real trouble because I think that staffs are not going to endure it again, that they’ll find other ways around it.

1b. On Home Quarantine

Similarly, many participants wondered whether home quarantine (requiring individuals to stay home voluntarily, for 10 days in the case of the SARS outbreak) was feasible or effective. A great number of participants strongly believed that home quarantine does not work, either because of logistic requirements or obstacles that it presents or because, many believed, individuals simply do not adhere to home quarantine. Other participants thought that, like work quarantine, home quarantine is not really quarantine at all and is itself a contradiction in terms. Participants by and large made the assumption that home quarantine is always voluntary. This is likely due to the fact that during the SARS outbreak, home quarantine orders were in fact voluntary in the sense that few, if any, enforcement measures were put in place.

One nurse addressed the matter of logistics, wondering how he could effectively quarantine himself from his family when living in a small apartment:

How would I quarantine myself from my own immediate family, just because of living space, living quarters? I mean, we don’t all live in four bedroom homes. I live in a 400 square foot apartment with another person. Should I stay on the balcony? It’s just not feasible.

Another participant, who also suggested that it would not be practical to be quarantined at home, wondered how the difficulties of caring for children would affect someone ordered into home quarantine:

Where do you go – you can’t really go home, can you? No. And what about women who are caring for children? I don’t know what you do then. What do you do with women who are single parents, who don’t have other resources?

A public health official raised similar issues, suggesting that it may in fact be more feasible to set up an institution-based quarantine:
We know from SARS that [voluntary quarantine] doesn’t work in many cases… It also posed a great dilemma within families, knowing that the children were on the other side of the wall, or supposed to be on the other side of the wall, where you wonder if it wouldn’t be better, in fact, to be completely removed from that situation and be in some institutional facility.

Arguing that people were not respecting home quarantine because it was too difficult for families to manage it, a public health nurse also wondered if an institution-based quarantine could provide another option for those who could not make it work at home. Recalling the responses she heard during the SARS outbreak, she said:

We did hear from families calling us back that it was really difficult to do [quarantine] at home and asked us how should we do it and what else can we do.

In addition to those logistical issues, and the perception that the obstacles they present make home quarantine ineffective or not feasible, many participants felt that home quarantine does not work simply because some people choose not to adhere to it. Indeed, many participants felt that others would not--or in the case of SARS, did not--comply with quarantine measures because, in their view, people invariably do not adhere to voluntary measures. (I will return to this point in the section on compliance.)

1c. On Institution-based Quarantine

As indicated above, some people suggested that an institution-based quarantine (requiring individuals to be quarantined in a designated place) could prove to be a viable option for some members of families looking for other ways to be in quarantine. Others suggested that it would be a more viable model in general, serving to overcome the problems inherent to the work and home-models of quarantine.

One nurse wondered:

What are we going to do in the hospital if this happens again? We talked about this. And we talked about people staying at the hospital, which was just insane – for single people, you can – I just can’t even imagine how that would unfold. It’d be crazy for anybody with kids or other responsibilities. But if you really want to take the whole notion of quarantine seriously, then if I’m a worker and I’ve been exposed and I have kids, I can’t go home to my kids. So, yes, we need to look at that – look at who’s going to feed us. Where are we going to eat? Where are we going to
sleep? We don’t have the facilities for that in hospitals right now, so where would we go? Would there be a designated residence for us?

Still others felt that an institution-based quarantine presented many more logistical obstacles than work or home quarantine, and more importantly that it raised deeply ethical issues that made it a “rather unappealing” model. Fundamentally different lines of argument in support of the institutionalization of quarantine were expressed by those who thought that it is a “necessary evil” to deal with non-compliance or to avoid the challenges inherent in the enforcement of voluntary quarantine. Here it is interesting to note the extent to which perceptions about effectiveness had a bearing on perceptions about ethicality. In other words, while some participants argued that a quarantine requiring institutionalization is deeply objectionable, others were willing to accept something so restrictive if they believed that it was effective. Because the discussion on an institution-based model of quarantine largely revolved around issues related to its restrictiveness and the ethical issues this raises, I will address it in the following section (on restrictiveness).

1d. On Designated Institutions

In addition to work, home, and institution-based models of quarantine, some participants wondered if it would not be better to design a model that would involve centralizing the care of SARS patients to a few institutions and, in this way, to limit both patients and health care providers to those designated institutions. Some participants also thought that it would be more effective to have designated institutions because it would allow health care providers to standardize procedures.

A nurse who worked as an administrator in a community hospital considered the advantages of such a model:
One of the things we talked a lot about was whether you should pool all those people together in one spot rather than having them spread throughout the city. I could see the pros and cons to that, but certainly that was one thing that we thought would have been beneficial in terms of making sure the standards were met and there could have been clearer direction in one facility. Public health and the ministry could have worked closely with one facility, which would have avoided this diversity that we had. We heard from our nurses, I worked at so and so and they’re doing this and I worked here and they were doing that and then I heard from others that they were doing this. So there was a lot of variation in what people were wearing, how they were wearing it, how they were caring for patients, etc. So having one or two places earmarked might have helped to standardize procedures. Most importantly, it would have meant that everyone working with SARS patients as well as probable cases, and the patients themselves, would have been placed in one institution.

She continued to talk about the disadvantages of such a model, highlighting the challenges around transferring patients to designated institutions, as well as the issues raised by imposing a much greater burden on some institutions and their staff. However she concluded that such a model would alleviate many of the problems, mostly of a logistical nature, inherent in other models of quarantine.

2. Restrictiveness

A regulator articulated the common view that the real concern lies in the application of quarantine – and not of its use per se – to emphasize that what is at issue is the restrictiveness of its application. He concluded that what “becomes a central issue” in decisions made about containment measures is “how you quarantine” (his emphasis) and not quarantine itself. Similarly, a physician commented on the polemic of how quarantine is put in effect. Noting that the scope of what quarantine means and entails is rather wide, he underscored that the kind of quarantine being ordered raises different ethical issues stemming primarily from the degree of its restrictiveness:

It depends on what sort of quarantine you’re ordering. If you’re ordering people to stay away from public places or their workplace and stay in their home, that’s a completely different quarantine than if you’re ordering a person to go to a specific place or institution and be more or less incarcerated there. There’s a big spectrum of what a quarantine order is – so certainly I think when you’re looking at the risk/benefit calculations…of quarantining someone in their home…the risks are not high. It’s somewhat inconvenient and there can be temporary economic losses that, depending on the situation, can be reimbursed. But when you’re talking about putting a whole bunch of people in a particular place where their rights and freedoms are being more infringed
upon [and] they're being put together with other people who are ill and they stand the risk, if they're not actually ill, of becoming ill--then there are certainly a lot more issues that have to be considered.

Other participants agreed that more restrictive measures, such as compulsory or an institution-based quarantine, or more restrictive surveillance measures such as electronic bracelets, raise fundamentally different issues than measures such as social distancing, restrictions on mobility, and home quarantine. Moreover, for many of the participants who talked about issues related to the restrictiveness of an intervention, different ethical issues were raised by different models of quarantine, with more restrictive models raising more issues. Participants questioned the ethicality of the measures themselves, which were thought to be largely determined by the degree of restrictiveness – *i.e.*, the greater the restriction, the more dubious its ethicality.

By factoring the restrictiveness of an intervention into its overall ethicality, a scale of appropriate or desirable models of quarantine took shape, ranging from the least restrictive measure to the most restrictive measure. Hence a voluntary quarantine was viewed by most participants as being more ethically acceptable than--and ought to be implemented before--more restrictive measures, *even as* they believed that it does not really work. For this reason, many participants felt that the least restrictive measure possible should be used to control an outbreak. In this way, they could be sure that measures taken during an outbreak would be--and should be in their view--used in proportion to the severity or risk of the disease.

One public health official stated:

*I think we have to be the least coercive as possible, so that we need to make sure that the measures are not extreme or are not more coercive than they need to be, and I think that we also need to be able to negotiate with people, to try to help them comply.*
A spiritual leader reinforced this view, arguing that interventions modeled according to the least restrictive measures possible are a way to respect individual rights. He explained:

To give due consideration to the reasonable rights of the individual, so that it’s not just some response out of some fear or scare – but that there is good evidence – given what we know about the disease, medically and scientifically – that the measures that are taken are reasonable so that the response is not – so that we’re not hitting a fly with a sledgehammer, but using a flyswatter – so that the remedies or the protective measures are appropriate to the situation.

In sum, there was very little consensus on what would be an ideal or viable quarantine. Perceptions of effectiveness among participants varied greatly, while many participants themselves seemed unsure as to which model would be best – at least in theory. In practice, however, the large majority were most willing to embrace the least restrictive measures possible, especially in regards to themselves.

In addition to conceptualizing the common good and discussing questions regarding the effectiveness and restrictiveness of coercive interventions, participants were concerned with the implementation and enforcement processes of quarantine. I will discuss these results in the next two sections, which revolved around issues of compliance and reciprocity.

D. COMPLIANCE

Issues related to the implementation of quarantine were largely framed as issues raised by the challenges surrounding the actual implementation of quarantine in order to bolster voluntary compliance (mechanisms for implementation), and the enforcement of quarantine to ensure compliance (justified coercion). There were two opposing views: 1) that compliance should be taken as a given, *i.e.*, it should be assumed that people will comply with a system based on voluntary compliance; and 2) that compulsory measures
had to be put in place in order to ensure compliance. Many participants, however, embraced both approaches, viewing it more as a sliding scale, ranging from voluntary compliance to justified coercion if and when necessary.

1. Mechanisms for Implementation

A large majority of participants questioned whether existing processes were adequate to support an effective quarantine, in turn arguing that there needs to be a more systematic mechanism to both implement and monitor it. One physician stated, “There wasn’t a well-used or well-known mechanism in place to implement quarantine. So certainly, had that mechanism been in place, it would have happened more quickly and easily and sooner.”

After acquiescing that it is appropriate to use quarantine measures during an outbreak, one regulator stressed the importance of “giving appropriate consideration ahead of time” to “the mechanisms that should be put into place in such circumstances.” Using the example of the application of protective measures such as the distribution of masks, he noted that during the SARS outbreak “there wasn’t really the time” nor any viable mechanisms in place “to learn how to use them.”

In turn, a public health official gave several examples to illustrate the impact of not having had – and the need for – mechanisms for the implementation of quarantine. However she cautioned: “There is fragmentation of public health thinking as relates to orders and guidelines,” rendering it difficult to implement measures “with any uniformity.” She ended her interview by emphasizing that “there should be much greater consistency.”
Many agreed with her that during the SARS outbreak there were at best insufficient, if not inconsistent, guidelines across institutions and communities. A member of the public observed that “it seemed as though quarantine orders were carried out on an ad hoc basis and most of the time nobody really knew how to actually implement quarantine – or what it meant to be in quarantine for that matter” (his emphasis).

In this same vein, a nurse recalled that many families called to complain that it was “really difficult to do this [home quarantine] and how should we do it.” She expressed her frustration over “the guidelines [that] were coming from public health that didn’t really guide us; no one was quite sure what to do with them, or what to do when they were just not doable,” especially with respect to home quarantine.

One regulator reinforced this view:

I think [home quarantine] is extremely difficult to enforce. I think that in most circumstances it does not work well because you’re asking people to adopt measures which are not part of their routine. To ask people within their own homes to start applying measures that they don’t fully understand and that they’ve never really applied in their lives, I think you’ve got to be realistic and no, I wouldn’t expect that there would be a high level of compliance with those measures in the home.

On this last point, many questioned whether compliance to quarantine was compromised when its measures were not feasible, while others asserted with greater certainty that compliance was indeed predicated on the feasibility of measures. As it turns out, very few people thought that measures were feasible, especially home and work quarantine, which, it is noteworthy, were the two models used during the SARS outbreak. As I discussed above, many people were concerned with the challenges associated with – and in many cases the infeasibility of – implementing a work or home quarantine effectively. For participants who talked about issues related to the implementation of
quarantine, there was a general consensus that more systematic mechanisms for implementation would further bolster voluntary quarantine and make it more effective.

2. Voluntary Compliance

The question of voluntary compliance proved to be a thorny issue. Consistent with the previously established premise that using the least restrictive means possible was preferable, most participants supported a voluntary quarantine. However many participants, especially members of the public, betrayed a sense of distrust for others and scepticism as to whether it could really work, all the while expressing an unwillingness to resort to more restrictive measures – at least, as far as they were concerned. To be sure, some remained steadfast in their conviction that quarantine ought to be always and only voluntary. One regulator stated:

I truly believe in the volunteer approach to things. At the time [of the SARS outbreak], there were a lot of discussions about whether quarantine should be voluntary or not. On one side we didn’t have enough army/police to enforce things, right? But I believe that the number of people that broke through quarantine are very few.... Overall I think the voluntary quarantine was an excellent idea. So I think that it just shows that voluntary is the way to go.

This view was not shared by many. While virtually all participants expressed a willingness to adhere to quarantine, as noted above, a great number of participants, especially members of the public, expressed concern that others would not voluntarily comply with any kind of measures (even if the least restrictive measures were used), especially in view of their perception that quarantine orders were not being respected during the SARS outbreak.

A spiritual leader who worked as a chaplain in a SARS-designated hospital in Toronto said:

It didn’t work with SARS…everybody thinks they’re the exception. A lot of people disregard voluntary quarantine. There’s always going to be some people who either don’t understand it or who don’t care and are going to break quarantine.
A nurse who was in charge of quarantining people in his program of study explained:

I think we have evidence of that [that voluntary quarantine does not work] obviously with SARS. I think it works to a certain extent; it works for certain people. If I were told that I had to go in quarantine, I know that I would follow what is dictated to me to the letter because I would be very concerned about the implications of not following that. I think for many people, including some people I know that I had to quarantine, there was a lot of resistance and I often wondered whether or not those people were actually going to leave work and follow the protocol, or if they were going to be back to work the next day. I know for a fact that many people did not honour my request [to go into quarantine].

Another nurse shared her experience:

Voluntary quarantine doesn’t work because we saw that it didn’t work. For most people, 90%, it probably does work, but there was 5-10% of the population – and we did see people here that we know – who did not obey their quarantine without any concern that they were breaking it.

A member of the public said:

I did not understand it as voluntary. It was mandatory. I was told I had to be quarantined. I was not given any choice. I was quarantined. But I know that other individuals didn’t see it that way. They did not honour their quarantine.

The perception that compliance was patchy at best led some participants to talk about issues related to the enforcement of quarantine.

3. Justified Coercion

The question of how to enforce quarantine, as well as what consequences should be applied to those who do not respect orders, provoked animated discussions. In fact it did so in light of the prevailing view that the enforcement of quarantine was much more problematic than any issues related to its implementation. As one spiritual leader put it, how to enforce quarantine raises “difficult questions that democratic societies do not know how to address.”

That more restrictive measures were largely viewed to be more problematic – and in most cases were deemed to be unethical – does not mean, however, that participants
regarded their use as unjustified in some circumstances. While some argued that a quarantine requiring institutionalization is deeply objectionable, others were willing to accept something so restrictive, and deemed it ethical, if they believed that it was effective. A few participants strongly argued for the implementation of more restrictive measures from the very outset of an outbreak. A member of the public stated categorically:

I didn’t think the whole idea of these voluntary quarantines that weren’t really being enforced or measured in any way was adequate. Voluntary quarantine is completely ineffective. I [am] a proponent of having more restrictive measures…such as a compulsory quarantine.

Another member of the public saw it as a necessary evil:

If people are failing to take steps that are decided are necessary for the health and the good of the community, then it does begin to seem reasonable [to take] steps like [forced confinement]. Certainly…a person [would be] doing a lot of harm by not adhering to more voluntary, less invasive, restrictive measures. So, if it turns out that that is a significant concern, then such measures would become a necessary evil.

Even those who found compulsory or coercive measures to be unacceptable, flirted with the idea that at times it may be necessary to turn to such measures – however regrettable it may be – out of concern that others would not comply. A member of the public wondered:

I’m not sure that there are other options that are possible. And I’m not exactly certain whether I want to say that coercive measures should be taken [against those who don’t comply], but it’s certainly something [the authority to mandate compliance] that public health has at its disposal. But it should be an absolutely last measure… I’m sure public health would have to use more coercive measures anyway since many people just don’t comply.

