Healthcare Workers and Decision-Makers' Understanding of Liberty, Harm, and the Harm Principle in the Case of Tuberculosis in Persons with Severe and Persistent Mental Illnesses

by

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A thesis submitted in conformity with the requirements
for the degree of Doctor of Philosophy

Graduate Department of Public Health Sciences
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Abstract

Background: The harm principle, which generally states that individuals are free to act so long as they do not harm other non-consenting persons, is commonly invoked to help determine the boundaries between an individual's liberty and the public good in public health and mental health. The case of tuberculosis (TB) in persons with severe and persistent mental illnesses (SPMI) provides the opportunity to evaluate the application of the harm principle in a real-world context. TB in persons with SPMI is an ideal case study because (a) the treatment of TB and SPMI are two examples where liberty restrictions are often justified by appealing to the harm principle and (b) the goal of arresting the spread of TB (e.g. through isolation) may conflict with the goals of mental health (e.g. reducing social isolation). However, it is unknown how healthcare workers in public health and mental health understand the notion of liberty and harm, and moreover, whether their views resonate with philosophical literature.

Methods: A mixed methods study that includes interviews and an online survey with healthcare workers and decision-makers in public health units and mental health centres in Toronto, Canada. Twenty interviews were conducted and analyzed via thematic analysis. An online

survey, where items were generated by reference to philosophical interpretations of the harm principle (including JS Mill, Joel Feinberg, Joseph Raz, and Immaunel Kant), was distributed and analyzed via factor analysis and t-tests. The response rate was 41.5% (n=91).

Results: Six themes emerged from the interviews, including accounting for the context surrounding liberty restrictions and the importance of supporting persons who have their liberty restricted for the greater public good. The survey findings suggest statistically significant difference between TB workers and mental health workers regarding the importance of directly observed therapy (DOT) and conceptions of risk.

Conclusion: The findings provide an understanding of how notions of liberty and harm are understood by public health and mental health workers. The participants demonstrated nuanced moral reasoning that can enrich and provide real-world context to the existing ethics literature on the topic of the harm principle and liberty restrictions.

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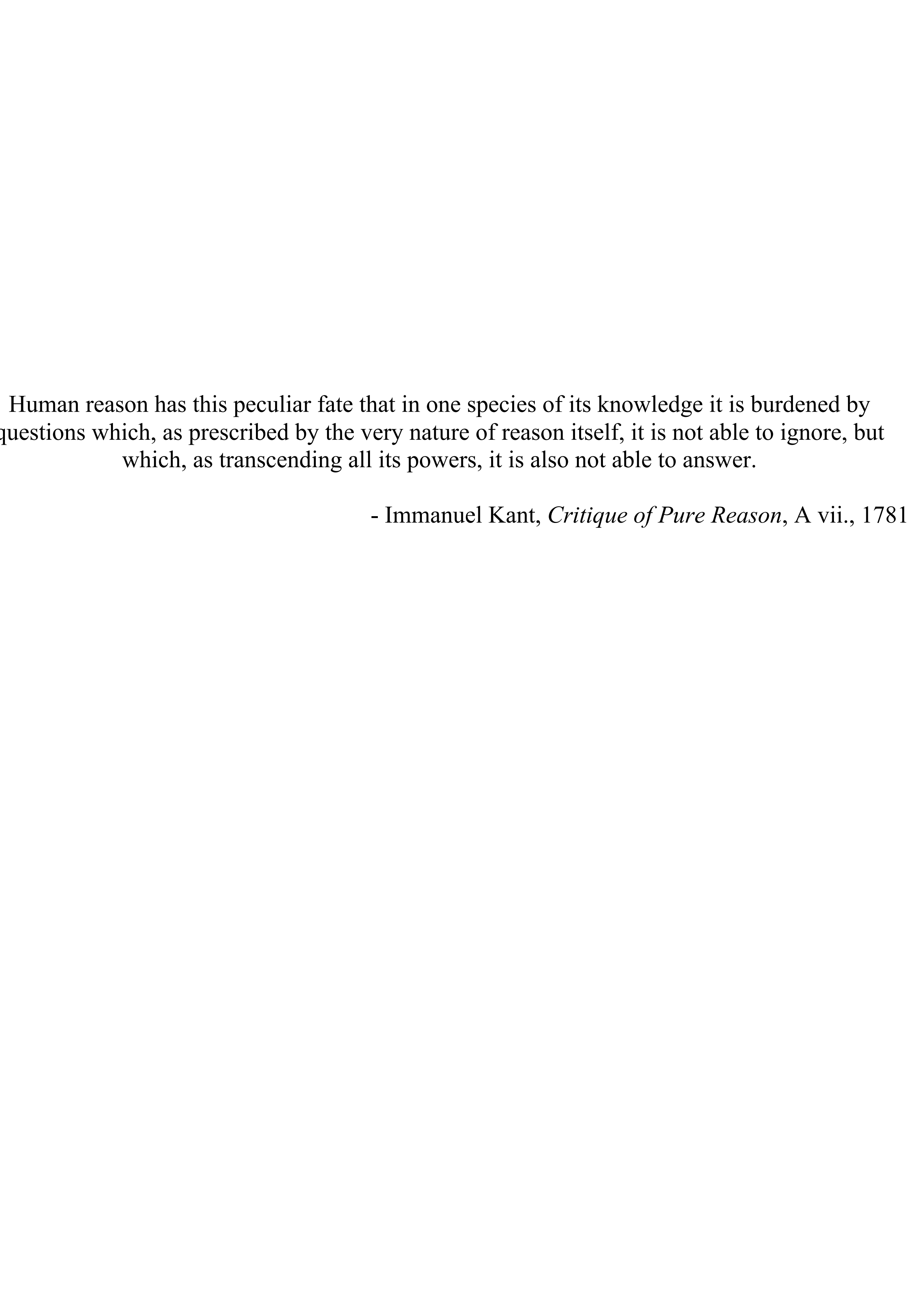
And then there's Maude…



Human reason has this peculiar fate that in one species of its knowledge it is burdened by questions which, as prescribed by the very nature of reason itself, it is not able to ignore, but which, as transcending all its powers, it is also not able to answer.

- Immanuel Kant, *Critique of Pure Reason*, A vii., 1781

Table of Contents

Abstract ………………………………………………………………………………... ii
Acknowledgements ………………………………………………………………… iv
List of Tables ………………………………………………………………………... ix
List of Figures ……………………………………………………………………… x
List of Appendices ………………………………………………………………….. xi

Chapter One: Introduction ………………………………………………………... 1

Chapter Two: Theoretical Background – Liberty and the Harm Principle ………………. 7
A. A Brief Synopsis of the Problem ………………………………………… 10
B. Philosophical Theories …………………………………………………… 12
i. Mill's conception of liberty and the harm principle ………….. 13
ii. Feinberg's conception of liberty and the harm principle …….. 18
iii. Raz's conception of autonomy and the harm principle ……… 24
iv. Kant(ian) conception of liberty and an objection to the harm principle ………………………………………………………… 29
C. Application of Theories in Discussions of TB and Persons with SMPI ….. 34
D. Conclusion ……………………………………………………………... 36

Chapter Three: Empirical and Regulatory Background – TB and Persons with SPMI ….. 38
A. Tuberculosis …………………………………………………………… 39
i. Bacteriology, epidemiology, and treatment …………………... 39
ii. A brief history of tuberculosis ……………………………….. 45
iii. Health Protection and Promotion Act (HPPA) ……………… 48
iv. Tuberculosis policy in Ontario ………………………………. 52
B. Mental Health and Severe and Persistent Mental Illness ………………… 53
i. Etiology, epidemiology, and treatment ……………………….. 53
ii. A brief history of mental healthcare and psychiatry ………… 57
iii. Mental Health Act (MHA) …………………………………... 59
iv. Mental health policy in Ontario ……………………………... 62
C. Tuberculosis and Persons with SPMI …………………………………….. 64
i. Epidemiology ………………………………………………… 64
ii. Treating TB in Persons with SPMI …………………………... 67
D. Conclusion ……………………………………………………………... 73

Chapter Four: Methods and Methodology ……………………………………………….. 75
A. Theoretical Underpinnings ……………………………………………….. 75
B. Research Objectives …………………………………………………… 76
C. Research Questions …………………………………………………… 76
D. Research Design ……………………………………………………….. 78
E. Research Sample ……………………………………………………….. 82
i. Study population ……………………………………………… 82
ii. Inclusion and exclusion criteria …………………………...…. 84

iii. Recruitment …… 85
iv. Sample size calculations …… 85
v. Sampling techniques …… 86
F. Survey Design and Item Generation …… 88
G. Data Collection …… 90
H. Research Ethics Considerations …… 92
I. Data Analysis …… 93
J. Conclusion …… 97

Chapter Five: Results – Online Survey …… 98
A. Descriptive Analysis …… 98
B. Factor Analysis and Generation of Scales …… 105
C. T-Tests …… 107
D. Conclusion …… 114

Chapter Six: Results – Interviews …… 115
A. The Goal of Care or Treatment …… 117
B. The Context Surrounding Liberty Restrictions …… 120
i. Why restrict liberty …… 120
ii. Material conditions or realities of clients …… 123
iii. Assumptions …… 131
iv. How to restrict liberty …… 139
v. The consequence of liberty restrictions …… 148
C. Discussions of Liberty, Control, and Choice …… 153
D. The Individual's Liberty and the Public's Health …… 158
E. Balancing the Goals and Values of Public Heath and Mental Health …… 161
F. Participants' Emotional Responses to Liberty Restrictions …… 164
G. Conclusion …… 165

Chapter Seven: Discussion and Conclusions …… 167
A. The Relation between the Results and Normative Theory …… 167
B. Comparing the Survey and Interview Results …… 170
i. Comparing results …… 170
ii. Participants' understanding of harm …… 177
iii. Participants' understanding of liberty …… 180
iv. TB care versus SPMI care …… 184
v. Adherence to law …… 186
C. Theoretical Observation and Questions for Future Research …… 188
i. Potential political ramifications of perceptions in public health and mental health …… 189
ii. The context surrounding the use of the harm principle …… 193
iii. Reciprocity …… 195
D. Limitations …… 202
E. Conclusion …… 207

References …… 213

Appendices ………………………………………………………………………….. 222

List of Tables

4.1 15 Point Checklist of Criteria for Good Thematic Analysis ……………………. 96

5.1 Response Rates ……………………………………………………………….. 98
5.2 Demographic Profile of Respondents …………………………………………… 99
5.3 Survey Questions and Responses (%) …………………………………………... 100
5.4 Definition of Scales and Questions ……………………………………………... 105
5.5 Group Statistics – TB/MH v Family Health …………………………………….. 107
5.6 Independent Samples Test – TB/MH v Family Health …………………………. 108
5.7 Group Statistics – TB v MH …………………………………………………….. 111
5.8 Independent Samples Test – TB v MH …………………………………………. 111

7.1 Definitions of Scales and Other Survey Items …………………………………... 172
7.2 Comparing the Qualitative and Quantitative Results …………………………… 174

List of Figures

5.1 Forcing Intake of TB Meds (Case 1) …………………………………………. 103
5.2 Forcing Intake of TB Meds (Case 2) …………………………………………. 104
5.3 Mean Score for DOT Scale – TB/MH v Family Health ………………………… 109
5.4 Mean Score for PH Order Scale – TB/MH v Family Health ……………………. 110
5.5 Mean Score for DOT Scale – TB v Mental Health ……………………………... 112
5.6 Mean Score for Risk Scale – TB v Mental Health ……………………………… 113
5.7 Mean Score for Kant Scale – TB v Mental Health ……………………………… 114

List of Appendices

Appendix One – Introductory Email to Potential Interview Participants ………………. 222
Appendix Two – Consent Form: Interviews ……………………………………………. 223
Appendix Three – Interview Guide …………………………………………………….. 225
Appendix Four – Introductory and Follow-Up Emails to Potential Online Survey Participants ……………………………………………………………………………… 228
Appendix Five – Consent Form and Online Survey ……………………………………. 230

Chapter One: Introduction

The agitator asserts his constitutional right to speak, the government asserts its constitutional right to wage war. The result is a deadlock. Each side takes the position of the man who was arrested for swinging his arms and hitting another in the nose, and asked the judge if he did not have a right to swing his arms in a free country. "Your right to swing your arms ends just where the other man's nose begins." To find the boundary line of any right, we must get behind rules of law to human facts.

- Zachariah Chafee, "Freedom of Speech in War Time", 1919

In its most general formulation, the harm principle maintains that *A* is free to do *x* and that *x* may be harmful for *A*, so long as *x* does not harm non-consenting *B*. *Prima facie*, it is an intuitively plausible principle that may help delineate between what an individual may or may not do in a public space. The principle is a hallmark of many liberal theories, i.e., theories that promote liberty as the (or a) primary political value must have means by which to distinguish between acceptable and unacceptable public behaviour, the harm principle being one such means. The use of the harm principle in liberal democratic states, such as Canada, is ubiquitous, while often implicit and simplistic. The harm principle can be found in legislation and policy documents in various fields, including but not limited to public health and mental health. Moreover, many people simply assert the harm principle in their everyday lives outside the context of politics or political theory (e.g., some notion of the harm principle might lie behind why children are taught not to hit others). However, the use of the harm principle to justify interference with liberty, in formal law or quotidian acts, is often not cited, and subsequently, rarely considered in a thoughtful manner.

The use of the harm principle as a justification for interference with liberty in both public health and mental health provides an important example of how the harm principle is commonly used in an implicit and perhaps simplistic manner. The *Health Protection and*

Promotion Act and the *Mental Health Act* in Ontario both use the harm principle to justify prohibiting certain actions that maybe harmful to others, the former to prevent the spread of diseases like tuberculosis (TB) and the latter to prevent physical harm to others. Moreover, the *Mental Health Act* justifies interfering with an individual if said individual poses a risk of physical harm to him- or herself; the prohibition against harming oneself, though traditionally not part of the harm principle, is included in some articulations of the principle (e.g., Joseph Raz, as will be described in the next chapter). Neither piece of legislation, nor any corresponding regulations or policy documents, explain or define what the legislators or government bureaucrat mean by harm.

Despite the sometimes implicit or unclear use of the harm principle in practice, there exists some important and seminal works on the principle, namely that of John Stuart Mill, Joel Feinberg, and Joseph Raz. These theorists provide a careful examination of the harm principle that is grounded in their particular theories of liberalism. It is at least possible for anyone to read the theoretical literature that describe the various articulations of the harm principle, if so inclined.

However, what remains hitherto unknown is what and how healthcare workers in public health and mental health understand the harm principle. Trying to understand what healthcare workers mean by 'harm' and the use of harm to justify restrictions on liberty is important because healthcare workers in public health and mental health are legally charged with executing legislation that uses the harm principle to implicitly justify interference with liberty. In other words, those who work in certain areas of public health and mental health are legally obligated to interfere with the liberty of persons for the protection of the general public (and sometimes the individual him- or herself), yet it is unknown how they determine

what actions to allow or prohibit in particular circumstances. The purpose of this thesis, therefore, is to begin to understand how healthcare workers and decision-makers think about liberty and harm in the context of their work. In particular, this study centers on the understanding of healthcare workers and decision-makers who work (a) in TB treatment or (b) the care of persons with severe and persistent mental illnesses (SPMI, which includes schizophrenia, schizoaffective disorders, and bipolar disorders). There are three guiding research objectives for this study:

1. To examine the philosophical literature as it pertains to conceptualizations of liberty, harm, and the harm principle.
2. To apply the philosophical literature related to liberty, harm, and harm principle in public health and mental health.
3. To examine the conceptualizations of liberty, harm, and the harm principle as it pertains to the case of TB and persons with SPMI from the perspective of frontline healthcare workers and decision-makers' in TB and mental health.[1]

There are four research questions that motivate the design and data collection associated to this study:

1. How do frontline TB healthcare workers and decision-makers conceptualize liberty, harm, and the harm principle?
2. How do frontline mental healthcare workers and decision-makers conceptualize liberty, harm, and the harm principle?

[1] Please note that the terms 'public health' and 'mental health' will be used to denote the fields of practice and research, while 'TB' and 'SPMI' will denote specific discussions relative to these two conditions. Moreover, 'TB in persons with SPMI' will mean those instances when a person with SPMI has both a psychiatric diagnosis and TB, while 'TB and SPMI (or persons with SPMI)' will refer to discussions about these two conditions but not necessarily in the same person, at the same time.

3. How do the study's empirical findings align with common ethical and political arguments justifying the use of the harm principle?
4. How do the study's empirical findings elucidate one's understanding of the application of the harm principle in public health (in particular, related to TB treatment) and mental health (in particular, related to SPMI)?

As will be described in greater detail throughout the thesis, research questions one and two will be answered via quantitative (i.e., an online survey) and qualitative (i.e., semi-structured interviews) methods; questions three and four will include an analysis of the empirical data vis-à-vis the preexisting philosophical literature. There are a number of reasons why the case of TB in persons with SPMI provides an important case by which to concretely study how workers in public health and mental health think about the harm principle, which includes: (a) the higher prevalence of TB in persons with SPMI; (b) the possible challenges of treating TB in persons with SPMI (e.g., adverse drug interaction, the potential negative effects of respiratory isolation on psychosocial care, etc.); and (c) the compounded vulnerability of having both TB and SPMI (i.e., two diseases, or group of diseases, that occur more readily in persons of lower socioeconomic status).

The purpose of this study is to evaluate how TB workers and those mental health workers who care for persons with SPMI conceptualize liberty, harm, and the harm principle relative to the case of persons with TB and SPMI. The data are generated by means of an online survey and face-to-face open-ended, semi-structured interviews, the results of which are then compared to the prominent political theories on the harm principle and one notable objection to the principle (i.e., stemming from the work of Immanuel Kant).

In chapter two, I present the three prominent theories that espouse the harm principle as a liberal justification for interference. Mill provides the initial formulation of the harm principle as justified by his utilitarian normative theory, which given his hedonistic view of the good entails that harm is pain, broadly construed, and includes more than mere physical pain. Feinberg reinterprets the harm principle as the prohibition of actions that wrongfully set back the interests of a non-consenting other, while Raz describes the harm principle as not only prohibiting actions of others that reduce future life opportunities but also acts that reduce one's own future opportunities (thus incorporating a sense of prohibition of harm to self in certain circumstances). Finally, Arthur Ripstein, drawing on Immaunel Kant's political theory, provides an objection against the harm principle by distinguishing between harm and wrongful actions. Chapter two ends with a brief evaluation of how said theories might affect the application of the harm principle in public health and mental health, in particular as it relates to the treatment of TB in persons with SPMI.

Chapter three provides an overview of the science, history, policies and laws of TB treatment and the care of persons with SPMI. The literature suggests that there is a higher prevalence of TB in persons with SPMI, that the antitubercular medications prescribed for TB may have adverse events in persons with SPMI (both given their baseline diagnosis and their antipsychotic medications), and that the ethos of TB care (namely, the protection of the public from infection) may, at times, interfere with the ethos of mental health, which focuses on empowering persons with SPMI to be independent members of their communities.

Chapters two and three provide the theoretical and empirical justification for the objectives and questions of the study, which are described in detail in the methods chapter (chapter four). The goal of this thesis, as described above and as will be described in greater

detail in chapter four, is to begin to understand how healthcare workers and decision-makers in TB and mental health conceptualize liberty, harm, and the harm principle in order to then compare and contrast those findings with the theoretical and empirical literature presented in chapters two and three. The study consists of a mixed methods study, including an online survey and interviews with persons working in TB programs in public health units and those who work with persons with SPMI in mental health centres in the Greater Toronto Area (GTA).

Chapters five and six are the results chapters of the thesis. Chapter five presents the results of the online survey, which consists of descriptive analyses and inferential statistics in the form of factor analysis and t-tests. Chapter six presents the results of the interviews, which are analyzed using thematic analysis. Finally, in the discussion chapter (chapter seven), the results from both the survey and the interviews suggests that the participants' understanding of liberty and harm is nuanced and belies any simplistic interpretation. Moreover, the data provides an important contextualization of the application of the harm principle in the case of TB and persons with SPMI, suggesting that future applications of the harm principle in public health and mental health should be sensitive to not only the complexity of the theoretical articulations of the harm principle, but also the complexity in the application of the harm principle in practice.

<u>Chapter Two: Theoretical Background – Liberty and the Harm Principle</u>

The goal of this chapter is to describe four theories of (a) liberty, (b) harm (including an objection to using harm as a normative idea, at all), and (c) the harm principle, i.e., why harm may or may not provide a justification for interference with an individual's liberty relative to actions that may harm others or self. These four theories may help shape one's understanding of certain restrictions in public health and mental health, in particular as it relates to the case of TB in persons with SPMI. After making some qualifications and clarifications in this introductory section, the first section will outline the general problem that the harm principle intends to address by outlining some very basic ideas related to liberty and liberal democracy. The second section will provide a description of the theories of liberty, harm, and the harm principle by John Stuart Mill, Joel Feinberg, and Joseph Raz, followed by an objection based on the political philosophy of Immuanel Kant. Mill provides the first description of the harm principle (though he never uses that term); Feinberg and Raz provide two different modifications of the principle; and Arthur Ripstein uses Kant's theory of the innate right of freedom to provide an objection against the very use of harm as a normative idea. Section three will provide some preliminary remarks about how the various theories explored in the second section might shape the application of the harm principle in public health and mental health, in general, and relative to the treatment of TB in persons with SPMI, in particular. The application of the theories will be explored in greater detail in the discussion chapter (see *Chapter Seven: Discussion and Conclusions*), after the empirical data are presented.

Some brief clarifications on the use of language: first, I will use the word 'liberty', except when discussing Kant who uses the word 'freedom'. 'Liberty' and 'freedom' are

synonymous, except that 'liberty' is derived from the French word *liberté* (which is itself derived from Latin) and the word 'freedom' is derived from the German word *freiheit*. English is unique insofar as it uses both 'liberty' and 'freedom'; most other languages only use one or the other word (Simpson, Weiner, and Oxford University Press 1989). Second, I will treat the verbs 'interfere', 'limit', 'curtail', and 'restrict', and their respective nouns, as synonymous when discussing liberty and harm, i.e., harm to others or self may justify the state to interfere, limit, curtail, or restrict the liberty of a given individual.

Some qualifications regarding this chapter: first, the harm principle is used in public health ethics and mental health ethics literature, often with no particular reference to any philosophical theory.[2] The harm principle is commonly (though not always) treated as a stand-alone principle that can guide deliberations in public health and mental health (Krom A. 2011). Although I acknowledge the importance of such efforts and that this body of literature exists relative to public health and mental health, I choose to set it aside for the purposes of the thesis, unless there is something particularly relevant from these readings that I judge can add to the understanding of the issues at hand (and if I do, I will do so in the discussion chapter after the empirical results are analyzed). I believe it worthwhile to acknowledge and briefly describe the different theories that underpin the notions of liberty, harm, and the harm principle to gain a better sense of the nuance that might apply in practice

[2] In terms of literature related to the harm principle and TB, please see, for example (Achmat 2006; Bayer 1994; Bayer and Dupuis 1995; Bayer and Fairchild 2002; Boggio et al. 2008; Booker 1996; Coker 2000, 2000; Doyal 2001; Fidler, Gostin, and Markel 2007; Gainotti et al. 2008; Gandy and Zumla 2002; Gostin 1993; London L 2009; Miller 2008; Porter and Ogden 1997; Ratzan 2007; Selgelid 2005; Selgelid, Kelly, and Sleigh 2008; Sherwin 1998; Upshur 2010; Upshur, Singh, and Ford 2009; Verma et al. 2004; Viens, Bensimon, and Upshur 2009). For literature related to the harm principle and mental health, please see, for example, (Adams and Drake 2006; Beauchamp 2009; Bloch and Green 2009; Castelein et al. 2008; Davis 2002; Dorn et al. 2006; dowd et al. 1998; Hansson 2006; Holloway, Szmukler, and Sullivan 2000; Holmes and Adshead 2009; malia et al. 2002; Peele and Chodoff 2009; Postert 2010; Prince et al. 2007; Ritchie CW, Hayes D, and Ames DJ 2000; Roberts and Geppert 2004; Scheyett et al. 2009; Sharma V et al. 2000; Steinert et al. 2005; Swanson et al. 2008; Szmukler 2009; Wasow 1999).

and in the mental health and public health ethics literature. Second, even after one gains a better understanding of the various articulations of the harm principle, important procedural questions remain; for example, assuming a harm does or might occur, who can judge said harm and what does a justified act of restriction look like? Who can legitimately enforce said limitations on liberty? Are there appeal mechanisms for those persons restricted? These and similar procedural questions are of utmost importance in the just application of the harm principle in practice; however, I will limit my analysis in this chapter, and in my thesis more generally, to the substantive issues related to the harm principle, since one might argue or assume that the substantive theories that ground the harm principle precede any procedural issues that may arise from its use.

Before beginning, however, it is important to note that the philosophical texts reviewed and analyzed below are far more complex than can be reflected in one chapter. The analysis conducted in this chapter will pertain to only those parts of the theories that are relevant to the treatment of TB in persons with SPMI (explained in greater detail in *Chapter Four: Methods and Methodology*). When conceptualizing and refining the issues and questions for this thesis, a decision was taken to include four potentially relevant theories of liberty and harm instead of taking only one theory or theorist's version of the harm principle; the reason for said decision was because it seemed intuitively plausible that how healthcare workers and decision-makers conceptualized liberty, harm, and the harm principle may not sit squarely with any one particular theory but may vary between and within participants. The trade-off, however, is that breadth of the subject matter rules out a detailed analysis of any one theory in particular. It is also worth noting that the various conceptions of liberty, harm, and the harm principle espoused by the different authors are grounded in more

foundational theories of the right or the good (e.g., Mill and utilitarianism, Raz and perfectionism, etc.); I will discuss these more foundational theories only insofar as it may affect one's understanding of the application of liberty and the harm principle to the research questions. Finally, no dissertation (even one in philosophy, let alone one in public health) can discuss all the previous literature on liberty, harm and the harm principle. The theories discussed in this chapter were chosen because of their foundational nature (e.g., Mill) or because they provide an evolution of thinking (e.g., Feinberg and Raz) or because they provide important objections (e.g., Kant) to the harm principle.

A. A Brief Synopsis of the Problem

Canada is, among many other countries in the world, a liberal democracy.[3] Liberal democracies presuppose that liberty is something worth pursuing and protecting. Isaiah Berlin famously and influentially noted (or rearticulated, depending on one's reading of classical liberal authors) that liberty could be either negative or positive (Berlin 2008). *Negative liberty* is being free from interference, whereas *positive liberty* is being able to make of one's life as one sees fit. Why liberty is worth protecting is a difficult idea to summarize and has been the subject of much debate. For the sake of this preliminary synopsis it suffices to presume that most people have an intuition that liberty is a good thing for people to have and enjoy. Much political philosophy, then, assumes that liberty is a good or a right and that it must be protected and promoted by states and individuals. However, what is subject to debate is how to understand the nuances of liberty and *what exactly are the*

[3] One might object and argue that many democracies are social democracies with strong welfare structures within their democratic states. Regardless, social democrats will value liberty as a good or a right and provide an interpretation of what liberty looks like in practice. For the purposes of this thesis, it is not important to note the differences and similarities of a social or liberal democracy, except to state that both social and liberal democrats are going to value liberty in some form or another.

limits to liberty, i.e., when can the state limit the liberty of an individual? There are several categories of justified interference with a person's liberty, both negative and positive. One traditional example is competition for resources; *A* obtaining limited resource *x* might dictate that *B* cannot obtain *x* at the same time or at all. For example, the allocation of healthcare resources is a common example of competition for limited resources.

Another common justification for interference with an individual's liberty is the harm an act might cause another individual. Most people have an implicit and unarticulated understanding of the *harm principle*, which states (in general terms) that *A* has a right to do *x* and that x may be harmful toward *A*, so long as *x* does not harm non-consenting *B*. People also have intuitions that in particular circumstances, harm to self might justify interfering with an individual's freely chosen actions. The purpose of this chapter is to provide four different accounts of the following: (a) liberty, (b) harm, and (c) why harm may or may not provide a justification for interference with an individual's liberty relative to actions that may harm others or self.

There are, at least, two reasons why this topic matters for public health and mental health: first, public health and mental health can and do exist within the broader legal and political context of liberal democracy, at least in Canada. Public health and mental health laws, policies, and standards must, and generally do, exist within the parameters of liberal democracies with a concern for the liberty of individuals. Second, public health and mental health explicitly use some simple and unarticulated understanding of the harm principle in practice, in a way often unseen in other parts of the healthcare system. For example, a public health nurse tells a student with the flu to stay home from school because the student could infect others and is justified to do so by appealing to the harm principle. In mental health, for

example, the reason a person with schizophrenia is prevented from, if possible, committing suicide is because the mental health worker deems the person with schizophrenia incapable of making an informed and free decision to self-harm. Therefore, those who work in public health and mental health, and those who are subject to public health and mental health law and care, exist in a world where notions of liberty and harm are ever-present and shape their realities and actions.