Very few participants qualified using coercive measures with the same vigour as did public health officials. While public health officials all agreed that the use of coercive measures can be justifiably necessary, all of them vehemently cautioned against using such measures without “due cause” or “evidence to support those measures.” One official
who had actively participated in the decision-making process during the SARS outbreak said:

I think we have to be careful whenever we use power. We have to be very, very careful. On the other hand, if I have good evidence to justify the means that I have to take, then I’m prepared to use them. It’s always important to try voluntary compliance first. I think most people will try hard to comply. And then I think you’ve got your other population that is neither able nor willing, or is not willing even though they may be able, and for that group, that sub-section, you have to be sure of why you are doing what you are doing, and you have to be very careful not to overstep our power.

Another official who had also been through the SARS outbreak said:

I think the use of restrictive measures has to be done with great caution. So if we are going to request isolation and quarantine, that in fact, we are aware of the evidence and we can use the evidence to support that request. I think we have to be the least coercive as possible so that the measures are not extreme or more coercive than they need to be.

A regulator restated public health officials’ commitment and conviction that restrictive and coercive measures have to be applied with forethought and moderation:

“There are circumstances in which I think you have to enforce quarantine measures, but when you do, the evidence that they are essential and should be enforced have to be very clear.”

Closely related to the view that coercion was at times unavoidable was the strong belief, held especially by public health officials, that safeguards ought to be built into implementation and enforcement processes in order to serve as a check and balance when coercive measures – however justified – are carried out.

One public health official explained:

You have to build in systems, so for example, when I write a Section 22 order on a communicable disease, when I’m ordering somebody to do something or not to work, they have a right to appeal and so you build in that right to appeal as a protective measure – so that you have the checks and the balances to make sure you haven’t overlooked something or you may be wrong. We’re human; sometimes we make a wrong decision, or some of our information may be wrong, and so therefore we have to be sure we build those levers into whatever intervention we establish in order to inform, negotiate and appeal if necessary.
Another public health official echoed this view: “We have to ensure that there is due process and the opportunity for an individual to challenge any orders that may be placed upon him or her as part of that process.”

In general, the views of public health officials on the use of coercive measures were much more nuanced and measured than any other constituent group. Almost every participant expressed the willingness (some rather forcefully, others with barely a kernel of acceptance) to justify the use of coercive measures for those who do not comply. Paradoxically, however, few were willing to respect such measures if applied to themselves, despite their expressed willingness to participate towards the overall goal of communicable disease control. By and large, participants balked at the idea of using restrictive surveillance measures, such as cameras in the home or electronic bracelets, especially for themselves, even after supporting the use of more restrictive measures to ensure compliance.

In sum, views on compliance and the means to achieve it varied greatly. Moreover there were many contradictions, often by the same participant, clearly illustrating that many were conflicted about how to ensure compliance. In contrast, there was no debate regarding what most thought would greatly facilitate voluntary compliance: The provision of services and adequate support. Indeed, just as participants vigorously supported quarantine in virtue of the common good, virtually all participants felt that providing support to those in quarantine was an obligation owed to them; it was thought to be a sine qua non condition for the implementation of quarantine. This view – which was largely unprompted – sent a near unanimous signal regarding reciprocal obligations to those in quarantine. The next theme on reciprocity discusses this point.
E. RECIPROCITY

The notion that government should provide supports as a form of reciprocal arrangement to those in quarantine seemed to be, for many, a given. Recalling the SARS experience in Toronto, one public health official emphasized the reciprocal relationship between the individual and society during a public health emergency:

“The individual was left shoudering all this collective responsibility themselves. It’s easier to get the mechanisms in place at least at the Health Department to decide who needs quarantine, how you do it, and how you enforce it. But the mechanisms for providing all the other supports for people were poorly worked out. It’s very easy to decide who needs quarantine but with that there needs to be supports in place. The individual has a responsibility [to respect quarantine], but then for society asking those people to do that, it also has a mounting responsibility to help that person carry out what we’re asking of them.

Speaking of the need to support someone in quarantine, a member of the public bluntly stated:

Quarantine has to be paid. If you send someone in voluntary quarantine and you don’t give him [or her] money to buy food or pay the bills, you don’t have to be so intelligent to understand that it’s not going to work.

Just like this member of the public’s candour, the discussion on reciprocity was direct and honest. Everyone wanted to comply with quarantine and other restrictive measures, but felt that the inherent constraints of such measures in accessing basic necessities were a barrier to compliance – or at the very least easily lead to a compromised quarantine. One public health official recognized this, saying: “Some people will need help in complying because even though they are willing, they may not be able.”

A member of the public – the same participant who said that is he a proponent of having more restrictive measures such as a compulsory quarantine because he believed that voluntary quarantine is ineffective – encapsulated the view of virtually every participant when he said:
I would much rather see, and I think most people would much rather see, resources going into making quarantine more livable so that people would adhere to it voluntarily, rather than putting resources into a policing system – a carrot rather than a stick. There should be supports and services, certainly. It is an imposition on people. It is a limitation on people and it does affect their ability to live their daily lives. It is something they’re doing for the good of everyone else, for the sake of the population in which they live. It seems reasonable that they would be compensated by that same population for that sacrifice they’re making.

Similarly, a spiritual leader said: “I think you really need to have something in place to identify people [in quarantine] and make sure that the basic necessities of life are provided.” A member of the public echoed this view: “In order for quarantine to work, that person has to have support services, i.e., food delivered or something like that, because if that’s not available, or if the person is worried about losing his or her job, then that person won’t comply with the quarantine.”

A respiratory technician spoke of his personal experience in quarantine:

I think somebody should be obligated to look after the needs of this person [in quarantine]. What was I supposed to do, sit here and starve for three days? You know? I had no milk, no vegetables, no fruit. Luckily I stocked up on a sale of spaghetti and luckily my brother has a farm and I got a side of beef. I lived on spaghetti and beef. And if I didn’t have these resources, I wouldn’t have any food. And how would I have gotten food? Otherwise I would have to go out and get it. Nobody called. Nobody offered anything. They told me that they were going to get me a mask and a thermometer so that I could gauge my temperature. They said they would contact me the first or second day I was quarantined. It never came… I think regular contact should have been kept with me to ensure my wellness, to make sure that my needs were being satisfied. It’s depressing sitting here by yourself.

Another member of the public stressed the need to provide job security: “If somebody has to go into quarantine, that person should be protected from losing their job, like with maternity leave – employers cannot fire you – so that their job is not in jeopardy.” Acknowledging that this could pose difficulties for small companies, he continued, stressing that individuals “must have some protections” regardless of the circumstances of their employment.

1. Lack of Specificity
Once participants established that there is an obligation to those in quarantine, few were able to specify what such an obligation would look like, or whose obligation it was to provide supports and services. Some participants ventured to answer who should be responsible, but none could articulate how and in what context supports should be delivered.

In some cases, the obligation was asserted to fall upon public health. Emphasizing what he viewed to be an obvious matter, one physician said:

*Of course* [public health] has obligations [to those in quarantine]. If they are going to single somebody out for the protection, for the greater good of society, that society is only as good as how well you take care of the people. In this situation, the public health approach is only as good as those people that you quarantine. You’re saying: If we’re going to do these things, then we have an obligation to look after you. If you’re taking away somebody’s rights, then you have to take all measures in order to prevent them from being out of society.

A member of the public was just as categorical: “I think that is the biggest function that public health serves. That’s their number one role – their primary responsibility.” He further explained that the obligation falls upon public health by definition: “It’s the duty of public health. That’s exactly what the words mean, the health of the public.” Another member of the public suggested that other agencies could provide support in addition to public health:

I think that the individual who must go into quarantine should have some protections that may have to come into law. I also think that public health and possibly other agencies – I don’t know what other agencies, some sort of social service agency – should provide support services for somebody in quarantine….

A public health official also questioned if the obligation lies with public health, though she conceded with some hesitation that it may in actual fact be its responsibility by definition: “I think the state does have an obligation. I’m not sure that it’s the duty of public health to do that…but…public health does act as the organ of the state to protect the health of the majority against the risks posed by a few.” In the next sentence,
however, she retreated from giving any specifics of public health’s role in providing support, speaking again in more general terms regarding the state:

And where it’s necessary to restrain the rights or activities of the few on behalf of the state, then I think the state does have an obligation to make sure that they don’t suffer from it – that’s an ethical obligation. There’s a sort of practical obligation that if you’re not providing somebody with the wherewithal to put bread on the table, they’re likely to ignore your quarantine order.

Moving further away from assigning responsibility to public health, a public health official asserted that “the government has an obligation. In a generic way, yes. Not public health.” A member of the public further reinforced this view, arguing in turn that it is not public health’s responsibility by definition: “Certainly, it’s someone’s responsibility. But I don’t think that those resources should come out of public health. The mandate of public health is to be concerned about the health of the public and not about the public’s ability to buy groceries.”

In sum, there was a great deal of ambiguity with regards to the specifics of reciprocity. That there are obligations to those in quarantine, however, was undisputed.

Finally, participants grappled with one issue that was deemed inherent in any communicable disease outbreak – uncertainty – and one issue deemed integral to the preparedness and management of communicable disease outbreaks – public deliberation. I will discuss these issues in the next section.

F. UNCERTAINTY

When asked if they thought it would be justified to use restrictive measures during an outbreak, most participants, especially public health officials and health care providers, readily said that they first required conclusive evidence substantiating the need for such an intervention.
One public health official said, “The use of restrictive measures has to be done with great caution in that we must make sure we have the evidence to support that request.” A nurse also emphasized the need to have solid evidence and remarked that “during the SARS outbreak, there was a lot of reactionary decisions without the evidence to support it,” adding that “it wasn’t okay.”

Another public health official stressed the importance of evidence:

If there’s a situation where there’s absolutely convincing evidence that quarantine is the definite route to go and will be responsible for the control of that disease, then I would hope that such a convincing case could be made for that – and citizens would not challenge a civic duty to protect others by following orders. In other words, if you have to, as it were, bribe them by payment for example, then you begin to wonder whether there’s really convincing evidence that this was necessary in the first place.

Moreover, others sought evidence of the effectiveness of quarantine. Arguing that there is “no direct evidence of the effectiveness [of quarantine] as a disease control strategy,” several public health officials questioned whether quarantine was all that necessary during the SARS outbreak.

A public health official pondered:

I’m not entirely convinced that the quarantine worked. If you go back and you do serology on those to prove whether or not they actually had SARS, you’ll find that a lot of cases didn’t. So you can’t really establish that it worked because there were no secondary cases. Well, there might have been no secondary cases because the person didn’t really have SARS in the first place. A lot of the epidemiologic and serologic evidence have yet to be presented in great detail to prove the effectiveness.

In general, participants who argued that evidence-based quarantine and proof of effectiveness are integral to the decision-making process did so out of concern that it would otherwise not be perceived as a legitimate intervention to the public at large. A regulator expressed this view: “You can be clear and say I don’t know – and I think we did say that – but people want answers. And what is a perception of when we don’t give a
clear answer…?” Arguing that it’s difficult to communicate to the public that evidence is not necessarily certain, one physician observed:

The public tends to look in black and white; yes or no; for sure. They don’t do well, and this has been studied extensively, that people don’t understand risk. People have a very difficult time perceiving very small risks – even a magnitude of higher risks, so that you have to communicate in more certainties and you have to communicate with a certain degree of confidence in your findings, so that presenting people with 25% chance or 10% chance is difficult because of the general public’s perception of risk, and the perception of personal risk versus public health is also difficult to understand.

Furthermore, some felt obligated to provide justification for it – justification, however, that was deemed to be valid only with “firm” and “solid” evidence. Yet here many more grappled with how to reconcile the need for certainty in the context of a new and emerging disease. Many noted – even after asserting the need for evidence-based quarantine – that this proved to be impossible during the SARS outbreak, reluctantly conceding that “when you have uncertainty” it would be justifiable to resort to quarantine despite the lack of evidence.

One public health official expressed this view:

I think [quarantine] has to be based on strong scientific knowledge. At the same time, I recall that for a time, there was concern that not all the knowledge was there. We didn’t quite know how the disease was transmitted, etc. I also recognize that sometimes, you can’t get all that information and I think that the best thing to do is to err on the side of the common good at the expense of personal liberty.

Some participants immediately recognized the impossibility of having conclusive evidence in an uncertain environment, and felt that it was never too early to use restrictive measures or implement quarantine.

An emergency physician, also working in public health, explained:

I can’t imagine there would be any time that would be too early to issue quarantine orders in this sort of situation. Because we didn’t know what the mode of transmission was, didn’t know exactly what the statistics were in terms of the attack rates and the morbidity/mortality associated with it, didn’t even know the incubation period. When you don’t have that kind of information and there’s a big potential for a lot of harm to either person or property, then you have to at least initially institute these sorts of measures until you do have more information.
A public health official reinforced this view:

If you’re faced with a situation where there’s uncertainty about the disease you’re dealing with – that is, if it’s a new and emerging disease – you have to take whatever information you have and act on it. You have to do what you have to do to protect the health of the public. If that may include the use of restrictive measures, then there are times when that may have to be done.

Acknowledging that it is difficult to provide evidence for the effectiveness of quarantine, another public health official clearly articulated what most participants hinted at or reluctantly stated:

The actual effectiveness of quarantine in the face of a communicable disease will vary according to the nature of the disease and the degree to which the restrictions are imposed and monitored. I don’t think we have a really good evidenced-based database to tell us what to do. So it becomes very much a sort of consensus-based evidence expert judgement position.

A few participants, mainly spiritual leaders, expressed implicit trust for the “experts making those decisions” and thought it was neither necessary nor appropriate to challenge their judgement.

A spiritual leader stated:

I’d leave latitude for our officials to give us some direction and I would support that. If another medical expert came with contradictory evidence, I would at least expect the justification of why they’re leaning in favour of one side or the other if there are two sides. But I would support whatever side they decide on.

Another spiritual leader said:

Once the medical field has decided what is necessary to be done based on their expertise…there’s an obligation on the community to follow what the doctors say. They’re the experts in the area. What the doctors say under those circumstances, we would follow as a generalization. This is philosophically and theologically grounded in the Torah.

Another spiritual leader said:

If the doctors feel that it’s an infectious disease, that other people can become infected, then of course it’s important to do that [quarantine]. The Bible speaks about quarantine. It’s very logical medically. As an individual, I have to give up my individual rights and my autonomy for the better of the society. If the doctors who are the experts in this area feel that it’s contagious, that we have to go into quarantine to control it, then they are absolutely right.
Still another spiritual leader simply said: “It’s a judgement call that experts make based on the potential harm and the kind of infection. It’s their call.” In a show of complete trust, another spiritual leader who has lived in many countries asked: “In matters of public health, laws are surely all just, aren’t they?”

The question of uncertainty during a communicable disease outbreak, especially in the context of a new and emerging disease, generated a great deal of discussion on the role of deliberation. Public deliberation is the most prevalent theme that emerged from the data; it was raised in discussions on the other five themes and thus constituted a cross-cutting theme that was important at every stage of the process, from justification to implementation to enforcement.

G. PUBLIC DELIBERATION

As the study progressed, deliberation emerged as the dominant theme. Nearly every participant pointed to communicative practices and deliberative processes as the means to inform the public, make decisions, resolve uncertainty, and formulate norms for public health emergencies. More succinctly, deliberation was viewed as a source of authority and legitimacy that ought to guide practice and policy both before and during public health emergencies. Broadly speaking, these discussions may be divided into two themes: The first concentrating on elements of risk communication during a crisis, and the second emphasizing the need for an open and collective process of public deliberation well before a crisis emerges. As such, deliberation was seen as integral to emergency preparedness and management.

1. Risk Communication
1a. Consistency in Public Communication

One of the most common themes identified as an element of risk communication was the crucial need for consistency and coherence in the messages that public health authorities and community leaders communicated to the public. Encapsulating the preponderant view that this was not the case during the SARS outbreak, one health care provider said:

> I think that sometimes too many people were involved, too many officials that have a fair amount of power. And sometimes, although it wasn’t totally contradictory, there were times that it was confusing. … I think at times people said different things about SARS and there needed to be a little bit more consistency regarding what exactly we need to do, what exactly it is, those types of things.

Pointing to the lack of consistency in the messages being communicated to the public, one spiritual leader implicitly suggested that there was both a lack of, and a need for, leadership during a crisis: “I don’t know whether anybody’s looked at all those [media] clips [during the SARS outbreak], but it just seemed to me that there were so many people who didn’t know whether they were coming or going. It’s so important. And that’s true of any emergency situation.” Similarly, a member of the public said: “I think leaders weren’t communicating somewhere along the way, and the information being relayed to us was late in coming and not altogether clear. It just wasn’t consistent.”

Another member of the public was exasperated when messages about what can and should be done were not only unclear and inconsistent at a societal level, but he started receiving inconsistent orders during his quarantine: “Somebody from public health said, ‘You’re out of quarantine now, you’re okay,’ and somebody else said, ‘No, you better stay’ – there was a constant discrepancy as to whether or not the quarantine was over for me, and that was hard to handle. I wish they had just told me that they didn’t know. That would have been easier.”

1b. Communication Uncertainty
Recognizing the uncertainty present during the SARS outbreak, the same participant expressed a view shared by many participants when he added: “Better tell us they don’t know than tell us one thing after another of this or that, out of thin air really.” That is, he, like many others, felt it was preferable, indeed more appropriate, to communicate uncertainty rather than to give inconsistent estimates or assessments of the situation.

In the same vein, a member of the public emphasized the importance of consistently communicating uncertainty and realistic expectations. He said:

Maybe the idea is, and this might not be from a scientific point of view – it might be from more of a leadership point of view or a political point of view – but the idea that if you undertake one type of course, you have to stay on message and you’re worried it might be more difficult to adapt because you might create uncertainty and confusion in the general public [if] you’ve given one message two weeks before and now you’re changing your tune. The idea is that you want to show that you’re changing it because of new information. That doesn’t always get out. As well, the certainty of information might not be there. Even though you’ve changed your decision, you might only be 95% certain, right? People want 100% certainty but that’s because it’s presented that way. They have to know if you’re only 95% certain. They want to know. So I think it’s a very commonly employed technique to continue with the same message, to stay on message from a public relations perspective, but that doesn’t work because circumstances are changing. That being said, changing your message without explaining what’s not known and why you’re changing your course of action or past decisions doesn’t work either.

Communicating uncertainty, however, does not preclude communicating with clarity and decisiveness, which was viewed to be integral to the management of public health emergencies. One health care provider emphasized the importance of communicating risk in such a way that not only informs the public, but also emboldens members of society to follow whatever measures are put in place. He explained:

I think the number one [issue], and it was shown so clearly, was that communication to the public is absolutely key to get the public onside if they can. And as we all know, Sheela Basrur was the voice of reason, and J. D. Young to a certain extent, and that was very helpful. It was clear, it was calm. Tell people clearly and calmly there’s a lot we don’t know but we are doing the best we can – not only are we doing the best we can, but we will win, we will succeed, you know – those sorts of messages are absolutely crucial when you are imposing restrictions on someone’s normal, everyday freedom to move around. It’s absolutely key to get the public on board, and that’s a tremendous skill that hopefully we will have in the future.

1c. Communication as a Means of Fostering Voluntary Participation
For many participants, open and transparent communicative practices fostered voluntary participation. For some participants, mainly members of the public, spiritual leaders, and health care providers, it was a way of engaging people in understanding what and why measures were needed. Echoing the common view that people did not adhere to quarantine orders, a member of the public said:

I think understanding what the risk really is…. People broke their voluntary quarantine [because] somehow they didn’t quite believe that they did pose a risk to other people. That’s the whole issue of communication, risk communication. It is fundamental to getting us close to full voluntary quarantine being adhered to. There are probably many things that could be done to improve what happened [during the SARS outbreak].

Similarly, a physician attributed the lack of adherence to quarantine measures during SARS to the fact that “people who were in quarantine didn’t know why most of the time.” Thus, communicating with the public was viewed to be integral to the imposition of, and adherence to, restrictive measures. A spiritual leader said, “A volunteer system of quarantine works if people understand the rationale of why they’re going to be quarantined…. That’s part of risk communication that needs to be understood in terms of what people need.” Sharing her experience during the SARS outbreak, one nurse recalled the impact of her discussions with her colleagues in the midst of the crisis:

There was a lot of communication when a directive would come out. You know, the management team would come down and say this is what the directive says. This is the way we’re interpreting it and what do you guys think? And we would have discussion and open debate about what was the best plan to go so that we felt there was some, I guess you could say commitment on our part and we were making sense of those directives together. It wasn’t just somebody sitting in an office in senior management saying, this is the way it’s going to be; it was a participative approach which helped. It was very open and honest, i.e., we don’t know what we’re doing is absolutely right, but this is the best that we can do right now. I know that staff, many staff, told me that they felt very supportive because management was honest and said we don’t know either, this is the best [information] that we have.

For other participants, mainly regulators and public health officials, communication fosters participation because it is an effective method of educating a passive public that is waiting for public health authorities to deliver information.
Supporting the view that education is “a central part of the process” of managing a communicable disease outbreak, one regulator put it bluntly: “People rely on it.” Yet more than that, not only were members of society viewed as simply being recipients of information, some regulators believed that information had to be somewhat filtered in order to manage an anxious public. Another regulator, although he supported openness and transparency, felt that information given during a public health emergency had to be distilled carefully. To him, the question of communication is an ethical issue, though not in the sense that communicative practices ought to be a requirement to engage citizens, but because providing too much information could plausibly have negative consequences. He argued:

Public communication is a big ethical issue. You know, and I mean, this is pre-disaster and post-disaster and it’s not a question of withholding information as much as a question of providing the information that there’s not inadvertently or accidentally increased anxiety level, and I think the answer there, not the answer but maybe the approach more than the answer, is to ensure that you’re saying things with common language, with basic language. Because if you use big words, although it’s correct, people are going to get more anxious by hearing the big words and the situation need not be more anxiety provoking, so it’s a very difficult, ethical issue to how much information and how to present the information, and I don’t believe in withholding information but you have to be careful that it may come to a point that you’re overwhelming someone and that overwhelming will cause more anxiety than the benefit too. So there are some ethical issues there as well.

Yet for the vast majority of participants, the management of public health emergencies and decisions about the use of restrictive measures not only requires a citizenry that is informed, it requires citizens that are engaged both during an emergency, in order to understand and participate in actions taken, and prior to an emergency, in order to make decisions and construct norms about what matters – and, most crucially, why it matters.

2. Public Deliberation
This is the crux of the findings: Just about every point of contention or source of tension that participants confronted in their own deliberations was believed to require more deliberation within a broader societal context. Those who were aware that they contradicted themselves chalked it up to the fact that they lacked information and thus found it difficult to navigate through the complex issues related to quarantine and other restrictive measures. Yet more than that, nearly every time an issue arose that participants could not, or did not, know how to answer, deliberation was presented as a crucial component, indeed a legitimate means, to resolve the complexity of these issues.

Arguing that most people, especially citizens, were largely uninformed during the SARS outbreak, one nurse encapsulated the view of many when he said that “there was really poor communication. But that’s because no one knew what to do. But that’s because we’ve never talked about these issues as a society. We need to do that.” A member of the public suggested that there should be an infrastructure facilitating and furthering debate and deliberation about the issues at stake. He continued:

I heard about the account near the end of SARS I, actually when they started explaining how horribly, horribly antiquated the reporting structure was to health officials: That there was no easy way to tally who was infected, who was released, who’s newly infected, the duration of each patient’s stay, etc. The statistics that would make informed judgments easier were just not there. People were marking up printouts from different hospitals and faxing them in and then having to collate those manually. This – it’s really inexcusable. This speaks to a larger issue there. I think there should be some sort of uniform medical reporting structure put in place. Goodness me, if Google can index billions of web pages and bring back beautiful search results in a tenth of a second, why does it take hours or days to get adequate reporting information for eight million Ontarians? It just doesn’t seem right. So, I would implement more robust structures as far as computers and databases and networking and communications go. And I would open it up to more people, to everyone. Because in a time like this, people are worried, they’re nervous, they want to know what’s going on – so I would open it up so that when these statistics are available, they’re available in real-time and not just to medical professionals and the media, but to average citizens as well – that they could punch in a web address and, even if the statistics mean nothing to them – at least they’re there. So, I would make it available to everyone, because I think a lack of information is much more detrimental than knowing the information even if the information is bad.
Another member of the public highlighted what many viewed as “inadequate” and “insufficient” mechanisms for decision-making in public health and society. Prefacing many of his comments by saying “we need to talk about this,” he explained:

Very often when we approach occurrences such as the SARS epidemic, we rapidly look to military models to deal with that. It’s interesting that the military is changing its models and decentralizing a lot of the authority. I think the U.S. Marines have written a very interesting book about that. They’re not exactly an example that I look to every day, but approximately two years ago, if I remember correctly, there was a book that discussed how, even within the military, they are decentralizing a lot of their approaches because they discovered that that is more effective than the more traditional chain of command which does not always play out in the way that we expect it to. I think that there are lessons to be learned here for the public health community, which is all of society really. We often turn to the military for their obvious you know, good organization, but we’ve had many examples that lead us to be a little more cautious about that. Even the military has been learning that, in this modern world, a very tightly knit pyramid, a hierarchical pyramid, is not always the best way of dealing with such matters, and I think that is very true of decisions about health care. I don’t believe that that is the way to go. I think it needs to be more nuanced than that. I don’t disagree with having an overview of resources and an effective collection of data which comes back to a central source. What I do disagree with is the chain of command because very often, what you find at the command post are people who are not particularly versed on all this, and it alienates those to whom measures which are required are applied. It has to be much more focused; it has to be taken to the periphery – yes, that’s right, that means the average citizen. So we should have a central repository database, of course, but not a command centre, a co-ordination centre. I do get concerned. I’ve seen a lot of highly centralized approaches here in Canada deal with a number of issues, and it’s not in our far distant past that we’ve not exactly been highly successful in dealing with public health episodes. That was certainly dealt with in a very centralized way, and the commands that were given from the upper levels I think were clearly not appropriate in many circumstances. Everyone has to get involved in making decision[s] before and during a crisis. You see, when it comes to public health, public health authorities are not the only experts.

Yet another member of the public succinctly expressed the importance of, the need for, and the impact of deliberation: “Our morals, if you will, certainly influence how we are going to make decisions, and you and I may not share the same philosophies or values and therefore this creates what seems like irresolvable conflict. But I think what helps resolve that is deliberation and hopefully, as a result of that, we’ll be able to come to some common ground on how and which and why decisions are made.”
CHAPTER 7:

DISCUSSION: THE PROBLEM OF JUSTIFICATION

Where technology is still unable to provide a solution to the spread of disease, people look to the law. But the law is also a limited instrument.

— Carole Levine, 1986, p. 2

I believe it would be useful to reflect on the notion of “subjective rights” used in the conception of human rights. In this way, our reading of the debate between individualists and collectivists brings about a double misunderstanding to light. For possessive individualism in its Western guise fails to see that subjective rights can be derived only from antecedent, intersubjectively recognized norms governing a legal community. Individual legal persons are, of course, endowed with subjective rights under the rule of law; however the status of such persons as the bearers of subjective rights is constituted in the first place in a political community based on mutual recognition. Now, by jettisoning the erroneous thesis that there exists an individual with innate rights prior to all socialization we can at the same time abandon the antithesis that accords priority to the claims of a community over the legal claims of individuals. The purported alternatives these two theoretical strategies afford dissolve into nothing if, contrary to both strategies, we incorporate the unity of processes of individuation and socialization into the core concepts of an intersubjective approach to legal theory: Legal persons in general become individuals through socialization.

— Jürgen Habermas, 2003, pp. 291-292

The factual recognition of norms does not necessarily rest on a belief of legitimacy.

— Jürgen Habermas, 1975, p. 97

A. INTRODUCTION

In this chapter, I examine the questions that I derived from my analysis of the findings. It is divided into three sections: 1) the common good and individual rights, 2) scientific legitimacy, and 3) legal legitimacy. In final analysis, I argue that moral legitimacy is the foundation of all of these.

The recognition of, and commitment to, the common good was found to be an overarching theme, thereby creating the possibility for a kind of basic justificatory power for the use of quarantine during communicable disease outbreaks. That the use of quarantine was largely unchallenged, and that virtually all participants accepted the
justificatory power of quarantine as one grounded in the “common good,” is an important finding. Not only does it indicate that quarantine continues to have normative force in our society, it is also consistent with the traditional conception of public health as a vehicle of collective action and with the historical view that the public health does, at times, legitimately trump individual rights. That is, this primary finding validates--and further bolsters--the justificatory power of public health itself that both mandates and enables it to implement and enforce restrictive measures to achieve public health goals. In sum, participants agreed that the common good matters.

Significantly, the vast majority did not articulate or specify what the common good means to them, as such reinforcing the dearth of analysis on what it means to serve (or promote, or cultivate) the common good. Yet many did begin to articulate concepts and values about the common good. Even though on a few occasions this led to an articulation of what it means to govern (or to be governed) by principles of the common good, it did point to different accounts of the good. Thus while participants agreed that the common good matters, they disagreed as to what it is, or how much it matters. Ultimately, this divergence of views gives some indication as to the conception of the common good which was implicitly invoked by participants

Based on the data, we can consider three conceptions to which participants appealed to justify the use of quarantine: Utilitarian, communitarian, and liberal individualist. However my aim here is not to determine which of these accounts is more satisfactory for this justificatory purpose, but to surface the dominant view that permeates the accounts of the participants; that is, one that might broadly be called liberal – a view that in effect mirrors our dominant moral and political culture.
This is not surprising given that we live in a liberal democratic society. Nonetheless, the preponderance of the liberal view in the data is significant because of two striking facts: First, participants’ accounts consistently reflected the inherent tension between the good and the right embodied in our society, a tension with which participants explicitly grappled in their deliberations on the use of quarantine; and second, while there is a prima facie agreement on the justification of quarantine premised on the condition of the common good, there is no agreement on anything else. This too reflects our moral and political reality within which there are different – and often inconsistent – visions and accounts of the ideal society (or systems or institutions or the role of the state), each with its own answers to the kinds of questions raised by the use of restrictive measures in modern society.

In this context, it would seem contradictory to argue that there is a single (liberal) philosophy – *an* answer – guiding our society. Yet here I agree with Sandel, who reminds us that “our practices and institutions are embodiments of theory…. For all our uncertainties about ultimate questions of political philosophy – of justice and value and the nature of the good life – the one thing we know is that we live *some* answer all the time” (Sandel, 1984), even in a pluralistic society such as ours. And while we may not live *an* answer, but answers that stem from different visions, a plurality of answers, proposes Sandel, “is itself a kind of answer,” and the philosophy “that affirms this plurality” is the liberal vision (1984, p. 81).

This is very much the case in this inquiry. At the heart of participants’ accounts is a liberal vision that appeals to the law (rights) and science (facts) to both justify and limit public health intervention. However, perhaps paradoxically, it also casts doubt on their
justificatory power and bears little consistency from one account to another. This lack of consistency is itself significant. Yet what is even more trenchant here is that there is a common thread running through the data, one that both inspires and moves beyond the dominant liberal view. This common thread is communication, which is largely presented as a panacea to resolving dilemmas and reconciling contradictions or inconsistencies engendered by the use of quarantine, or resulting from divergent views as to what constitutes a legitimate, effective, or necessary quarantine. Here participants imputed great value to communication, but, what is more, they reasoned from the assumption that dialogue and deliberation will move us towards greater clarity and, ultimately, greater justificatory power.

This is perhaps the most important finding of this inquiry. It both reflects and reinforces--and provides empirical support for--the Habermasian paradigm of communicative action. In so doing, it points to a veritable model of moral legitimacy.

In this discussion, I will examine how the tension that exists at the heart of the liberal vision between the good and the right finds expression in participants’ accounts of the common good and the place they accorded to individual rights. Further, I will examine the tension found in participants’ claims that paradoxically seek and reject legal and scientific legitimacy, and eventually seek and affirm moral legitimacy through discourse. In final analysis, I will consider whether a discourse model of legitimacy moves us towards greater clarity on the problem of justification.

B. THE COMMON GOOD AND INDIVIDUAL RIGHTS

I will begin this section by considering the different conceptions of the common good that appear in the data, with an emphasis on liberal accounts and their inherent
relationship to rights. At issue in considering the use of restrictive measures is whether
the common good is at odds with individual rights – *i.e.*, do they conflict and contradict,
or whether they are compatible – *i.e.*, can they be reconciled.