The case of treating TB in persons with SPMI presents a specific and intriguing case of the application of the various understandings of liberty, harm, and the harm principle for reasons that will be explained in *Chapter Three: Empirical and Regulatory Background – TB and Persons with SPMI*. For now, it suffices to note that understanding the treatment of TB in persons with SPMI may provide a greater and deeper understanding of the differences and similarities in thinking behind the application of liberty and harm in public health and mental health.

B. Philosophical Theories

In this section, I will outline the main arguments in favor of the harm principle by John Stuart Mill and Joel Feinberg; Feinberg's articulation of the harm principle modifies Mill's articulation. Next, I will explore Joseph Raz's conception of the harm principle, and how it contains an additional obligation to not harm oneself under certain conditions. Finally, Immanuel Kant, and in particular Arthur Ripstein's application of Kantian arguments, will be used to provide an objection to any use of the notion of harm as a normative concept that could justify interference with liberty.

i. Mill's conception of liberty and the harm principle: The purpose of Mill's influential text, *On Liberty*, is to understand "the nature and limits of power which can be legitimately exercised by society over the individual" (Mill 2009). Mill is concerned with promoting liberty because of what is sometimes referred to in political philosophy as the problem of 'tyranny of the majority', i.e., that the majority in a democracy will impose their beliefs on the minority members of a society, either through government or by the more subtle imposition of social customs (e.g., through religion). Mill's goal is to provide a defense of liberty and liberalism that is grounded in utilitarianism. This raises an important question, namely, what does Mill mean by 'liberty' and 'utilitarianism'? According to Mill, utilitarianism is the theory that "actions are right in proportion as they tend to promote happiness, wrong as they tend to produce the reverse of happiness" (Mill 2007) where happiness is understood as pleasure and unhappiness as pain. Mill's version of utilitarianism appears to be at least aggregationist (i.e., one adds up the amount of happiness in a given situation between *A* and *B* and chooses which option produces the most happiness); his hedonist articulation of happiness, in turn, must be understood in the broadest possible sense, so that it is not merely, or even primarily, physical pleasure that ought to be promoted but higher pleasures, such as contemplation (e.g., "…better to be Socrates dissatisfied than a fool satisfied" – 8). Mill is, therefore, explicit that all his arguments in favor of liberty as a guiding principle of politics are grounded in utilitarianism (Mill 2009).

For Mill, liberty consists of three domains: first, "the inward domain of consciousness" (15) meaning one should have the freedom to hold thoughts, beliefs, opinions and sentiments that are his or her own, even if they are in opposition to that of most other people. The second domain of liberty "requires liberty of tastes and pursuits; of framing the

plan of our life to suit our own character" (15), i.e., to be autonomous individuals that follow their own consciousness as a means of shaping their lives as they see fit. The third and final domain of liberty is freedom of assembly or association, or "freedom to unite, for any purpose not involving harm to others" (16). Briefly then, Mill provides two categories of utilitarian arguments in favor of liberty; first, that expressing one's individuality is generally a good to be promoted so as to advance thinking, both of the individual and society (67-91), and second, that there are good reasons against assuming the infallibility of knowledge and beliefs to be imposed by *A* over *B* (19-66). However, as Powers and colleagues rightfully make clear, not all liberties are of equal value for Mill: "only certain individual choices merit some degree of strong state protection because of their connection to crucially important aspects of individual self-determination as an ingredient of well-being" (Powers, Faden, and Saghai 2012).[4] Therefore, actions that are associated with Mill's three domains of liberty should garner greater protection than other potential liberties; in fact, Mill acknowledges that some liberty will be curtailed by virtue of promoting the liberty of others. For example, not everyone will be able to have all the material possessions he or she wishes to have, or may not receive certain employment, because other persons are free to pursue these same options; "… society admits no right, either legal or moral, in the disappointed competitors, to immunity from this kind of suffering" (Mill 2009, 116).

Despite Mill's goal of promoting liberty as the primary value governing public actions among individuals and between citizens and states, in public health ethics he is primarily remembered (Powers, Faden, and Saghai 2012) for his postulation that:

[4] It is unclear the extent to which Mill's conception of liberty can be described as either negative or positive. Powers and colleagues interpretation of Mill's understanding of liberty as related to self-determination seems to suggest that Mill is arguing that the liberty worth protecting is not merely negative liberty. Moreover, his second domain of freedom, that "framing the plan of our life", seems to suggest that Mill's conception of liberty is positive.

> 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[5], against his will, is to prevent harm to others. His own good, either physical or moral, is not a sufficient warrant (12).

This position is commonly referred to in present-day literature as the 'harm principle'. For Mill, the most society or individuals in society can do when it feels that another individual is harming him- or herself is to try to instruct the person to do otherwise; promoting an individual's good by overriding his or her liberty, especially liberty with regards to the domains described above, is not morally acceptable because it will generally bring about bad outcomes. Mill writes:

> 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 (Ibid).

Although Mill spends little space explaining what he means by this principle (again, his goal in *On Liberty* is to provide a defense of liberty), he does acknowledge that there may be difficult cases where the line between an individual's choices and their effects on him- or herself and others is blurred and when it may be morally permissible to interfere with a person's liberty. For example, Mill considers a man who, do to his drinking or gambling, is unable to care for his family; here, there may be morally justified reasons for interfering with the individual, "but it is for the breach of duty to his family or creditors, not for the extravagance" (98-99), i.e., the state may interfere because of what this individual owes others and the duties he is unable to fulfill because of his drinking or gambling, but not

[5] Mill's whole argument applies only to 'civilized' communities that have adopted democracy as their form of government.

because of the drinking and gambling, *per se*. The case of the gambler or drinker is instructive for this thesis since it suggests that Mill acknowledges that there may be actions that have unintended consequences, such that these unintended consequences (stemming from gambling or being intoxicated) harm or potentially harm innocent others to the extent that it justifies interfering with an individual's liberty (e.g., with TB, the goal of public health is to arrest the transmission, not to isolate an individual as a form of punishment because he or she has TB). Another important example for this thesis is when a given action by an individual is not actually free due to some limitation of knowledge (e.g., not knowing one has TB or not realizing one has a mental illness). Mill provides the following example: "… anyone else saw a person attempting to cross a bridge which had been ascertained to be unsafe, and there were no time to warn him of his danger, they might seize him and turn him back without any real infringement of his liberty; for liberty consists in doing what one desires, and he does no desire to fall into the river" (118). Thus, even Mill's prohibition against interfering in the lives of individuals who cause no harm to others is subject to exceptions when individuals are deficient in their ability to make choices they would not otherwise make.

Another important insight into Mill's understanding of liberty and the harm principle can be derived from his objections to the *Contagious Disease Acts of 1866 and 1869* in the United Kingdom (*The Evidence of John Stuart Mill Taken Before the Royal Commission of 1870, on the Administration and Operation of the Contagious Diseases Acts of 1866 and 1869*. 1870). In 1870, Mill provided arguments against the Acts, which was legislation that attempted to curtail the high prevalence of sexually transmitted infections (STI) in British naval officers (who would then transmit the STI to their wives) by requiring that sex workers

submit to examination and hospitalization for STIs, by allowing plain clothes 'medical police' to conduct routine and random genital inspections of suspected sex workers, and mandating that sex workers be licensed (Waldron 2006). Mill opposed the legislation for several reasons, including that it removed personal liberty from sex workers directly and all women indirectly; that the legislation removed the responsibility of men to not transmit STIs to their wives; and that it treated men and women unequally (*The Royal Commission of 1870*). Mill seems not only concerned with the liberty of individuals, but with the distribution of liberty between persons as a matter of equality. As Waldron writes: "[t]he question for the Harm Principle is whether the particular impact on liberty is warranted by the prevention of harm. As we have seen, that is understood not just as a matter of quantum – how much liberty is affected and how much harm is prevented? – but as a matter of distribution and discrimination so far as liberty is concerned" (Waldron 2006, 37). Given the emphasis on equal applications of standards of liberty by Mill, one may question how the harm principle should be interpreted and applied in situations when infectious diseases disproportionately affect one population or group of persons more than others (e.g., as will be discussed in the next chapter, TB disproportionately affects persons of lower socioeconomic status).

Despite the foundational role of *On Liberty* in Western political philosophy, there exist some important limitations in the application of Mill's version of the harm principle in public health and mental health. First, Mill does not seem to consider how his theory of liberty should or should not be applied in situations of persons with mental illnesses. He does state that his theory only applies to "human beings in maturity" and that "[t]hose who are still in a state to require being taken care of by others, must be protected against their

own actions as well as against external injury" (Mill 2009, 12-13). It is unclear the extent to which said brief statements may or may not apply to persons with an SMPI. Second, it is unclear to what extent Mill considers situations where *x* may be good or morally neutral for *A* but bad for *B*; this differs from the example of someone who drinks or gambles in excess, since most persons usually agree that drinking or gambling in excess is, generally speaking, harmful for the drinker or gambler him- or herself. For example, isolation of persons infected with TB, though clearly good for others, is not of immediate benefit to the individual with TB; in fact, it is usually a detriment since it affects the individual's ability to work and take care of him- or herself. Mill does not seem to provide any explicit guidance in these types of trade-off situations.

ii. Feinberg's conception of liberty and the harm principle: Joel Feinberg's conception of the harm principle is perhaps the most popular modern articulation of the principle. Feinberg begins by providing a non-utilitarian articulation of the harm principle that purports to balance the competing needs of different parties from within the harm principle itself. The theoretical basis for his argument is intuitionism, which may or may not explain his particular kind of balancing scheme (17-18). While perhaps sympathetic to Mill's form of utilitarianism, Feinberg does not adopt a utilitarian position because he claims that utilitarianism does not distinguish between the distribution of harms and benefits (189).

Feinberg's interest in the harm principle stems from his attempt to elucidate when a person's liberty may be limited by criminal law (7-9). Feinberg assumes that some notion of liberalism is true as a starting point for his deliberations (14-16). For Feinberg, liberty is understood as a welfare interest and as having as many open options available for oneself, i.e., "I have an open option with respect to a given act *X* when I am permitted to do *X* and I

am also permitted to do *not-X* (that is to omit doing *X*), so that it is up to me entirely whether I do *X* or not" (207). Feinberg's articulates his version of the harm principle by claiming that, "state interference with a citizen's behavior tends to be morally justified when it is reasonably necessary… to prevent harm or the unreasonable risk of harm to parties other than the person interfered with" (11).[6] Feinberg defines *harm* as "states of set-back interests that are the consequences of wrongful acts or omissions by others" (215). An *interest "*consists of all those things in which one has a stake" (34). Feinberg goes on to distinguish between *welfare interests* and *ulterior interests* (37), where the former refer to basic physical interests necessary for human life (e.g. an interest in procuring food and shelter) while the latter refer to personal aims and aspirations that are the goals of living (i.e. those things that make life worth living – for example, art, relationships, knowledge, etc). Stated differently, securing one's welfare interests is a means toward securing one's ulterior interests. Given the difficulty for the state to directly protect one's ulterior interests, coercive state powers will usually protect people from harms directed toward their welfare interests (37-38, 112). However, not all cases of set-back to interests will be protected by the harm principle; only those set-backs as a consequence of *wrongful* harms or omissions are subject to restrictions (107-109). A set-back to interests is wrongful only if it violates someone's *right*, where a right is someone's *justified reasons* for demanding protection of an interest against the conduct of another individual (e.g. a right to protect one's property against burglary) (110).

Feinberg maintains that one must not only account for actions that will result in certain harm, but also *risk* of harm. For Feinberg, evaluating the risk of harm must balance three considerations: magnitude, probability, and independent value (191). The 'magnitude'

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[6] Feinberg also discusses the offense principle as a justified liberal principle that may limit liberty; however, it is not pertinent to the thesis and will therefore be ignored.

refers to the amount of harm that could occur, while ‘probability’ refers to the likelihood of harm occurring; thus, the greater the magnitude of harm, then *prima facie* the lower the probability of its occurrence being sufficient to warrant prohibition. This formula, in turn, should be balanced with the ‘independent value’ of the risk of harm, i.e. the value of the potentially risky act independent of the harm it may produce (e.g. driving automobiles will certainly cause deaths but is imperative for modern life).

Of particular interest, Feinberg acknowledges that persons making decisions on the basis of the harm principle need some kind of concrete method by which to balance competing needs, i.e., Feinberg argues that “a certain kind of activity has a tendency to cause harm to people who are affected by it, but effective prohibition of that activity would tend to cause harm to those who have an interest in engaging in it… because other substantial interests of these persons [the instigators] are totally thwarted” (203). Feinberg concedes a concrete formula of weights for different persons’ interests cannot be achieved. Feinberg suggests three ways to ‘measure’ differences in competing interests, which are (it seems in descending order of importance) (a) vitality, (b) the degree to which other public or private interests are being protected, and (c) the interest’s “inherent moral quality” (204-205). First, according to Feinberg, certain interests are more vital to the rest of a person’s set of interests as a whole (e.g., an interest in eating seems intuitively more vital than an interest in having a television). So when the interests in conflict are of different vitalities, the interest of higher vitality should be protected against the interest of lower vitality (e.g., having the last sandwich at a given deli is more vital to someone who only has access to this one sandwich than the competing person with ample food supply at home). Second, one must take into account the relationship between interests, since some interests reinforce and affect other

interests in the long-term. At this stage one ought to consider how the interests in conflict affect not only the individual's interests, but also the broader community's interests (e.g., an interest in playing loud music for a musician may be vital for him or her, but doing so at all hours of the night might affect the long-term interests of the neighbours by causing annoyances, affecting their sleep, interfering with there ability to work the next day, etc). Finally, Feinberg maintains, "all reasonable persons can be expected to agree that certain interests, simply by reason of their own natures, quite apart from their relations to other interests, are less worth protecting than others", i.e. interests will differ on the basis of their inherent moral qualities and generally, people will agree as to what are those interests (204).

The description of Feinberg's position, so far, only applies to his understanding of the harm principle as a morally justified limit on an individual's liberty; however, Feinberg also considers when harm to self may justify interfering in a person's life (Feinberg 1986). When an individual or state interferes with the actions of another person for his or her own sake due to the potential harm he or she may cause him- or herself, this is generally understood as *paternalism* (or what Feinberg calls, "legal paternalism" – 4). For Feinberg, the harm that paternalism intends to prevent is *any* setback to interests, as opposed to the harm that is the subject of the harm principle, namely *wrongful* setback to interests (11). Feinberg makes a further distinction between hard paternalism (i.e., when *A* interferes with *B* to prevent harm to *B* and only *B* regardless of whether the harm or risk of harm was undertaken voluntarily) and soft paternalism (i.e., when *A* interferes with *B* to prevent harm to *B* and only *B* if and only if there are reasons to believe that *B* is acting involuntarily – 12). He maintains that while hard paternalism is illiberal and hence morally impermissible, soft paternalism is in keeping with liberalism because the protection of an individual from him- or herself is only

permissible in cases where the individual is acting involuntarily (12-16). To argue against hard paternalism, as Feinberg does, is to make an important distinction between one's right and one's good, namely that one has a right to pursue things which are bad for oneself.

Feinberg's discussion of harm to self, however, moves the reader beyond any simple understanding of liberty as deployed in his explanations regarding the harm principle. Preventing an individual from self-harm, according to Feinberg, requires that an individual have more than merely liberty (as open options), but an articulation of autonomy, i.e., when determining the morally justified limits of interference into the lives of individuals for the purposes of *A* versus *B*, what matters is their liberty, but when discussing the possible interference into the lives of any one individual for his or her sake, then autonomy must be discussed since it is, perhaps, a more morally robust concept. In other words, liberty is sufficient when adjudicating between parties but an insufficient concept when contemplating interfering with an individual him- or herself (27-28). For Feinberg, autonomy denotes a concern with the domains of responsibility that an individual has over his or her life, in particular, "how to make critical life-decisions" (54). In other words, autonomy is concerned with that which "primarily and directly affects only the interests of the decision-maker" (56). One key aspect of autonomy, then, is the voluntary nature of the actions undertaken by a given individual. For Feinberg, what it means for an individual to act voluntarily will differ depending on the individual's context and the choices being made (117-124). Voluntariness is a matter of degree, which includes an individual's capacity to choose, that the individual chooses under conditions free of duress, and that the individual has the relevant information prior to acting (113-117); however, the individual must not have a perfect capacity to choose, be under no duress, and with all the information possible to declare an act voluntary (again,

voluntariness is a matter of degrees). Returning to Feinberg's description of soft paternalism, one can begin to be appreciate what he means by justifying interference into the lives of individuals for their own sake in order to prevent self-harm in instances of involuntary choices or actions.

Finally, for the purposes of this thesis, and in relation to discussions of soft paternalism and harm to self, Feinberg considers cases of persons who suffer from "neurosis" or what otherwise may be described as a psychiatric or mental illness (162-171). At first, it may seem that a person with a mental illness, in particular SPMI, may feel compulsion to act in a certain manner, or that he or she is mistaken about the facts upon which they make choices; as such, it seems that this would provide a sufficient ground upon which to invoke soft paternalism if a person with SPMI is about to harm him- or herself. With this description of neurosis, one might conclude that although there is no second-party that is actually compelling a person with SPMI to act in a self-harming manner, it is as if said actions *are not of the individual* him- or herself, i.e., there exists *A* and then there exists *A's* compulsion toward self-harming behavior. On the other hand, Feinberg is clear that this might not be the only or most appropriate characterization of a compulsion toward self-harming behavior on the part of a person with SPMI; Feinberg writes:

> What the real self is, of course, is a deep philosophical question which… I could not hope to enter. But if the neurotic structure [i.e., the actual psychiatric illness or condition] is part of that self then it is a trait properly predictable of the person, like his bone structure and eye color, his talents and deficiencies, his character virtues and flaws – for better or worse part of they way he is (165).

If this second characterization of mental illness is true, then the presence of mental illness alone is insufficient to justify the application of soft paternalism; indeed, for Feinberg, the presence of a mental illness "becomes part of the background against which we look for

(other) voluntariness-diminishing factors, like factual ignorance and external coercion" (170-171). It is beyond the scope of this thesis to discuss the metaphysics of the self and what that means in cases of persons with SPMI; however, Feinberg's understanding and nuanced application of soft-paternalism in the case of persons with SPMI stands in contrast to what may be referred to as a simple 'physicalist' understanding of self-harm in the case of persons with SPMI, namely, that any attempt to physically harm oneself is sufficient to warrant interference (Peele and Chodoff 2009).

iii. Raz's conception of autonomy and the harm principle: Whereas Mill's harm principle is established relative to his notion of liberty, and whereas Feinberg argues for the harm principle relative to liberty but soft-paternalism relative to his conception of autonomy, Joseph Raz articulates his version of the harm principle, which constitutes protection from harm to others *and* self, solely from his own perfectionist articulation of autonomy. Raz's goal is to establish a coherent understanding of political liberty by grounding it in morality, not by liberty being understood as a distinct or independent value or concept from morality (Raz J 1986).[7] Perfectionism refers to a group of moral theories that maintain that there are certain goods or rights that all people should have or strive to have regardless of historical, cultural, or geographical context; these goods cannot be justified but rather explain the general intuitions that most people have about how to act in one's life and what is good for one's life in order to obtain personal well-being (287-289). Briefly then, according to Raz, personal well-being consists of setting and attaining goals upon which a given individual confers independent value through reasons. Raz argues that the goals, and the reasons given

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[7] For example, John Rawls' theory of justice and political institutions argues for a separation between morality and political philosophy, such that one can maintain the vital importance of liberty as a political ideal without reference to specific moral theories; Raz argues against these kinds of positions.

for the goals, are themselves, in part, taken up by individuals with reference to what is considered valuable within his or her society, i.e., what Raz calls "social forms" (308).

If a person's well-being is tied to his or her being able to establish and pursue goals, then it follows for Raz that individuals need to be free to pursue said personal goals (369). Thus, Raz introduces his understanding of autonomy, whereby what is morally important to protect and promote politically is an individual's ability to be self-creating, i.e., set and pursue goals (370). Raz proposes three conditions for the exercise of autonomy: "appropriate mental abilities, an adequate range of options, and independence" (372). First, regarding one's mental abilities, Raz does not provide much detail as to what he has in mind, except to say that it includes the "minimum rationality" necessary to create and pursue goals (373). Second, a range of options is adequate for a person's life if it includes "options with long term pervasive consequences as well as short term options of little consequence, and a fair spread in between" (374); in other words, an adequate range of options will include the ability to make long-term goals for one's life (e.g., go to university, find a partner, etc) and short-term trivial goals (e.g., go to the movies, have sushi for dinner, etc). Moreover, the options that one ought to have do not include, for Raz, morally bad options. Autonomy "should be used for the good" (380) and "only very rarely will the non-availability of morally repugnant options reduce a person's choice sufficiently to affect his autonomy" (381). Finally, one must have the independence to pursue one's choices, which means that one will be free from external coercion or manipulation (377-378). As alluded to in the preceding paragraph, Raz's conception of autonomy is more robust than a mere negative conception of liberty (i.e., freedom from coercion or restrictions) but rather posits a positive notion of liberty (i.e., the freedom to make of one's life as he or she chooses given a range of

options) (408-409). For Raz, "…negative freedom, freedom from coercive interferences, is valuable inasmuch as it serves positive freedom…" (410).

The independent value of autonomy is grounded in the fact that autonomy is a necessary condition to pursue the myriad of goals in one's life, i.e., autonomy is not one aspect of life that is valuable among other aspects, but rather it is a necessary condition for pursuing other goods. Raz writes:

> The value of personal autonomy is a fact of life. Since we live in a society whose social forms are to a considerable extent based on individual choice, and since our options are limited by what is available in our society, we can prosper in it only if we can be successfully autonomous. We may do so to various degrees. Some people may base more of their lives on these aspects, such as parenthood, where choice is more limited [i.e., once one chooses to be a parent, certain moral obligations follow]. Others may improvise in their own lives and vary common forms to minimize the degree of choice in them. But ultimately those who live in an autonomy-enhancing culture can prosper only by being autonomous (394).

Note how for Raz, even choosing to foreclose future options by, for example, choosing to be a parent, is an autonomous choice. Autonomy, in turn, is a matter of degree and will largely be dependent upon whether one's environment furnishes individuals with an adequate range of choices and the independence to pursue goals, i.e., to pursue one's well-being (392). Regardless, "… the conditions of autonomy concern a central aspect of the whole system of values of a society…" and therefore, autonomy is not merely one good to value among a host of other possible goods (394).

In addition to arguing for the role of autonomy as a necessary condition for well-being and describing the three constitutive parts of autonomy, Raz argues that autonomy and autonomous choices will allow different people to lead different lives that are equally worthy (or "virtuous") but incommensurable, a position referred to as 'moral pluralism' (395-399).

Stated differently, choosing to be a doctor may preclude one from also choosing to be a stay-at-home mom with a large family, all of which may be worthwhile options that society should provide individuals; in addition, being a doctor is not better or worse than being a stay-at-home mom but they are fundamentally different goods, i.e., they are incommensurable. The existence of multiple possible lives with multiple incommensurable goods might (or will likely) lead to what Raz calls 'competitive pluralism' whereby there may be a tendency of persons to act in an intolerant manner toward the autonomous choices of other members of society (404). Raz gives the example that the traits that make a person good at balancing multiple goals in life (e.g., the atheist doctor who volunteers at the food bank and climbs large mountains on his or her day off) might be intolerant of a person who wishes to pursue only one goal or cause (e.g., the theologian who spends most of his or her life reading and analyzing biblical passages). Thus, the existence of competitive pluralism suggests that although there may be an inclination to act in an intolerant manner toward those different and incommensurable life goals, tolerating each others' lives is important and necessary to promote autonomy; it is also necessary, however, to understand when and under what conditions one (e.g., the state) may rightful interfere with the choices of individuals (406-407); stated differently, when might one be rightfully intolerant of another's choices?

Raz's articulation of the harm principle is intended, in part, to help guide decisions as to when it is or is not acceptable to interfere with the autonomous actions of an individual. For Raz, a harm occurs "…when one's action makes the other person worse off than he was, or is entitled to be, in a way which affects his future well-being" (414). In other words, "[r]espect for the autonomy of others largely consists in securing for them adequate options, i.e., opportunities and the ability to use them" and therefore, removing options such that it

frustrates an individual's "… pursuit of the projects and relationships he has set upon" is harmful (413). Stated yet another (third) way, if autonomy is a necessary condition for securing well-being, and well-being consists of setting and attaining goals in one's life, then eliminating the ability to set and attain goals by eliminating options and opportunities is harmful. It follows that for Raz, the harm principle consists of the "…the prevention of harm to anyone (himself included) as the only justifiable ground for coercive interference with a person" (412-413). Here is the uniqueness of Raz's articulation of the harm principle: that given his argument stems from a perfectionist interpretation of autonomy, the harm principle applies not only to protecting others from harm, but in the same principle, protecting persons from self-harm. By addressing self-harm, this version of the harm principle, then, deviates from Mill's articulation of merely protecting others from harm as a justification for coercion and from Feinberg, who considers harm to self in only very limited circumstances, namely, in the absence of voluntariness and is an altogether different principle (or justification) of interference from his version of the harm principle.

Raz foresees, however, an objection against his perfectionist interpretation of the harm principle: "Autonomous life is valuable only if it is spent in the pursuit of acceptable and valuable projects and relationships. The autonomy principle permits and even requires governments to create morally valuable opportunities, and to eliminate repugnant ones. Does not that show that it is incompatible with the harm principle?" (417). However, a government under a perfectionist theory "subsidizes certain activities, rewards their pursuit, and advertises their availability encourages those activities without using coercion", i.e., the promotion of worthy life options and opportunities that are in keeping with social forms need not be made by use of the harm principle alone or in the first instance (Ibid). Moreover,

according to Raz, the government is not in a position to restrict morally repugnant options because "… there is no practical way of ensuring that the coercion [via the application of the harm principle] will restrict the victims' choice of repugnant options but will not interfere with their other choices", i.e., taking seriously autonomy means that it will be difficult, or impossible, in practice for governments to only limit repugnant options, so that the government is only allowed to not promote repugnant options, not necessarily take away all repugnant options (419).

For the purposes of the thesis, Raz's articulation of the importance of autonomy as a kind of positive freedom and his version of the harm principle presents a possible counter-balance to Mill's and Feinberg's more narrow version and scope of the harm principle.

iv. Kant(ian) conception of liberty and an objection to the harm principle: Immanuel Kant never wrote about the harm principle; he did, however, argue for a particular understanding of liberty that purports to include the justification for coercion therein. Moreover, Arthur Ripstein provides a possible argument against the soundness of the harm principle from a Kantian viewpoint that acts to counterbalance the preceding sections on Mill, Feinberg, and Raz.

Before describing what Kant means by 'freedom' and how this might counter any argument in favor of the harm principle, it is important to understand (or, at least, acknowledge) Kant's postulate of freedom and his distinction between law (or politics) and morality. First, Kant holds that the existence of freedom cannot be proven or disproven through experiments or argumentation; nonetheless, one must necessarily assume that human beings are free in order to makes sense of moral responsibility and make sense of human experience. Stated differently, Kant postulates that human beings are free because otherwise

human experience, including the experience of being responsible for one's actions, does not make sense (Kant 1996). Second, for Kant, morality and law/politics are two separate spheres of life, at least conceptually. Political philosophy for Kant is about how persons can coexist and what actions the state can enforce; morality about what we should do but is not enforceable (6:218). As Ripstein notes, just political institutions "…provide the only possible way in which a plurality of persons can interact on terms of equal freedom. Kant's concern is not with how people should interact, as a matter of ethics, but with how they can be forced to interact, as a matter of right" whereby 'right' "…refers to the domain of enforceable obligations" (Ripstein 2009).

According to Kant, then, there exists an innate right of freedom: "[f]reedom (independence from being constrained by another's choice), insofar as it can coexist with the freedom of every other in accordance with a universal law, is the only original right belonging to every man by virtue of his humanity" (Kant 1996, 6:237). There are at least five key aspects to the previous sentence: first, whatever freedom is, all human beings have it by virtue of being human (i.e., "belonging to every man by virtue of his humanity"). Second, whatever freedom is, it applies to all people at all times equally (i.e., "in accordance with a universal law"). Third, whatever freedom is, it is the only enforceable right and obligation upon which all other political rights and obligations rest (i.e., "is the only original right"). The fourth and fifth aspects of the sentence are Kant's concept of freedom (i.e., "freedom (independence from being constrained by another's choice")) and coercion (i.e., "insofar as it can coexist with the freedom of every other"); they will be described in turn.