### 1. The Good and the Right: The Liberal-Communitarian Divide Reproduced

To speak of the common good in liberal democratic societies such as ours seems very un-
liberal today. The pervasiveness of the language of rights that dominates moral and
political discourse seems to have precluded the very idea that the common good still
matters, or that it is desirable or even conceivable. And the possibility that anyone in their
right mind would willingly accept constraints in pursuit of the common good may in fact
seem unconvincing. Yet, as I reported in the previous chapter, participants clearly
demonstrated a community-sensitive approach to communicable disease control. There
was no question in anyone’s mind that quarantine is both a valid concept and a tool that
serves the purpose of promoting the good of society. While participants disagreed on
whether it was actually needed during the SARS outbreak, they did so on epidemiological
grounds (e.g. given the transmissibility of SARS), although they all believed that
quarantine in and of itself promotes a common good – a healthy society – to which they
were willing to contribute (by complying to a quarantine order), and for which they are
willing to accept the constraints necessarily engendered by such circumstances.

Significantly, the view that the use of restrictive measures (in particular
quarantine) is justified in virtue of the common good was wholly unprompted. In the vast
majority of interviews, it was raised by participants from the very outset in response to
the first question: Do you think it is necessary and valid to use restrictive measures
during communicable disease outbreaks? Immediately after acquiescing (usually
emphatically, with statements such as “yes, absolutely,” “most definitely, I do”), participants explained their rationale without further questioning. For those who did not do so on their own, I asked them to elaborate on their answer, and their response closely resembled those who elaborated on their own.

A notable exception occurred during interviews with public health officials and most regulators. Many of them were reticent to categorically support the use of quarantine and give an unqualified answer, stipulating that if the use of restrictive measures is ever justified (a common emphasis), it is contingent on the circumstances of the disease, i.e., which disease and which measures are in question. One public health official emphasized that “it depends on what the infectious disease is and if restrictive measures are necessary to control the spread.” A second public health official began with a similar premise: “It’s the degree of infectivity and the means by which various agents are spread that really determines what restrictive measures may be required. The measures that you would take to control infection with HIV that causes AIDS or Hepatitis C are going to be very, very different from a disease which is highly infectious by the small drop or airborne route such as Influenza or Chicken Pox.”

In turn, I asked them if they felt that the use of restrictive measures, in particular quarantine, was justified for highly infectious diseases such as the examples given above, or for an unknown pathogen such as SARS. Yet here too they avoided answering the question directly. The first official explained: “It’s very difficult for me to be critical of that decision, not having been there in that situation and only knowing the facts as they’ve been presented to somebody outside the situation…. So whether that was right or wrong, I don’t really think I’m in a place to say.” I continued my line of questioning and
asked him: “Under what conditions or circumstances would you feel that it would be legitimate to implement quarantine?” His response was elusive: “I think it is when you have a situation of a communicable disease where quarantine is regarded as an accepted public health measure to interrupt the transmission of the disease.”

When I asked him to be more specific, the circularity of his line of reasoning, as well as his reticence to justify the use of quarantine, was evident: “I really can’t be specific. It would depend on the situation. It would depend on the disease. It would depend on the mode of transmission…. I don’t think I can be specific…. There are a number of factors that have to be considered before you would enter into the quarantine situation.” Similarly, the second official stalled when I asked him if he thought that the use of quarantine was justified in the context of SARS. Instead of giving a direct answer, he reflected on the historical use of quarantine, exclaiming, “The word ‘quarantine’ strikes some very negative images in my mind.” He went on to describe his experiences as a young child, when “houses were quarantined with placards.” I continued to probe whether he could justify the use of quarantine in any circumstances, as I did with most of the public health officials, but he did not give a definitive answer. This reluctance to commit to invoking quarantine in some circumstances, indeed to justify its use, stems from a deep-seated conundrum and the uncertainty surrounding public health decision-making. I will return to this point in the section below on scientific legitimacy.

By and large, however, participants supported the use of quarantine, and many did so enthusiastically by grounding their justification in the common good. Despite the ambiguities in participants’ assumptions about the nature of the good, the commitment to the good is a significant finding. It validates, indeed further bolsters, the traditional
conception of public health as a vehicle of collective action and public health’s traditional utilitarian pursuit that both mandates and enables it to implement and enforce restrictive measures to achieve public health goals. Yet just as a discussion on the common good cannot be separated from a discussion on individual rights in liberal theory, likewise participants did not speak of the common good independently of individual rights. In fact for the vast majority, they could not--or were not willing to--talk about one without the other, indicating the participants’ perception or understanding that there is an inextricable link between the two concepts. Importantly, it reveals that in most cases how one understands the common good is relative to the status she or he accords to rights. This allows us to understand what conception of the common good underpins participants’ accounts and the implications this has for shaping – or how we ought to shape – interventions and policies pertaining to communicable disease outbreaks.

Here we start seeing nuggets of ideas through which participants appealed to different values, distinguishing, although in subtle ways, different conceptions of the common good: Utility (utilitarianism), rights (liberal individualist), equality (liberty equality), liberty (libertarianism), and community (communitarianism). While this plurality of values found in the interviews is important, it can be somewhat misleading. This is because the first four – utility, rights, equality and liberty – essentially embrace the basic tenets of liberal democracy and all sit alongside views focused on the community. Taken together, the focus on liberal theories and community-sensitive approaches that animated participants’ views essentially reproduces the liberal-communitarian debate that has characterized the political (philosophical) debate of liberal democracies since the early 1980s. While it is beyond the scope of this analysis to
adequately survey this debate, it provides us with a critical point of analysis with which to frame the issues starkly, and gives us a point of reference from which to interpret the data.

In large part because communitarianism evolved as a critique to modern liberalism, it would make sense to begin with a brief delineation of some basic liberal tenets. First and foremost, the foundational liberal value is self-determination, and concomitantly the rights to individual liberty and equality, which shape the conditions that determine the common good. Liberal theories, such as those that appear in the data, while offering different accounts on how to show equal concern for people’s interests, converge at a fundamental level: They all presuppose that individuals have the capacity, and should have the autonomy, to define and pursue their own conception of the good in order to choose what sort of person they want to be and what sort of life they want to lead (Kymlicka, 2002, p. 212). Here the self remains prior to the shared ends (of living a good life), meaning, as Kymlicka puts it, that participants “reserve the right to question even [their] most deeply held convictions about the nature of the good life” (Kymlicka, 2002, p. 224). The self is not constitutive of shared ends, as Sandel would envisage (Sandel, 1982, pp. 55-59, 152-154; quoted in Kymlicka, 2002, p. 224); it is an end in itself.

In this logic, “the common good in a liberal society is adjusted to fit the pattern of preferences and conceptions of the good held by individuals” (Kymlicka, 2002, p. 220; emphasis mine). It is “the result of a process of combining [individual] preferences, all of which are counted equally” (Kymlicka, 2002, p. 220). The community is conceived as an aggregate of individuals. All preferences have equal weight, Rawls explains, “not in the sense that there is an agreed public measure of intrinsic value, or satisfaction with respect
to which all these conceptions come out equal, but the sense that they are not evaluated at all from a [public] standpoint” (Rawls, 1982, p. 172). Thus the role of the liberal state is to provide and protect the rights and resources of members of society in order to enable them to determine and pursue their own conception of the good. The state stays neutral towards different conceptions of the good in that it does not justify state policies on the basis of the inherent worth of these conceptions, nor does it attempt to steer members of society towards any particular way of life in order to respect the value of self-determination.

In diametrical opposition to a liberal view, communitarians argue that the value of community ought to be prior to--and not a derivative of--rights (to liberty and equality), since the latter is only made possible within the community, tied as we are to existing social practices and arrangements. In this view, a conception of the common good should include an independent principle of community, and not as simply an aggregate of individuals.

2. Understandings of the Relationship Between the Good and the Right

To further articulate or clarify participants’ insights into how they understand the relationship between the good and the right, even if few actually articulated a clear vision of what the common good is, we can extract what they said from the contours of the liberal-communitarian debate. As a starting point, we know that participants made room for the common good, but more than that, they affirmed that we *must* make room for the common good and defend what is considered to be the essential need of public health to create the conditions for a healthy society – in this way articulating the possibility for the conceptualisation of the good taking shape through state intervention. The data points to
two preconditions for conceiving of the good: One is the explicit acknowledgement that this good can only be achieved in a communal context, or as Sandel puts it, a politics that “enables us to know a good in common that we cannot know alone” (1982, p. 183); and the second is the implicit acknowledgement that there are indeed shared ends that are worth pursuing – in this case, invoking quarantine to control an epidemic.

This in itself is significant given that critiques of modern liberal democratic societies, including communitarian critiques, argue that the liberal vision is too individualistic and does not take into account the ways in which members of society are bound within, or are dependent on, the community. Yet that is not the case here: Participants accepted the idea that they are embedded in a shared social context and part of a common good woven through the state. The real debate, therefore, is not whether participants recognize the ideal of community and the legitimate pursuit of the good; we know, and I have already established, that they do. The crux of the issue here is where they place the value of community relative to the status they accord to rights.

As a second starting point, participants expressed the view, often implicitly, that rights are foundational. This is a dominant view in the data and a widely unchallenged assumption. Most participants viewed the use of restrictive measures, in particular quarantine, for the common good as being a legitimate restriction on self-determination by infringing on (some of their) rights only because quarantine is limited in time and space. That is, it does not question (or challenge, or undermine, or alter, or invalidate) the nature or the value of rights. So whether participants felt that members of society have a responsibility or an obligation to the community, or that the common good ought to be balanced against rights, or that the necessity of attending to the common good
legitimately overrides rights, all of them reasoned from liberal assumptions (“first there is individual liberty and then there is the common good” or “who is responsible for ensuring that the rights of individuals are maintained?” or “how do you balance rights within quarantine?” or “as long as certain basic human rights are preserved”). They affirmed and reinforced that rights exist and, despite the necessity of the circumstances of an outbreak, what matters is that they remained individual bearers of rights. Thus for the participants, what was at stake was not the existence of rights – that was a given – but rather which rights the state can legitimately infringe upon, when, and for how long.

Here we begin to form an understanding of (the majority of) participants’ accounts of the common good – and in what sense their notion of the good is fundamentally liberal. It is legitimate, indeed desirable, that the state provides the resources and conditions necessary to control an outbreak – a good which virtually all participants judged to be instrumentally valuable and to which they were willing to adhere. However the common social arrangements put in place during an outbreak do not underpin any particular way of life, which a communitarian view supports, for the shared pursuit of the communal goal (of controlling an outbreak) is viewed as a temporary and voluntary association. Moreover, participants did not define themselves “as bearers of a particular social role [or] a particular social identity,” as communitarians would have it, insofar as the capacity for self-determination is not deemed to be exercised within social roles (pre)defining the ends (MacIntyre, 1981, p. 204). Rather, the ends are defined by self-determining individuals even, and most crucially, during communicable disease outbreaks. Thus while participants saw themselves embedded in a shared social context from which they could not, or ought not, opt out, a view that is consistent with a
communitarian view of the self, they did not conceive of a community that defines, or is constitutive of, their identity (Sandel, 1982, p. 150).

What mattered for these participants is that quarantine, or more generally restrictive measures, create particular social arrangements that are only temporary precisely out of the primary concern to respect individual rights. Restrictive measures are limited in time (“as long as…there is an understanding that these are temporary measures” or “we’re not talking about permanent quarantine; we’re talking about a limited amount of time” or “it’s an instance where personal freedom just needs to go on the back burner for a little bit”) and in scope (“as long as certain basic human rights are preserved” or “you’re limiting their right to travel freely, and that’s only one right out of a whole array of rights”). The impermanence of—and what undergird these—restrictions still makes it possible for individuals to be bearers of rights and to decide how to lead their lives.

In sum, participants largely espoused a rights-based account of the common good. This dominant view, which emerges from the data, reinforces what Kymlicka and others have observed on notions of the self in liberal democratic societies: “The communitarian conception of the embedded self is not a plausible conception of the self-understandings of most citizens in Western democracies” (Kymlicka, 2002, p. 228). Participants’ reflections rested on a shared concept, and perhaps even a shared value. While it could be argued that the self is seen as necessarily “embedded” at certain times, such as during public health emergencies, it is not seen as predominantly embedded. Most fundamentally, the location of moral value in nearly every account is the self.
However this dominant rights-based account is not without nuance. I can decipher two important instances that give equal status to individual rights and public health considerations – an objective that forms the basis of this inquiry. First, the view that “certain basic rights” ought not be violated under any circumstances – that is, rights to which persons are entitled without qualification – is consistent 1) with the deontological view that a person has moral rights that are inalienable and indefeasible by virtue of her being a person with inherent moral standing and 2) with human rights law that posits that some rights are, as a matter of law, inviolable. Second, this view also corresponds with the rationale offered in support of public health in human rights law – further reinforcing what I deem to be the desire not to compromise, indeed to uphold, what is essentially a liberal notion of agency, even as there is clearly a desire to support public health intervention and contribute to the good. Though participants began from liberal assumptions (that traditionally give priority to the right), the vast majority therefore weighed in equally on the requirements of the good. Most of them did not, indeed were unable to, explicitly articulate or identify their commitments, oscillating instead between views firmly grounded in liberal values and views based on communitarian notions.

This reveals a deep-seated sense of ambivalence found in modern society. Yet more than that, participants showed a desire to redefine the relationship between the right and the good, wherein the question is not a matter of which is prior under what circumstances, but rather how to make them co-exist under all circumstances. What begins to surface here is a view of the common good and of the relationship between the good and the right that transcends the dominant liberal positivist conception. As I will discuss in the final section of this chapter on moral legitimacy, the latter takes shape in,
and is defined by, a communicative rationality, which is itself a liberal conception founded on the liberal notion of the self-determining agent, not on communitarianism. As I will show, however, it shares important assumptions with communitarian notions of community.

Before concluding the discussion on the common good and individual rights, there is yet another significant instance in participants’ accounts of rights that deserves attention. Participants’ normative statements about what they or society ought, or ought not, to do implicitly refer to both moral and legal rights. This introduces an important distinction between what participants think they are entitled to by virtue of being persons with inherent moral standing – *i.e.*, rights that are inalienable and indefeasible, and what they think they are entitled to by convention – *i.e.*, rights that come into existence within the law. The distinction between moral rights and legal powers raises important questions about the role--and duties--of the state (and hence public health as an organ of the state) to individuals who are in quarantine or affected by it. According to practically every participant, the state has a reciprocal duty to provide for those in quarantine. Yet while there was a near-unanimous view that the state should satisfy individual needs – indeed, to provide that to which they are *entitled* to – participants grappled with what that should look like. Moreover, what counts as an entitlement – *i.e.*, what should be provided and by whom was a source of great discord.

3. **Reciprocity: The Role of the State Revisited**

Nearly every participant mentioned and placed a great emphasis on the importance of reciprocity – understood to be the *obligations* of the state to individuals in or affected by it – as being integral to the success of quarantine. In effect, there was a near-consensus
that those affected by quarantine are entitled to and ought to be guaranteed some form of assistance through a system resembling that of welfare provision ("of course [public health] has obligations" or "individuals must have some protections" or "the individual has a responsibility [to respect quarantine], but then for society asking those people to do that, it also has a mounting responsibility to help that person carry out what we’re asking of"). The notion that government should provide supports to those in quarantine was presented as a given by virtually everyone. Indeed, with very few exceptions it was viewed as a *sine qua non* condition for the implementation of quarantine.49

However participants had different views on whose responsibility it was to provide such assistance, and what it would look like. Some participants ascribed responsibility to public health itself, while others, who did not think that responsibility fell upon public health as such, ascribed responsibility to an organ of the state or some kind of government program funded by the state. In addition, many participants pointed to specific needs or services that should be delivered, but none clearly articulated how and in what context such supports should be delivered. It is no less important to note that there were many contradictions, often within individual interviews themselves, which was a clear indication of participant appreciation for the complexity of the issues at stake. Overall, while there was wide disagreement and a lack of specificity, participants did provide a powerful justification for the role of public health as an aspect of the welfare state, or for the welfare state itself.

49 Only two participants saw the value of reciprocity as a violation of liberal precepts, a view more in line with libertarian approaches that argue against the state having an obligation to provide any type of support under any circumstances (see for example, Nozick, 1981, 1974). Another view was expressed largely by spiritual leaders. While they too understood the provision of supports and adequate care as a given, they did not ascribe responsibility to the state. Rather, they discussed the role of their communities, which in their view, ought to--and in most cases actually did--provide such supports during the SARS outbreak. This does not mean, however, that they challenged the view that the state has such obligations, nor do I believe they would have if I had asked them directly about it. They simply did not think of it in such terms.
Against the backdrop of the dominant liberal view that emerges from the data, the finding that participants endorsed a further deepening of the role of the state is significant. This view would appear to be antithetical to the prevailing notion that individual rights are paramount even when the use of restrictive measures is required – a view, as I discussed above, that is consistent with the classical liberal conception of the “independent agent” or “autonomous self” tied as it is to dominant constructs of human rights.

Yet even here many participants’ understanding of the role of the state (or specifically, public health) is consistent with a liberal view of the welfare state which, lest we forget amid claims to rights and self-determination, leaves room for state intervention (or what some may conceive as “acts of paternalism” [Kymlicka, 2002, p. 231; see also for example, Moon, 1988]). That participants affirm the centrality of rights and reinforce the role of the state mirrors the tension at the heart of liberal theory and the welfare state: On one hand, the liberal conception of agency presupposes that individuals are autonomous, independent agents, and therefore ought to be free to be self-determining and organize their lives through voluntary association; on the other hand, liberal theory (at least contemporary liberal understanding) recognizes that the state ought to provide benefits to all those facing certain contingencies; in this case, for the constraints inherent to quarantine.

In essence, the findings of this inquiry remind us that even, or perhaps especially, in liberal societies, individuals should not be expected to, as one participant said, “shoulder all this collective responsibility themselves” in the event of a communicable disease outbreak that requires the use of restrictive measures such as quarantine. This is
an important reminder because most of the members of the public who were quarantined during the SARS outbreak in Toronto felt that they were “left in the lurch” or “abandoned,” and because some public health officials believed that public health (or the state) did not have obligations to individuals in quarantine (though most did concede that it may be a “moral call by society” that cannot be ignored). Recent studies have further bolstered the view that public health carries the dual responsibility of enforcing compliance and providing support to those in quarantine (Blendon et al. 2008; Blendon et al., 2006; Cava et al., 2005).

Participants’ claims that a system of provision ought to be integral to the implementation of quarantine appeared to have both intrinsic and instrumental value. On the one hand, public health (or more generally, the state through the agency of government) has a duty of reciprocity simply because, as several participants said, it is “the right thing to do.” In other words, it is an intrinsically right intervention because it acts in respect of persons; it is an end in and of itself. Given that persons have indefeasible rights by virtue of their being intrinsically valuable, there is a corresponding categorical duty of reciprocity to respect these beings. Moreover, there is a correlative duty to provide the conditions enabling members of society to be self-determining independent agents, to be an end in and of themselves.50 On the other hand, reciprocity

---

50 The idea that the state must provide such conditions is a 20th century concept of rights that departs from that espoused in the 18th century. As Facione et al. explain, “Eighteen century [normative thought] conceived of moral rights as entitlements that hold independently of any governmental structure. Freedom of speech, freedom of worship, freedom of assembly, and freedom of the press were thought of as things to which human beings were entitled by virtue of their being human. The correlative duties attending them, if there were any, were at most duties of non-interference. The duty of the other agent, in other words, was not conceived as a duty to act in a certain way, but at most as a duty to refrain from doing anything that would interfere with the exercise of the right.” However the notion of rights that has dominated much of political theorizing in the 20th century has been redefined to now encapsulate both negative rights and positive rights, meaning that individuals have rights that “are not thought of as arising out of human nature as much as they are described as goals” (right to education, right to health, etc.). It thus follows that the
has instrumental value according to the participants, for it facilitates compliance to quarantine. That is, it is a good that leads to something else that is good; it is a means to an end. Indeed, it was strongly believed that providing supports to those in quarantine would further bolster compliance because it would prevent them from breaking it in order to meet basic needs.

The relationship that was established by participants between reciprocity and compliance is crucial because it raises the broader question of enforcement and, with that, the difficult issue of negotiating what constitutes legitimate measures to ensure compliance. Before taking up this important aspect of quarantine, however, it is still necessary to examine questions around the decision-making process involved in grappling with decisions about quarantine, e.g. when and what model is justifiable? This in turn gives way to the broader question of what constitutes adequate evidence to justify the decision to invoke quarantine in the first instance, and what constitutes a legitimate degree of restrictiveness of measures.

In the next section, I will discuss important issues implicit in the decision itself to quarantine. In particular, I will explore the role of evidence and effectiveness in decision-making for quarantine in the context of scientific uncertainty. Although the SARS outbreak brought to light how scientific uncertainty can permeate—even dictate—public health decision-making, some participants, primarily public health officials, contended that the ability to implement quarantine or other restrictive measures ought to be supported by a strong evidence base, even though they recognized – albeit with prompting – that this proved to be impossible during the SARS crisis. Exploiting the state has the correlative duty to “take positive steps” in order to ensure these rights (Facione et al., 1978, pp. 134-136). Most importantly, the concept of rights that underpins the corpus of human rights norms, for example, the Declaration of Human Rights, is this later redefinition of rights.
instances in which these participants conceded that scientific uncertainty did indeed permeate the decision-making process during the SARS crisis, I offer the following interpretation of this finding, subtly observed by one public health official: The effectiveness of a public health intervention should not--and cannot--be defined exclusively in scientific terms, but rather ought to be conceptualized relationally and normatively to make room for uncertainty. However jarring to public health officials’ understandings of (the role of) scientific validity, I will argue that it may indeed be a necessary – but certainly not a sufficient – condition to justify the legitimate use of restrictive measures, especially with regards to quarantine.

C. SCIENTIFIC LEGITIMACY: THEMATISING EFFECTIVENESS IN PUBLIC HEALTH

Nowhere is the tension between scientific validity (facts) and moral legitimacy (norms) more pronounced than in decision-making for quarantine during an emerging communicable disease outbreak. Their intersection is a critical point in my analysis: addresses the problem of justification and it challenges dominant notions of justification. The SARS crisis forced us to explicitly acknowledge the relationship between science and uncertainty, thus challenging the dominant positivist logic that guides policy and decision-making in public health. In spite of this, public health officials, some of whom were themselves involved in decision-making during the SARS crisis, adamantly believed that the decision to quarantine ought to be based on evidence, thereby underdetermining in my view the normative nature of decision-making in quarantine.

When confronted with the fact--and although they conceded--that the SARS crisis demonstrated that decisions cannot rest only on scientific validity to justify public health intervention, most of them stalled when I prompted them to consider on what other basis
decisions regarding quarantine should be made, especially when data is not available. With the exception of one public health official, they ultimately refused to consider the idea that public health decision-making can legitimately be--or more precisely, has to be--based on anything other than science. Indeed, few were willing to rethink the relationship between the adequacy of evidence for the effectiveness of an intervention and its role in the justification of public health intervention. In so doing, they reinforced the unchallenged authority of science--and the role of evidence and effectiveness--in public health decision-making. However uncertainty during a communicable disease outbreak, or during any public health emergency for that matter, forces us to rethink the centrality of evidence implicit in the tenets of public health decision-making and what we mean by the concept of effectiveness (or the effectiveness of an intervention [see for example, Verma et al., 2004]).

In his article What is Clinical Effectiveness? (Ashcroft, 2002), Ashcroft paves a path for us on which to consider these questions in and for public health. He addresses the question of how effectiveness is established by challenging the notion that it is an objective assessment, claiming that it is just an intrinsic property, “a physical property in its own right” (Ashcroft, 2002, p. 224), attributed to treatments (or interventions, or outcomes). He argues that effectiveness cannot be established meaningfully on the basis of objective measurements of the physical properties of treatments. Instead, it is established on the basis of what he calls “a family of properties” that includes physical (intrinsic) properties and relational (intersubjective) properties. For something to be effective, it has to be a function of something else; in other words, it only makes sense in relation to that against which it is measured, analyzed and compared, be it against
objective endpoints, patient preferences, or societal or cultural commitments to constituent communities. In the sphere of clinical medicine, and by extension that of public health, what is deemed to be effective is inextricably tied to, and largely the product of, understandings of ideas, interpretations of (community and patient) preferences, and cultural commitments. Effectiveness is, as Ashcroft (2002) puts it, “effectiveness for some purpose,” and thus the multiple and complex considerations that accompany definitions of, or conclusions about, effectiveness are necessarily bound to claims to effectiveness, and are often used to justify such claims.

As public health action involves multiple communities, it seems reasonable to suggest, therefore, that claims to effectiveness must necessarily seek and engage multiple perspectives. This would entail, or perhaps require, a reconceptualization or broadening of effectiveness that both recognizes and incorporates its relational and normative properties. That is, having evidence of the effectiveness of an intervention derived from a study, no matter how compelling it may be, neither resolves uncertainty about its effectiveness nor sets a necessary course of action (Ashcroft, 2002, p. 232; see also for example, Upshur and Colak, 2003). It certainly does not exhaust the concept of effectiveness.

By definition, then, effectiveness entails much more than empirical and scientific considerations; rather, it involves disparate perspectives that reflect the broader intellectual, institutional, and social context in which public health policies and interventions are made. At the centre of public health practice are persons and practices, woven within the context of ideas and institutions that are the product of a complex social reality that is situated, historical, intersubjective. Hence it follows that arguments about
effectiveness cannot rest on what is simply one privileged perspective among many other legitimate interests and views.

Viewed in this way, the evidence used in policy and decision-making processes is no longer understood exclusively as a scientific pursuit driven to measure effectiveness (or probabilities, or risk), but is instead constitutively provisional and intersubjective. It therefore functions normatively in decision-making only when it is inclusive in its definitions and consultative in its process. Evidence-based decision-making, while it can be extremely useful, is thus insufficient. Although it should be used to reflect upon what constitutes a reasonable and well-justified decision, it cannot be understood or used as an outcome of a decision-making process that is rendered as an objective and absolute assessment. It ought to be understood and used as a process of reasoned or deliberated justification, one that takes into account a diversity of perspectives.

If the logic of this account of effectiveness is correct, then assessing effectiveness on either *a priori* grounds or by virtue of empirical evidence alone is insufficient. The decision to deem quarantine as being effective or not depends as much on evidence from epidemiological studies as it does on explicitly identifying and addressing the preferences and cultural commitments of the affected and involved communities. It follows that public health ought to engage our communities and prompt a dialogue on how best to confront communicable disease control, as well as on which restrictive measures are acceptable to our communities and why.

Further, by establishing that effectiveness has intersubjective dimensions, we necessarily need to reconceive the fact/value epistemological gap inherent in public health policy and decision-making. In other words, we need to reconsider our
understanding of fact, which relies on scientific reasoning and value, which in turn relies on normative ethical analysis. This way, we explicitly recognize that public health decisions actually “carry with them varying levels of empirical certainty” (Callahan and Jennings, p. 173), often blurring the line between the fact/value distinction. Hence the effectiveness of an intervention cannot be the central criterion for justifying interventions, if only because the dominant scientific and empirical notions of effectiveness in both theory and practice do not satisfy a claim to proof.

In the next section, I will turn to the questions raised by participants concerning the enforcement of quarantine and the dilemmas these kinds of questions pose for ensuring compliance to quarantine. By and large, deliberations on compliance focused on – and are the only instance in which participants explicitly appealed to – the law. I will therefore frame the following discussion in terms of the perceived remedial power of the law to address dilemmas around voluntary quarantine & compliance versus compulsory quarantine & justified coercion. This discussion speaks of the role of legal legitimacy in justifying the legitimate use of restrictive measures, more particularly quarantine.

D. LEGAL LEGITIMACY: THEMATISING PUBLIC HEALTH COERCIVE POWERS
The vast majority of participants were concerned with (a perceived lack of) compliance. This is an intriguing finding in my view, in light of the fact that virtually all of them conveyed a genuine desire and voluntariness to support and comply with a quarantine order. Broadly speaking, two main reasons for this emerged from the data: First, compliance was thought to be at times marginal, or at best compromised, because of the oft impracticability of measures and the inherent constraints that such measures pose in accessing basic necessities (hence the essentiality of reciprocity). Second, and more
fundamentally, compliance was thought of as marginal because there was an *a priori* belief that (other) people did not comply with voluntary measures, *even as* participants strongly favoured, and usually advocated, the least restrictive and voluntary measures.

Indeed, although there were differing and often contradictory views on how to bolster and enforce compliance, participants seemed to gravitate towards the view that enforcement measures should be put in place according to a sliding scale, ranging from voluntary compliance to justified coercion. As a general rule, the vast majority supported the use of voluntary measures first and mostly. Yet – and this is where the question of voluntary compliance becomes perplexing – these very same participants, *especially* members of the public, betrayed a sense of distrust towards others and scepticism for whether it could really work, all the while expressing an unwillingness to have recourse to more restrictive measures. Yet again, though still unwilling to use more restrictive measures, participants did ultimately justify the use of coercive measures for those who did not comply. Moreover, they balked at the idea of using restrictive surveillance measures, such as cameras in the home or electronic bracelets—especially for themselves—even after supporting the use of more restrictive measures to ensure compliance.

What is remarkable here is that nearly every participant agreed that increasingly restrictive or coercive measures could be justifiably used for those failing to comply, *as long as* none of these measures were applied to them. Moreover, few were certain that they would comply in the event that any such measures would be broadly applied. Such measures were deemed to be legitimately used in the case of others only (who after all did not comply), because these were not needed for them (who after all did comply). Even a member of the public, who was quarantined at home and honoured what he
genuinely believed to be his duty to comply, admitted that he broke his order of quarantine several hours ahead of its completion in order to attend a friend’s wedding. He was not the only one to say that “everyone thinks they’re the exception…” He was, however, the only one to add, “As I did…” This candid account perfectly illustrates the push and pull that participants felt regarding questions of enforcement. Caught between their commitment to use voluntary measures (which least infringed upon rights) and their recognition of the need to use more restrictive measures in order to ensure compliance (despite their greater infringement on rights), participants were left with the dilemma of how best to exercise the use of these measures.

Perhaps the most intriguing finding here is that as participants explored or accepted the use of increasingly restrictive and coercive measures as a “necessary evil,” they turned to the law as a way to remedy and regulate the inauspicious effects of such measures. Indeed, the existence of laws which serve to protect individual rights seemed to mitigate the malaise that many participants experienced in their deliberations about (enforced) compliance. We can thus discern another underlying belief among participants: As measures get more restrictive, the law plays—and ought to play—a greater role. Here the importance that participants attached to the role of the law is consistent with the dominant view that rights have foundational value, since modern law is itself grounded in the notion of autonomy. It is thus not surprising that participants would appeal to the law as a means of protecting rights against coercive measures.

That the law serves to protect rights against such measures does not, however, address the question of legitimate enforcement. It affirms the legitimacy of the law to protect rights in the context of the use of coercive measures, but it does not affirm the
legitimacy of the law to have recourse to such measures in the first instance. In other words, many participants explicitly articulated the view that the law plays a positive, indeed essential, role in protecting individuals in the unfortunate event that compliance must be coercively enforced, yet very few discussed the legitimacy of the law to coercively (en)force compliance.

Participants asserted the validity of the law to enact and protect rights, which we know were deemed to be inherently legitimate with regards to self-determination. They further recognized, indeed justified, the validity of the law in granting authority to the state to exercise its mandated role in using restrictive measures, and they provided justification for the existence and use of such measures in virtue of the common good. However the vast majority of the participants were silent when it came to the validity of the law to use coercive measures, or increasingly restrictive measures. More importantly, participants were silent with regards to the validity of such measures themselves. In many instances participants took this as a given (“if people don’t comply, there are laws for that” or “certainly if someone doesn’t comply, I would invoke a Section 22 order”). However no one was reflective regarding in terms of how or why they would legitimise such measures. It was presented as a matter of fact – i.e., it’s the law.

This, of course, begs the question: Why are such measures legitimate, even necessary, for others but not for themselves?