Kant describes freedom as a quality that human beings have to be their own "masters" (6:238) and one that applies equally to all persons, i.e., "independence from being

bound by others to no more than one can in turn bind them" (6:237). Equal freedom is something that people have (or being equally free is something that people are); it is a *quality* of being human, irrespective of what can be *achieved* with said freedom (Ripsteain 2009, 33). As Ripstein notes, equal freedom

> …is not a matter of people having equal amounts of some benefit, however to be measured, but of the respective independence of persons from each other…. a system of equal freedom is one in which each person is free to use his or her own powers, individually or cooperatively, to set his or her own purposes, and no one is allowed to compel others to use their powers in a way designed to advance or accommodate any other person's purposes (Ibid).

Each person, then, has the freedom to independently choose to set goals and purposes and go about attaining said goals and purposes. Being a 'master' of oneself, in turn, means that one's ability to set and attain goals and purposes is not at the discretion or use of another person. This understanding of freedom, however, is only compatible with the freedom of others to set their own goals and purposes in life; moreover, the innate right of freedom does not entail that merely frustrating the an individual's achievement of a goal or obtaining a good constitutes an infringement on his or her freedom. For example, a mutually exclusive competition for a resource between *A* and *B* suggests that if *A* obtains the resource, *B* will not, and vice versa; this is morally permissible and to be expected. However, if *A* somehow removes *B's* ability to obtain a particular resource (e.g., through threat of force), then *A* wrongs *B*. To not allow competition runs contrary to Kant's notion of equal freedom, since "[t]o insulate one person from all the effects of the choices of others would subordinate everyone else to that person's choice" (39).

For Kant, then, under a mutual or reciprocal understanding of freedom between all individuals, a hindrance on said freedom is a wrong; but a "hindering of a hindrance to

freedom" is right (Kant 1996, 6:231), i.e., *B* or *C* can hinder *A's* freedom if *A* is hindering *B's* freedom. A straight-forward example is the case of self-defense: if *A* is about to assault, or is assaulting, *B*, then *B* has a right to defend him- or herself and *C* (a third party) also has a right to defend *B*, even if doing so constitutes a hindrance on *A's* ability to assault (since *A* would not have a right to assault in the first place). As such, coercion is an extension of the idea that freedom is equal, or mutual, or reciprocal among individuals since coercion is seen as a particular instance of a limitation or interference on freedom that is right if it is used to interfere with interference on freedom. As Ripstein writes, "[c]oercion is objectionable where it is a hindrance to a person's right to freedom, but legitimate when it takes the form of hindering a hindrance to freedom (Ripstein 2009, 55).

Therefore, if we summarize the preceding two pages, the foundational idea of Kant's political philosophy, which grounds all other rights (both private and public), is that freedom is the ability for each person to be a master of his or her own life, such that he or she has the ability to set goals and pursue them, such that all other persons have the same reciprocal right of freedom, and all of this is possible merely by virtue of being human (or rather, what it means to be human is to have this innate right to equal freedom).

Kant's notion of the innate right of freedom can generate a Kantian objection to the harm principle, namely, that harm is not the reason *A* cannot harm *B* without *B's* consent, but rather, that in doing so *A* uses *B* in a way that hinders or interferes with *B's* freedom. Consider the following:

> Suppose that, as you are reading this in your office or of the library, I let myself into your home, using burglary tools that do no damage to your locks, and take a nap in your bed. I make sure everything is clean. I bring hypoallergenic and lint-free pyjamas and a hairnet. I put my own sheets and pillowcase down over yours. I do not weigh very much, so the wear and tear on your mattress is nonexistent. By any ordinary understanding

> of harm, I do you no harm. If I had the same effects on your home in some other way, nobody would suppose you had a grievance against me, let alone that you should be able to call the law to your aid. You objection is to my deed, my trespass against your home, not to its [non-harmful] effects (Ripstein A 2006).

Recall that for Kant, an individual is wronged if he or she is not allowed to act as a master over him- or herself. In other words, a person is wronged when their ability to be free (e.g., the ability to choose how to rightfully dispose of one's property), is removed, even temporarily. The objection one might have to the harmless trespass is that the trespasser uses your property in an unsanctioned manner and thereby usurps, or interferes with, your freedom, i.e., your right to be a master over yourself. At first, then, it appears that the harm principle is unable to cope with cases of harmless wrongs. It becomes clear why Feinberg and Raz, then, need to provide an explanation of why harm alone is insufficient to warrant prohibition of an action (e.g., market transactions and competition), and why an illness, though harmful, is not a wrong whereby the infirmed can make claims against anyone else. As Ripstein notes,

> Bodily injury reduced your powers no matter how it comes about, but it only violates your independence if another person injures you. Any injury potentially reduces your ability to set and pursue your own purposes, but intentional injury does something more: if I set out to deprive you of powers you have, I subordinate your ability to use your powers to set and pursue your own purposes as you see fit to my pursuit of my purposes. I set myself up as your master by deciding that you will no longer have them. Intentional injury is despotism [i.e., mastery over another] by another name. Harm merits prohibition when it is a manifestation of despotism, but not otherwise (Ripstein 2009, 45).

Those who use a notion of harm to others (or self) to establish justified interference with the liberty of others must provide an explanation of why not all harms justify interference; the Kantian has a more simple explanation, namely, that harm does no normative work in explaining wrongs but rather that Kant's conception of freedom alone can be used to

distinguish cases of harmless wrongs and harms that are not wrongful (Ripstein 2006, 227-229).

C. Application of Theory in Discussions of Tuberculosis and Persons with SPMI

Although how the theories of Mill, Feinberg, Raz, and Kant are applied to help resolve ethical issues related to the treatment of TB in persons with SPMI, and how the relate to the empirical results, is presented in greater detail in *Chapter Seven: Discussion and Conclusions*, one can make some preliminary observations. First, there are no clear, simple, or straightforward applications of the harm principle, or limitations on the basis of self-harm, in practice, including public health or mental health. The various articulations of the harm principle, and corresponding theories of liberalism, require a careful consideration of how they may or may not apply in the case of the treatment of TB and SPMI and TB in persons with SPMI. Moreover, although the application of all four theories may lead to similar conclusions, namely a justification of the limitation of the freedom of movement in persons with TB and SPMI during periods where they are contagious, the justifications will most certainly differ; in turn, this may affect how the limitations are conceived (e.g., how much restriction is justified) and what are the rights and obligations of the various stakeholders (e.g., clients, health care workers, the general public, etc.).

Second, all of the theories provide a rich description of what is liberty. Across all the theories, one can make the argument that the restrictions on the freedom of movement and whether one can or must submit to treatment (explained more in *Chapter Three: Empirical Background – TB and Persons with SPMI*) relative to TB or SPMI involve fundamental issues that strike at the core of liberal protections. In other words, one's body and what one

can or must do with it is of utmost importance for liberals. One's body falls within the three domains of Mill's idea of liberty, is a vital welfare interest under Feinberg's theory, is a necessary condition for the autonomy of a person for Raz, and is the primary focus of political interactions between persons for Kant's idea of the innate right of freedom.[8] Thus, the application of the harm principle to the research questions presents a situation whereby the harm that *A* poses *B* is not trivial, but neither is the act that is subject to limits. For example, the inebriated acts of *A* towards *B* may harm *B* but do not necessarily benefit *A*; the ability of *A* to go to work to provide for his or her family, which is curtailed when a persons is infected with TB, so as to not infect *B*, is not a trivial good or liberty.

Third, different justifications for limits on free actions may or may not apply when thinking about harm to other versus harm to self. For example, for Raz, the same considerations apply when considering harm to self or other, but that is not the case for Feinberg (who has different justifications for the harm principle and soft-paternalism). The differences between the two are important when we consider harm to others and harm to self in the context of mental health. For example, Raz does not seem to consider whether his version of the harm principle applies to persons with SPMI, although he states that (but never really provides an argument for) persons need "appropriate mental abilities". Feinberg clearly gives persons with "neurosis" due consideration, to the extent that he seems to caution against any simple application of soft-paternalism to persons with SPMI. It is unclear how mental illness factors into the theories of liberty for Mill and Kant; Mill writes of the ability of free persons to take care of oneself and Kant's idea of freedom entails the notion of mastery, so perhaps a persons with SPMI may have the ability to care for him- or

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[8] Although beyond the scope of this chapter, the whole of Kant's idea of the political person begins with the truism that persons exist in space; hence his idea that political obligations have to do with what we owe each other as persons who share physical space (Kant 1996).

herself and be their own master sometimes but not others. Determining when someone with SPMI is or is not free or autonomous may require greater thought when applying Mill, Raz, or Kant.

Finally, none of the theories analyzed herein provide a clear discussion of the role of personal history and context in the application of the harm principle, i.e., all the theories are presented in abstraction and in context-neutral language. What I mean by personal history and context are the events and conditions that lead a person to reach a point where their liberty may have to be curtailed because they pose a risk of harm to self or others. For example, does it matter to those who support the theories presented in this chapter whether the person with active pulmonary TB, is new to Canada, and is responsible for the material well being of other family members? Do such factors shape the application or provide counters to the application of the harm principle in practice? Mill provides an example against what may seem like a straightforward application of the harm principle in the case of infectious diseases and sex workers; for Mill, no simple application of the harm principle exists if power imbalances exist between the various stakeholders. As the case of the *Contagious Diseases Acts* demonstrates, for Mill liberty must apply the same for everyone, as does the harm principle. Perhaps this ethos is in keeping with Kant's emphasis on the equal application of the innate right of freedom as a universal right.

D. Conclusion

This chapter provided an overview of four theories of liberty, including three that make use of the harm principle (i.e., Mill, Feinberg, and Raz) and one that provides an objection to the use of harm as a normative principle (i.e., Kant). The four theories differ in

how liberty is conceptualized, which in turn affects how harm may or may not be used to justify limitations on liberty, which in turn eliminates any simple or straightforward application of the harm principle in public health and mental health practice. In the next chapter, the empirical background is given and an argument set forth for why the treatment of TB in persons with SPMI provides an important and challenging case for the application of the various articulations of the harm principle in the practice of public health and mental health.

Chapter Three: The Empirical and Regulatory Background – TB and Person with SPMI

This chapter provides an overview of the science, history, policies, and laws regarding TB and SPMI, and the intersection of TB and SPMI, particularly (though not exclusively) as it relates to Toronto and Ontario (as will be described in *Chapter Four: Methods and Methodology*, the Greater Toronto Area is the focal point of the empirical research). There are discussions of the history of TB and SPMI beyond Toronto since it provides some broader context and grounding for this study and its objectives; however, any discussions about the history, as well as the policies and laws, related to TB and SPMI are intentionally brief because their purpose is only to provide context and justification for the thesis research.

There are two main conclusions that one may draw from the preexisting literature on TB and SPMI: first, the case of TB in persons with SPMI provides an important and unique lens by which to investigate conceptualizations of liberty and harm with reference to public health and mental health. Those who work in TB and mental health are subject to, implicitly and explicitly, laws and practices that may place an individual's liberty against the protection of the broader public from harm; however, whether deference is given to liberty or the protection of the general public may differ between these two health fields. Second, it is unclear what should occur in those instances when the treatment of TB may conflict with the treatment, or perhaps more precisely the care, of those with an SPMI.

A. Tuberculosis

i. Bacteriology, Epidemiology, and Treatment: Mycobacterium tuberculosis is a bacterial infection that can only live in human hosts and affects a person's lungs, as well as other organs. TB is transmitted through the inhalation of airborne droplets expelled through an infected person coughing, sneezing or spiting. Of those humans infected with TB globally, approximately 95% will not become diseased and 85% maintain a lifetime of latent, asymptomatic TB. The probability of developing active TB is higher in immuno-compromised individuals (e.g. ~37% of persons with HIV/AIDS develop TB within five months of exposure). TB that affects the lungs is the primary source of morbidity. Although the rate of transmission varies between the different strains of TB and is greater from persons with active TB than those with the latent form, transmission is also dependent upon environmental factors. Since TB particles have a slow setting rate once airborne (i.e. the rate at which particles descend after emission), poor air circulation and greater proximity between an infected agent and other humans in damp, humid locations increases the likelihood of transmission. TB particles do not survive once lodged in inanimate objects such as tables or chairs, or in dry locations and in the presence of direct sunlight. The circulation of fresh air in a building's ventilation system decreases the amount of TB particles in a given indoor air space and subsequently decreases the probability of transmission (Public Health Agency of Canada 2007).

Globally, in 2010, there were an estimated 8.8 million incident cases (128 cases per 100,000 population) and 12 million prevalent cases (178 cases per 100,000) of active TB. Of the incident cases, approximately 1.1 million TB infectious disease cases occurred in persons who were HIV-positive. Most of the incident cases occurred in Asia (59%) and Africa

(26%). Approximately 1.1 million HIV-negative persons died from TB in 2010; an additional 500,000 of fatalities caused by TB were observed in persons who were also HIV-positive. Most cases of active TB leading to morbidity and mortality occurred in lower income countries (World Health Organization 2011). In Canada, the incident rate of TB is much lower than the global rate; in 2009, there were approximately 1,600 (4.8 per 100,000 population) new active and re-treatment cases across the country (Ellis et al. 2010). Of note, during 2009, 63% of all incident cases in Canada were from foreign-born persons, while Aboriginal Canadians accounted for 21% of reported cases (Ibid). The rate of TB in Aboriginal persons was almost six times higher than that of the general Canadian population (Ibid). In Ontario in 2009, there were 580 new active and re-treatment cases with an incidence rate of 7.1 per 100,000 population; 255 of the province's cases occurred in Toronto (Toronto Public Health 2011).

As one can begin to deduce from the epidemiological data, TB disproportionately affects persons of lower socioeconomic status (SES) and is described as a "disease of poverty" (World Health Organization 2009). Persons of lower SES (e.g. persons who are homeless) often suffer from physiological conditions (e.g. cardiopulmonary diseases) and live in social situations (e.g. living in shelters) that enable easier TB transmission and increase their susceptibility of having an active case (Gostin 1993; Lopez 1994). For example, poor standards of ventilation and the proximal living conditions of persons using homeless shelters led to an outbreak of TB in this population in the late 1980s in New York City (Bayer and Dupuis 1995; Coker 2000).

Treating cases of active TB and reducing the rate of transmission requires both public health and pharmacological responses. In terms of public health goals, domestic and

international healthcare systems have certain responsibilities. Domestically, governments provide the legislative and regulatory structures, and laboratory and surveillance capabilities, to track and manage active cases of TB. Internationally, information on new drug-resistant strains, as well as epidemiological information, is shared between governments and non-governmental organizations (e.g., WHO) in order to treat the global burden of TB and to improve international standards of TB treatment and prevention. Pharmacologically, treatment of active TB with medication usually includes prescribing a combination of four drugs: isoniazid, rifampin, pyrazinamide, and ethambutol. A first-time standard course of treatment runs between six and 24 months and until the patient's sputum is clear of bacteria (Public Health Agency of Canada 2007). A patient who is deemed unlikely to comply with TB treatment is often required to remain in voluntary respiratory isolation until they are considered non-infectious (Ministry of Health 2008) where 'respiratory' isolation denotes arresting the transmission of airborne particles by any plausible means (e.g. wearing an N95 mask)(Public Health Agency of Canada 2007). Although a person with active TB is most likely to infect others prior to treatment and during the first two months of treatment (Ontario Lung Association 2009), TB is communicable as long as bacteria remains in a person's sputum (Lederberg, Oaks, and Shope 1992). The goal of drug treatment is two-fold: first, to treat (and hopefully cure) a person from his or her active TB, and second, to use clinical treatment as a public health strategy toward arresting the transmission of TB (Public Health Agency of Canada 2007).

TB drug regimens, however, have two challenges, which lead to poor completion rates and raise a host of additional public health challenges. First, the drugs used to treat TB often produce adverse reactions, including hepatoxicity, renal toxicity, and neuropathy; of

particular interest for this dissertation, a rare adverse reaction to isoniazid may include psychotic episodes (World Health Organization 2006, 2009; Angelini, MacCormack-Gagnon, and Dizio 2009) and negative interactions between a person's psychiatric illness and between the rifampicin and clozapine (a common drug used in the treatment of schizophrenia and sometimes bipolar disorder) (Joos, Frank, and Kaschka 1998; Peritogiannis et al. 2007). Second, due to the length of course of treatment, the social supports often necessary to complete treatment (e.g. family members needed to procure food during isolation), along with the possibility for adverse reactions, persons with active TB sometimes fail to finish their prescribed course of treatment, which has led many TB researchers to postulate that non-adherence to treatment is responsible for the rise of multidrug resistant tuberculosis (MDR-TB) and extensively drug resistant tuberculosis (XDR-TB) (Public Health Agency of Canada 2008, 2007; World Health Organization 2009).

Before describing M/XDR-TB, it is important to discuss public health's standard response to non-adherence to TB drug treatment, namely the use of Directly Observed Therapy (DOT). DOT (or DOTS where the 's' stands for 'short-course' when short course chemotherapy treatment is indicated) consists of a public health practitioner or healthcare worker observing a person with TB swallow his or her requisite pills. The place of supervision is determined on a case-by-case basis and should be as least disruptive to the patient's life as possible (World Health Organization 2006). Some studies suggest that treatment completion rates reach 90% with the use of DOT because of the support that DOT workers provides patients, e.g., reminding patients to take their antitubercular medications (Blumberg MH, Leonard MK, and Jasmer RM 2005); hence the World Health Organization endorses DOT as a standard course of treatment for everyone requiring TB treatment (World

Health Organization 2006). Bender and colleagues note in their qualitative study of TB nurses that DOT might be construed as a "welcome intrusion" by those with TB, meaning that even though "[s]urveillance, with its implied limits on freedom and autonomy, is a foundational element of the [DOT] job"; nonetheless, "what formerly was experienced as intrusive visits by a public health official shifts to non-intrusive and even welcomed meetings with a familiar person" due to the support provided by TB nurses (Bender et al. 2011). In Canada, due to the differing levels of resources that provinces and public health units may have, TB specialists recommend using DOTS preemptively and for the full duration of drug treatment when a person with TB falls within a population with historically poor treatment adherence, including persons who are homeless or have psychiatric illnesses (Public Health Agency of Canada 2007; Ministry of Health 2008). Despite the recommendations of the WHO and other scientists, some researchers have argued that the evidence regarding the effectiveness of DOT remains inconclusive (Verma et al. 2004; Zwarenstein et al. 1998; Walley et al. 2001). Finally, if someone is non-adherent even when participating in a DOT program (i.e. refuses to adhere to TB treatment despite the best efforts of public health officials), then some jurisdictions, including Ontario, have laws that allow for the involuntary detention of such persons for the protection of the general public (*Health Protection and Promotion Act, R.S.O. 1990, Chapter H.7* ; Bayer and Dupuis 1995; Coker 2000).

As mentioned above, the reason there is such an emphasis on adherence to TB treatment is because of the morbidity associated with TB and because the TB bacteria may mutate and develop varying degrees of drug resistance. MDR-TB and XDR-TB present unique challenges with traditional public health response precisely because of the increased

morbidity and drug-resistance of the mutated strains. MDR-TB is any TB strain that is resistant to isoniazid and rifampicin (the two most commonly used first-line drugs), where resistant bacteria is acquired externally or develops from preexisting non-drug resistant strains in a particular individual. MDR-TB is treated through DOT and the combined use of fluoroquiolone and second-line anti-TB injectable drugs, which are amikacin, kanamycin, and capreomycin. XDR-TB is defined as TB bacteria resistant to isoniazid, rifampicin, some fluoroquinolone or second-line anti-TB injectable drugs; treatment of XDR-TB is limited to using any fluoroquinolone and any second-line anti-TB injectable drugs that are not deemed resistant upon laboratory confirmation of bacterial strains (World Health Organization 2010; Public Health Agency of Canada 2008).

Globally, there were an estimated 440,000 incident cases of MDR-TB in 2008, which represented approximately 3.5% of all active TB cases. Most cases of MDR-TB occur in Eastern Europe and Central Asia, resulting in approximately 150,000 deaths globally in 2008. Approximately 5.4% of MDR-TB cases are XDR-TB (World Health Organization 2010); one study from Korea places the morality rate for XDR-TB at 48% (Jeon DS et al. 2009). Despite these figures, there has been a global decrease in MDR-TB, attributed to early identification and aggressive treatment of the disease (World Health Organization 2010). MDR-TB is not considered more virulent than non-drug resistant TB (Public Health Agency of Canada 2007). Risk factors for M/XDR-TB are similar to the risk factors associated with non-drug resistant TB. In Canada, up to and including 2008, there were a total of 181 cases of MDR-TB, representing approximately one percent of all TB cases between 1998-2008; there were four cases of XDR-TB in Canada during that time (Public Health Agency of Canada 2008). It is important to note that the rise of M/XDR-TB is not

limited to non-adherence to TB treatment that has led to bacterial mutation, but is also a result of "poor infection control practices in congregate setting", like homeless shelters (Raviglione 2006). M/XDR-TB has been described as a "tragic" result of human complacency and failure toward TB treatment (Upshur 2010; Coker 2004).

In terms of relevant adverse effects of second-line drugs, cycloserine (usually given in conjunction with other drugs) may result in psychotic episodes and is contraindicated for persons with depression, severe anxiety or psychosis (World Health Organization 2006). Of particular note is the WHO's recommendation vis-à-vis cycloserine: they state that if cycloserine is important for TB treatment in a particular case and the patient has a history of psychiatric illness "the benefits of using this drug may outweigh the potentially higher risks of adverse events" (World Health Organization 2006). The WHO's position invites the question: for whom does the benefits outweigh the risk: the patient or the general public? Moreover, the WHO insists that if a patient develops signs of psychosis, then cycloserine should be discontinued "if this can be done without compromising [TB] regimen" (World Health Organization 2006); again, it is unclear whether deference is given to the protection of the public from M/XDR-TB, or at least completion of chemotherapy, than the psychiatric well being of the patient. One might infer that for WHO, the protection of the public should come at the expense of an infected individual's mental health, if no other alternatives exist; whether or not that is the intended message of the WHO is unclear.

ii. A Brief History of Tuberculosis: This section is not intended to provide an exhaustive history of TB treatment in Canada and abroad, but rather an overview to further contextualize the study design, results, and discussion. As early as the late 19th century, shortly after Robert Koch discovered the tubercle bacillus, tuberculosis was understood not

only as an infectious disease, but also "it was defined as a disease of only some, not all, people, essentially the immigrant and the poor, not the middle or upper classes" (Rothman 1994). Rothman argues that although in the United States, public health officials acknowledged that TB was a bacteria and that the background conditions leading to TB infection needed to be altered (e.g., improve housing conditions for recent immigrants), individuals with TB needed to ensure that they took responsibility for being cured and moreover "… the [public health] campaign moved along the spectrum from persuasion to outright compulsion, with each measure justified by an appeal to the welfare of the community" (Ibid, 186). Thus, one shared response to TB in much of the Western world in the 20th century has been to isolate individuals with TB from those members of the public without the disease in order to reduce or eliminate transmission. In the early 20th century, prior to the use of antitubercular drug regimens popularized in the 1950s, sanatoriums provided a place not only to separate the infected from the non-infected, but also provided a space to receive treatment, including "rest, nutritious food, fresh air, education and rehabilitation" (Grzybowski and Allen 1999). With the advent of antitubercular drugs, persons with active TB could be treated in their homes and communities; however, infection control remained in the form of respiratory isolation and improved with the advent of DOT in the 1980s in response to the epidemic in New York (Grzybowski and Allen 1999; Coker 2000; Houston CS 1991; Houston 1991).

In his book, *From Chaos to Coercion*, Coker notes that the history of the response to the TB epidemic in the late 1980s-early 1990s in New York City (although perhaps his arguments extend beyond this place and time) should not only attend to a study of the proximal causes and responses to the epidemic, but must also take stock of who was at risk

of active TB and why. As noted earlier in this chapter, those most at risk for TB are persons of lower SES; likewise in New York in the 1980s-1990s. As such, Coker argues that the lack of basic primary healthcare, in conjunction with the deterioration of social welfare in the 1980s, placed persons who were socially, economically, and politically marginalized at greatest risk for TB. These individuals, in turn, were less likely to seek immediate care for TB and were suspicious of the public health system, often leading to high rates of non-completion of anti-tubercular drug regimens. The public health response to non-compliance, and the mere threat of being non-compliant (i.e., fitting the profile of those who tended to not comply, namely, those socially and politically disenfranchised), was to remove liberty and autonomy via DOT and heavily enforced isolation. Coker asks his reader:

> Often policymakers forget that the ultimate goal of tuberculosis programs is not to make as many patients as possible complete therapy but to reduce the incidence of tuberculosis, including drug-resistant tuberculosis, in a community. So one must ask, have alternative approaches to preventing relapse and the subsequent development of drug resistance been considered adequately, and if not, why not? (Pg. 7)

The background factors that lead to active TB and, in turn, non-compliance, were ignored by public health in New York, often because public health decision-makers lacked the capacity to alter the background conditions in the first place, not because they were oblivious to the ultimate causes of the epidemic. One of Coker's conclusions, particularly relevant for this thesis, is that "[o]ne common thread runs through all of these public health areas, vaccination and immunization, mental illness, and the historical approach to tuberculosis. Coercion began with those who were least able to protest or resist: children, the mentally ill, and the poor. And alternatives, unless forced by popular mandate, were rarely considered" (Coker 2000).

Despite the use of DOT and isolation for the public good, there have been voices that have called for considering not only the responsibilities of those with TB to not infect others, but also the responsibility of the state and society to support those persons with TB discharge their obligations. In light of the epidemic in New York City, Dr. Thomas Frieden claimed that "while these patients must accept responsibility for their actions, society must also accept responsibility for creating and allowing to flourish the conditions for non-compliance: poverty, homelessness, drug abuse, lack of access to medical care, and mental illness" (102) and Dr. Ron Bayer noted that "there is an implicit recognition of the responsibility [of the state] to provide the conditions that will enhance patient cooperation" (Coker 2000).

In Canada, there is a tradition of providing social and material support to those persons who have TB. Grzybowski and Allen note that "[i]n 1911 a free dispensary opened in Toronto, which provided soup, eggs, milk, clothing, sputum boxes and free medicines and paid the rent of deserving patients with TB" (Grzybowski and Allen 1999); the Toronto Free Hospital for Consumptive Poor was the first of its kind in the world (Gale 1979). Moreover, under the guidance of Dr. RG Ferguson, Saskatchewan in the late 1920s became the first jurisdiction in North America to provide free diagnosis and treatment regardless of the patient's ability to pay. Dr. David Stewart, a contemporary of Ferguson from Manitoba noted of Saskatchewan's success, that "[w]e would never have eradicated smallpox if a man had had to mortgage his farm to pay for the treatment" (Pg. 84), thus implying that any hope of eradicating TB would require treating not merely the disease but caring for those with TB in a more holistic manner (Houston 1991).

iii. Health Protection and Promotion Act (HPPA): The HPPA, along with relevant regulations, provides the legislative framework for infectious disease control in Ontario

(*Health Protection and Promotion Act, R.S.O. 1990, Chapter H.7* ; *Health Protection and Promotion Act, R.R.O 1990, Regulation 569* ; *Health Protection and Promotion Act, O. Reg. 558/91* ; *Health Protection and Promotion Act, O. Reg. 559/91*). The HPPA classifies infectious diseases by three categories, in descending order of level of harm: virulent, communicable, and reportable. All virulent diseases are also classified as communicable, and all communicable are reportable. TB is identified as only one of 12 virulent diseases in Ontario. Two sections of the HPPA are worth noting: first, s.22(1) allows that a medical officer of health (MOH) "by a written order may require a person to take or refrain from taking any action… in respect of a communicable disease" which may include, as articulated in s.22(4):

> c) requiring any person that the order states has or may have a communicable disease or is or may be infected with an agent of a communicable disease *to isolate himself or herself and remain in isolation from other persons*;
>
> (f) requiring the person to whom the order is directed to submit *to an examination by a physician* and to deliver to the medical officer of health a report by the physician as to whether or not the person has a communicable disease or is or is not infected with an agent of a *communicable disease*;
>
> (g) requiring the person to whom the order is directed in respect of a communicable disease that is a *virulent* disease to place himself or herself forthwith *under the care and treatment of a physician*;
>
> (h) requiring the person to whom the order is directed *to conduct himself or herself in such a manner as not to expose another person to infection*. (Emphasis added)(*Health Protection and Promotion Act, R.S.O. 1990, Chapter H.7*)

Section 22, then, is essentially a letter given to someone with a communicable disease who has not been abiding by previously orally articulated public health orders and must fulfill certain written requirements. In particular, note that an order under s.22 allows an MOH to require an individual to remain in isolation and to be examined by a physician if the disease is *communicable*, but submit to *treatment* if the disease is *virulent*.