What should one make of this finding? It is possible that those participants who expressed this view did not intend to establish a different and more stringent rule of law for others, while excluding themselves? Is this not ostensibly incongruous with their expressed willingness to support and act on behalf of the common good, which the vast
majority affirmed in no uncertain terms? Is it not incongruous with their reliance on the law as a route, or a resource, for governing the use of increasingly restrictive or coercive measures?

It is here, it seems to me, that the argument (in support of legal legitimacy) comes undone. If participants wanted to act on behalf of the common good, would they not unconditionally subject themselves to the law (and attendant laws) without placing limits? In arguing for the caveat that such laws do not apply--and need not be applied--to themselves, does that not undercut the very system upon which they nonetheless depend? More fundamentally, if they do not recognize the use of more restrictive or coercive measures as being legitimate for themselves, does this not indicate that they do not view these as legitimate in the first instance?

Clearly, this finding opens up a Pandora’s Box of issues and questions. If it is possible to capture the contradictions present in participants’ deliberations on compliance, I would submit that there is an implicit distinction to be made therein. This finding suggests that incongruity exists between the acceptability of (the inherent validity of) the institution of law to protect basic rights, even to govern the use of restrictive measures, and the unacceptability, or the questioning, of (the inherent validity of) laws themselves. The tension between these two seemingly contradictory poles creates a dialectic that leads me to a more fundamental synthesis. That the tension inherent in participants’ accounts can be understood as intimations of the paradoxical nature of: 1) the historical and conceptual power of the law to both guarantee rights and give authority to the state to use restrictive measures (to achieve public health goals); and 2) the philosophical failure of the law to provide justification for those laws themselves,
especially concerning the justification of the use of restrictive measures and, more poignantly, measures that can be legitimately coercively enforced.

In essence, the ambiguities and contradictions found in participants’ accounts regarding compliance reflect what I perceive to be the uneasy embodiment—and ultimately the indeterminacy—of the law and the coercive role of the state in liberal democratic societies. Legal legitimacy, like scientific legitimacy, is neither absolute nor can it be taken as a given, such that a legal positivist viewpoint would underpin. I agree with Sumner, who incisively observes that

...in normative debates on public issues, appeals to rights are not, or are not only, appeals to legal rights. Instead, or additionally, they are appeals to moral rights which cannot, by their nature, be authoritatively declared by any legal institution (Sumner, 1987, p. 6).

Put simply, laws are not necessarily legitimate just because they have been enacted through Parliament or a legislative body. Rights claims and appeals to the law function normatively as moral considerations that require foundational conditions—or as Sumner puts it, “a standard of authenticity” (1987, pp. 1-14) —to satisfy a claim to legitimacy. As Sumner further comments:

Legal rights are the creatures of institutions, and especially of legislatures and courts. Since legal institutions and legal systems are themselves subject to assessment for the extent to which they respect basic rights, their pronouncements cannot provide an authoritative standard of authenticity for such rights (Sumner, 1987, p. 6).

Thus the question arises: What makes the law (or laws or legal authority) legitimate? The importance of this question is obvious: It underlines the fact that legality or constitutionality does not correspond to legitimacy, though, as Habermas (1975, pp. 97-102) emphasizes and I will discuss below, legality and legitimacy are often taken to be one and the same (see for example, Boggio, 2008). In view of the fact that participants
did not question the nature or the legitimacy of the law (the law is presented as a matter of fact), it would seem plausible to conclude that they too would be inclined to treat legality and legitimacy as unproblematic and, as such, the question of what makes the law legitimate would be rendered irrelevant. Such a conjecture, however, does not explain the inconsistencies that underlied participants’ accounts, especially with respect to questions of compliance. And if we are to adequately grasp embedded meanings in the data, I believe that we have to account for the discontinuities and contradictions which, I want to argue, point to sources of tension inherent to legitimacy claims in liberal democratic societies.

If the foregoing analysis is correct, I believe that this points to the possibility, indeed the reality, that different laws or uses of the law command different levels of legitimacy in the eyes of participants. The view that participants may hold of the (nature of the) law can be understood against the backdrop of the following considerations: On the whole, there is a kind of reflexivity interwoven in the participants’ deliberations that finds expression in two interrelated, though distinct, ways. First, the data raises more questions than answers. Participants themselves often acknowledged that they raise more questions than give answers and in so doing, they reflexively (re)examine views or notions that they initially formulated. Many participants also suggested, albeit at times implicitly, that everything pertaining to quarantine or the use of restrictive measures ought to be constantly (re)examined, (re)interpreted, and (re)formed in light of new incoming information and knowledge. Second, what I call this discourse model of reflexivity leads the vast majority of participants to propose a medium for addressing these questions by way of deliberation, which is, in and of itself, reflexive.
Put simply, the rationale for this view hinges on the assumption that concerns about public health intervention can be tackled through the medium of public deliberation. As such, practically everyone turned to communication as a major, perhaps the only, strategy to both negotiate and justify decisions made on public health grounds. Here we can discern another underlying belief among participants: The greater the degree of communication, the greater the legitimacy of public health measures or interventions. Through this lens, we begin to see that participants superimpose communicative norms on their expectations (albeit unchallenged) of legal norms and their expectations of public health measures taken for the common good.

And it is here that we begin to see the glimmerings of communicative action consonant with Habermas’ theory of communicative rationality (or discourse ethics). The tacit presupposition embedded in participants’ accounts is that the question of what makes the law (or legal authority, or the use of restrictive measures) legitimate requires an argumentative framework that can yield a set of conditions to provide a foundation for--and which shape--the lawmaking and policy processes. In other words, the legitimate use of restrictive measures requires a legitimate (lawmaking and policy) process which, in turn, can only derive from a process of (moral) argumentation.

Implicit in this view is the insufficiency of appealing to legal legitimacy in order to provide justificatory power for the legitimate use of restrictive measures during communicable disease outbreaks. As I will discuss in the next section, moral legitimacy both forms the basis and complements the requirements of legal and scientific legitimacy in justifying the legitimate use of restrictive measures.
The data underscores what was already apparent from our experience during the SARS crisis, namely that there is a lack of mutual understanding – an ethos – within the community of citizens itself, and between the latter and public health, with regards to what constitutes legitimate norms for communicable disease control. Furthermore, there is a lack of mutual engagement – a procedure – for vindicating the validity of such norms. It is enormously significant that the participants expressed a willingness to reach a common understanding, and that the decisive force in shaping the fabric of such an understanding is communication. This could provide an empirical basis upon which to construct such an ethos and a procedure. By asserting the importance of—and the need for—communicative practices, participants began to articulate what for me is a democratic notion of discursive and participatory politics.

This is remarkably consonant with a Habermasian theory of communicative action, according to which argumentation is both the foundation and the vehicle to determine the validity of (the formation of shared) norms. What’s more is that the participants, like Habermas, were committed to a dual vision of autonomy and community, and they proceeded from the perspective that the individual is a bearer of rights within that community. As I discussed earlier, this is not a surprising finding, for in its essence it is consistent with the self-understandings of the vast majority of citizens in liberal democracies. That being said, although the large majority of participants expressed views that were on the whole consistent with liberal values – in fact those committed to some form of communitarianism (without regard for the status of rights) were largely spiritual leaders – they expressed or hinted at values that reveal a yearning for the ideal of community, not only for temporary arrangements such as quarantine. Like
Habermas they were able to conceptualise, indeed regard as crucial, that the society in which they live--or ought to live in--is not only a community of rights-bearing individuals who accord each other equal rights and liberties via a social and/or private contract. They are--or ought to be--an organised social structure that communicates, coordinates and cooperates in order to establish a community with common norms and goals for the life of the community as a whole. By recognizing the need for some kind of social solidarity, participants looked towards communication practices that confronted these issues in order to develop a shared understanding and agreement on what counts, what matters, what is appropriate.

This is significant inasmuch as this view took shape reflexively. Participants wavered and vacillated between (often contradictory and conflicting) views before committing to both the common good and individual rights, not to one or the other. A further significance is that their commitment was not entirely consistent with either (dominant) liberal or communitarian views. Furthermore, a large majority of participants ultimately gave equal status to the common good and individual rights, even if they began from liberal assumptions (that necessarily give priority to rights). This duality serves two important purposes: First, it challenges dominant notions of agency. By placing equal weight on the individual and the community, while still retaining the status of the self-determining agent, participants transcended, like Habermas, the positivist notion of the “unencumbered” or the “disembedded” self and instead embraced an intersubjective understanding of agency. In other words, the individual is no longer the only valid source of moral authority, which instead is conceived to reside within--and is shaped by--the community of citizens (the public sphere). Corollarily, this view transcends the deeply-
entrenched dichotomy between the right and the good (which leaves us in a stalemate) by providing the foundation to begin moving towards a model wherein they co-exist.

If the foregoing analysis is correct, it can be argued that the data mirrors a Habermasian analysis of modern society: That our society ought to be rooted in a notion of intersubjectivity framed in communicative terms, from which legitimacy claims rest on the vindication and acceptance of these claims. Habermas gives expression to what is implicit in the participants’ accounts: He reconstructs the notion of the autonomous individual so as to be consistent with the notion of the good, or the public sphere, not antithetical to it. In this sense he provides a real alternative, not only to recreate the synthesis between the individual and the community, but to fuse public health and human rights into an integral, seamless relationship. What this requires, and is largely missing in (dominant) liberal institutions and practices, is a positive notion of the public citizen deliberating in a public sphere. And what this requires, in turn, is that we reconstruct the conditions for the possibility of a legitimate order – a reconstruction necessary to move beyond the instrumental logic of positivism within which the conditions for a legitimate public discourse have been expunged.

Yet how do we conceive of a public citizen that maintains her rights and freedoms while establishing and vindicating norms that are no longer independently derived? That is, how is it possible to make both the private and public spheres a moral priority, without giving a privileged justification to either one? This is an important and complex question for our inquiry into the relationship between public health and human rights. It allows for an analysis of the status accorded to rights in relation to public health and, most importantly, it creates an opening to question the dominant positivist paradigm that
privileges both rights and a deontological understanding of agency. Only by doing this will be possible to reconceive their relationship. Before elaborating on how this is possible from a Habermasian perspective, let us return to the data and reflect upon the empirical resonance of the notion of the public citizen.

As a point of reference, if we look to theories of democratic citizenship, the political imperative for these is to elucidate the virtues and responsibilities of democratic citizens. Yet although most of the participants of this inquiry expressed the view that respecting quarantine is a “civic duty,” none of them talked about the civic virtues of citizenship or what it means to be a virtuous citizen. It would be plausible to argue that most participants implicitly understood themselves to be public citizens that are part of a greater web, in view of the finding that they already had a notion of the “common good” (despite the differences in interpretation of what this represents).

Furthermore, the large majority viewed themselves not only as receivers of information and expert knowledge, but also as members of a community, citizens who have the ability to make useful and necessary contributions to the process of establishing appropriate norms and practices relevant to communicable disease outbreaks – or more generally, a situation that concerned everyone. Thus while they did not talk explicitly about the virtuous citizen, there was an awareness of their capacity for public citizenship.

A notable exception was found during interviews with public health officials and spiritual leaders, who relied instead upon expert knowledge and largely viewed members of society as recipients of information. Although it is not within the scope of this analysis to discuss the significance and relevance of this finding among the spiritual community, it is especially significant that public health officials thought this because it speaks to two
intersecting considerations: First, that they, at present the primary – if not the only actors – who make decisions during emergencies, reinforce the positivistic scientific discourse on knowledge (of expertise and democratic deficits\textsuperscript{51}); and second, that the relationship between citizens and (agents of) the state is at best precarious, and they hold different understandings of what constitutes a legitimate decision.

Furthermore, it would be plausible to argue that participants did speak of (what would basically be) the “unrighteous” citizen by emphasizing the (perceived) common occurrence of those who did not adhere to measures. It is especially significant that the majority of participants expressed this view because it underpins a concept of “otherness,” an essentially individualistic understanding of society that is completely devoid of trust in the citizenry, even as they embraced the desire to establish networks of communication with this same citizenry. I decipher two things from this: That what matters to participants is not necessarily issues of civic virtues required for public deliberation – \textit{i.e.}, how to “create” the virtuous citizen in order to properly deliberate, but that what does matter–and takes precedence–is the \textit{process} of deliberation itself – \textit{i.e.}, how to deliberate in order to achieve a desired outcome).

Thus for most participants, the question is not only about what is required or appropriate during public crises, but also about \textit{how} to resolve ambiguities around what is required or appropriate. In this vein, three things clearly emerged: 1) what is required or appropriate is tightly tied to the exigencies of society as a whole – better yet, it is tied to the process of becoming a greater whole; 2) the process of what is required or appropriate

\textsuperscript{51} The view of democratic deficits presupposes public ignorance on scientific knowledge or a public that is uninformed about the facts. It views the person “as a repository of knowledge” that requires information and education (Irwin and Michael, 2003, p. 26; as quoted in Thompson, 2005, p. 34) to “remedy” the rejection or misunderstanding of the science.
has to be determined largely through communication based on facts (what we know, namely epidemiological data) and norms (what is relevant, namely the kinds of measures and what we need, namely the question of reciprocity); and, finally 3) the law is seen as a channel that legitimately regulates interventions, even though, paradoxically, participants thought that attendant laws were either irrelevant or inappropriate for themselves.

If the foregoing analysis is correct, it can be argued that these findings provide empirical support for Habermas’ understanding of modern law and law-related processes – i.e., that legality is not legitimacy. If participants would agree that the justification of norms ought to be derived discursively and that the medium of the law is viewed as an institution that legitimately secures rights, then it follows that the production (lawmaking) of legitimate law ought to be achieved discursively. That is, the standard for the legitimacy of the law ought to be the discourse principle.

From this basis, it can be interpreted that participants would agree with Habermas’ view that the law is--or at least ought to be--the institutionalised domain of practical discourse. In other words, while communicative action provides the conditions for the possibility of making a claim to validity discursively, the medium of the law provides the conditions for the possibility of a legitimate order by making communicatively-achieved decisions binding. That is, in order to achieve collective decisions that are binding, to secure them through the application of sanctions, if necessary, we must institutionalize practical discourse through legal and political powers. The legitimacy of these institutions themselves, however, is achieved discursively (Habermas, 1996, Postcript).
What this means is that the law in its capacity as a coercive instrument must be able to hold society together, while the conditions for the possibility of its coercive application is that it is valid (Rasmussen, 1996, p. 28). Therefore a legitimate order (or legitimate laws, or legitimate authority, or legitimate claims, or legitimate restrictive measures) depends entirely on the legitimacy of law- and policy-making processes. These occur, according to Habermas, on two inextricably linked levels: 1) through “legally constituted political will-formation” procedures – achieved via private autonomy; and 2) in the “communicative flows of autonomous private spheres” (Habermas, 1989, p. 154; as quoted in Guibentif, 1996, p. 57) – achieved via public autonomy – or put another way, the use of a public reason (public deliberation) anchored in a public sphere. The point here is that there is an inextricable link between private and public autonomy; that is, the autonomy of citizens and the legitimacy of norms are inextricably linked through discursive will-formation. This, according to Habermas, is the essence of the conditions for a legitimate order.

This means that the establishment of laws, or more broadly norms, implies the guarantee of individual liberties – basic rights – which are implicit in every democratic order. This does not mean, however, that human rights take precedence or are originary. The specific content of these rights become legitimate only as products of deliberative political processes. Put another way, they must be completed through deliberative and participatory processes. This way, as Rasmussen explains, “The substance of human rights is written into the very discursive shape of the process of reaching an understanding which derives autonomy intersubjectively” (Rasmussen, 1996, p. 29). Against this background, the law-making discretion of judges is discursively recast. The
establishment and vindication of shared norms would necessarily refer beyond the immediacy of a judgement of an individual to the intersubjectivity of enfranchised citizens. Thus the universal right to equal liberties (conceived as human rights) allows the undertaking of the establishment of positive law (political rights) not because it *precedes* the process of lawmaking, but because it is *written into* the very discursive process of lawmaking – *i.e.* the deliberative process of political opinion- and will-formation to achieve collectively binding decisions in the medium of law.