The second relevant section of the HPPA is s.35, whereby an MOH can ask the court (s.35(1)) to take into custody and detain for the purposes of *examination or treatment* any person suspected or known to have a *virulent* disease (s.35(3)(a,b,c)) for a period of no more than six months (s.35(7)) if that person failed to comply with an order from an MOH to remain in isolation or submit to examination or treatment by a physician (s.35(2)(a,b,c). Section 35(7.1)(a,b) states that the *Health Care Consent Act, 1996* does not apply to persons under examination or treatment of a virulent disease (*Health Protection and Promotion Act, R.S.O. 1990, Chapter H.7*). There are two important differences between s.22 and s.35; first, s.22 is an order that must be complied with voluntarily, while s.35 allows for involuntary detention. Second, s.22 applies to both communicable and virulent diseases, while s.35 only applies to virulent diseases. It is important to note that in both s.22 and s.35 of the HPPA, an MOH may order not merely isolation but *treatment* of persons with virulent diseases like TB.

Although there are only two cases on s. 35 of the HPPA that have entered the court system, these two cases provide an important insight into how the judiciary in Ontario understands harm to others in the context of a virulent disease like tuberculosis. First, the case of Basrur v. Deakin provides an answer to whether s.35 of HPPA, which permits a member of the executive branch of government (e.g. the MOH) to treat a person involuntarily, would violate s.7 of the *Constitution Act, 1982* (including *The Canadian Charter of Rights and Freedoms*), which guarantees the right to “security of person” (*The Constitution Act, 1982, being Schedule B to the Canada Act 1982 (U.K.), 1982, c. 11.*). Mr. Deakin was detained in a specialized hospital with a long-term TB unit and was refusing to take medications. The court ruled that Mr. Deakin’s rights under s. 7 of the Charter were violated, but were justly violated under s. 1 of the Charter due to the threat of transmission of

TB to staff (Basrur v. Deakin 2002). Furthermore, the judge ruled that it was not feasible ("unrealistic and impractical" – paragraph 30) to indefinitely detain someone with TB but not treat them at the same time:

> 27. The submissions of the Attorney General are commendably well articulated. Paragraph 7 of the brief encapsulates the issue and deserves to be quoted in full.
>
> 'Further, the s. 7 case law required the Court to strike a balance, both substantively and procedurally, between the interest of the person who claims his right has been limited and the protection of the public. Section 35 is not overbroad in requiring a person with contagious tuberculosis to subject himself to treatment after a full oral hearing in which his views can be considered. The alternative to treatment is the indefinite warehousing of the patient at West Park Healthcare Centre until he dies, which could be up to 14 years. During this period he will become more contagious and will present an ever-increasing threat to the health of staff that will be required to care for him. He will pose a tremendous risk to the public should he, as he has done on two occasions recently, leave the facility. Further, while not in and of itself a determining factor, the tremendous cost to the public purse of housing individuals with tuberculosis for the rest of their lives when they could be cured by undergoing approximately 6 months of treatment is an additional factor that the Court may take into account. Finally, with respect to this case in particular, were the patient to now be permitted to stop taking his medications he could develop a drug resistant form of tuberculosis which would be more difficult to treat and would be even more dangerous to all persons with whom he has contact.' (Basrur v. Deakin 2002)

Although reference is made to the cost of keeping Mr. Deakin isolated indefinitely without treatment, it seems that the main impetus of the Attorney General's comments, as quoted in full by the judge, is the potential harm that untreated TB could cause other persons.

Second, in the case of Toronto (City) Associate Medical Officer of Health v. McKay, Mr. McKay suffered from alcohol addiction as well as XDR-TB and was not deemed capable of complying with public health isolation and treatment orders, despite his best intentions and despite proof that he had a fiancée that was willing to help him overcome TB. Although this case, which occurred five years after Basrur v. Deakin, did not consider s. 7 of the Charter, it did provide an understanding of how the court interprets risk of harm vis-à-vis

possibly untreated XDR-TB. According to the court, risk demands considerations of the harm of a given act, as well as the probability of the act occurring:

> 27. The function of calibrating risk is an elusive one. Risk takes its meaning from the context in which it is engaged. Risk is concerned with predicting the likelihood of the occurrence of defined events. In this case, the concept of risk entails two inter-related aspects - the probability of the event occurring and the harm associated with the event. It is not seriously disputed that the potential harm associated with the contingent event (Mr. McKay once again becoming infectious) is enormous…. If Mr. McKay becomes infectious again, this lethal virus may be unwittingly spread among the general population, creating a public health crisis of enormous proportions.
>
> 28. The real issue on this application concerns the probability of this event occurring if Mr. McKay is released into the community. On all of the evidence, I am satisfied that the risk of this occurring is significant. I have reached this conclusion after assessing the plan to release Mr. McKay into the community, not just left to his own devices, but under the strict orders of the Chief of Officer of Health, subject to the threat of swift detention in the event of defalcation.
>
> *****
>
> 31. I wish to be clear that Mr. McKay is not being detained because he is an alcoholic. He is being detained because he suffers from a virulent disease that could easily become infectious if his treatment is compromised. Among other factors in Mr. McKay's life (such as his preferred diet and its harmful impact on his diabetes), his problem with alcohol is directly and negatively related to the success of his treatment for XDR TB. Moreover, if Mr. McKay becomes infectious once again, his dangerous drinking behaviour potentially puts others at risk, such as the medical personnel who may be called upon to assist him (Toronto (City) Associate Medical Officer of Health v. McKay 2007).

In this case, the court concluded that the gravity of the harm was relatively easy to determine (i.e., XDR-TB is extremely harmful) and that given how harmful the consequences of transmission were in this case, and given his inability to care for himself due to his alcohol addiction (although not *because* of his addiction), nothing short of in-patient detention would counter the low probability of him actually complying with treatment in the community.

iv. Tuberculosis Policy in Ontario: The three levels of government (i.e. federal, provincial, and municipal) share the responsibility of developing legislation and policy to

regulate the surveillance, prevention, and treatment of TB in Canada (Public Health Agency of Canada 2007). Federally, the Public Health Agency of Canada provides standards and recommendations for the provinces and acts as an intermediary on issues of surveillance and epidemiology between the provinces and the international public health community (Public Health Agency of Canada 2007). In Ontario, the HPPA provides the legal foundation for tuberculosis control and policy. In addition, Ontario has published a *Tuberculosis Prevention and Control Protocol* intended to "identify the minimum [mandatory] expectations for public health program and services" at the local level in order to comply with the HPPA (Ministry of Health 2008). Public health units can exceed this protocol when local officials feel there are specific populations needs that require further support. Public health units are required to abide by provincial law and protocol rules regarding operational roles and responsibilities, surveillance, identification and management of active and latent TB cases, and managing the contacts of persons infected with TB (Ministry of Health 2008). Finally, the Ontario Lung Association, in conjunction with the province of Ontario, has recently produced a detailed information manual for frontline healthcare workers; this document outlines the basic epidemiology, modes of transmission, screening, diagnosis, treatment and reporting requirements for active and latent forms of TB (Ontario Lung Association 2009).

B. Mental Health and Severe and Persistent Mental Illness

i. Etiology, Epidemiology and Treatment: A 'mental illness' (or a 'mental disorder'), as defined by the American Psychiatric Association, is "a clinically significant behavioral or psychological syndrome or pattern that occurs in an individual and that is associated with

present distress… or disability… or with a significantly increased risk of suffering death, pain, disability, or an important loss of freedom" (*Diagnostic and statistical manual of mental disorders: DSM-IV-TR* 2000). A mental illness does not refer to normative disagreements regarding an individual's beliefs relative to his or her society, nor any distress commonly associated to life events (e.g. the death of a family member) (Ibid). Note that the American Psychiatric Association's definition of a mental illness lists "loss of freedom" as a possible consequence of disease apart from, or in addition to, any distress or physical or emotional disability. This emphasis on gaining, regaining, or maintaining personal freedom is in keeping with the more recent history of mental healthcare (see section *B.ii. Brief History of Mental Health and Psychiatry* below).

The notion of a 'severe and persistent mental illness' is difficult to define because there is a lack of consensus as to the parameters of the term (Schinnar et al. 1990). The Ministry of Health and Long-Term Care in Ontario has defined SPMI via three dimensions: disability (i.e. inability of a person to function in a daily life activity, for example, eating or bathing), duration (i.e. that the SPMI is both acute and chronic), and diagnosis (i.e. primarily persons suffering from schizophrenia, mood disorders, organic brain syndrome, and other forms of paranoia and psychosis) (Ministry of Health 1999). A more recent definition of SPMI that has gained traction in the literature (Parabiaghi et al. 2006), which evolved from the National Institutes of Mental Health definition, is as follows: a person has an SPMI when he or she requires treatment for two or more years for organic or non-organic psychosis and has a disability as measured by a Global Assessment of Functioning (GAF) score of 70 or below (Ruggeri et al. 2000). Two points of clarification: first, the term psychosis "refers to delusions, any prominent hallucinations, disorganized speech, or disorganized or catatonic

behavior" (*Diagnostic and statistical manual of mental disorders: DSM-IV-TR* 2000). Second, the GAF is a tool intended to help clinicians' judge an "individual's overall level of functioning"; for a score of 70, to take the highest score possible under a definition of SPMI, disability occurs if there are "some mild symptoms or some difficulty in social, occupational, or school functioning, but generally [the person is] functioning pretty well, [and] has some meaningful interpersonal relationships" (*Diagnostic and statistical manual of mental disorders: DSM-IV-TR* 2000). Despite the requisite presence of long-term psychosis, a GAF score of 70 sets the threshold of disability low; one possible reason might be that this gives the treating healthcare worker for a given client a 'healthcare worker's prerogative' and the possibility of being overly inclusive in order to facilitate access to a particular form of treatment. In practice, three psychiatric conditions usually fall within the scope of SPMI: schizophrenia, schizoaffective disorders, and bipolar disorder (Ruggeri et al. 2000; American Psychiatric 2000).

Despite the disagreements regarding the definitions and thresholds for what constitutes varying kinds of mental illnesses, Eaton and colleagues estimate that mental illnesses account for 21% of the total global burden of disease, with schizophrenia and bipolar disorder causing the greatest amount of disability amongst psychiatric conditions; only infectious diseases and cardiovascular disease have a greater burden of disease globally (Eaton et al. 2008). Schizophrenia "is a disorder that last at least 6 months and includes at least 1 month of active-phase symptoms (i.e., two [or more] of the following: delusions, hallucinations, disorganized speech, grossly disorganized or catatonic behaviour, negative symptoms)" (*Diagnostic and statistical manual of mental disorders: DSM-IV-TR* 2000). Bipolar disorder is a mood disorder that is characterized by one or more occurrences of

manic episodes (i.e. "an abnormally and persistently elevated, expansive, or irritable mood" - 357) or mixed episodes (i.e. a combination of a manic episode and a major depressive episode - 362)(*Diagnostic and statistical manual of mental disorders: DSM-IV-TR* 2000). The cause of both schizophrenia and bipolar disorder are not completely understood, but studies suggest that a combination of factors lead to these diseases, including biological (e.g., genetics) and environmental factors (Sadock and Sadock 2007). Schizophrenia and bipolar disorder each affect 1% of Canadians (Health Canada 2002) with similar prevalence rates globally (Mueser and McGurk 2004; Eaton et al. 2008). Onset of schizophrenia and bipolar disorder usually occur in early adulthood (Health Canada 2002) and are associated with other physical co-morbidities including obesity, substance abuse, and cardiovascular disease, as well as higher rates of suicide than in the general population (McGrath et al. 2008; Wilkins 2004). Persons with schizophrenia and bipolar disorder are usually of lower SES, though it is unclear the extent to which being of a lower SES increases the risk of succumbing to the diseases or whether having these diseases, which makes activities such as sustained employment difficult, leads to economic disadvantage (Health Canada 2002; Mueser and McGurk 2004; Wilkins 2004).

Treatment of the variety of SPMI illnesses generally combines pharmacological approaches with psychosocial therapy, the former chemically targeting the neurological dysfunction, while the latter aims to improve a person with SPMI's psychological and social functioning by providing education and supports to help with day-to-day living. In particular, Intensive Case Management (ICM) and Assertive Community Treatment (ACT) were developed to assist those with SPMI function and thrive in a community environment by providing intensive and prolonged interaction with healthcare professionals (including

physicians, nurses, and a variety of therapists) in the community itself. ICM is intended for those with moderate needs (i.e., those persons somewhat self-sufficient), while ACT is intended for those persons with greater, more severe needs for psychosocial support.

The primary motivation behind ACT and ICM is empowering persons with SPMI to help them achieve a sufficient level of functioning so that they can exercise their right to live as individual members in the community. For example, the goal of ACT programs is to "help persons with mental disabilities become integrated into their communities *as individuals* (emphasis added)" (Stein and Santos 1998). The founders of ACT claim that persons with SPMI "coveted their autonomy" (11) and that "the people [ACT teams] are working with [clients who] are first and foremost citizens of the community… because it is their right" (Stein and Santos 1998).

ii. A Brief History of Mental Healthcare and Psychiatry: Although the history of psychiatry is complex and multifaceted, certain historical events can help better situate current trends in mental healthcare. Generally, persons with mental health illnesses have been subjected to intense stigma and discrimination throughout history and across the world. 'Madness' was once attributed to a person's religious failings in parts of the Western world, and care for persons with mental illnesses fell upon family members who were often ashamed of their afflicted relatives and tried to help their loved ones through prayer. During the Middle Ages in Europe, hospitals that tended to psychiatric patients proliferated, and while they often preached empathy and pity toward patients, those persons institutionalized were treated predominately as children with little-to-no rights or responsibilities (Porter 2002; Musto 2009; Shorter 1997).

There exists at least two historical moments in Western mental health of note for the purposes of this thesis. The first event that helped shape modern mental healthcare was the Enlightenment and that period's emphasis on using rational thought over emotions and mythic or religious teachings. Rene Descartes posited that the world was made up of material objects, like the human body, and incorporeal objects, like the mind (the mind being considered the seat of rationality and morality). However, the mind controlled the body through the pineal gland, thus connecting the material and the immaterial world. It was under this and similar dualistic models of the human that gave rise to the notion that those persons with mental illnesses lacked the ability of rational thought, the ability to control emotion, and subsequently, the ability to distinguish right from wrong, i.e. an inability to be moral beings (Porter 2002). In 18th century France, the cause of mentally ill persons' stunted reason was often deemed socially caused (Musto 2009). This approach, popularized by the 18th century French physician Philippe Pinel during the height of the French Revolution's philosophical emphasis of individual liberty, stated that treatment of persons with mental illnesses should be based on reason and should use restrictions only when absolutely necessary and as a last resort (Porter 2002; Musto 2009; Shorter 1997) .

The second pertinent historical moment in Western mental healthcare, that of deinstitutionalization, occurred in the 1960s with the civil rights movement in the United States and Canada, but can be traced as far back as the 1940s in the United Kingdom. Until then, most of mental healthcare was delivered in in-patient psychiatric institutions, whose original intent was to treat persons with mental illnesses in a burgeoning medico-psychiatric model. In approximately the late 1950s, mental health advocates and politicians called for deinstitutionalization, which meant that care for persons with mental illnesses would no

longer fall under the auspices of the federal or local governments. For many, this was a practical move that was intended primarily as a means of saving taxpayers' money; for others, deinstitutionalization was seen as a means of normalizing mental illness and affording marginalized persons the civil rights that were being appropriated by African Americans/Canadians and women during the same time period (Shorter 1997; Porter 2002).

The two important historical results, that of an emphasis on liberty and deinstitutionalization, continue to be relevant today: first, respect for the liberty, individuality, and dignity of persons with mental illness remains an important component of the mental health field's attempt to counter the stigma of persons living with psychiatric conditions (Musto 2009; Porter 2002; Shorter 1997). Second, an unintended consequence of deinstitutionalization was that there were few plans made for community treatment (i.e. former psychiatric in-patients were being discharged to their families, or more often, to the streets). This lack of post-institutionalized planning was the primary motivation for present-day community care models, including ACT and ICM (Stein and Santos 1998).

iii. Mental Health Act (MHA): The MHA is the primary source of Ontario legislation regarding the care and treatment of persons with psychiatric illnesses, including SPMI (*Mental Health Act, R.S.O. 1990, Chapter M.7*). Section 12 of the MHA grants anyone who requires psychiatric care or treatment voluntary or informal admission to a psychiatric facility (whereby 'informal' means decisions taken via a substitute decision-maker). Voluntary admission assumes that a person is capable of wanting treatment, where a person is deemed capable "if the person is able to understand the information that is relevant to making a decision about the treatment… and be able to appreciate the reasonably foreseeable consequences of a decision or lack of decision" (*Health Care Consent Act, S.O. 1996,*

Chapter 2, Schedule A). The MHA also allows for involuntary admission under certain conditions, the broadest which are found in s.20(5), which states a psychiatrist, after examining a patient, may issue a certificate for involuntary admission for no more than two weeks without renewal (s.20(4)) if, pursuant to s.20(5):

> (a) …the patient is suffering from mental disorder of a nature or quality that likely will result in,
>
> (i) serious bodily harm to the patient,
>
> (ii) serious bodily harm to another person, or
>
> (iii) serious physical impairment of the patient,
>
> unless the patient remains in the custody of a psychiatric facility; and
>
> (b) that the patient is not suitable for admission or continuation as an informal or voluntary patient [i.e. the person is incapable of consenting to treatment and has no substitute decision maker] (*Mental Health Act, R.S.O. 1990, Chapter M.7*).

A non-psychiatrist physician may also apply for a psychiatric assessment under s.15(1) when he or she believes that a patient is a serious threat of bodily harm or physical impairment to the patient or others as a result of a psychiatric illness. Under s.20(1)(a,b,c), the physician who conducts the psychiatric exam shall (i.e. not 'may') admit involuntarily to treatment a patient if said patient has shown positive results to previous treatments for an illness that causes a serious threat of bodily harm or physical impairment to the patient or others and the patient is incapable of admitting him or herself to treatment; unlike the HPPA, the MHA explicitly uses the word "harm" and provides a preliminary understanding of its uses, namely, harm as physical or bodily harm. In summary, s.15 and s.20 of the MHA allows for involuntary treatment of a patient suffering from a psychiatric illness if the patient poses a serious threat of harm to him or herself or others but not for therapeutic benefit of the patient alone.

Finally, s.33.1 of the MHA allows physicians to issue community treatment orders, the purpose of which are:

> …to provide a person who suffers from a serious mental disorder with a comprehensive plan of community-based treatment or care and supervision that is less restrictive than being detained in a psychiatric facility…. a person who, as a result of his or her serious mental disorder, experiences this pattern: The person is admitted to a psychiatric facility where his or her condition is usually stabilized; after being released from the facility, the person often stops the treatment or care and supervision; the person's condition changes and, as a result, the person must be re-admitted to a psychiatric facility (*Mental Health Act, R.S.O. 1990, Chapter M.7*).

An extensive list of criteria for the order are enumerated in the MHA, including that the physician believes that a person without a community treatment order would decompensate and pose a serious threat of harm to him or herself or others (s.33.1(4)(c)(ii)), that the person can abide by the requirements of the community treatment order (s.33.1(4)(c)(iv)), and that the person or their substitute decision-maker consent to the order (s.33.1(4)(f)). As opposed to s.15 or s.20 of the MHA, a community treatment order requires patient consent and contains the legal right to appeal the order (s.33.1(4)(e)); however, in practice, "[f]ailure to adhere to the treatment plan may trigger apprehension by the police and return to hospital for psychiatric evaluation" (Hunt et al. 2007) and as such, these orders may be seen as coercive and limiting a person with SPMI's right to refuse. In Ontario, community treatment order user rates were estimated to be 17 per 100,000 population, while 37% of all orders were issued in Toronto; persons usually suffered from schizophrenia (73.7%) or mood disorders (24.6%) (Hunt et al. 2007). Persons issued community treatment orders are often referred to ACT programs due to the severity of their conditions and they need to be monitored by a physician while in the community (O'Brien AM, Farrell SJ, and Faulkner S 2009).

iv. Mental Health Policy in Ontario: Starting in the 1980s, the Government of Ontario and its Ministry of Health and Long-Term Care undertook reforming the mental healthcare delivery system in the province, and in later years evaluating the success of these reforms. Throughout the last 30 years, Ontario's direction has been toward more community services that view clients as whole persons as opposed to persons with illnesses, coupled with viewing clients as individuals who have rights and should have a voice in how mental health services are delivered (Ministry of Health 2003). Much of the province's reform centered on providing better supports for persons with SPMI. The first such report, in 1988, was the Graham Report, which stated that Ontario had done an inadequate job moving away from in-patient psychiatric settings while having clients receive the necessary levels of care in the community. The report identified several groups that required further concentrated support moving forward, among them "the chronically mentally ill", which based on the descriptions of this population meant persons with SPMI. The Graham Report makes a number of recommendations, including that mental health care should be individualized (i.e. tailored to the needs of the client with his or her input) and delivered in a community environment that makes use of a client's pre-existing social and familial relationships, when possible, while recognizing the multi-dimensional nature of mental illnesses (Graham R 1988). A later report in 1993 echoed the conclusion and goals of the Graham report regarding persons with SPMI, but added further emphasis that SPMI affects individuals from all races, ages, cultures, and genders; therefore, services for persons with SPMI should be sensitive to the diverse experiences of those who suffer from SPMI (Ministry of Health 1993).

As Strike and colleagues argue, "many risk and protective factors for mental health lie outside the domain of the mental and physical health systems" (Strike, Goering, and Wasylenki 2002). In this vein, two documents in 1993 further cemented Ontario's direction toward comprehensive community mental health services. The first document, *Making it Happen: Implementation Plan* articulated the different characteristics that a reformed mental health system would have, including: a continuum of services (e.g. treatment, rehabilitation, and long-term support) for a variety of levels of needs (i.e. from those persons in great need to those with less needs); streamlined access whereby services would be sensitive to different people's cultures while delivering services in a timely manner with as little bureaucracy as possible; integrating the mental health system with a variety of services that persons with mental illness would want and need beyond mere clinical services (e.g. vocational assistance, recreation, family supports, etc); and articulated the need for an accountability framework to guide evaluation and future management (Ministry of Health 1999). The second document, *Making it Happen: Operational Framework*, articulated what supports and services should be used to bring to fruition the goals articulated in the implementation document, including first line services (i.e. emergency programs), and intensive and specialized services (e.g. ACT or ICM). In 2003, Ontario released its *Mental Health Accountability Framework*, which outlined eight domains of accountability and numerous measures for each domain. In particular, the report articulated the need for acceptability (i.e. services meet the expectations of "service users, community, providers, and government"), accessibility (i.e. clients should obtain relevant services in a timely fashion), and appropriateness (i.e. services are relevant to clients' needs) (Ministry of Health 2003).

Although the mental health system in Ontario has many areas of success, there remains room for growth. Koegl and colleagues conclude that the province is doing a satisfactory job providing community-care for persons requiring intermittent or weekly care and are also providing adequate levels of support for persons requiring residential treatment and in-patient care. Where the provincial mental health system can improve is with programs aimed at persons with SPMI who require community care on a daily basis (e.g. ACT or ICM) so as to prevent the need for future residential or inpatient care (Koegl, Durbin, and Goering 2004). The Community Mental Health Evaluation Initiative reached similar conclusions: namely, that intensive community services, like ACT, are proving beneficial, but that moving forward, the province needs to give greater attention to the social aspects of the lives of persons with SPMI, including greater housing and employment support, as well as trying to integrate and support family members when possible and helping clients integrate better into their communities so as to reduce isolation (Community Mental Health Evaluation Initiative and Government of Ontario 2004).

C. Tuberculosis and Persons with SPMI

i. Epidemiology: To reiterate, in 2010, there were 12 million prevalent cases of active TB, or 178 cases per 100,000 persons, which is equivalent to 0.002% of the world's population (World Health Organization 2011). Despite the fact that few studies exist regarding the possibility of an increased risk of TB infection in persons who have mental illnesses, there is piecemeal evidence that the rate of active TB in persons with SPMI is higher than in the general population (Prince et al. 2007; Mishin et al. 2008). In one chart review study of a hospital's inpatient psychiatric unit in California, the author found that

eight patients of a total of 43 (19%) in a two month period had TB (Lopez 1994). In New York, a two year case study of infectious diseases in a men's homeless shelter found that of 85 persons who suffered from mental illnesses and agreed to TB testing, 32 suffered from TB (36.7%) (Saez et al. 1996). Between 1960 and 1978, 82 of 3,251 persons (2.5%) with schizophrenia had TB in Nagasaki, Japan, which was higher than the expected rate of TB (27 persons) given the annual incidence rate of TB in that city's general population relative to the number of persons with schizophrenia (Ohta et al. 1988). For the three studies above, the authors do not distinguish between latent and active TB; in the California and New York studies, given the large percentage of persons infected with TB, one might assume that the cases counted include that of latent TB. In the Japan study, the 2.5% rate of TB could be interpreted as active TB given its proximity to the global rate of incident case of active TB globally (though the Japan study concluded many years before the recent global resurgence of TB). Still, since the authors are not explicit about the kind of TB being measured, there is no way of verifying which are rates of active or latent cases.

Two additional studies are worth mentioning since they are more explicit about the type of TB reported: first, one study in 1993 from New York tested for TB in clients from the psychiatric day treatment program of a teaching hospital and found that among 71 clients, 12 tested positive for latent TB only (17%)(McQuistion et al. 1997) when the incidence rate for latent TB in the United State in 1993 was 7.3% (Centers for Disease Control and Pervention 2007). Another study, from a psychiatric hospital in Boston, Massachusetts in 1997 found that 108 of 535 clients (20.2%) screened positive on tuberculin skin tests, which includes latent and active TB, when an estimated 5% of the general public screened positive for latent and active TB in the United States during this same time period (Pirl et al. 2005). These two

studies, which are explicit about the type of TB they are measuring (i.e. whether latent or active), suggest increased rates of TB infection in persons with mental illness than in the general population.

With the exception of the chart review in the California study, the remaining four projects found the differences in the rates of latent and active TB between persons with mental illness and the general population to be statistically significant(Saez et al. 1996; Ohta et al. 1988; McQuistion et al. 1997; Pirl et al. 2005); of these four studies, two included small sample sizes that may limit the generalizability of their results (Saez et al. 1996; Pirl et al. 2005). Only the project from Japan explicitly studied a population that can be classified as suffering from SPMI (i.e. persons with schizophrenia). Finally, the reason the locations of the studies are important to note (i.e. one from Japan, one from California, one from Massachusetts, and two from New York) is to demonstrate that these higher rates of TB in persons with mental illnesses were occurring in countries with generally the highest standards of infectious disease prevention and care, and therefore, generally lower rates of TB than other places in the world.

Several factors have been posited as possible causes of, or catalyst towards, the higher rates of TB in persons with SPMI. Ohta and colleagues argue that "poor dietary and sanitary conditions" (45) lead to greater physical illnesses and compromised immunities, making persons with mental illnesses susceptible to TB infection and disease (Ohta et al. 1988). Moreover, since persons with mental illnesses, especially those with SPMI, tend to be of lower SES, have difficulties with social functioning, often have difficulty caring for themselves (including proper nutrition and hygiene)(Mishin et al. 2008), are often precariously housed leading to time spent in crowded shelters, and often undergo periods of

psychiatric institutionalization (Strike, Goering, and Wasylenki 2002), their life-styles make them particularly susceptible to TB infection (Prince et al. 2007; Gostin 1993).

ii. Treating TB in Persons with SPMI: Although drug treatment for TB is the same or similar for persons with SPMI and the general population, there are three unique challenges of treatment non-adherence within the SPMI population that may arise. First, the very presence of a mental illness (in particular the symptoms of delusion and paranoia associated with severe illnesses such as schizophrenia and bipolar disorder, which are often coupled with depression and anxiety) makes adhering to *any* treatment difficult (Lau and Ferson 1997; Gostin 1993; American Psychiatric 2000; Stein and Santos 1998). For example, in a surveillance study of TB in the homeless population of suburban Sydney, Australia, approximately 50% of participants with abnormal chest x-rays for TB did not appear for follow-up tests; the authors concluded that one possible reason was the high prevalence of mental illness in homeless populations (Lau and Ferson 1997).

The negative effects of SPMI on adherence are, however, amplified when coupled with poor socioeconomic conditions. A study from California used public health records from 11 counties with high rates of TB in 1994 and 1995 to (a) describe the types of patients civilly detained due to persistent non-adherence to TB treatment, (b) measure how many finished TB treatment while in detention, and then (c) compare them to a control group. Although there are important questions regarding study design as reported in the journal (e.g. no record of how many subjects were in their control group, and that the authors did not use the same inclusion and exclusion criteria to measure the completion of therapy between study groups), which leads to questions regarding the validity of their comparisons, their descriptions of those who were detained by public health units remain enlightening. Public

health officials detained 67 persistently non-adherent patients; only 66% of those detained completed TB therapy. Twenty-eight percent had mental illnesses, including schizophrenia and bipolar disorder. Those detained were only inconsistently offered standard incentives or enablers for treatment completion; for example, only eight of 19 documented persons with mental illnesses (42%) were referred to mental health services (although it is unclear if the remainder were already receiving psychosocial treatment) and only 16 of 26 of persons who were homeless (62%) were offered any type of housing support. Oscherwitz and colleagues conclude that enhancing the care of persistently non-adherent TB patients requires that public health officials have "the resources… to make reasonable attempts to provide housing, psychiatric care, and substance abuse treatment before detaining such patients", i.e. before curtailing patients' liberties through detention (Oscherwitz, Tulsky, and Roger 1997). Other researchers, such as Coker, Gostin and Franke, reach similar conclusions, namely that addressing the problem of noncompliance of TB treatment is difficult because an individual's actions are caused by various interdependent factors (Gostin 1993) especially if he or she is homeless, has co-morbidities, lacks a supportive social network, and suffers from a mental illness; addressing these issues are paramount to enhancing compliance to TB treatment in the SPMI population (Gostin 1993; Franke MF et al. 2008; Coker 2000).

Second, the difficulty in treating persons with SPMI for TB might stem from the potentially different theoretical perspectives of public health and psychiatry. For example, Fagerhaugh maintains that there is general consensus as to the etiology and necessary course of treatment for TB, but much less so for the myriad and range of mental illnesses (Fagerhaugh 1968; Fagerhaugh SY 1970). Moreover, TB *treatment* is "concrete, routinized [sic], and relatively predictable" whereas in mental health, *care* is less predictable and there

is less consensus amongst practitioners (Fagerhaugh 1968). Finally, in TB treatment, maintaining the healthcare worker-patient relationship is of secondary importance relative to ensuring the protection of the public by limiting transmissibility, whereas the trust between the healthcare worker and client is of utmost importance for successful mental health care (Fagerhaugh 1968; Fagerhaugh SY 1970). Fagerhaugh's ethnographic studies conclude that the goals of public health (i.e. protection of the public) may conflict with that of mental health (i.e. primarily the clinical improvement and empowerment of individuals) and leads to difficulties in treating persons with TB and SPMI.

A third difficulty in maintaining TB treatment fidelity in persons with SPMI may have to do with the adverse effects of TB medication. As described above, psychosis is considered a rare adverse event associated to isoniazid, a commonly prescribed first-line TB drug; however, Mishin and colleagues found that, when comparing 72 psychiatric inpatients with schizophrenia and TB and a group of patients with TB but no diagnosis of schizophrenia, those with schizophrenia were 2.6 times more likely to have adverse drug reactions relative to those with no schizophrenia (63.9% compared to 25%, respectively); in particular, the authors concluded that isoniazid contributed to 47.8% of adverse drug reactions in persons with schizophrenia. In addition, those persons with schizophrenia were 2.5 times more likely to still have bacterial discharge after intensive TB drug treatment after three months than those with no schizophrenia. Mishin and colleagues attribute the differential treatment success rates to the fact that because of adverse drug reactions and drug interactions, "[i]t was necessary to change the combination of drugs, reduce the amount of anti-tuberculosis agents to 3 and finally switch to the intermittent mode of drug administration" (Mishin et al. 2008). In addition to the study by Mishin and colleagues, there

have been some reported cases of adverse drug interactions between clozapine and isoniazid (Angelini, MacCormack-Gagnon, and Dizio 2009) and between clozapine and rifampicin, another first-line TB drug (Peritogiannis et al. 2007; Joos, Frank, and Kaschka 1998).

Cycloserine, a drug often given in conjunction with other second-line medication in the treatment of MDR-TB, is contraindicated in persons with a history of depression, anxiety, or psychosis (although it is unclear whether this entails absolute contraindication) (World Health Organization 2006). As such, the issue regarding psychosis as a possible adverse event is a more important when treating M/XDR-TB. In a chart review study in Latvia, 133 of 1,021 of patients (13%) suffered psychiatric episodes as a result of adverse effects from MDR-TB medication (Bloss E et al. 2010). Another multisite (and multi-country) chart review study found 28 cases of psychosis in 818 MDR-TB patients (3.4%) where adverse drug reactions was the suspected cause (Nathanson E et al. 2004). The challenge in evaluating these two studies is that the authors do not state whether there were any baseline psychiatric diagnosis that can then help distinguish between psychiatric symptoms due to adverse drug reactions from that of preexisting conditions.

In a chart review study from Turkey, Torun and colleagues found that of a total of 263 MDR-TB patient with no psychiatric co-morbidities who received varying amounts of cycloserine, psychiatric symptoms, including psychosis, were present in 56 cases (21.3%) (Torun T et al. 2005). Torun and colleagues state that the symptoms of 32 patients were successfully managed with additional medication (e.g. antidepressant) or by tapering their TB medication, but that the 24 patients whose symptoms could not be managed were removed from cycloserine “in a mean time of 7 months” (Torun T et al. 2005). Although it is unclear whether the mean is the proper measure for removal of patients from cycloserine

(i.e. whether mode or median would give a better understanding of the context given the small sample size), one could argue that seven months in a course of treatment for MDR-TB that last approximately 24 months is a significant amount of time to be suffering from psychiatric symptoms before removing the suspected drug.

In a retrospective chart review study from Peru, Vega and colleagues found that from 1996-1999, 75 patients were treated for MDR-TB in Lima, and all but one were taking cycloserine as part of treatment. Forty-two patients suffered from depression or anxiety prior to MDR-TB treatment, none suffered from baseline psychosis. Nine patients (12%) developed psychotic symptoms because of MDR-TB treatment and the authors assumed that it was because of the cycloserine. The only risk factor identified that was statistically significant was younger age (i.e. persons between the ages of 24 and 30 years). Of the nine patients with psychosis, seven patients received either reduced doses or temporary suspension of cycloserine; eight received anti-psychotic medication. Three patients required anti-psychotic medication throughout the duration of their treatment, and one patient required continuation of antipsychotic medication beyond 45 days after the cessation of MDR-TB treatment. The median duration of psychosis was four weeks. Two of the nine patients defaulted from treatment. Vega and colleagues recommend that managing psychiatric complications because of MDR-TB treatment requires prompt identification on the part of healthcare workers, use of psychiatric medications, and access to psychosocial support groups. The authors conclude that adverse psychiatric effects can be successfully managed (Vega et al. 2004).

Despite the hope this study provides about the possibility of managing the psychiatric adverse effects of TB medication, several important limitations should be noted: first, as

Vega and colleagues suggest, a larger sample size is needed in order to make findings generalizable, particularly in the context of psychosis as opposed to depression and anxiety (Vega et al. 2004). Second, since none of the patients in the study had baseline psychosis, it remains unclear the extent of the adverse effects of cycloserine and other antitubercular drugs in persons with pre-existing psychotic conditions. Third, this study does not describe the adverse effects of the anti-psychotic medications themselves, which is particularly pertinent in the cases of the three patients who had to take anti-psychotic medication throughout the duration of MDR-TB treatment. Currently, there appear to be no studies regarding the adverse effects of anti-tubercular drugs, in particular isoniazid or cycloserine, in patients with baseline psychosis.

The very presence of mental illnesses in persons with SPMI, the potentially varying goals of public health and mental health, and the adverse psychiatric effects of anti-tubercular drugs all combine to create challenges in TB treatment adherence in persons with mental illness including SPMI. Maintaining drug adherence is important to arresting the spread of TB and minimizing the resurgence of TB and the transmission of M/XDR-TB. To reiterate, the Public Health Agency of Canada recommends automatic DOT for anyone belonging to a high-risk group for non-adherence to TB treatment (e.g. persons with mental illnesses) (Public Health Agency of Canada 2007); persistent non-adherence in most jurisdictions means that involuntary detention can be imposed (Oscherwitz, Tulsky, and Roger 1997). Although many in public health acknowledge that negative psychosocial factors, including a lack of sustainable housing and basic life provisions, increase the probability of non-adherence to TB treatment in persons with SPMI, addressing such

underlying issues are secondary in light of an infectious disease with the possibility of producing high levels of morbidity in the general population (Coker 2000).

D. Conclusion

One can begin to see a tension between the philosophies of public health and mental health and how that might affect the treatment of TB in persons with SPMI. First, the WHO's recommendation of automatic DOT for all persons with SPMI removes the responsibility (and corresponding liberty) of drug management from the client. The reason for such measures is due to the perception that persons with SPMI will likely not adhere to antitubercular drug regimens. Such measures are taken with this population regardless of whether the individual patient has a history of general medication adherence or not (i.e., by virtue of merely being a member of this population). Although this may be a necessary step to protect the public from infection, it may still function as a potential disproportionate curtailment of the liberty of a person with SMPI. Second, those persons with SPMI who must undergo treatment for TB are subject to restrictions on liberty in a manner that not only affects their freedom of movement but may also, in fact, run counter to their mental health treatment and care. For example, although being in respiratory isolation and adhering to antitubercular drug regimens may be difficult for anyone, TB treatment may negatively impact the care of persons with SPMI by removing them from support networks and limiting their integration into the community. The underlying foundation for public health's interventions is protecting the public from harm (i.e. the harm that *A* could cause *B* by transmitting TB); a question remains whether, or to what extent, such a presumption is

justified in the context of certain populations that may be disadvantaged by the very public health measures themselves.

Mental health has a recent history of advocacy for the rights and liberties of persons with mental illness, including the right to refuse treatment. This liberty can be legally curtailed in light of imminent harm to self or others; yet this is grounded on the basis of a psychiatric illnesses being the ultimate cause of potential harm to others. In the case of limiting liberties of persons with SPMI to treat TB, there is an introduction of a unique source of harm that is indirect and external to the person's mental state, namely the TB. It remains unclear whether there is a material difference in the perception of liberty restrictions for persons with SPMI depending on the cause of the restriction (i.e. restrictions due to psychotic episodes as opposed to restrictions due to TB).

Despite the existing empirical literature on TB in persons with SPMI, and the laws and policies that govern the treatment of TB and SPMI, there are no studies that evaluate the understanding of liberty and the justification of liberty restrictions via the harm principle in the treatment of TB or SPMI from the viewpoint of frontline healthcare workers and decision-makers; yet it is the workers in public health units and mental health centres (or psychiatric hospitals) who have the responsibility to discharge the laws and policies that are commonly justified by reference of the harm principle. In the next chapter, I describe the research objectives and questions for this study, particularly as they relate to the political theory and the background literature described in this and the preceding chapter.

Chapter Four: Methods and Methodology

In this chapter, I introduce the methods and methodology used for the study. In particular, the research objectives and questions are presented on the basis of the theory and empirical background articulated in the two previous chapters. In addition, I present the research design (mixed-methods) and the methodology that underpins both the data collection and interpretation, namely that of moral and political philosophy.

A. Theoretical Underpinnings

This study uses empirical methods to investigate political and ethical issues in public health. The conceptualizations of liberty and harm that are sought from frontline healthcare workers and decision-makers are interpreted on the basis of ethics and political literature; questions of epistemology, related to the study design, are intentionally set aside.

'Ethics' can be described as "the general study of goodness" and the "general study of right action" (Audi 1999). Though it is worth noting that they are sometimes considered distinct concepts, I will treat 'ethics' and 'morality' as synonymous since *moralis* is the Latin translation of the Greek *ethikos* (meaning 'character') and because the thesis does not turn on any possible distinctions between them. Based on the Ancient Greek meaning of the word *polis* (meaning not only 'city' or 'city-state' but 'citizenship' relative to a city-state), I will use 'politics' or 'political theory' or 'political philosophy' interchangeably to mean the study and application of ethics and ethical theory on civic matters or public affairs, which may or may not include the coercive powers of states.

Questions related to the epistemology of the study design are generally set-aside for the purposes of this thesis. The goal of this study is to answer the research questions, which

are created and analyzed on the basis of philosophical interpretations of the harm principle. However, if one were to describe briefly a general epistemology that guides this thesis it would be that of pragmatism. One of the key features of pragmatism is to question the soundness of the fact/value distinction, which states that moral (or other value) propositions cannot be derived from states of the world; in other words, one cannot derive an 'ought' statement from an 'is' statement (i.e., statements of the form 'one ought to value *x* because *x* is the case in the world'). Therefore, one of the hallmarks of pragmatism is to hold truth and knowledge as fallible (i.e., no product of "any inquiry [is] immune from criticism"), which leads to experimentation (e.g., trial and error) as an important means of producing knowledge and evaluating value propositions as true or false (Putnam 2004; 110). Although I would like to further investigate the soundness of pragmatism in the future, both as an epistemological theory and as it relates to empirical research in public health, one should note at the outset that mixed-methods studies (as will be discussed in greater detail below) are driven by pragmatism insofar as the problems they seek to address (i.e., the research questions) and are oriented toward real-world practice (Creswell and Plano Clark 2007)

B. Research Objectives

There are three guiding research objectives for this study:

1. To examine the philosophical literature as it pertains to conceptualizations of liberty, harm, and the harm principle.
2. To apply the philosophical literature related to liberty, harm, and the harm principle in public health and mental health.

3. To examine the conceptualizations of liberty, harm, and the harm principle as it pertains to the case of TB and persons with SPMI from the perspective of frontline healthcare workers and decision-makers' in TB and mental health.

A *frontline healthcare worker* denotes anyone with direct patient care responsibilities (e.g. DOT nurse with a defined case load of TB patients or a psychiatrist in a hospital). A *decision-maker* denotes anyone within an organization with the capacity to develop and implement policy and practice change (e.g. an Associate Medical Officer of Health). The definitions of 'frontline healthcare worker' and 'decision-maker' are intentionally broad in order accommodate the variety of titles and structures of the various organizations involved in this study.

C. Research Questions

There are four research questions that motivate the design and data collection associated to this study:

1. How do frontline TB healthcare workers and decision-makers conceptualize liberty, harm, and the harm principle?
2. How do frontline mental healthcare workers and decision-makers conceptualize liberty, harm, and the harm principle?
3. How do the study's empirical findings align with common ethical and political arguments justifying the use of the harm principle?
4. How do the study's empirical findings elucidate one's understanding of the application of the harm principle in public health (in particular related to TB treatment) and mental health (in particular related to SPMI)?

As will be described in greater detail below, research questions one and two will be answered via qualitative (i.e., interviews) and quantitative (i.e., an online survey) methods; questions three and four will include an analysis of the empirical results vis-à-vis the preexisting philosophical literature. The interview guide and a copy of the survey are provided as appendices at the end of this book (see *Appendix Three* and *Appendix Five*). As for the online survey, the following hypothesis were tested during analysis:

1. The participants working in mental health will place greater value in liberty as a good or right in itself than those participants working in TB.
2. There will be no statistically significant differences between the participants working in TB and mental health regarding the importance of protecting self and others from harm.
3. Participants working in the family health program will place less value in protecting self and others from harm than those participants working in mental health or TB.

The hypotheses were generated with reference to the empirical literature and the qualitative interviews. However, the hypotheses were only generated to guide the statistical analysis of the online survey, not to guide the broader study; the thesis is intended to be hypothesis generating rather than testing (as will be describe throughout the rest of this chapter).

D. Research Design

Since this is the first time that frontline healthcare workers and decision-makers were asked to describe their understanding of liberty and harm from an ethics viewpoint, particularly as it relates to the subject matter of TB and persons with SPMI, the study was intended to be exploratory rather than explanatory.

This study used a mixed methods design as described by Creswell and Plano-Clark. Creswell and Plano-Clark define mixed methods research as focusing on "collecting, analyzing, and mixing both quantitative and qualitative data in a single study or series of studies. Its central premise is that the use of quantitative and qualitative approaches in combination provides a better understanding of research problems than either approach alone" (Creswell and Plano Clark). Their methodology is grounded in pragmatism, which they describe as focusing on "the consequences of research, on the primary importance of the question asked rather than the methods, and multiple methods of data collection to inform the problems under study. Thus it is pluralistic and oriented toward 'what works' and practice" (Ibid, 23). The central premise of their mixed method design is that combining qualitative and quantitative methods helps one understand certain problems in a more comprehensive manner. Qualitative and quantitative methods can support each other and offset possible weaknesses; the qualitative data set generally provides the context and depth of understanding of a subject matter that is difficult to ascertain with quantitative data, while a quantitative data set allows for greater breadth and greater number of participants into a research study that may lead to a better possibility of generalizing the findings of the study (Ibid, 8-9).

Creswell and Plano-Clark argue that research questions that are complex often "necessitate the understanding of multiple contexts, building trust between researchers and research participants, and developing meaningful ways of addressing concerns of diverse groups" (Ibid, 27). Given this claim, I maintain that the subject matter of the ethical issues of TB in persons with SPMI is currently under researched; ideally, this topic requires gaining the perspectives of as many relevant stakeholders as possible (obtained via quantitative

methods), while at the same time understanding in greater depth the concrete ethical issues that arise (using qualitative methods). The most common mixed method design is the convergence model of the triangulation design, whereby "the researcher collects and analyzes quantitative and qualitative data separately on the same phenomenon and then the different results are converged (by comparing and contrasting results) during the interpretation" (Ibid, 62).

The quantitative component of the study consisted of a cross-sectional internet survey modeled on Dillman's Tailored Design Method. The goal of the Tailored Design Method is to develop "procedures that create respondent trust and perceptions of increased rewards and reduced costs for being a respondent, that take into account features of the survey situation, and that have as their goal the overall reduction of survey error" while maximizing the number of respondents (Dillman 2000). Dillman's method is based on social exchange theory, which posits that action can be predicted on the basis of rewards (i.e., what someone will receive for a given act), costs (i.e., what someone gives up to act at a given moment), and trust (i.e., that the rewards outweigh the costs); therefore, the goal of the Tailored Design Method is to provide rewards and build trust between the researcher and the respondents while reducing the costs to the respondent in order to increase the potential respondent's motivation to actually complete the survey (13-14). The means used in this study to increase the level of reward included providing positive written reinforcement and saying 'thank you' in all email correspondence and on the survey itself; I tried to reduce costs by using simple language and trying to make the survey as short and accessible as possible; and I attempted to engender trust by conveying to the potential participants the importance of the study and how they (as frontline healthcare workers and decision-makers) were in a unique position to

speak about the issues of the survey. Moreover, as described in greater detail below (see section *G. Data Collection*), and in keeping with the Tailored Design Method assumption that multiple attempts at obtaining a response require repeat contacting of potential participants, the survey was sent out three times to the selected participants.

The survey consists of comparisons across three arms: (a) persons primarily working in TB care and control, (b) persons primarily working in mental health, and (c) persons primarily working in family health programs in public health units. The purpose of separating respondents into these three categories is as a point of comparison across the populations. The justification for comparing the similarities and differences between those working in TB as opposed to mental health is to see how different healthcare contexts may affect the participants' understanding of liberty, harm, and the harm principle despite both sets of participants working in settings where the harm principle motivates laws, policies, and practices. The family health program arm was used to act as a control arm relative to the first two arms, to simplify recruitment of the control arm, and because this arm consists of frontline healthcare workers and decision makers who although they might deal with infectious diseases and mental health in their work, are not primarily focused on either of those subject matters or have to address issues of liberty and harm as explicitly or routinely as the other two groups. One of the points of exploration for the study is to see whether there were any differences in the conceptualizations of harm between types of workers (i.e. frontline or decision-makers) based on whether they specialize in TB, mental health, or family health programs.

The qualitative component of the study consisted of open-ended, semi-structured interviews with frontline healthcare workers and decision-makers in TB units and mental

health centres in order to try to gain depth of knowledge of the subject matter. The question guide was developed on the basis of Patton's general qualitative methods, which are (like Creswell and Plano-Clark) grounded in pragmatism. According to Patton, the research question or questions should drive what methods one uses; judging the quality of a study entails being aware of the purpose of the study, the resources available at the researchers' disposal, the context behind the study, and the audience of the study (Patton 2002). According to Patton, the interview guide is created to ensure that the same line of enquiry is taken with all the participants; however, the researcher is "free to build a conversation" thereby allowing a researcher to shape the questions relative to the answers provided by the participant (Ibid, 343). In particular, the question guide (which is described in more detail below, see section *G. Data Collection*) uses a series of opinion and values questions; this category of questions is "aimed at understanding the cognitive and interpretive processes of people" by asking questions about people's "opinions, judgment, and values" (Ibid, 350). The questions strived to be open-ended (i.e., allowed the participant to respond to the question as he or she saw fit), singular (i.e., asking about one thing at a time), and clear.

E. Research Sample

i. Study Population: The study population included frontline healthcare workers and decision-makers from three public health units (Toronto, Halton, and York) and two psychiatric hospitals (the Centre for Addiction and Mental Health – CAMH – and Ontario Shores Centre for Mental Health Sciences – Ontario Shores) that broadly constitute the

Greater Toronto Area (GTA).[9] The justification for sampling from public health units is that they are charged with caring for persons with TB and moreover, are responsible for case-finding and arresting the spread of TB in the community through public health measures (e.g. isolation orders); stated differently, public health units are in charge of prevention, protection, and promotion with regards to TB. The justification for sampling from CAMH and Ontario Shores is that they have in-patient care units, as well as community-based programs (e.g. intensive case management, assertive community treatment), thereby having programs that are representative of the different kinds of mental healthcare in Ontario, which include tasks ranging from clinical medicine to social programs. The reason that the scope of the study included only public health units and psychiatric hospitals in the GTA was for reasons of feasibility and cost-management.

Contact was initiated with all public health units by requesting a meeting with the Medical Officers of Health regarding the study, which in turn either met with me or set up meetings between me and the relevant administrators. At Ontario Shores and CAMH, contact was initiated with Vice Presidents identified as most likely relevant from the centres' websites. Formal agreements to participate as organizations in the study included research ethics board approval from the University of Toronto, CAMH, Ontario Shores, Public Health Services (York Region), and Toronto Public Health, as well as an informal internal review process in the Halton public health unit. Each partner organization was asked to provide a point-person internal to the organization with which I had regular contact regarding the rollout of the study.

[9] There are two other public health units in the geographic region of the GTA: Peel and Durham. Peel declined to participate, as an organization, in the study; although Durham initially agreed to participate, the unit ignored subsequent emails and phone calls.

ii. Inclusion and Exclusion Criteria: Inclusion criteria for the TB arm of the survey were any frontline healthcare worker or decision-maker who worked in the infectious or communicable diseases control program in the public health units in Toronto, Halton, or York and who at least part-time worked in some capacity in TB prevention, care, or control (e.g. surveillance). Inclusion criteria for the mental health arm of the survey were any frontline healthcare worker or decision-maker who worked at least part-time in CAMH's Schizophrenia Program (which includes both in-patient and out-patient and community services); given the large number of workers in the Schizophrenia Program, participants were randomly selected (see section *E.v. Sampling Techniques* below). Ontario Shores did not agree to abide by the random selection criteria citing privacy concerns (see section *E.v. Sampling Techniques* below) and hence were excluded from the survey. For the family health program arm of the survey, inclusion criteria included any frontline healthcare workers or decision-makers who worked at least part time in the family health program of the Toronto and Halton public health units but did not work in infectious diseases, including TB. The family health program at York did not agree to abide by the random selection criteria because they insisted on having staff volunteer to be approached prior to the randomization (see section *E.v. Sampling Techniques* below) and hence were excluded from the survey.

Exclusion criteria is generally the opposite of what is in the inclusion criteria, which includes frontline healthcare workers or decision-makers outside public health units (TB and family health programs) and mental health centres of Toronto, Halton, York, CAMH, or Ontario Shores, or people who work in public health units and mental health centres of Toronto, Halton, York, CAMH, or Ontario Shores but in a capacity that does not place them

in either the frontline healthcare worker or decision-maker categories (e.g. administrative assistants) of the relevant arms. Of particular note for exclusion criteria, there were individuals who worked in some way in mental healthcare in a public health unit; however, for the sake of simplicity, they were ineligible for the purposes of this study, unless they worked at least part time in TB or family health.

As for the interview portion of the study, participants were included if they were frontline healthcare workers or decision-makers of either the TB arm or the mental health arm in the aforementioned categories (excluding the family health program arm) in the Toronto, Halton, or York public health units or at CAMH or Ontario Shores.

iii. Recruitment: For the survey, each randomly selected participant was provided with a letter of invitation, consent form, and online link to the survey via email. The consent form was the first screen of the survey. As for the interviews, possible participants were contacted via email on the basis of conversations with point-persons in each organization as to who might be interested in participating in interviews or those with experience with TB in persons with SMPI; the potential interviewees were also provided with the consent form in the initial email (see *Appendix Two* for consent forms). In addition, prior to the dissemination of the survey, I met with the frontline healthcare workers and decision-makers in each organizations during team meetings to promote the survey and encourage participation. The goal of the meetings was to establish trust between the potential participants and I, as recommended by the Tailored Design Method.

iv. Sample Size Calculations: With regards to the survey, no sample size calculations were performed because of a lack of previous studies on which to base the calculations and because the study was designed to be exploratory in nature. Conceptually, part of the reason

in calculating a sample size is to determine the number of subjects necessary to find a significant difference between two groups vis-à-vis a hypothesis about the possible differences between two groups (e.g., intervention versus placebo in a traditional clinical drug trial). Since this study is exploratory with no preconceived notion of the extent of the differences that might be found, then there are no *a priori* assumption regarding the differences between groups and a sample size calculation is inappropriate.

For the interviews, the goal was to interview between three to five persons per organization, for a total of 15-20. This sample size was selected based on studies demonstrating that saturation is often achieved between 12-20 interviews (Guest G, Bunce A, and Johnson L ; Mason M).

v. Sampling Techniques: Sampling for the survey was based upon the Tailored Design Method and included two means: first, for the TB arm, all possible participants were contacted; second, for the mental health and family health program arms, I used a stratified random sampling per partner organization. The process for sampling was as follows:

(a) Given the inclusion and exclusion criteria specified above, the organization's point-person and I generated a list of all possible participants for the TB arm of the survey across the Toronto, Halton, and York public health units.

(b) The total number of TB frontline workers and decision-makers was 73. All 73 potential participants from the TB arm were invited to participate in the survey. There were 59 potential participants from Toronto, six from Halton, and eight from York. Since the number of possible participants from the TB units was smaller than the other two arms of the survey, the other two arms of the survey were capped at 73

potential participants per arm, in order to maintain sampling consistency throughout the three arms of the study.

(c) Using the contact persons from the Schizophrenia Program at CAMH and the family health programs in Toronto and Halton, a list of all the names and emails of frontline healthcare workers and decision-makers was compiled.

(d) In the case of the Schizophrenia Program at CAMH and the family health program from Toronto, D Silva placed all the names and email addresses in an Excel file in two different columns. In a third column, a random number was assigned using the =RAND function. After turning off Excel's automatic recalculation function, the lists were sorted in descending order. The first 73 names and emails were chosen from the list of the Schizophrenia Program; the first 67 names were chosen from the Toronto family health program list.

(e) The names of potential participants from the family health program at Halton were randomly selected by creating a list of all potential participants, then gave each a number and used SPSS to randomly select 10 of those numbers. A member of the Halton public health unit conducted this randomization process. Once the names were selected and passed along to me, the first six were chosen and invited to participate in the survey, thus bringing the total of those potential participants in the family health program to 73 between Toronto and Halton.

It should be noted that this sampling technique was intended to reduce the possibility of error in the data analysis phase. If the number between the groups were too different, then weights or post-hoc test sensitive to unequal sample sizes would need to be applied to the arm(s) with less number of participants, thereby introducing a potential additional source of possible

error. The assumption was that there would be a relatively similar number of participants, or response rate, across all three arms.

For the interviews, snowball sampling was used, starting with identifying individuals at each organization via the point-person. The point-person suggest possible participants who might be interested in participating in interviews because of a prior interest in ethics, because they might have decision-making capabilities within the organization, or those workers with experience of TB in persons with SMPI.

F. Survey Design and Item Generation

The survey attempted to test four attributes related to whether harm could be used to ethically justify restricting a person's liberty (i.e., the harm principle). Moreover, the survey also consist of two case vignettes that attempted to get at differences in the conceptualizations of harm in the case of TB and persons with SPMI. The design of the survey is based on the work of Stiggelbout and colleagues, whereby they used prominent philosophical theories of personal autonomy to create survey items given to patients and physicians to evaluate their ideals of autonomy in clinical medicine and then conducted factor analysis to create an autonomy scale (Stiggelbout AM et al.).