Without it, there can be no unfettered political public sphere; that is, there can be no deliberative community. However while the discourse principle presupposes such a community, it is not a precondition to--it does not ground--political participation because it remains indeterminate until it is tested, indeed completed, through deliberation. Rather than ascribing a greater role to agency, where individuals use their communicative liberties to enter into a contract with a view to pursuing their own values and interests, the deliberative paradigm is constitutive of an intersubjectively exercised civic autonomy, wherein citizens use their communicative liberties for the purpose of the public use of reason – *i.e.*, with an orientation toward the common. Thus the Habermasian view that law and morality have a complementary relation, meaning that law is not subordinate to--does not draw its legitimacy from--a higher ranking moral or natural law, makes it possible to reposition public health (as political rights) and human rights (as subjective liberties) in relation to one another rather than against or in opposition of one another.

In sum, while the individual retains her ontological status accorded to her in modernity, the rights of the individual, and the individual herself, exist through, but not prior to, political rights, or more broadly, her socialization. That is, as the participants of
this inquiry affirmed, she is still conceived as an autonomous self-determining agent but, as they discerned, she is not self-contained, which the dominant liberal paradigm presupposes. Decisions about the good life are not a private matter or a question of self-determination (private autonomy), but are made through the public use of reason (public autonomy). Individuals use their capacity for self-determination, not only to make self-determining choices, but also to make collective choices. There is thus a crucial distinction that is made: While the self is prior to the ends, rights are not necessarily prior to the good. In this way, Habermas places the source of justification on a dual foundation of public autonomy – the public use of reason to make decisions about the good life – and private autonomy – the capacity for self-determination that makes it possible to make these decisions. Unlike the dominant liberal paradigm, wherein the good depends on the right, in this sense there is a symbiotic relationship where the right also depends on the good; one cannot exist without the other.
CHAPTER 8:
CONCLUDING REMARKS

For more than a century, as the divorce between spheres themselves and the disjunction, the *antinomie*, between social structures and the development of an independent subject against its community have continued to deepen, we find ourselves in a feverish revolutionary transformation of values engendered by science and technique that privileges speed, rhythm, movement...where mass consumption takes the form of a vector of individualisation where the do-it-yourself, self-help, self-care, self-improvement kit is valued. We find ourselves, individualised and narcissistic, living in the "era of emptiness."


The *democratic process* bears the entire burden of legitimisation.

– Jürgen Habermas, 1996, Postcript

A. REDEFINING THE RELATIONSHIP

This final analysis brings to light how we can reconceptualise the relationship between public health and human rights. To date, the debate has been largely focused on the need to integrate human rights considerations into public health practice. Attempts to reconcile public health and human rights considerations have amounted only to *recognition* of each other – *i.e.*, that both are important and one takes precedence at certain times, while the other takes precedence at other times. There is a presumed dichotomy, and an inherent indeterminacy, in the interpretation of what takes precedence and when and to what extent and according to whom? What is more, the so-called intrinsic links that were established between them during the HIV/AIDS debate to attempt to render them compatible are merely conceptual in nature, and recent experiences have shown that there is no real synthesis.

Attempts to reconcile both institutions have foundered, I contend, because none addresses the root of the dilemma, which is operative at a metaphysical/ontological
debate/level. Indeed, the problem stems from the privileging of the claim that the right is prior to the good, not only in that its claims take precedence, except under extraordinary circumstances, but also in that its principles are independently derived (i.e., the modern individual is presumed to enjoy personal freedom, imbued with a natural right). No matter how we try to incorporate rights considerations with a view to the common good, if the liberal notion of the moral principle – i.e., grounded in individual conscience that necessarily, which is to say unthematically, guarantees the autonomy of citizens – remains the sole source of legitimacy, the bases for justification of public health and human rights are neither compatible nor reconcilable. Thus, we must confront the public health/human rights debate at the level of ontology, viewed in terms of the relationship between, or the (modern) differentiation of, the private and public spheres.

It is my contention that we should broaden the debate by bringing in dialogue public health ethics and a Habermasian theory of communicative rationality and concomitant philosophy of law (instead of simply attempting to bring human rights to bear on public health). This provides a different point of departure for conceptualizing their relationship. Habermas transcends what for him is the exceedingly subjective character of the dominant notion of rights by making a clear-cut distinction between private autonomy (human rights) and public autonomy (political rights). He gives equal weight to both conceptions of autonomy based on the assumption that both spheres are co-original, that is to say they are reciprocally granted through discursive will-formation, or put another way, communicative action (Habermas, 1996, Postscript). In this reconceived logic, there is a dialectical--rather than a competitive--relationship between
private and public autonomy. To exist, they must refer to each other. Communicative action bridges the gap between individual liberty and collective political engagement.

Previous articulations of the idea of a political community of free and equal persons have foundered on their inability to resolve the conflict between private and public autonomy – the problem, that is, is that both positions are rooted in notions of subjectivity (Roderick, 1986, p. 12). For Habermas, however, a political community (or collective political engagement) cannot be premised on subjectivity because “it cannot itself serve as the basis for explanation of moral justification or knowledge claims” (Roderick, 1986, p. 6), or it cannot explain how social interaction is possible, which is why he adopts an intersubjectivist paradigm. He attempts to resolve the dilemmas of subject-centered reason by broadening what many view as the (dominant) too limited Kantian vision of reason by reason understood as communicative action. As Strong and Sposito aptly put it, Habermas’ project is to “throw out the subjective bath water while retaining the reasonable baby” (1995, pp. 268-269).

To do this, he reconstitutes a positive notion of the public citizen that deliberates in an unfettered public sphere through an intersubjectivist paradigm. In theories of citizenship, for example, there is an underlying assumption, broadly speaking, that the responsibility “to live up to the demands of democratic citizenship” and “display the civic virtues it requires” (Kymlicka, 2002, p. 294) falls on--is contingent upon--its citizens’ integrity, competence, etc. In other words, it is the responsibility of citizens to exercise civic virtues conducive to the viability of democracy; it is a matter of individual responsibility that requires “cooperation and self-restraint in the exercise of private power” (Kymlicka, 2002, p. 285). Yet here too the proper object of justice is still seen in
individualistic terms, which does not in my view, convincingly transcend the bifurcation of the individual and the collective. Moreover, theories of citizenship aim to identify which and how institutions and practices inculcate civic virtues in terms of their instrumental importance (to sustain just institutions). Thus, theories of democratic citizenship largely seek to define the ideal public citizen that acts to promote and sustain just institutions, while Habermas recasts the public citizen in a reconstituted public sphere; in a sense, metaphorically speaking, the former takes unthematised institutions and practices to a public citizen yet to be shaped, while Habermas takes the public citizen to the institutions and practices yet to be shaped. This way, he places the public citizen at the centre of the process of legitimation.

Thus conceived, the marriage of public health and human rights becomes an integrative process at the intersubjective level conjoining the processes of public health policy- and law-making through discourse – or more fundamentally a public health ethics that discursively makes explicit what is required or appropriate in the process of public health policy- and law-making for communicable disease outbreaks. Today, the foundations and the ambit of public health law and, more broadly, understandings of public health practice, are in flux. The confluence of recent events presents a propitious opportunity to rethink the basis of public health law and practice, especially in the context of emergencies, to warrant legitimacy. The legitimacy of the law and decisions about the use of restrictive measures--and how to warrant them--is especially crucial in the face of an environment operating within conditions of uncertainty and incomplete information, such as was the case with SARS. What is more, the interrelated processes of production and legitimation of public health policy- and law-making for communicable
disease outbreaks are even more crucial in new or evolving legal and ethical environments, such as is the case with public health emergencies today, that raise complex ethical questions and that require moral discernment.

The requirements of moral legitimacy can no longer continue to be eclipsed by the imperatives of scientific and legal systems of legitimacy or take as a given positivist rationality, which has achieved an institutionally secured predominance, narrowing the issues to technical problem-solving, and excluding, almost predominantly, their contextual and contested character that gives a voice to non-scientific, non-technical perspectives, experiences, preferences, cultural commitments, norms, values, interests – what Habermas calls the lifeworld.

B. PUBLIC HEALTH AS A DELIBERATIVE PRACTICE

At the centre of this inquiry is the question of what constitutes the legitimate use of restrictive measures. Collectively, participants’ accounts hone in on a fundamental political-philosophical divide in our society that substantiates the relevance of this question. *There is a genuine support* for the use of restrictive measures as a channel for the individual to participate in the common good – *i.e.*, the use of restrictive measures, or any other coercive intervention for that matter, is for the “good of society,” it is “for the community;” *yet there is a lack of genuine support* for the kinds of measures that the common good demands – *i.e.*, the validity of all kinds of measures used during the SARS outbreak is in question consistently throughout participants’ accounts. Hence it may be argued that the use of restrictive measures is given theoretical justification, but lacking any undergirding in genuine popular sovereignty, we are left with no empirically-based
claim to legitimacy from those to whom these measures are applied, the community of citizens.

The participants of this inquiry reinforced Habermas’ claim that the appropriate source for establishing and determining the legitimacy of the use of restrictive measures derives from the perspectives of those to whom it is applied – rather than from the canons of statistical methods. Thus, they established the supremacy of discursive processes over bureaucratic authority and, in this way, fractured assumptions that policy and decision processes are at best objective or ought to be done by experts.

The decision to implement a system of quarantine cannot be justified or grounded in a notion of effectiveness simply determined in scientific terms. Uncertainty is never fully resolved and as such, evidence based decision-making ought to be used to reflect on what constitutes a reasonable and well-justified decision – not because it was scientifically-measured or objectively assessed – but because it can serve as a process of reasoned or deliberated justification. The tendency to impart a fixed set of prescriptions and to reduce complex situations to technical problems resolvable by scientific expertise (Nelkin, 1987, p. 1) can be compelling in the face of so much uncertainty. Yet in a democratic society, expertise cannot be legitimately limited and left to scientific experts.

By validating other legitimate interests and perspectives in public health decision-making, we would simply be acknowledging what is already a reality in how decisions are made, especially as they relate to decisions about quarantine. Even if data is available – thus rendering what would be deemed to be a definitive evidence base for decision-making – the nature of decisions will always and inevitably involve making judgements by virtue of the fact that what is construed as “evidence” is itself made based on a series
of judgements made along the way – from the selection about what counts as fact (Irwin, 2001, p. 14) or what constitutes relevant data to decisions made about how to interpret or cast the results. Thus conceived, claims to legitimacy are not based upon an ostensibly neutral expertise – it cannot derive from a set of proven and verifiable data.

What is more, causal generalizations upon which positivist rationality might base policy interventions, which regard policy as a purely technical matter, have proven to be thoroughly elusive. Established orientations to policy formation and analysis fail to take account of the broader political and social context, where communicative interaction looms large, mostly because they have a common root in a purely instrumental notion of policy rationality. They bracket the communicative element in the elaboration and application of policies and laws, in the same way that the clear-cut distinction between production and consumption suggests a sharp separation between the elaboration and the application processes.

Following the suggestion of Habermas, research design ought to be developed such that it joins observations of the production process of policies and laws with observations of their application, in order to confirm empirically the links between discussions surrounding the production and attitudes in the application contexts. For example, a public health ethics could make explicit and illustrate the relevance of the view that legitimation occurs through deliberation.

There is no question that deliberation has become a pivotal notion, if not the pivotal notion, in both discourse and practice in today’s society. Nearly every philosophical tradition – liberalism, communitarianism, feminism, multiculturalism – has
adopted what was largely the domain of critical social theory elucidated by Habermas
and embraced the need for a broadened deliberative view. As Talisser expressed:

That the literature on deliberation admits of greater crossover and
intercommunication between otherwise divided theorists provides a prima facie
reason for thinking that the turn to deliberation marks a decisive improvement
over the liberal-communitarian problematic (Talisser, 2001, p. 286),

which had largely arrived at a stalemate. The growing theoretical and empirical literature
on deliberation and deliberative democracy clearly shows that it has entered mainstream
acceptance (see for example, Guttman and Thompson, 1996, 1997; Abelson et al., 2004,
2003a, 2003b, 2002); Beetham, 1992; Benhabib, 1996; Bohman, 1996; Bohman and
Rehg, 1997; Dryzek, 1990). Moreover, the last two decades or so have seen an increasing
number of institutional and social developments whose very claim to legitimacy rests on
the informed participation and consent of those most affected. New forums for
deliberation that include public inquiries, citizen juries, town hall meetings,
environmental and social impact assessments, mediation, informal dispute resolution,
among others, seem to be redefining processes of policy-making (see for example,
Thompson, 2005; Einsiedel, 2002).

Even on an international scale, there is a growing literature on the use of--and the
need for--communicative action in international politics based on two Habermasian
preconditions for rational deliberations – that of an ideal speech situation and a common
lifeword (Mitzen, 2005; Kapoor 2004; Müller 2004; Risse, 2000). The discursive
landscape of 2003 World Trade Organization (WTO) Decision (World Trade
Organization, 2003) that defined conditions under which a country could export
pharmaceutical products to another under a compulsory license (stemming from the 2001
Doha Declaration on the TRIPS Agreement and Public Health (World Trade
Organization, 2001), intended to reconcile intellectual property rights and access to medicines [Roffe, Spennemann & von Braun, 2006, p. 10]) is a case in point. As Morin and Gold (2008) argue:

Officially, under the Agreement Establishing the WTO, an interpretation of the TRIPs Agreement regarding the use of compulsory licenses could have been taken by a three-fourths majority. In practice however, this procedural rule was not followed and a norm of consensus dominated the process. No country ever requested a vote and no NGO actively promoted this option. Although the issue was presented as a matter of life and death by some delegations, WTO members were determined to take the time necessary to convince each other and overcome any resistance. Even when the December 2002 deadline elapsed with the US remaining the only country resisting the proposed waiver, the norm of consensus-seeking remained unbroken.

Indeed, deliberation is now often seen as the most desirable process to govern trade-related matters (Wolfe, 2005; Kapoor, 2004; King 2003).

The impetus to democratize decision-making processes, in other words, to create space for public engagement and participation, has been driven from the bottom up largely in response to the ubiquitous power of science to essentially modify how we live, what we eat and who we are. As such, it is becoming virtually impossible today to make policy decisions without considering the broader intellectual, institutional, and social context in which the concerns about science are arising and must be addressed. Greater public participation in considering the support, application and commercialisation of new technologies, for example, has become both necessary and desirable.

To a great extent, public health has been shielded from this trend. This is because, I suspect, matters of public health have only recently become visible, derived from the emergence and re-emergence of communicable disease outbreaks and other public health emergencies that have had tragic consequences for entire communities. To be sure, the Public Health Agency of Canada has begun opening its processes of policy-making to
deliberation (Public Health Agency of Canada, 2004). The ethical conflicts and the moral contradictions such tragedies and emergencies raise are palpable, not just for those involved in making decisions about interventions, but for those to whom these are applied, which clearly came out in the interviews I conducted. It is greatly significant, in my view, that the large majority of participants viewed themselves not only as receivers of information and expert knowledge but as members of a community who have the ability to make useful and necessary contributions to the process of establishing appropriate norms and practices relevant to communicable disease outbreaks – or more generally, a situation that concerns everyone.

Thus, I want to conclude, both members of the public and what we consider experts ought to participate in making these decisions both in the process of considering policy but also, or perhaps especially, in setting policy. This is necessary inasmuch as participants’ deliberations are fraught with ambiguities and contradictions and there were many more questions raised or left unanswered than answers. For example, while participants agreed that the common good matters, they disagreed about what it is, or how much it matters. Moreover, while there was a near-unanimous view that the state should satisfy individuals’ needs, that is, provide that to which they are entitled, participants grappled with what that should look like. What counts as an entitlement – i.e., what should be provided and by whom – or what constitutes an effective or an appropriate intervention was the source of great discord. This is where the findings of this inquiry grow most interesting and offer contextual insight. But, more than that, this is where these kernels of conflict and ambiguity show the greatest potential for new developments in public health policy- and law-making.
Following a Habermasian lens, I want to argue in final analysis, that public health, and a public health ethics that underpins it, ought to open its processes of decision-making to a moral-practical discourse, that is to say, a new understanding of legitimacy, to expand the scope of moral argumentation of public health deliberations on--and ultimately to ground the justification of--the use of restrictive measures. Like Habermas contends, democratic legitimacy is measured, not just by law being enacted by a majority, but also in terms of the discursive quality of the deliberative processes by which collective binding decisions were generated.