As described more fully in *Chapter Two: Theoretical Background – Liberty and the Harm Principle*, there are three prominent theories of the harm principle, each with their own understanding of harm based on different understandings of liberty. To recapitulate: first, Mill's conception of harm denotes a broad sense of 'pain', which includes bodily, psychological, social, economic, and political pain; thus, the harm principle of Mill is an attempt to limit the pain that that individuals may cause other individuals without consent

(Mill). Second, Feinberg defines harm as wrongful setbacks to interests and the harm principle is a manner by which the state protects the interests of individuals against the wrongful setback to their interests from other individuals (Feinberg). Third, according to Raz, governments should limit some self-harming acts in order to promote an individual's ability to be autonomous at some future moment (i.e. protecting positive liberty) (Raz J). Finally, in addition to the three aforementioned theories of liberty and the harm principle, one might argue that there exists a presumption in favor of freedom as the only political conception of 'right' and that governments have the legitimate right of coercion and enforcement of laws only as a means of protecting liberty; as such, limitations to freedom are not founded on any conception of harm but are rather already present within an understanding of freedom (i.e. the Kantian position) (Kant ; Ripstein A).

From these four philosophical positions, four attributes were generated, which are:

1. Harm to others can justify limiting an offending agent's liberty (Mill).
2. Wrongful setback to interests to others can justify limiting an offending agent's liberty (Feinberg).
3. Harm to self can justify limiting an offending agent's liberty (Raz).
4. Only the protection of liberty may justify limitations of liberty, not the presence of harm (Kantian).

The survey consisted of 28 non-biographical items (plus six additional biographical questions), 25 of which were five-point Likert scales (from Strongly Disagree to Strongly Agree); of the remaining items, question 16, was a five-point Likert scale that tested the respondent's comfort with an abstract amount of risk to others (from 20% to 100% in 20 percentage point increments). Questions nine and 10 provided categorical choices. The

attributes based on philosophical theories were used to generate 18 items. Two additional items (questions 13 and 14) were taken from Tracy et al.'s survey (Tracy, Rea, and Upshur) on the public's perception of quarantine and isolation because they applied to the subject matter of the thesis study and as a means of incorporating previously validated items. Four items were presented twice to respondents after two different case vignettes. The point of the vignettes was to present two similar cases about an individual with tuberculosis, except in the second case the individual suffers from schizophrenia in addition to tuberculosis. The same four items were presented after each case. The objective of these cases and items was to (a) see whether the respondents would differ in their answers between the two cases on the basis of the presence of schizophrenia, and (b) to test whether there existed differences between different demographic groups, most notably between those who work in TB units and those who work in mental health centres. The case vignettes are not designed to test differences between respondents on the basis of the different philosophical theories discussed above. *Appendix Five* provides the survey in its entirety.

G. Data Collection

The survey was disseminated by the Tailored Design methods via emails using a computer-assisted self-interviewing (CASI) system. The CASI system used was fluidsurveys.com, since it was relatively inexpensive, contained multiple features and survey designs, was easily converted to an SPSS worksheet, and the data were (and will be) kept in Canada and only accessible to the research team. Each respondent was assigned a random invite code through fluidsurvey.com that was linked to the respondent's email address. The email addresses were kept throughout the duration of the data collection phase and used to

send out reminders to complete the survey. Email addresses and messages were deleted after data collection was completed. Intended to be available to answer for eight-weeks, the survey was sent to the potential participants of the TB units and family health programs during August and September 2011, with follow-up emails four weeks and six weeks from the original date of distribution; however, due to confusion as to whether the email reminders were sent or not (see section *D. Limitations* in *Chapter Seven: Discussion and Conclusion*), subsequent emails were resent at the end of November and the survey remained open until the first week of December 2011. The survey was distributed to potential participants at CAMH's Schizophrenia Program during an eight-week timeframe from mid-October to mid-December 2011, with follow-up emails four weeks and six weeks from the original date of distribution. The survey was distributed to each group as soon as the programs and units granted permission. The survey was designed to be completed in approximately 10 minutes and could be completed when most convenient for the participant. The survey itself consisted of new items (with the exception of two questions, 13 and 14 from Tracy et al., as noted above) and therefore was void of pervious validity checks. As such, the survey was first piloted with subject experts (i.e., persons with a specialization in public health ethics, survey design, or philosophy) to test for comprehensibility and ambiguity of items, as well as to test for face and content validity.

An interview guide was prepared in consultation with the thesis committee and vetted with two additional researchers who specialize in qualitative interviews (see *Appendix Three* for interview guides). Two interview guides were created: one for participants in TB units and the other for participants in mental health centres. The guides were the same except the language that was used changed relative to the group. For example, while the interview

guide for the participants from the TB units asked questions about DOT and respiratory isolation, the interview guide for participants form mental health centres spoke of watching clients swallow medication and observation/restraints. The goal was to ask about liberty and harm in a manner that would resonate with the two groups of participants but maintain certain similarities in terms of content and form.

The interviews lasted approximately an hour. I conducted the interviews in person and the interviews were audio recorded. The location and dates of the interviews were at the discretion of the participant. The interviews were conducted between May and June of 2011. Twenty interviews were conducted; 13 participants (nine frontline healthcare workers and four decision-makers) from TB units and seven (five frontline healthcare workers and two decision-makers) in mental health centres. A professional transcriber, who had been previously hired by members of the research team, transcribed the interviews. I verified the transcripts by reading the script while listening to the associated audio file.

H. Research Ethics Considerations

This was a low-risk study with a low-vulnerability group. An ethical concern was protecting the privacy of participants and maintaining their confidentiality. All potential participants for both the interviews and survey were approached by me so as to encourage potential participants to decline the invitation to participate, if they wished to do so, and so that they did not feel coerced to participate by their organizations. All interview recordings, interview transcripts, and raw survey data were only accessible to the thesis committee and me. All encrypted electronic data were kept in a password-protected computer and all hardcopies of materials (i.e., the transcribed interviews) were kept in locked cabinets. All

data sets were de-identified prior to analysis. Research ethics board approval was sought and granted by the University of Toronto, CAMH, Ontario Shores, Toronto Public Health, and Public Health Services (York Region).

I. Data Analysis

Statistical analyses were conducted using SPSS 20 software. The demographic profile of the respondents is presented in a table with suppressed data (Table 2 in *Chapter Five: Results – Online Survey*), i.e., as per the guidelines of Statistics Canada, "a statistic is suppressed if the number of actual records used in the calculation is less than 4" (Statistics Canada 2011). In the case of this thesis, data are suppressed "to ensure non-disclosure of individual respondent identity and characteristics" because low numbers in any one cell of a demographics table may increase the likelihood that someone from a given organization that reads the table may deduce that a colleague did or did not participate in the survey (Ibid). The data were suppressed using both primary suppression (i.e., the cells that actually contain a recorded number of less than 4) and secondary suppression (i.e., cells that contain a recorded number of 4 or greater but that may reveal the number of a primary suppressed cell in the same column or row when given the total value of the column or row). Therefore, any demographic statistic that was suppressed was replaced with "---". The survey data were analyzed first using descriptive statistics and cross-tabulations for each item of the survey and the demographic variables, in particular stratified on the basis of whether the participant worked in TB, family health, or mental health (the key demographics variable as it related directly to the research questions and objectives). Due to the low number of respondents in total and per question (less than 100 in total and less than five per question (Norman G and

Streiner D 2008; Field 2009; Gorsuch 1983)) factor analysis was completed in order to derive scales for analysis rather than in order to create psychometrically valid scales. In other words, while the response rate did not allow for the creation of valid scales, factor analysis did create scales that simplified inferential analysis and decreased the probability of committing a type I error. Factor analysis was conducted using a varimax rotation (i.e., maximizing the sum of variation) of the correlation matrix per attribute and factor, with an attribute loading of .5 or higher to compensate for the ultimately small sample size; varimax rotation is the most commonly use rotation in factor analysis (Norman G and Streiner D). After deriving scales, t-tests were used per scale (as the dependent variable) and per type of organization (as the independent variable). In particular, t-tests were applied first by comparing those working in TB units and mental health centres versus those working in the family health teams (to compare and contrast those who have to apply the harm principle as part of their daily work routine and those that do not, respectively), then t-tests were applied to compare between those working in TB units versus those working in mental health centres.

The interviews were coded using thematic analysis as described by Braun and Clarke (Bruan V and Clarke V). Thematic analysis "is a method for identifying, analyzing and reporting patterns (themes) within data" (79). A theme is a "patterned response or meaning within a data set", which attempts to answer a part or whole of a research question (82). One of the benefits of Braun and Clarke's articulation of thematic analysis is it non-reliance on any preexisting social science theory: "[w]hat is important is that the theoretical framework and methods match what the researcher wants to know, and that they acknowledge these decisions, and recognize them as decisions" (80). As noted above, the theoretical perspective

of this thesis is one of moral and political philosophy, whereby themes relating to liberty, harm, and the harm principle were derived and constructed from the transcripts. Braun and Clarke note that the researcher must decide whether to provide a "rich description" of the data (whereby the researcher reports all of the "predominant or important themes") or a "detailed account" of particular themes as they relate to the research questions (83). Thus, in this thesis I used a detailed account of particular aspects of the interviews, namely those that answer the research questions related to liberty and the harm principle, as opposed to any broad ethical issues related to TB and/or SPMI in order to more explicitly answer the questions posed at the beginning of this chapter. For example, although there was some discussion about stigma as it related to having TB or SPMI, this was not considered relevant because it did not help answer the research questions of the study; however, issues of stigma related to being in isolation for TB or in observation because the client posed a threat of harm to others was included in the analysis since it was relevant to the study's research questions and objectives. Braun and Clarke also note that themes can be derived through an "inductive approach", i.e., a 'bottom up' approach where "the themes identified are strongly linked to the data themselves", or through a "theoretical thematic analysis" where the coding is "driven by the researcher's theoretical or analytic interest" (83-84). For this thesis, themes were derived using both an inductive and theoretically driven reading of the transcripts, meaning that the analyses were driven by the preexisting political theory (i.e., theoretically driven) but the themes were derived directly from the transcripts themselves, the goal being to provide textual evidence throughout the results chapter to support all theoretically derived interpretation. I coded all the interviews using N/Vivo 9 as well as using paper copies of the transcripts. Themes were then constructed on the basis of the codes and were verified by the

thesis committee. N/Vivo 9 was used to manage the data and organize and keep a record of codes and themes. The coding process followed Braun and Clarke's directions of familiarizing oneself with the transcripts (i.e., re-reading the transcripts with the audio recording); generating random initial codes that were descriptive of, and derived from, the data; collating the codes into themes; and reviewing the themes relative to the transcripts and the theoretically informed research questions (86-94). The quality and rigour of the thematic analysis was maintained by adhering, as best as possible, to Braun and Clark's 15-point criteria (See Table 4.1 below).

Table 4.1: 15-point checklist of criteria for good thematic analysis (copied *verbatim*, Braun and Clark, 96)

Process	No.	Criteria
Transcription	1	The data have been transcribed to an appropriate level of detail, and the transcripts have been checked against the tapes for 'accuracy'.
Coding	2	Each data item has been given equal attention in the coding process.
	3	Themes have not been generated from a few vivid examples (an anecdotal approach), but instead the coding process has been thorough, inclusive and comprehensive.
	4	All relevant extracts for all each theme have been collated.
	5	Themes have been checked against each other and back to the original data set.
	6	Themes are internally coherent, consistent, and distinctive.
Analysis	7	Data have been analysed - interpreted, made sense of - rather than just paraphrased or described.
	8	Analysis and data match each other - the extracts illustrate the analytic claims.
	9	Analysis tells a convincing and well-organized story about the data and topic.
	10	A good balance between analytic narrative and illustrative extracts is provided.
Overall	11	Enough time has been allocated to complete all phases of the analysis adequately, without rushing a phase or giving it a once-over-lightly.
Written Report	12	The assumptions about, and specific approach to, thematic analysis are clearly explicated.
	13	There is a good fit between what you claim you do, and what you show you have done - i.e., described method and reported analysis are consistent.

	14	The language and concepts used in the report are consistent with the epistemological position of the analysis.
	15	The researcher is positioned as active in the research process; themes do not just 'emerge'.

Finally, in keeping with the triangulation required within a mixed-methods design, a concurrent analysis of the qualitative and quantitative data sets was conducted through comparisons between the results emanating from both sets of data. Since the comparison of the two data sets is not merely descriptive but also interpretive (i.e., the results of one data set are compared and contrasted relative to the other data set, and vice versa); as Creswell and Plano Clark note, "…mixed-methods authors will report a statistical result (descriptive result or inferential result) and then follow it up with specific quotes or information about a theme that confirms or disconfirms the quantitative results (or the order could be reversed)" (Creswell and Plano Clark 2007). This comparison will be presented in the discussion section, *Chapter Seven: Discussion and Conclusions*.

J. Conclusion

This chapter presented an overview of the mixed methods design used in this study. The study consists of an online survey and open-ended, semi-structured interviews with the goal of triangulating the data with the theoretical literature on the harm principle in *Chapter Seven: Discussion and Conclusions*. In the next chapter, I present the results from the online survey.

Chapter Five: Results – Online Survey

This chapter presents the analyses of the online survey data. Presented first are the descriptive analyses, which are followed by the factor analyses and the results of the t-tests. The main finding is that while there was a statistically significant difference between the participants of the TB group versus those in the Mental Health group on the DOT, Risk, and Kant scales, there was no statistically significant difference between the groups on the Harm to Self, Harm to Others, and Public Health Orders scales.

A. Descriptive Analysis

Table 5.1 presents a summary of the response rates for the survey. Ninety-one respondents completed the survey (41.5% completion rate); 51 (69.9%) from the TB arm, 10 (13.7%) from the mental health arm, and an additional 30 (41.1%) from the family health program arm.

Table 5.1: Response Rates

Group of Participants	Response Rate & Percentage
Total number of participants who partially completed the survey	110/291 = 50.2%
Total number of participants who fully completed the survey	91/219 = 41.5%
TB program participants who fully completed the survey	51/73 = 69.9%
Mental health program participants who fully completed the survey	10/73 = 13.7%
Family health program participants who fully complete the survey	30/73 = 41.1%

Table 5.2 presents the demographic questions of the respondents. The majority of respondents were frontline workers (83.5%) and identified as women (90.1%). Seventy-

three participants (81.1%) had worked in their current positions between one and 15 years and most were born between 1950 and 1980 (72%).

Table 5.2: Demographic Profile of Respondents

		At what type of organization do you work?			Total
		TB	Mental Health	Family Health	
Position	Frontline	40	7	29	76
	Administrator/ Decision-maker	---	---	---	11
	Other	---	---	---	4
Total		51	10	30	91
Time at current position	< 1 year	---	---	---	6
	1-5 years	15	---	---	28
	6-10 years	16	---	---	25
	11-15 years	10	---	---	20
	16-20 years	---	---	---	4
	> 20 years	4	---	---	8
Total		51	10	30	91
Year of birth	<= 1950	7	---	---	8
	1951 - 1960	17	4	5	26
	1961 - 1970	13	---	7	21
	1971 - 1980	9	4	12	25
	> 1981	4	---	---	8
Total		50	9	29	88
Identify as:	Woman	---	---	---	82
	Man	---	---	---	9
Total		51	10	30	91
Born in Canada?	No	20	5	18	43
	Yes	31	5	12	48
Total		51	10	30	91

Note: “---“ denotes that the statistic was suppressed to protect participant confidentiality.

Before analyzing the differences in responses between the different arms of the survey via the various scales (see section *C. T-Tests* below), one can make some general descriptive observations about the data, in particular as it relates to the five items that did not load on any one scale (see section *B. Factor Analysis* below). Table 5.3 provides an overview of the percentages of responses per question without distinguishing between the participant groups.

Table 5.3: Survey Questions and Responses (%)

	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
Case 1: A 27 year old male from Russia presents with active pulmonary tuberculosis. Although he is new to Canada, his English is good. He lives with a roommate in a two-bedroom apartment. He has a part-time job as a janitor at a local high school. He is on no other medications. He does not have any contraindications toward the antitubercular drugs he must take.					
1. He should receive directly observed therapy for his tuberculosis treatment (whereby a healthcare worker watches him swallow the tuberculosis medication).	7.1	15.2	5.1	36.4	36.4
2. He should be treated for his TB in a specialized environment (e.g. a hospital with a tuberculosis unit), away from the broader community.	25.3	40.4	13.1	12.1	9.1
3. He is a high risk client likely to spread tuberculosis.	6.1	25.3	21.2	27.3	20.2
4. If he does not voluntarily comply with tuberculosis drug treatment, he should be physically forced to take antitubercular medications.	11.1	36.4	6.1	34.3	12.1
Case 2.: A 27 year old male from Russia presents with active pulmonary tuberculosis. Although he is new to Canada and his English is good, he suffers from schizophrenia, which is currently under control. He lives with a roommate in a two-bedroom apartment. He has a part-time job as a janitor at a local high school. He currently receives antipsychotic medications and is responding well to community psychosocial support. He may have some contraindications toward the antitubercular drugs he must take. In particular, the antitubercular medication may lessen the effectiveness of his antipsychotic medication.					
5. He should receive directly observed therapy for his tuberculosis treatment (whereby a healthcare worker watches him swallow the tuberculosis medication).	3.1	10.2	3.1	32.7	51
6. He should be treated for his TB in a specialized environment (e.g. a hospital with a tuberculosis unit), away from the broader community.	9.2	42.9	16.3	22.4	9.2
7. He is a high risk client likely to spread tuberculosis.	2	22.4	19.4	29.6	26.5
8. If he does not voluntarily comply with tuberculosis drug treatment, he should be physically forced to take antitubercular medications.	10.2	32.7	8.2	32.7	16.3

11. An individual should obey a public health isolation order even if it causes him or her psychological distress.	0	3.2	15.8	49.5	31.6
12. An individual should obey a public health isolation order even if it makes him or her psychiatrically ill.	0	15.8	20	44.2	20
13. An individual should obey a public health isolation order even if it worsens a preexisting psychiatric illness.	0	18.9	25.3	38.9	16.8
14. Public Health should have the power to order people into quarantine during infectious disease outbreaks.	0	0	4.2	57.9	37.9
15. If someone is given a quarantine order by Public Health, they should follow it no matter what else is going on in their life at work or home.	1.1	5.3	15.8	50.5	27.4
17. It is wrong for an individual to harm innocent bystanders by causing them physical pain.	1.1	0	0	26.1	72.8
18. It is wrong for an individual to harm innocent bystanders by causing them psychological pain.	0	0	4.3	34.8	60.9
19. It is wrong for an individual to harm innocent bystanders because it interferes with the bystanders' ability to provide for their own basic necessities.	0	2.2	20.7	32.6	44.6
20. It is wrong for an individual to harm innocent bystanders because it interferes with the bystanders' ability to achieve their life goals.	0	3.3	19.6	39.1	38
21. Individuals with a psychiatric diagnosis should not be allowed to physically harm themselves.	1.1	2.2	8.8	53.8	34.1
22. Individuals without a psychiatric diagnosis should not be allowed to physically harm themselves.	2.2	5.5	17.6	42.9	31.9
23. Individuals with a psychiatric diagnosis should not be allowed to act in such a way as to reduce opportunities later in life.	4.4	14.3	37.4	29.7	14.3
24. Individuals without a psychiatric diagnosis should not be allowed to act in such a way as to reduce opportunities later in life.	6.6	19.8	37.4	24.2	12.1
25. Trespassing on another person's property is wrong even if the owner never finds out.	0	4.4	11	41.8	42.9
26. Trespassing on another person's property is wrong even if it does not disturb the property.	0	6.6	13.2	41.8	38.5
27. Silencing an individual's freedom of speech is wrong even if that individual never finds out.	0	5.5	5.5	41.8	47.3
28. Looking through an individual's bag is wrong even if that individual never finds out.	1.1	3.3	4.4	39.6	51.6
	20%	**40%**	**60%**	**80%**	**100%**
16. If there is a _____ chance that an individual's action may accidentally harm another person, then that action should not be allowed.	52.7	12.9	10.8	4.3	19.4
	TB interferes with a person's ability to provide for him or herself.	**TB reduces a person's future life options or opportunities.**	**TB physically harms a person.**	**TB interferes with an individual's personal freedom.**	
9. Which of the following answers best describes the reason why the spread of tuberculosis should be stopped:	4.2	13.5	76		6.3

	Untreated schizophrenia interferes with a person's ability to provide for him or herself.	Untreated schizophrenia reduces a person's future life options or opportunities.	Untreated schizophrenia physically harms a person.	Untreated schizophrenia interferes with an individual's personal freedom.
10. Which of the following answers best describes the reason why persons with schizophrenia should take antipsychotic medication and receive psychosocial support:	47.9	39.6	11.5	1

Three observations are worth noting: first, the respondents seem to disagree whether or not the individual in the case studies should be forced to take antitubercular medications (representing a bimodal distribution). In case one, question four, 47.5% of respondents either strongly disagreed or disagreed that the individual should be forced to take antitubercular medications, while 46.4% of respondents either agreed or strongly agreed that he should be forced to take the medications; on question eight, which relates to the case of individual with schizophrenia, 42.9% of respondents either strongly disagreed or disagreed with forced intake of medication, while 49% either agreed or strongly agreed. Moreover, the polarized responses to these questions are distributed relatively even among the three groups of respondents, with no statistically significant results found running ANOVAs (i.e., TB v. MH v. Family Health) or t-tests (i.e., TB/MH v. Family Health; TB v. MH) per these two questions. The similar polarized patterns between and within the groups can be more easily seen in Figures 5.1 and 5.2.

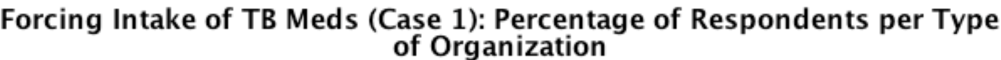


Figure 5.1: Forcing Intake of TB Meds (Case 1)

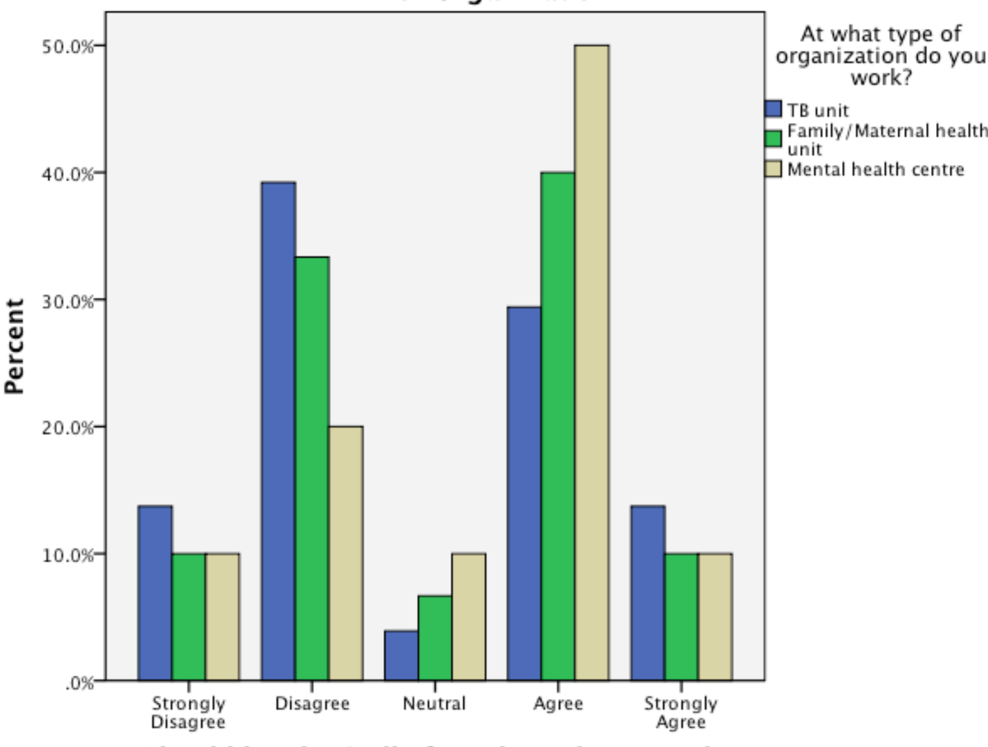
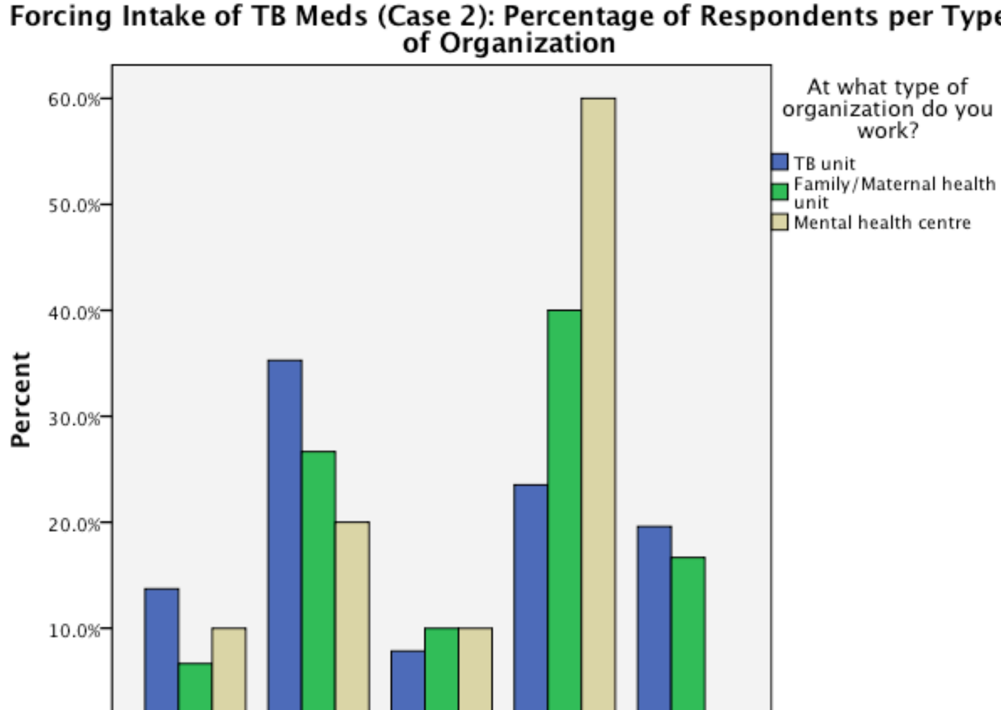


Figure 5.2: Forcing Intake of TB Meds (Case 2)



Second, a majority of respondents (52.7%) replied that a 20% chance of an individual accidently harming another person via action *x* is sufficient to warrant prohibiting *x* (question 16); this question did not specify what was the action or activity that possibly required prohibition. Third, while a strong majority of respondents (76%) felt that the reason that the spread of TB should be arrested is because the disease harms a person (question nine), when asked why a person with schizophrenia should be given psychosocial supports and antipsychotic medications (question 10), 47.9% of respondents answered because schizophrenia interferes with a person's ability to care for him- or herself, while 39.6%

answered because schizophrenia reduces future life options and opportunities (only 11.5% answered because schizophrenia harms the individual).

B. Factor Analysis and Generation of Scales

While the response rate did not allow for the creation of valid scales, factor analysis was used to create scales that simplified inferential analysis and decreased the probability of committing a type I error. Based on a theoretical analysis of the content of items that loaded onto each individual factor, five scales were derived using factor analysis, which were named: Risk, Public Health Orders, Harm to Others, Harm to Self, and Kant. An additional scale, DOT (Directly Observed Therapy), was created solely on a subjective and theoretical basis and not via factor analysis; since there was an insufficient sample size to conduct factor analysis for the sake of developing valid scales, it was assumed that logically defendable scales could be created in order to help reduce the probability of committing a type I error during inferential analysis. The interpretation of the scores per scale and the questions associated to each scale is provided in Table 5.4.

Table 5.4: Definition of Scales and Questions
DOT (Directly Observed Therapy) (out of 10) – The greater the score, the more likely the respondent will answer that DOT is necessary for TB treatment. 1. He should receive directly observed therapy for his tuberculosis treatment (whereby a healthcare worker watches him swallow the tuberculosis medication). 5. He should receive directly observed therapy for his tuberculosis treatment (whereby a healthcare worker watches him swallow the tuberculosis medication).
Risk (out of 20) – The greater the score, the more likely the respondent will answer that it is okay to interfere in the life of x if x poses a risk of harm to community. 2. He should be treated for his TB in a specialized environment (e.g. a hospital with a tuberculosis unit), away from the broader community.

3. He is a high risk client likely to spread tuberculosis.
6. He should be treated for his TB in a specialized environment (e.g. a hospital with a tuberculosis unit), away from the broader community.
7. He is a high risk client likely to spread tuberculosis.

Public Health (PH) Orders (out of 25) – The greater the score, the more likely the respondent will answer that public health orders must be obeyed despite the consequences to the individual.

11. An individual should obey a public health isolation order even if it causes him or her psychological distress.
12. An individual should obey a public health isolation order even if it makes him or her psychiatrically ill.
13. An individual should obey a public health isolation order even if it worsens a preexisting psychiatric illness.
14. Public Health should have the power to order people into quarantine during infectious disease outbreaks.
15. If someone is given a quarantine order by Public Health, they should follow it no matter what else is going on in their life at work or home.

Harm to Others (out of 20) – The greater the score, the more likely that the respondent will answer that an individual cannot harm others.

17. It is wrong for an individual to harm innocent bystanders by causing them physical pain.
18. It is wrong for an individual to harm innocent bystanders by causing them psychological pain.
19. It is wrong for an individual to harm innocent bystanders because it interferes with the bystanders' ability to provide for their own basic necessities.
20. It is wrong for an individual to harm innocent bystanders because it interferes with the bystanders' ability to achieve their life goals.

Harm to Self (out of 20) – The greater the score, the more likely that the respondent will answer that an individual cannot self-harm.

21. Individuals with a psychiatric diagnosis should not be allowed to physically harm themselves.
22. Individuals without a psychiatric diagnosis should not be allowed to physically harm themselves.
23. Individuals with a psychiatric diagnosis should not be allowed to act in such a way as to reduce opportunities later in life.
24. Individuals without a psychiatric diagnosis should not be allowed to act in such a way as to reduce opportunities later in life.

Kant (out of 20) – The greater the score, the more likely the respondent will answer such that what is “wrong” is a separate and distinct idea from “harm”.

25. Trespassing on another person's property is wrong even if the owner never finds out.

26. Trespassing on another person's property is wrong even if it does not disturb the property.
27. Silencing an individual's freedom of speech is wrong even if that individual never finds out.
28. Looking through an individual's bag is wrong even if that individual never finds out.

C. T-Tests

Independent t-tests were conducted to compare the scores on the six scales between the TB and Mental Health groups relative to those respondents in the Family Health group. Tables 5.5 and 5.6 provide an overview of the means, as well as the t-tests per scale.

Table 5.5: Group Statistics – TB/MH v Family Health

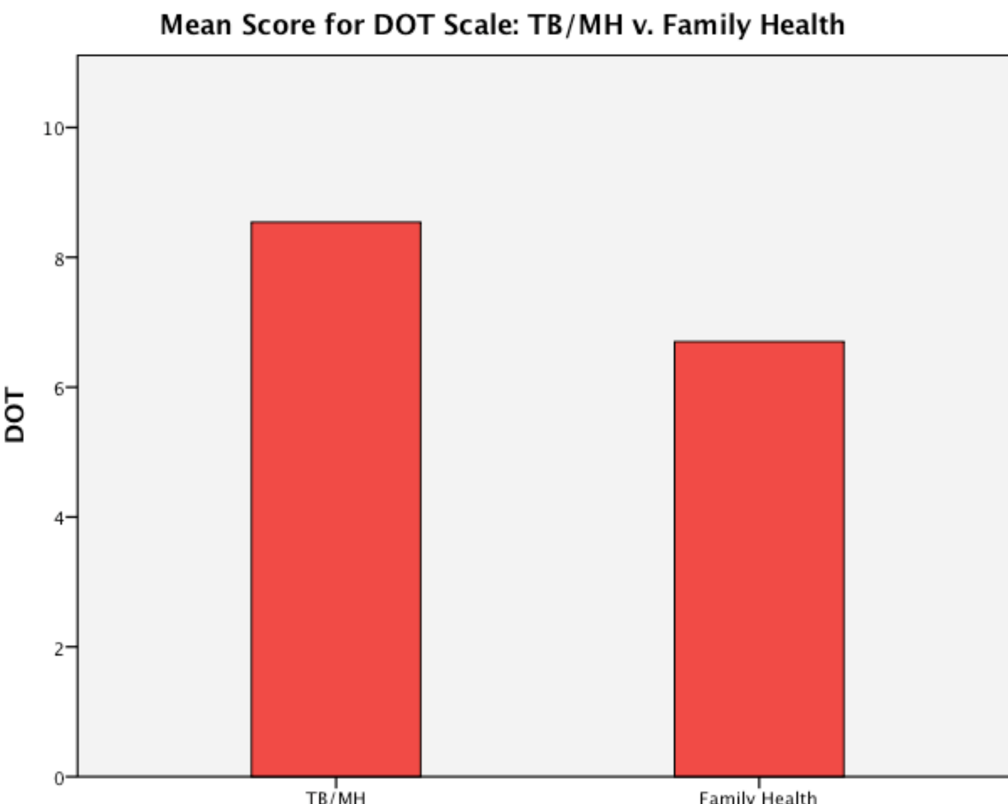
	Org – TB/MHvFam	Mean	Std. Deviation	Std. Error Mean
DOT	TB-MH	8.54	1.885	.241
	Family Health	6.70	2.292	.418
Risk	TB-MH	11.49	3.832	.491
	Family Health	13.20	4.230	.772
PH Orders	TB-MH	20.57	3.175	.407
	Family Health	17.93	3.373	.616
Harm to Self	TB-MH	14.69	3.165	.405
	Family Health	14.57	2.885	.527
Harm to Others	TB-MH	17.56	2.320	.297
	Family Health	17.67	2.383	.435
Kant	TB-MH	16.92	2.597	.332
	Family Health	17.27	3.403	.621

Table 5.6: Independent Samples Test – TB/MH v Family Health

	t-test for Equality of Means		
	t	df	Sig. (2-tailed)
DOT	3.812	48.889	.000
Risk	-1.931	89	.057
PH Orders	3.654	89	.000
Harm to Self	.178	89	.859
Harm to Others	-.209	89	.835
Scale Kant	-.542	89	.589

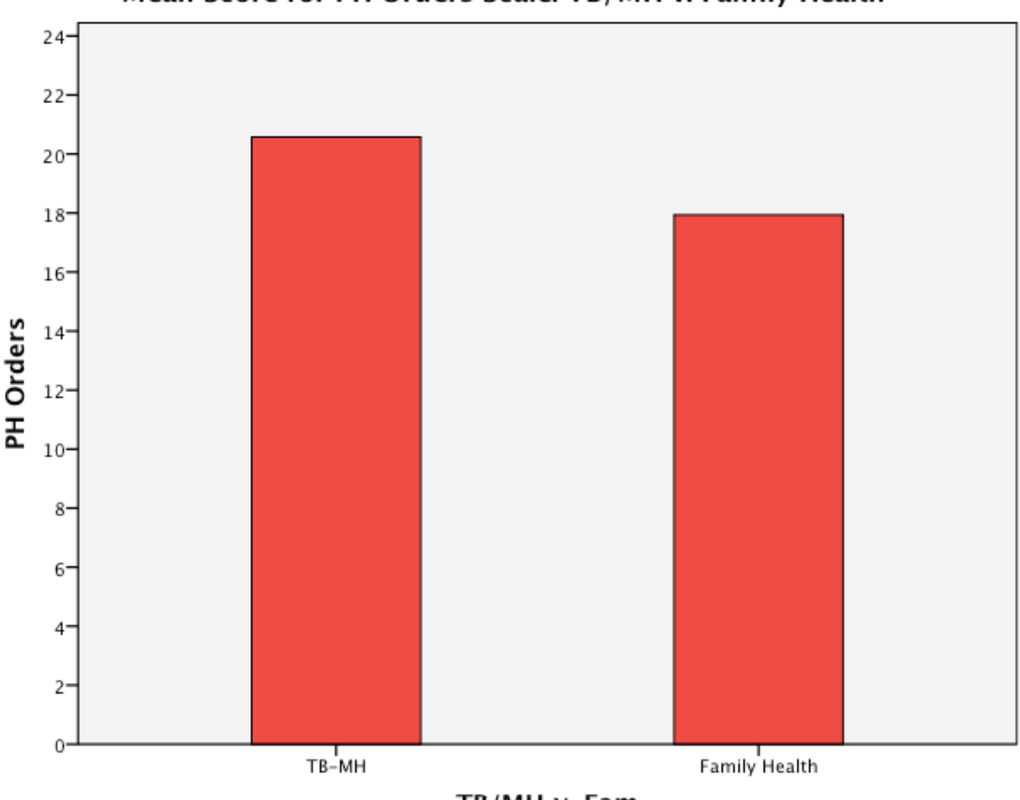
Two statistically significant differences were found between the TB-Mental Health groups and the Family Health group at a $p<.05$ level. First, there was a significant difference in the mean scores for the DOT scale (TB-MH, M=8.54, SD=1.88; and Family Health, M=6.70, SD=2.292); $t(48.889)=3.812$, $p=.000$, indicating that the TB-Mental health groups were more likely to believe that DOT is necessary for TB treatment than the Family Health Group. See Figure 5.3 for a visual representation of the differences in means score for the DOT scale between the TB-Mental Health groups and the Family Health group.

Figure 5.3. Mean Score for DOT Scale – TB/MH v. Family Health



Second, there was a significant difference in the mean scores for the Public Health Orders scale (TB-MH, M=20.57, SD=3.175; and Family Health, M=17.93, SD=3.373); t(89)=3.654, p=.000, indicating that the TB-Mental health groups were more likely to believe that public health orders should be followed at the expense of individuals than the Family Health group. See Figure 5.4 for a visual representation of the differences in means score for the Public Health scale between the TB-Mental Health groups and the Family Health group.

Figure 5.4: Mean Score for PH Order Scale – TB/MH v. Family Health



Independent t-tests were conducted to compare the scores of the six scales between the TB group relative to those respondents in the Mental Health group. Tables 5.7 and 5.8 provide an overview of the means, as well as the t-tests per scale.

Table 5.7: Group Statistics – TB v MH

	Org –TBvMH	Mean	Std. Deviation	Std. Error Mean
DOT	TB	9.00	1.183	.166
	MH	6.20	2.936	.929
Risk	TB	10.88	3.327	.466
	MH	14.60	4.858	1.536
PH Orders	TB	20.39	3.020	.423
	MH	21.50	3.923	1.241
Harm to Self	TB	14.82	2.666	.373
	MH	14.00	5.164	1.633
Harm to Others	TB	17.45	2.257	.316
	MH	18.10	2.685	.849
Kant	TB	16.55	2.602	.364
	MH	18.80	1.619	.512

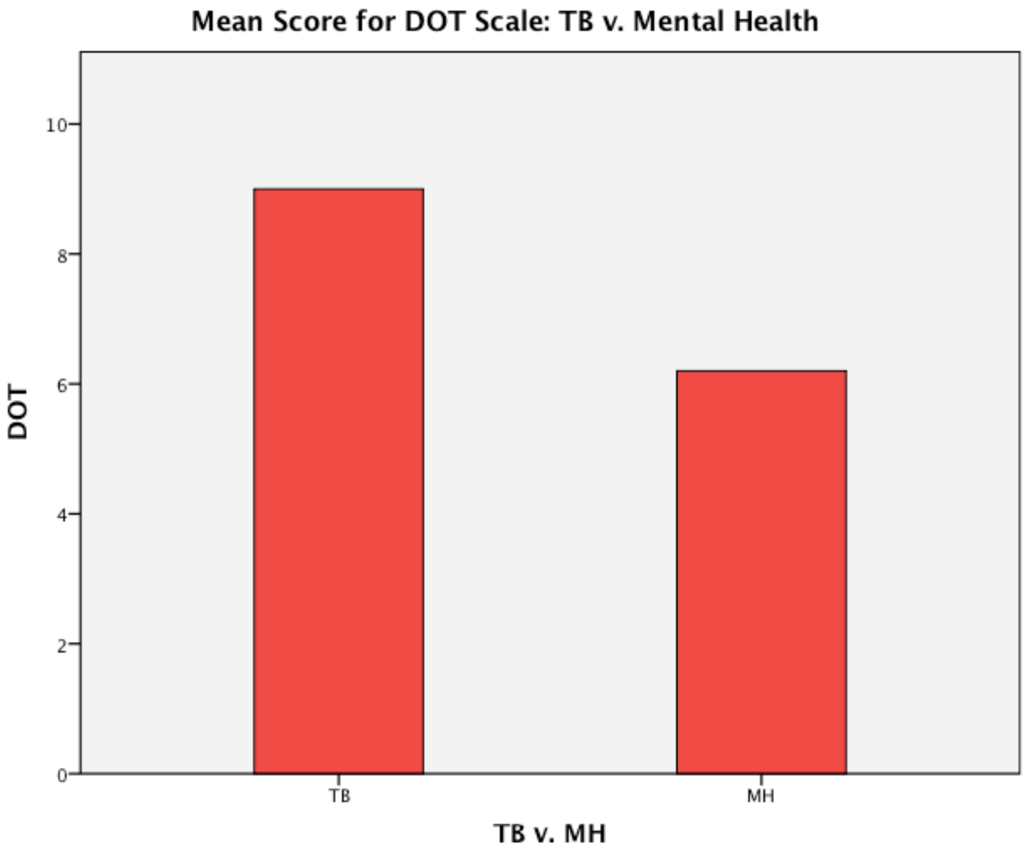
Table 5.8: Independent Samples Test – TB v MH

	t-test for Equality of Means		
	t	df	Sig. (2-tailed)
DOT	5.119	59	.000
Risk	-2.316	10.715	.041
PH Orders	-1.009	59	.317
Harm to Self	.492	9.960	.634
Harm to Others	-.806	59	.423
Kant	-2.627	59	.011

Three statistically significant differences were found between the TB group and the Mental Health group at a $p<.05$ level. First, there was a significant difference in the mean scores for the DOT scale (TB, M=9.00, SD=1.183; and Mental Health, M=6.20, SD=2.936);

t(59)=5.199, p=.000, indicating that the TB group was more likely to believe that DOT is necessary for TB treatment than the Mental Health group. See Figure 5.5 for a visual representation of the differences in means score for the scale between the TB group and the Mental Health group.

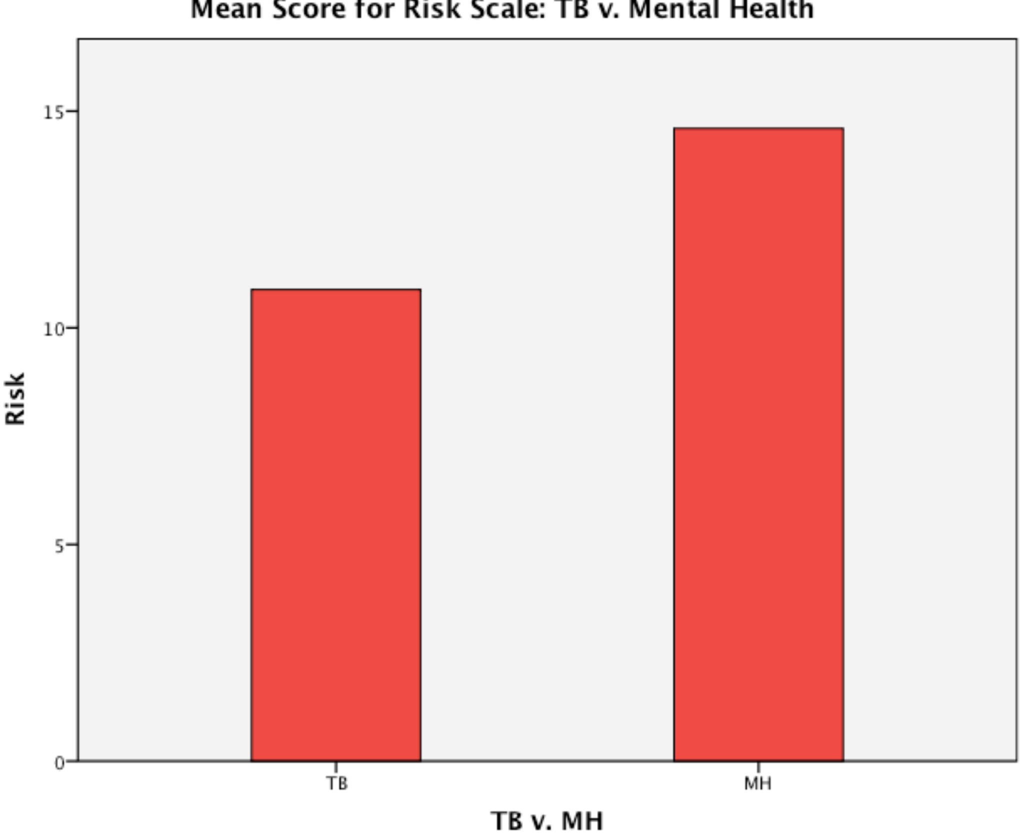
Figure 5.5: Mean Score for DOT Scale - TB v. Mental Health



Second, there was a significant difference in the mean scores for the Risk scale (TB, M=10.88, SD=3.327; and Mental Health, M=14.60, SD=4.858); t(10.715)=-2.316, p=.041), indicating that the Mental Health group was more likely to believe that it was necessary to interfere with an individual if he or she posed a risk to others than the TB group. See Figure

5.6 for a visual representation of the differences in means score for the scale between the TB group and the Mental Health group.

Figure 5.6: Mean Score for Risk Scale – TB v. Mental Health



Third, there was a significant difference in the mean scores for the Kant scale (TB, M=16.55, SD=2.602; and Mental Health, M=18.80, SD=1.619); t(59)=2.627, p=.011), indicating that the Mental Health group was more likely to believe that "wrong" is a distinct notion from "harm" than the TB group. See Figure 5.7 for a visual representation of the differences in means score for the scale between the TB group and the Mental Health group.

Figure 5.7: Mean Score for Kant Scale – TB v. Mental Health

Mean Score for Kant Scale: TB v. Mental Health

TB v. MH	Kant Scale (approx. mean)
TB	~16.5
MH	~18.8

D. Conclusion

This chapter provided a description of the quantitative results derived from the online survey. There were statistically significant differences between the TB/Mental Health respondents and the respondents from the Family Health program on the DOT and Public Health Orders scales. There were statistically significant differences between the TB respondents and the Mental Health respondents on the DOT, Risk, and Kant scales. The next chapter presents the results from the interviews.

Chapter Six: Results – Qualitative Interviews

In this chapter, the results from the qualitative interviews are described via six themes: (a) the goal of care or treatment; (b) the context surrounding liberty restrictions (including discussions about why to restrict liberty; the material conditions of clients; assumptions by the participants; discussions of how to restrict liberty; and finally, the consequences of liberty restrictions); (c) discussions of liberty, control, and choice; (d) the individual's liberty and the public's health; (e) balancing the goals and values of public health and mental health; and (f) the participants' emotional responses to liberty restrictions. The six themes presented in this chapter speak to the conceptualization of liberty, harm, and the harm principle as expressed by the participants through the case of treating persons with TB or persons with SPMI.

First, participants described the goal of directly observed therapy (DOT) for TB and mental healthcare for SPMI as the clinical and psychosocial improvement of those with persons suffering for TB and SPMI, respectively. However, respiratory isolation for TB was described as a means of protecting the general public from the spread of the bacteria.

Second, the participants described or discussed several conditions, assumptions, and consequences associated to being in isolation or observation for TB or SPMI, i.e., the context surrounding liberty restrictions. In particular, the participants described various material conditions that can affect the manner in which a client experiences liberty restrictions, including poverty, cultural differences, and a lack of support systems. Participants also introduced the need to support clients while in isolation under the value of reciprocity. Finally, participants discussed the consequences of being in isolation, which include a loss of

income and possibly being forced to adhere to medication regimens if clients choose to ignore public health or mental health orders.

Third, participants discussed the liberty of persons with TB or SPMI in terms of the control and amount of choices they may or may not have. In addition, participants described the need to balance the liberty of individuals with the public's health. In particular, the participants from both the mental health and TB group agreed that the public's safety from violence or transmission of TB trumped the client's liberty; however, some participants seemed to struggle with exactly how to balance individual liberty and public safety.

Finally, participants from both groups described the need to balance the values and goals of public health with that of mental health care in the treatment of TB in persons with SPMI. Of note, participants in the mental health group were concerned that the need for isolation as part of the public health measures related to TB would interfere with the psychosocial care that a client would normally receive. In turn, the participants in the TB group discussed how the presence of a psychiatric condition could negatively affect the client's adherence to antitubercular drug treatments and isolation orders.

The interviews were conducted between May and June of 2011. Twenty interviews were conducted: 13 participants (nine frontline healthcare workers and four decision-makers) from TB units and seven (five frontline healthcare workers and two decision-makers) in mental health centres. Finally, a note on language: I will borrow from the language of the participants in this chapter, which entails using the word "client" as synonymous with "persons with SPMI".

A. The Goal of Care or Treatment

As described in *Chapter Three: Empirical and Regulatory Background – TB and Persons with SPMI*, the literature related to the care and treatment of persons with TB or SPMI can be divided between literature that focuses on the clinical treatment of an individual with TB or SPMI versus the measures taken to ensure the safety and well-being of others. The participants described the goal of care or treatment in a similar fashion as in the literature, namely, the client's recovery and the safety of the public from harm.

The first goal of care, according to participants, was being cured from TB or the psychiatric improvement for persons with SPMI. For TB workers and decision-makers,

> The goal of DOT is to make sure you take your medication and that you get well. – PH-FW-19
>
> I: How do you conceptualize the goal of DOT?
> R: Just to get people safely through their TB treatment so that their TB is cured and they don't stop too early then get sick again in two years. – PH-FW10

For participants, DOT, and not isolation, is seen as the focal point for the clinical improvement of persons with TB, to protect them against the possible side-effects of antitubercular medications.

> The pills do cause side effects and that's one of the reasons we go in is to monitor the rashes and the fact that you might go into liver failure, so there's that part of it – PH-DM-15
>
> And I also want to be able to see if you're starting to have side effects because if your liver doesn't like this medication, if it can't handle it, you're going to get into trouble, you need your liver so that's where I come in. – PH-FW-10
>
> I say the medications because they do have side effects and some of them cause depression, some of them cause mental disturbances and so that's why our DOT nurses are in there five days a week if at all possible. – PH-FW-9

> Yes, we might be here to make sure you take your medication but the main purpose is, we're here to make sure you're not having problems. – PH-FW-11

Unlike the TB workers and decision-makers, the participants in the mental health group did not focus on protection from side-effects of their clients' medications; rather, there was a focus on not only psychiatric improvement, but also, at least in part, establishing the independence of their persons with SPMI.

> So that's why you're monitoring the meds, to hopefully develop…to help them get well and hopefully they'll develop more insight around that and then you can actually negotiate more on the medications and they'll be able to take them on their own eventually. I mean that's the goal, the ideal goal. – MH-DM-5

> You want people to meet their full potential of where they can be in their recovery, in their journey. It doesn't mean that they're always going to be symptom free, but it's going to be the best place that they can be at and we don't want to hinder or set them back or you know, we, we have to respect their dignity too – MH-FW-6

Another difference in the mental health participants' understanding is that the goal of care or treatment is not necessarily recovery or being "symptom free" (as stated by participant MH-FW-6), but rather some kind of stability whereby the client can function independently (or somewhat independently) of others.

In addition to the clinical and psychosocial improvements of clients, participants from both groups claimed that a second goal of treatment is protecting self or others from harm. Participants from the mental health group conceptualized protection of harm from self *and* others.

> That's the bottom line is the safety for themselves and the safety of others. – MH-FW-7

> They're not going to hurt anyone, they're not going to harm themselves and so they're fairly safe. – MH-FW-6

For participants from the TB group, the goal is the protection of the 'public' or 'community' (they seem to use these terms interchangeably) from harm rather than protecting persons with TB from self-harm. Moreover, there is a sense that public health measures, such as isolation, are only intended for the benefit of others, not those with TB.

> The goal of isolation is to keep you from giving it to someone else. – PH-FW-19

> The goal of home isolation, the main point is to make sure that the community and those around them are protected from the TB. So the home isolation to me does not have many benefits to anyone other than everybody else. – PH-FW-16

Not only did some participants in the TB group conclude that the protection of the public from harm is the goal of isolation, but also that it was their obligations as healthcare workers to ensure the public's safety from the spread of TB.

> I have no doubt that a lot of people, they want to get rid of their TB but it's also that we have to ensure that they're taking their medication, especially with active TB cases so that they're not exposing other people to the same. – PH-FW-1

> So our obligation is to protect the health of the community. – PH-FW-13

One should note that neither group of participants, however, provided a clear definition or description of what they meant by 'protection', 'harm', or 'safety'. Perhaps one can infer that in the case of the participants from the TB group, protection was understood as protection from infection, thus the harm was the illness associated to being infected with TB. One participant from this group, though, presented harm for the public not merely in terms of being infected with TB, but also the monetary costs associated to untreated TB.

> We basically deal with compliance, making sure they take their medications for tuberculosis so that they don't infect other people and we protect the public. At the same time, we also monitor them from side effects from the medications and make sure, you know, being compliant, that they don't become multi drug resistant and cost our health care system more money by using second line drugs, if that was to happen. – PH-FW-19

For participants in the mental health group, one could speculate that the harm in question was the threat of violence toward self or others.[10] Moreover, the participants did not distinguish between protecting self or others from harm and ensuring the safety of self or others; it appears that 'protection from harm' and 'promoting safety' were conceptually similar or the same.

B. The Context Surrounding Liberty Restrictions

Participants in both groups provided justifications or reasons why sometimes liberty ought to be restricted in light of TB or SPMI. In addition, participants described the context surrounding liberty restrictions, i.e., they described the backdrop to, the process of, and the consequences of restricting liberty. In particular, participants described the material conditions or realties of those who are commonly affected by TB or SPMI, revealed assumptions about their conceptions of liberty and restrictions, discussed the conditions that need to be present to justify restricting liberty, and described some of the consequences of restricting a person's liberty. Before presenting the results of this section, it is important to note that participants do not provide any descriptions or definitions of what they mean by terms such as 'liberty', 'autonomy', or 'rights', if and when they use these terms; at best, one can infer certain understanding of these terms.

i. Why restrict liberty: Participants maintained that the justification for restricting liberty, or at least one reason to restrict liberty in the context of TB and SPMI, is harm to self

[10] This understanding of harm to self or others as violence toward self or others is described in greater detail below, in section *B.i. Why restrict liberty*.

or others.[11] Participants did not explicitly state that harm to self or others is the only justification for liberty restrictions, but they rarely presented any other reasons (as discussed below). This theme builds from the previous section, where the goal of treatment was, in part, the protection of self or others from harm; however, here the need to limit liberty is a direct result of the potential (whether perceived or real) harm a person may pose to self or others.

> If it's honestly like a risk and they're actually like risking vulnerable people, if we feel that they're a risk to the community, there are steps that we take, not on a regular basis, probably more often then we would like but there are some legal orders to support us to get some of these non-compliant individuals into the TB Unit at the designated hospital in Toronto. – PH-FW-16

However, whereas protection from harm, in the form of being infected with TB, was seen as a goal of treatment for participants in the TB group, justifying liberty restrictions because of the potential physical harm (often taking the form of violence) that persons with SPMI may commit was overwhelmingly the description provided by the participants in the mental health group.

> I: What's non negotiable?
> R: Violence, aggression towards others or towards themselves. – MH-FW-14
>
> If we feel suddenly that a patient is de-compensating and may be a harm, then we can take it upon ourselves to put them on a close observation or constant. – MH-FW-7
>
> I: So the greater the risk of safety to self or others, the higher the observation or…
> R: Absolutely. To the point of having continuous…
> I: Continuous observation.
> R: Yeah. Yeah. Absolutely. – MH-DM-4

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[11] As one participant noted, restricting a person's liberty is only to be used as a last resort to ensure safety; instead "we challenge ourselves and the team to look at what are the alternatives to any kind of restraint or restricting of movement" (MH-DM-4).

Moreover, the genesis of the threat of harm to self or other seems to be the psychiatric condition itself.

> If it's a psychiatric problem because you know, you've already tried to hit a number of other patients and so to keep you safe and the other patients safe, we need to seclude you in this room. – MH-DM-4

> We don't use physical restraint in this program, but I know that on occasion, other programs at _____ would actually, physically tie someone down. But it's usually, again, for very serious psychiatric issues, like they're threatening to hurt themselves or others. – MH-DM-4

> Now locked seclusion is used mainly for psychiatric issues where the welfare of the individual or others are [sic] at risk. – MH-DM-4

Finally, for at least one participant, past instances of harm to self or others is sufficient to warrant increased observation (whereby a person is closely monitored and which is considered a less intrusive measure for ensuring safety than restraints).