C. LIMITATIONS AND CAVEATS

One may wonder whether the findings of this research would hold in other scenarios given that this research was generally oriented towards the SARS epidemic. However, while this project was born out of the SARS experience in Toronto, discussions with participants revolved around communicable disease outbreaks in general. Likewise, participants were not limited to SARS-impacted institutions. As well, given that I conducted this inquiry against the backdrop of the threat of pandemic influenza, this prospect, and the wide media coverage surrounding it, informed participants’ views. Moreover, many participants drew on their past experiences during outbreaks of polio, tuberculosis, and malaria. As such, I believe that the findings of this inquiry are directly applicable to the current debate on pandemic influenza preparedness and other newly emerging communicable diseases, such as XDR-TB. That being said, it is important to underscore that the aim of this inquiry was not to achieve quantitative or demographic representation but rather to explore what is representative for the development of
meaning, or what we might call theoretical representation, by surfacing the ethical issues raised by communicable disease outbreaks.

One may wonder whether there were any important differences or similarities in the general views of those interviewed. As noted in the discussion, there was a significant gap in perspectives between public health officials and members of the public, especially when it came to the question of reciprocity and the acceptability of restrictive measures, further reinforcing the need, in my view, for engaging the voices of the public in public health policy-making. Overall, however, there were in fact very few significant variations in views among the constituent groups, which gives further legitimacy to the idea that it is possible, as Habermas surmised, to articulate views with an orientation towards the common good and the liberal concept of rights-bearing individuals is compatible with and capable of unity regarding fundamental shared norms.

One may question whether empiric findings are necessary or sufficient for the normative claims I make and perhaps argue that it may be more appropriate to simply report the findings without making such claims. However, it is my view that research is neither wholly empirical nor normative, which I believe is a false dichotomy. If empirical scholars did not seek to make normative claims based on the findings of their research, then it is unclear what would be the objective of empirical research – if not to interpret data and derive normative claims to inform policy and practice. This was indeed the aim of this qualitative inquiry. I sought to establish an empirical basis for the legitimate justifiability of using restrictive measures during communicable disease outbreaks - i.e., to interpret data and derive normative claims to inform policy processes and public health practice.
WORKS CITED


American Civil Liberties Union (February 1988) Isolation or Quarantine of HIV-Infected Persons. AIDS Project Briefing Paper.


Chapin CV (1910) Sources and Modes of Infection. New York: Wiley.


Facione PA et al. (1978) *Values and Society: An introduction to ethics and social philosophy*. Prentice-Hall.


Forster TIM (1832) *Facts and Enquiries Respecting the Source of Epidemia*. Keating and Brown.


Hancock T (1821) *Researches into the Laws and Phenomena of Pestilence; including a medical sketch and review of the plague of London in 1665; and remarks on quarantine*. W. Phillips.


Jacobson v. Massachusetts (1905) 197 US Supreme Court.


Leshner AI (January 2008) Tension often exists between scientific advances and human values. 28th Annual Joseph W. Mountin Lecture.


Markel H (2005) When Germs Travel: Six major epidemics that have invaded American since 1900 and the Fears they have Unleashed. New York: Pantheon Books.


Morse JM (March 2007) Qualitative Researchers Don’t Count. *Qualitative Health Research*. 17(3): 287.


World Health Organization Constitution

Accessed April 2009.


WERE YOU LIVING IN TORONTO DURING SARS?

If so, researchers at U of T would like to hear your thoughts on the many ethical issues raised by infectious disease outbreaks.

- Should public health officials have the power to quarantine people?
- Do citizens have a civic duty to respect a quarantine order?

All interested persons qualify. Short telephone interviews to be scheduled at your convenience. All data will remain strictly confidential.

To enrol in the study or for further information, please contact Cécile:
Phone: 416-480-6100 ext. 7095
E-mail: cmb7095@yahoo.ca
WERE YOU WORKING IN A HOSPITAL DURING SARS?

If so, researchers at U of T would like to hear your thoughts on the many ethical issues raised by infectious disease outbreaks.

- Should hospital employees (cleaners, administrators, nurses, etc.) have the right to refuse to come to work during an infectious disease outbreak?
- Should clinical staff be forced to treat highly-contagious patients?

All interested hospital employees qualify. Short telephone interviews to be scheduled at your convenience. All data will remain strictly confidential.

To enroll in the study or for further information, please contact Cécile:
Phone: 416-480-6100 ext. 7095
E-mail: cmb7095@yahoo.ca
October 2004

Dear [Name]:

RE: Study on Ethical Issues during Public Health Emergencies

We are currently conducting a study on the ethical issues that are raised during a public health emergency, such as the one experienced during the SARS epidemic. In particular, the aim of this study is to increase our understanding of the effectiveness of quarantine and the use of other restrictive measures to contain the spread of infectious diseases. We would like to gather the views of health care providers, such as yourself, on the benefits and harms of quarantine as well as the conditions that would justify implementing such measures. We hope to obtain many different perspectives and viewpoints on this important topic.

We would like to invite you to participate in a 30-minute interview that will give you the opportunity to share your views with us. The interview would be scheduled at your convenience in person or by telephone. Please note that all data collected as well as the identity of all participants will remain anonymous in all of the reports originating from this research. As well, participants can withdraw their consent at any time. Your input is extremely important because it will ensure that future public health policies will appropriately guide public health decisions during times of emergencies.

I have asked Cécile Bensimon, research associate on this study, to contact you regarding your potential participation. In the meantime, please do not hesitate to contact her with any questions or concerns you may have. She can be reached via electronic mail at cecile.bensimon@utoronto.ca or by telephone at (416) 480-6100 ext. 7095.

Thank you very much for your time and consideration.

Sincerely,

[Signature]

Dr. Ross E.G. Upshur, MA, MD, MSc, FRCPC
Director, Primary Care Research Unit
Sunnybrook and Women’s College Health Sciences Centre
Associate Professor, Departments of Community Family Medicine and Public Health Sciences
University of Toronto
October 2004

Dear [Name]:

RE: Study on Ethical Issues during Public Health Emergencies

We are currently conducting a study on the ethical issues that are raised during a public health emergency, such as the one experienced during the SARS epidemic. In particular, the aim of this study is to increase our understanding of the effectiveness of quarantine and the use of other restrictive measures to contain the spread of infectious diseases. We would like to gather the views of public health officials, such as yourself, on the benefits and harms of quarantine as well as the conditions that would justify implementing such measures. We hope to obtain many different perspectives and viewpoints on this important topic.

We would like to invite you to participate in a 30-minute interview that will give you the opportunity to share your views with us. The interview would be scheduled at your convenience in person or by telephone. Please note that all data collected as well as the identity of all participants will remain anonymous in all of the reports originating from this research. As well, participants can withdraw their consent at any time. Your input is extremely important because it will ensure that future public health policies will appropriately guide public health decisions during times of emergencies.

I have asked Cécile Bensimon, research associate on this study, to contact you regarding your potential participation. In the meantime, please do not hesitate to contact her with any questions or concerns you may have. She can be reached via electronic mail at cecile.bensimon@utoronto.ca or by telephone at (416) 480-6100 ext. 7095.

Thank you very much for your time and consideration.

Sincerely,

Dr. Ross E.G. Upshur, MA, MD, MSc, FRCPC
Director, Primary Care Research Unit
Sunnybrook and Women’s College Health Sciences Centre
Associate Professor, Departments of Community Family Medicine and Public Health Sciences
University of Toronto
APPENDIX 5: RECRUITMENT LETTER III

October 2004

Dear :

RE: Study on Ethical Issues during Public Health Emergencies

We are currently conducting a study on the ethical issues that are raised during a public health emergency, such as the one experienced during the SARS epidemic. In particular, the aim of this study is to increase our understanding of the effectiveness of quarantine and the use of other restrictive measures to contain the spread of infectious diseases. We would like to gather the views of regulators of health care provider Colleges, such as yourself, on the benefits and harms of quarantine as well as the conditions that would justify implementing such measures. We hope to obtain many different perspectives and viewpoints on this important topic.

We would like to invite you to participate in a 30-minute interview that will give you the opportunity to share your views with us. The interview would be scheduled at your convenience in person or by telephone. Please note that all data collected as well as the identity of all participants will remain anonymous in all of the reports originating from this research. As well, participants can withdraw their consent at any time. Your input is extremely important because it will ensure that future public health policies will appropriately guide public health decisions during times of emergencies.

I have asked Cécile Bensimon, research associate on this study, to contact you regarding your potential participation. In the meantime, please do not hesitate to contact her with any questions or concerns you may have. She can be reached via electronic mail at cecile.bensimon@utoronto.ca or by telephone at (416) 480-6100 ext. 7095.

Thank you very much for your time and consideration.

Sincerely,

Dr. Ross E.G. Upshur, MA, MD, MSc, FRCPC
Director, Primary Care Research Unit
Sunnybrook and Women’s College Health Sciences Centre
Associate Professor, Departments of Community Family Medicine and Public Health Sciences
University of Toronto
October 2004

Dear :  

RE: Study on Ethical Issues during Public Health Emergencies

We are currently conducting a study on the ethical issues that are raised during a public health emergency, such as the one experienced during the SARS epidemic. In particular, the aim of this study is to explore questions such as health care providers’ duty to care for patients with an infectious disease as well as the use of quarantine and other restrictive measures to contain the spread of infectious diseases. In particular, we would like to look at the role that religious and secular communities can play during public health emergencies as well as how religious communities understand the duty to care and the use of restrictive measures. We would thus like to gather the views of spiritual and community leaders, such as yourself.

We would like to invite you to participate in a 30-minute interview that will give you the opportunity to share your views with us. The interview would be scheduled at your convenience in person or by telephone. Please note that all data collected as well as the identity of all participants will remain anonymous in all of the reports originating from this research. As well, participants can withdraw their consent at any time. Your input is extremely important because it will ensure that future public health policies will appropriately guide public health decisions during times of emergencies.

I have asked Cécile Bensimon, research associate on this study, to contact you regarding your potential participation. In the meantime, please do not hesitate to contact her with any questions or concerns you may have. She can be reached via electronic mail at cecile.bensimon@utoronto.ca or by telephone at (416) 480-6100 ext. 7095.

Thank you very much for your time and consideration.

Sincerely,

Dr. Ross E.G. Upshur, MA, MD, MSc, FRCPC  
Director, Primary Care Research Unit  
Sunnybrook and Women’s College Health Sciences Centre  
Associate Professor, Departments of Community Family Medicine and Public Health Sciences  
University of Toronto
APPENDIX 7: CONSENT FORM

Theme A: Quarantine – Consent Form for Personal Interviews

Sunnybrook and Women’s College Health Sciences Centre
University of Toronto Joint Centre for Bioethics

Research Project Title: Ethical Challenges in the Preparedness and Response for SARS: An Interdisciplinary Research Study

Principal Investigator: Dr. Ross Upshur, Director, Primary Care Research Unit, Sunnybrook and Women’s College Health Sciences Centre

Funding Agency: Canadian Institutes of Health Research (CIHR)

Study Objectives: This study seeks to determine the social, psychological, and ethical implications of quarantine for SARS and non-SARS infected patients. It also seeks to determine how quarantine is understood by various stakeholders and to generate insight into how it has impacted the lives of patients and health care providers. This study is carried out under the auspices of the University of Toronto Joint Centre for Bioethics.

Should you choose to participate, you will take part in a group interview or “focus group” moderated by a professional researcher. The questions and discussions will be about your experiences and understanding of life under quarantine. There are no right or wrong answers to any of the questions that will be asked.

This consent form, a copy of which will be left with you for your records and reference, is only part of the process of informed consent. It should give you the basic idea of what the research is about and what your participation will involve. If you would like more detail about something mentioned here, or information not included here, you should feel free to ask. Please take the time to read this carefully and to understand any accompanying information.

I, ______________________________, understand that the Primary Care Research Unit at Sunnybrook and Women’s College Health Sciences Centre and the Joint Centre for Bioethics at the University of Toronto are conducting a study of the ethical aspects of infectious diseases.

I understand that I will participate in a focus group that will last around 60-90 minutes. The focus group will consist of 6-10 other participants. I understand that with my permission the interview will be audio-recorded and later transcribed. I am aware that the audio-tapes and transcripts will only be used by the research team. No other person will have access to them. The audio-tapes and transcripts will not have my name or any other
identifying information on them. A research code number will be used instead. All data
will be kept on a secure computer which will be password protected. Access to the
computer will be secured by use of specific passwords known only to the research team.
The completed interview schedules, transcriptions, audiotapes and other research data
will be stored in a secure, locked cabinet. No information will be released or printed that
would disclose any personal identity and all such research data will be destroyed after
five years. I am aware that I will not receive any compensation for my participation.
Travel expenses can be reimbursed.

Any questions I have asked about the study have been answered to my satisfaction. I
have been assured that no information will be released or printed that would
disclose my personal identity and that my responses will be completely confidential.
Any risks or benefits that might arise out of my participation have also been
explained to my satisfaction.

During focus group sessions, all participants will be reminded that the information
shared during the session is confidential, and is not to be repeated to those outside of
the group. However, there is a limit to the researcher’s ability to ensure
confidentiality for information shared during these sessions.

I understand that my participation is completely voluntary and that my decision either to
participate or not to participate will be kept completely confidential. There are, however,
certain limits to the confidentiality of the information collected in group settings
(because, for example, other people may hear what I say). I understand that
confidentiality can only be guaranteed to the extent permitted by law. I understand that I
waive no legal rights by participating in this study. I further understand that I can
withdraw from the study at any time without explanation and without negative
consequences. I understand that I may refuse to answer any questions or complete any
part of the procedure. I am aware that I may request a copy of the final report. I
understand that the final report may be published in scholarly journals and other media
sources, or be used in presentations by the researchers. I am aware that regardless of
publications, my identity will remain strictly confidential.

At the end of the interview, if there are questions or issues that require discussion, a
follow up counselling session will be arranged.

I hereby consent to participate in this study.

Signature of Participant: _________________ Date: _________________

Signature of Investigator: _________________ Date: _________________

For further information about this study, please contact Dr. Ross Upshur (Principal
Investigator) at 416-480-6100 ext. 1691 or Shawn Tracy (Research Associate) at 416-
480-5048.
APPENDIX 8: INTERVIEW GUIDE

1. What do you think of the idea of using restrictive measures?

2. In your view, what should be taken into consideration to justifiably implement restrictive measures? Can measures be implemented too early?

3. Are you concerned about the rights of individuals when it comes to using restrictive measures?

4. Do you think that the use of forced confinement measures or surveillance techniques has any role in the control of infectious diseases?

5. Do you think that Public Health has obligations to those quarantined in terms of providing assistance?
APPENDIX 9: REB APPROVAL

University of Toronto
OFFICE OF RESEARCH SERVICES

PROTOCOL REFERENCE #11689 June 7, 2004

Dr. R. Upshur
Sunnybrook & Women’s College Health Sciences Centre
2075 Bayview Ave., Ste. 349B
Toronto, ON
M4N 3M5

Dear Dr. Upshur:

Re: Protocol entitled, “Ethical Challenges in the Preparedness & Response for SARS: An Interdisciplinary Research Study” by Dr. R. Upshur

ETHICS APPROVAL

Original Approval Date: November 27, 2006
Expiry Date: June 6, 2005

We are writing to advise you that the Health Sciences 1 Research Ethics Board has granted approval to the above-named research study, for a period of one year. Ongoing projects must be renewed prior to the expiry date.

The following documents (revised versions dated May 31, 2004) have been approved for use in this study: Consent Forms (Appendix A – Themes A-D), Question Guides (Appendix B – Themes 1, 2, C, 4), Research Tools (Appendix C), Advertisements and Bulletin (Appendix D), and Study Information Sheet (Appendix E). Participants should receive a copy of their consent form.

During the course of the research, any significant deviations from the approved protocol (that is, any deviation which lead to an increase in risk or a decrease in benefit to participants) and/or any unanticipated developments within the research should be brought to the attention of the Ethics Review Unit.

Best wishes for the successful completion of your project.

Yours sincerely,

[Signature]
Mariam Richardson
Ethics Review Coordinator

cc: Dr. N. Kreiger, Chair Health Sciences 1 Research Ethics Board
    Prof. L. Nasmith, Chair, Dept. of Family & Community Medicine

Simcoe Hall 27 King’s College Circle Toronto Ontario M5S 1A1
Telephone 416-978-5165 Fax 416-946-5769 email: Mariam Richardson@utoronto.ca

252