> We could have someone who comes to the hospital and they have had a past suicide attempt or they have had some aggression in the past and they're very agitated and irritable, so then maybe we would put them on a higher level of observation. – MH-FW-6

One participant from the mental health group seemed to make a distinction between what is in the best interest of the person as potentially opposed to the protection of self or others from harm.

> We look at what's best for the patient but if someone is to the point where they could potentially harm someone, then we have to keep them safe as well as the rest of the milieu and the staff too, until they can be, you know, until they're able to be safer and we can help them, and they're agreeable to treatment. – MH-FW-6

Note that for this participant, "helping" the person is conjoined with the idea of being "agreeable to treatment". Although there will be greater discussion of what it means for participants to identify the 'best interests' of persons below (see section *B.iii. Assumptions*), it is unclear the extent to which participants understand that being treated for one's

psychiatric condition is in the best interests of the person. The intersection between best interests and treatment becomes important when one considers that a person's psychiatric disorder may or may not be a sufficient condition to justify restricting his or her liberty, thereby moving away from considerations of harm as the sole justification for restrictions in mental health. For example, one participant noted that,

> As long as they're not a threat to themselves, a threat to others, like their mental status, like if they're really experiencing a lot of auditory hallucinations or delusions or paranoia then we wouldn't let someone like that out by themselves…. If the patient is really ill, the doctor can find them unfit and fill out the appropriate paper work and make them incapable to consent and in that case, medications would have to be forced upon them. – MH-FW-7

However, the same participant seemed to later concede that there are instances when not adhering to treatment might not be sufficient to justify restricting the client's liberty:

> I: So the question is on those rare instances, where the person doesn't comply with treatment, but isn't a safety risk to self, for others, what then?
> R: As far as, uh…
> I: As far as best treatment, as far as observation…
> R: Well, I mean, if they're not going to comply with treatment and medications or any other treatments, sometimes they'll just, the doctor will just say 'Okay, then discharge them'. – MH-FW-7

ii. Material conditions or realities of clients: Participants from both the mental health and TB groups described what they perceived as the material conditions or realities of those with TB and SPMI, i.e. that persons with TB or SPMI usually have similar kinds and amounts of resources or life support, for example family, that may affect how persons react to, and cope with, liberty restrictions. In particular, participants described the different barriers that persons had to address as, or before, they dealt with their illnesses, such as social isolation, not understanding English, or cultural differences between Canada and their countries of origin.

To begin, participants from both groups discussed differences in cultures, i.e., between 'Canadian' and 'non-Canadian', and language as possible difficulties affecting TB treatment or psychosocial care.

> We had to bring interpreters to tell why he was being kept in observation and why he is on this medication and so forth and so on, yes. So language and education level. – MH-FW-3

> But when you have somebody who has just recently arrived to Canada, unless they've been diagnosed with active TB, they don't speak the language, especially when you first come to Canada, you're kind of struggling to, you're putting two and two together and everything is different than back home and you're just trying to get used to a huge culture shock, so then to have this diagnosis and be isolated and it will probably be more stressful on somebody that has recently immigrated than somebody who is established in the country – PH-FW-1

> Sometimes they actually sleep with their spouse, their children, depending on their culture and all that stuff. So sometimes it's kind of a shock when I'm saying it's not for one night, it's sometimes three weeks, six weeks, sometimes longer that they have to find a way to sleep separately. – PH-FW-16

> I mean just because you have schizophrenia or just because you are homeless doesn't mean you don't come with your own cultural backdrop, right? – PH-DM-20

However, one participant argued that workers should guard against assuming that clients will have particular beliefs about TB or mental health just because they belong to a particular culture.

> I think that if we, starting to look at culture and that kind of thing, we're kind of, in my opinion it's kind of a racist thing anyway, just because you're from this country doesn't means you're going to think this particular way or you're going to go this particular way. – PH-FW-17

Participants from both groups also identified housing, and lack of housing, as a preexisting or ongoing concern for clients, which might affect how they can cope with their illnesses or

liberty restrictions.[12] Participants from the mental health group described the importance of housing in terms of reintegrating persons with SPMI into their communities.

> If someone say is in a community setting, or they're able to function in the community setting but they have no housing, then we would look at, they need – maybe they're ready to go but they have no where else to live, then we would maybe send them to another unit where it's more for a longer term until they [have] housing. – MH-FW-6

> Sometimes they're stable and their housing isn't set up yet. So they no longer require to be [sic] on this unit, they're just waiting for housing and then we will send them to another ward and if they're ready to be discharged. – MH-FW-7

In turn, participants from the TB group described how homelessness could factor into TB treatment plans. In particular, participants described how living in shelters or closed quarters negatively affects public health measures to ensure isolation and arrest the spread of the bacteria.

> Many of them [persons with SPMI and TB] end up getting housed in boarding homes where there's shared bedrooms. Most boarding homes, it's two people in a room. If they do end up becoming homeless, they end up in the shelters, so you really have a lot of closed quarters. – MH-DM-5

> You know you can't…there's no shelter that you would be able to isolate somebody. I mean that would just be crazy putting somebody infectious into a shelter. – PH-FW-10

> They would keep them there [in prison] until they were no longer infectious which isn't really fair to the person if they're served their time but if they're homeless, where can they go? – PH-FW-10

As the last quote indicates, there are specific issues related to isolating persons with TB in correctional facilities. Although it is beyond the scope of this research project to examine the treatment of infectious diseases in correctional facilities, one participant told a story of how

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[12] Some participants also described challenges related to housing as a result of being in isolation for TB, e.g. not being able to pay rent because a person was unable to work (see section *B.v. Consequences of liberty restrictions*).

being in a prison with TB could effectively eliminate all of one's liberties far beyond what is necessary from a public health perspective.

> I once had a guy who was in jail and had TB and that, I think, was the worst because he was in an isolation cell which would be what they call 'the hole' right, it's a bad place, so it's like about half the size of this room and it would be just like no window, nothing, just the door with a little mail slot with a window, that's how they could see out, and he was stuck in that room all day and all night and I said, don't the guards take you out every day and he said they didn't, and it's because again, they were afraid or they didn't have time because they need to have two people and in the meantime they have to organize everything to take him out and I remember bringing him to the nursing station on purpose because he had this wild look in his eye, like he was claustrophobic already and stuck in there for so long and you know, saddled by a window, and the whole time he was looking out the window while he was with me and I thought you know, that's torture almost. So, and he had to stay there until he wasn't infectious or until he got out of prison – PH-FW-16

Certain challenges that participants identified seemed to arise more commonly in one group as opposed to the other. Participants in the TB group described how during times of respiratory isolation, persons with TB may have to rely upon family, friends or community groups to assist them with daily living activities, e.g., procuring food. This need for support, however, assumes that persons suffering from TB have access to informal support systems prior to the onset of illness. According to some participants in the TB group, persons with TB are often lonely or socially isolated, and as such, lack the necessary support systems that could help mitigate the negative effects of public health measures, such as isolation.

> I wanted to be sure we don't miss anything [side effects], especially if they're loners and they don't want to talk much. – PH-FW-9

> As there are in any part of any disease, you know, there's that segment of the population that is socially isolated and lonely. – PH-DM-15

> Some other people are completely alone and they have nobody to call, to call on or to get support from. – PH-FW-11

> It just amazes me how people let you enter their lives. One of the nurses said yes, we're so good aren't we? I said no, that's not it. It's that they're that lonely,

> they're that isolated. They just are happy to have you know somebody who is interested. – PH-FW-10

Participants described how persons who are new to Canada might be dependent upon their cultural, religious, or ethnic communities for supports for daily living prior to the onset of TB.

> I mean, especially if you're a recent immigrant, that [community] means a lot more for you than if you've been in Canada for ten or fifteen years – PH-FW-1

Persons with TB also may or may not have a family that can help them live through the stresses associated with isolation.

> Other people are isolated in their home and you know, they still have people around them so they might have a family living with them, it's not so bad because they can still come out to say you know, say hi and that sort of thing, or, they still have those people physically near to them. – PH-FW-11

While participants in the mental health group did not seem to raise explicitly the issue of social isolation as a challenge for persons with SPMI, they did state that families may either act as supports for their clients or may be absent from their lives.

> Initially that is something that one has to have a conversation with and then if there's any family or significant others, the person wants involved in their care, wants us to inform, then we have to facilitate that. In fact, you know, it's often not the individual that is your patient but often the family as well. Again, taking your queue from the patient because some patients don't want family involved, you know, they don't have a good relationship and so again, checking that out. – MH-DM-4

> Other people live with their families, a lot of families too, so it just depends on the level of what they need and so a lot of people, families will say, we'll take our family member home with us but we would like to get an ACT team to come and make sure, to check up and make sure that they're still okay. – MH-FW-6

Participants in the mental health group discussed some material conditions or barriers that were perhaps unique to, or occurred with greater frequency in, persons with SPMI. The very presence of an SPMI, i.e. the psychiatric illness, made understanding treatment plans

difficult or temporarily impossible, including the need for isolation in cases of infectious diseases like TB.

> There are times when there's just no way that trying to negotiate or talk to the patient is going to work at all because they're not hearing you, because the squirrels are coming into their ears and they're chewing on their eardrums – that's what's happening. – MH-FW-14

> It's not great you know in terms of managing someone who may…you know it's hard to restrict their movements [during isolation for an infectious disease]. Again if you're psychotic, you're misunderstanding and that sort of thing, it's pretty tough. – MH-DM-5

> A lot of patients don't have a general understanding of their mental health issues, let alone any sort of physical or communicable disease issues – MH-FW-14

In addition, some participants from the TB group described how drug addictions, as a type of co-morbidity for those living with SPMI, might negatively affect their TB care and abilities to abide by treatment plans.

> What more gets in the way often than someone just understanding and refusing is usually more addictions, like other things may get in the way of the treatment so if someone has really strong addictions that you know, they are not able to maintain their daily appointments or make their appointments or take their medications because they're also consuming large amounts of alcohol. – PH-FW-13

> Many people with severe mental illness also have substance abuse problems. So that in and of itself is a whole other layer of challenges, partly because of behavioural issues but also if alcohol is your substance of choice you could wind up with liver problems which may in turn mean that you are not tolerating your TB medication very well. – PH-DM-20

When the various material conditions are evaluated as a whole, i.e., lack of housing, imprisonment, social isolation, linguistic or cultural differences, one begins to note that persons who suffer from TB or SPMI are "marginalized in a lot of different ways and may have difficulties [with] certain barriers in accessing the health care system" (PH-FW-13). In part, marginalization means that many persons suffer from poverty or have little income.

Participants claimed that poverty is a concern for clients in both responding to their illnesses, as well as coping with any restrictions.

> If somebody is poor and in the hospital and in isolation, they can't afford a TV, they can't you know, so they're just like stuck there and like four walls and if they don't speak English it's even worse because they don't know what's happening and people come in and maybe yell at them for doing something that they don't really understand anyway and that kind of thing. It's not a happy time for anybody. – PH-FW-17

> Again, you're working with a population too that gets a limited income, so they're not going to necessarily be going out there to buy fruits and vegetables as such, it may be more packaged, more convenient food that in turn contributes to that [obesity]. – MH-FW-14

> I really believe that dealing with poverty is one of the biggest stresses that people can have, right? And if you're worrying about how you're going to get food or the fact that you have no roof over your head, it's the whole Maslow hierarchy of needs thing, right? If you're worrying about those things then getting to your TB clinic appointment is not necessarily your top priority right, if you haven't eaten, right, in two days. – PH-DM-12

Marginalization, according to participants, seems to also include a lack of rights and a fear (or distrust) of government or the state prior to the onset of illness.

> We've had many times unfortunately, employees are fired because they don't show up, they lose their jobs. Many of our employees are contract and they're new immigrants so they're obviously at the bottom of the bottom in terms of rights. - PH-DM-15

> If someone asks them [a person who is homeless] to do something or tells them to do something, it's not going to work, for the most part, just because, you know, often they're living in a world without those sort of authoritative regimes, where they haven't necessarily felt supported by the system or the system hasn't supported them, both of those things. – PH-FW-13

> Sometimes depending on where they're coming and their status, there's a whole fear of 'the system' in general, in terms of the Public Health System because they've come from countries where they're either refugees or they've been badly treated by the system and no supports from the system and condemned by the system, politically or whatever, so that they come here and they're not really sure, they're afraid. – PH-DM-2

> Especially given you know, some of the countries that persons have come from, sure, they're fearful of anything related to the government, they don't want people asking questions, they're not sure how this is going to impact their lives, and so I think we need to understand that and move very, very slowly. – PH-FW-11

The poverty and range of material, social, and political challenges often a part of the lives of persons with TB or SPMI prior to the onset of illness appear to create a power imbalance between the healthcare worker (whether TB or mental health) and the client.

> Someone said 'Oh, so you're the law?' I've had the people call and say 'Oh, the law giver is on the phone.' No, I'm not the lawgiver. – PH-FW-9

One participant acknowledged that the very role of a healthcare worker granted him or her power over persons.

> I hold a lot of power in the role that I do have. Yeah, I mean, just the fact that we're a locked unit alone. This unit is locked. Linen closets are locked, the shower rooms are locked. When they have a shower, it's up to me whether I let that door get unlocked or not. I hold a lot of power in the role that I do have. Those right there [holding up keys] hold a lot of power. It's how I use or don't use those. Those don't come out. I don't have to show them that, to keep that power and control in check, you know, by keeping your keys hidden away. I don't need to walk down the hall with my keys visible. They already know who I am and what I can do. I don't need to walk around like a warden. I don't. I think that this type of nursing [mental health field] will bring out the abuser, or can, it can, because you do, you hold a lot of authority and control just by not letting someone into a shower for five minutes, or off that ward for five minutes. – MH-FW-14

Marginalization is not necessarily a material condition or reality in-and-of-itself; however, it may be a consequence of difficult and preexisting material conditions. One participant explicitly noted the complexity of background material conditions that can negatively affect how a client copes with both treatment and liberty restrictions.

> Also many people with severe mental health and addition problems are progressively more marginalized so if you are homeless with no social supports and you have got chronic schizophrenia and you have substance abuse problems, you are really stacking up lots of daily challenges and then you are sticking TB on top of that. – PH-DM-20

iii. Assumptions: There were two kinds of assumptions that participants from both groups expressed throughout the interviews: assumptions about what could or could not be known (i.e. epistemological assumptions) and assumptions about their inability to question public health and mental health law. The word 'assumption' is used to denote participants' beliefs that were implicit and unquestioned, and in the context of the project, might affect how they conceptualize harm and liberty.

Beginning with a discussion of participants' epistemological assumptions, participants in both groups described whether and how to predict the actions of persons, and in particular, the likelihood of persons adhering to treatment orders. Medication adherence seemed to be a challenge identified by the participants in the mental health group, but less so for participants in the TB group.

> I: Is that [med adherence] a big issue?
> R: It is, for us. I don't know if other individuals in other programs would have things to say. – MH-DM-4
>
> Sometimes we'll have a couple [of persons] that will refuse [medications] and sometimes it seems most of them are refusing – MH-FW-7
>
> I: How compliant are people both with the isolation and adhering to drugs?
> R: I'd say 98% are compliant. There's always the person who decides he has the right to do what he wants when he wants to do it but that's society. So I figure 98% is a pretty good number. – PH-FW-9

Participants in the TB group described how certain physical markers, e.g. youth or alcohol dependence, or patterns of behaviour, e.g., asking too many questions about when isolation would be finished, could be indicators of clients who would breach isolation orders, and thus, require greater observation on the part of the healthcare worker.

> I: How can you predict who is going to comply with DOT?
> R: Some people are more obvious like if somebody is a big alcoholic you know or denies their diagnosis or takes an hour to swallow their pills or like a child or

> teenager, like any teenager I wouldn't trust for sure, because they're invincible for sure! – PH-FW-17

> If you get the sense, like some of these people, you get the sense that they would like to return to work…. If we get the sense that they're asking me every day, when can I return to work, you know, they would not be a candidate to reduce the number of nursing visits. – PH-FW-16

> I: how do you determine when you can rely on somebody or give somebody a responsibility?
> R: I think that probably comes in terms of seasoned practitioners. You're looking at how they're managing with the tasks inside the house, you know, are they able to fill the dose out, are they able to do the medication and stuff like that? You know, have they been responsive? – PH-DM-2

Participants in the mental heath group described how worsening conditions while clients are allegedly taking their medications is often a sign of non-adherence to medication.

> We actually monitor their medications of psychotropics. If you know that you've given this medication in a whole week and all of a sudden the lab results level is so low, than you have to suspect that [they are not taking their medications]. – MH-FW-3

> We assess and if we all of a sudden notice that somebody who is fairly stable or their symptoms begin to worsen and we wonder and then like I said, we have rounds and we'll discuss, and we're like, 'Ah, this person, their medication hasn't changed, they're all of a sudden not doing really well and we're kind of wondering, so maybe we need to watch more to see if they're taking their medications.' – MH-FW-6

However, both groups of participants concluded that it is difficult to predict treatment adherence.

> The nurses will often say, 'I just know he'll take the meds. I just know he'll take them. Don't worry about this guy, he's okay.' I'm much more cynical, I've been around longer. – PH-DM-15

> But even, I've been wrong. People that I thought there's no way that guy is going to take the meds, and they've been fine, so…I can't tell you! – PH-FW-17

> It's not always foolproof, because I've seen that as a nurse myself – you swear the person took the pill, you've also asked them to open their mouth, you don't see anything – there are ways they can cheek their pills and that, so it's not

> foolproof and certainly on an inpatient setting when they're with you, you might have a little bit more control. – MH-FW-4

Due to an inability to accurately predict treatment adherence behaviour, one participant noted "Usually [clients are] put on close observation when they first come in, just because we don't know them and it's just to keep a closer eye on them" (MH-FW-7).

The second issue regarding 'knowing' were participants' descriptions of risk of harming others via the spread of infectious diseases like TB (an issue that arose for both groups of participants). Participants began by stating that persons with TB do not generally intend to infect others.

> I don't think most TB persons would go out knowingly and try to infect somebody else, right? So I think they're often concerned about their contacts. Most often, they're concerned about their own family first – PH-DM-2

> Not many people have a desire to go out and infect people or anything, if they're not making money or anything. There's not [sic] many people that just get on the TTC and just go out. – PH-FW-16

> So it's actually very straightforward. The huge majority of people with TB don't want anyone to catch it from them, least of all the people that mean the most to them. – PH-DM-20

In fact, participants described how sometimes clients' perception of risk is too high and would lead to being overly cautious or fearful of spreading TB.

> We actually sometimes have to have people who are probably go overboard in terms of respiratory isolation and staying away from grandchildren or something like that, well beyond the point where they really need to in terms of actual likelihood of transmission. They are so worried that they might give TB to their grandkids or something like that. – PH-DM-20

> You'll ask for the contacts and then they'll be [persons] calling you back three days later because they think of five more. 'Oh, I forgot about so and so and they have a baby' and you know, all of a sudden you understand they're processing the information in terms of risk factors, and I think people stress themselves. – PH-DM-2

> Even though you say, you can still talk to your children or whatever, you know, your isolation is done, but some of them, they are just over cautious. You just have to kind of sit back and say if this was you, wouldn't you be paranoid too or like obsessed with the idea and I guess you would, but because I deal with it every day you just feel like they're over reacting because you know what the real answer is. – PH-FW-16

Some participants noted that lay members of the public would also overestimate the likelihood of infection, and in a similar manner as clients, be scared of TB exposure.

> We go into a school where there's no risk, there is no risk, okay? We'll test the classroom or anybody, anybody who was near the person with TB, but we're sure not going to do the whole school and we're not going to do the bus drivers that drop other kids off at the school, or the crossing guard who works across the street, but they all call and they're terrified that they got TB because they were at the school, okay? There's the risk, peoples' risk that they think they might have been exposed. It's that fear. It's the public health risk, perceived or real. The real I can deal with because I can talk to you about, you know what, you really have been exposed. I'm going to check you for disease, I'm going to check you for infection and if you're just infected I'll offer you treatment. Okay. The perceived is harder. Dealing with peoples' perceptions and how they perceive reality is often more difficult. – PH-DM15

> In this particular workplace we went in with a team and we did air quality assessment and so the workers in the place saw us doing the air quality and there were lots of bay doors, so the workplace was the low risk exposure, so to be able to go in and say this workplace was a low risk exposure, peels them off the ceiling. – PH-DM-2

The public's perception of risk of infection can be contrasted with participants' perception of risk as healthcare workers. Participants noted how 'seeing' risk in a concrete situation affects a healthcare worker's understanding of clinical or statistical risk.

> So there's statistics and studies and probabilities and then there is real people in front of you. People are always, real people are always way more complex than any study could possibly capture, right? But you have a better appreciation of what risk means if you've actually seen it play out in real people. It's not that you ever necessarily want to see it play out in real people but if you hang around long enough it will. – PH-DM-20

> I can remember a situation where an employee came from a country where TB is endemic, it wasn't a big deal whereas the Canadian born staff were like panicked

> about it so there's a difference sometimes in personal experience with certain illnesses or certain infections etc. and how people react to that. – MH-DM-5

A healthcare worker's perception of risk of infection is, in turn, interpreted differently if one is either a public health or a mental health worker. A mental health worker, who is less accustomed to encountering certain infectious diseases, like TB, are perhaps more likely to take greater precautions than someone who constantly deals with the disease.

> It felt to us from the TB end that in a psych facility people were going way overboard on the infection control side. The respiratory isolation doesn't have to mean social isolation, right? This was a guy [a mental health person with TB] who would have breakfast, head out for the day and not come back until bedtime. He was used to spending 12 – 16 hours a day outside. And from a TB point of view there was absolutely no reason why he couldn't do that. He didn't have a bath for weeks until we found out that he hadn't had a bath and worked out an arrangement for them that met infection control precautions that they could walk him down to a shower down the hall and how to manage that in terms of infection control. – PH-DM-20

> They [mental health workers] often feel less prepared [to deal with an infectious disease] because they don't deal with it every day like you do in a general hospital. – MH-DM-5

Finally, some participants acknowledge that one of the challenges associated with addressing the risk of infection from TB is that the science in support of a diagnosis of TB is not always reliable and that the disease course with TB can be difficult to predict.

> Our persons will say 'Well, tell me exactly how long I have to stay in isolation? How long? When can I come out? When can I start to…' and it's one of those things where we have to test them in an ongoing basis and it's something that you can't predict. It would be total guesswork if you told that person 'Oh, I think it would be x number of weeks.' It's like your guess is as good as mine – PH-FW-11

> We'll get these smear results back and the smears will be negative and then in fact, the culture comes back positive; the person really does have it, right? So here you think, okay, we've got the negative smear back, which means they aren't infectious, which is a good thing, which means we found them early, you know, and they haven't probably transmitted TB to anyone else, but then you think, oh, my gosh, the culture has just come [back positive]. – PH-DM-12

The final epistemological assumption is related to the idea of understanding the viewpoint of persons and acting in their best interests. Participants from both groups stated that it was important to 'know' or 'understand' the client's viewpoint in order to serve them empathetically during care or treatment.

> The adage that all human behaviour has meaning, so let's try to understand the behaviour that we're seeing and maybe channeling it, if possible, into some other activity to decrease that risk. – MH-DM-4

> I create that space where I can meet them where they are, or try to meet them where they are, try and understand where they are and where they're coming from. – MH-FW-13

> I think you just have to really, really understand where your persons are coming from…. I don't think you could exist in this program without sensitivity, like that's just, if you can't, if you don't get where your person is coming from, then I think there would just be a huge clash, so it's, yeah. It's certainly an understanding of just you have to put it in perspective of maybe your person's previous experiences and whatnot. – PH-FW-11

However, it is important to note that most participants did not question this assumption, namely, what it means to understand the client's viewpoints or the extent to which that is possible. In turn, participants from both groups (although more so from those in mental health) described acting in the 'best interests' of clients.

> Our relationship went, you know, not great, so what we've been able to do is just have a different nurse come and see them and it's regardless of what I had to do with it, which was a lot actually to getting them there, you know and it's only in their best interest, in theory, that we were able to give them a different nurse to see them. PH-FW-17

> Observing someone is intrusive and so that kind of decision to do a constant observation is not taken lightly. Really, you have to think about is this the best for this person. – MH-DM-4

> We all seem to come up with a team decision and say okay, this is what we have to do, what's best for the patient and what do we have to do – the least restraint possible to get them better, to further recovery…. Sometimes some may have to be in seclusion or something or restraints because we're able to help them accept treatment so they can get better. MH-FW-6

One participant noted that healthcare workers acting so as to protect the best interests of the client is potentially paternalistic.

> So I really do think that it is, and this is hopefully not too paternal, but I do think that it [TB treatment] is for their best interest, whether they see it that way or not, is the hard part. – PH-FW-13

Two participants did seem to question a healthcare worker's ability to know what is best or good for the client.

> Each of us has their own opinion of life and how things should be and respecting that but also respecting that I only apply the law, I don't apply any other values. – PH-FW-9

> When I say the best interest of the person, I'm not pretending I'm God by any means, and I know best, because sometimes that can be in this, you know, you carry the keys you know, that sort of thing, but when I know it's in that persons best interest because I know if they don't do that and they don't do that, and they don't do that, this is what they're going to suffer with. You know, and that's just knowing that patient in that capacity. MH-FW-14

Note how both participants, after acknowledging that there may be challenges associated with 'knowing what is best for the person' appeal to some objective criteria for their actions; PH-FW-9 appeals to law as the only values that he or she applies, while MH-FW-14 seems to appeal to some kind of vague empirical (perhaps anecdotal) evidence of what happens when the client does not abide by certain directives. Therefore, for these two participants, one might infer, perhaps, that in light of the subjectivity of values, i.e., 'best for' or 'good for', one can rely on some kind of objective standard vis-à-vis *something* (whether law or past behaviour) to guide action.

The second type of assumption made by participants was an acceptance to abide by law as a necessary condition of their jobs (or mandates) as healthcare workers. In other words, when discussing the need to isolate persons with TB or enforce treatment for those

with SPMI, e.g., through a community treatment order in Ontario, participants from both groups did not question, or sometimes explicitly stated the need to, abide by laws and regulations.

> There are certainly some individuals with serious mental illness who may be, for example, on a community treatment order. These are people who have become very ill over and over, they've been admitted to hospital, their illness has been so serious over time and it's shown that treatment works in the past and the physician can go through a legal process where they actually feel that a community treatment order is warranted. You have to go through all the legal hoops. – MH-DM-5
>
> When you have somebody who is on a treatment order, doesn't have the capacity to consent for treatment or for finances and that sort of thing, that is, those are the laws in mental health and those capacity issues where that is non- negotiable. – MH-FW-14
>
> My job is to ensure the person complies [with] the legislation, public health legislation for the province of Ontario in terms of maintaining isolation, accepting treatment, doing well on treatment. – PH-FW-9
>
> We do what the Public Health department mandates. - MH-FW-6
>
> You always start off with what's the legislation, since I've been here anyways, when they would go in they'd always tell them about the legislation, the requirements under the legislation to report, to keep that person's name confidential. – PH-DM-2

One participant, however, did question the legislation; in particular, the participant claimed that the current public health legislation in Ontario is inadequate insofar as a healthcare worker is unable to detain immediately someone with TB. The participant described how mental health legislation, which does allow a physician to immediately restrain a person's movements on psychiatric grounds (*see Chapter Three: Empirical and Regulatory Background – TB and Persons with SPMI* for more information on legislation in Ontario), was used to detain someone who the participant thought might be a credible threat to spread TB.

> There's a legal resource that I wish I had, really, really wish I had. There is no provision under the *Health Protection [and] Promotion Act* right now to detain somebody more or less on the spot…. So if you can imagine if you have got highly infectious tuberculosis you could potentially do a lot of damage in that time. So in those situations the people involved have sometimes used the mental health act to form somebody, just to contain an immediate risk and we all knew that we were on the margins on it. *Mea culpa*. But I think it is a real gap in public health resources to have no, really no ability to immediately, to contain an imminent public health risk from an infectious disease, in that way. – PH-DM-20

iv. How to restrict liberty: Participants from both groups described what processes and actions needed to occur when restricting liberty, i.e. how to restrict liberty in a manner that respects the person with TB or SPMI as best as possible given the circumstances. Participants identified the need to work collaboratively with other healthcare workers in order to build trust between the client and the health team. Treating the client in a holistic manner, which included protecting his or her privacy, was described as integral to help the client through times when liberty is restricted. Finally, participants described the many ways in which they supported individuals' whose liberty was curtailed, i.e. participants pointed toward some notion of reciprocity for those individuals whose liberties were restricted for the safety of others.

To begin, the participants in the TB group noted that when a decision to restrict a person's liberty is made, whether to ensure the safety of the person him or herself or others, decisions need to be made collectively and in consultation within and between healthcare teams.

> I have one now, though, she's having panic attacks and she's afraid of hot water and it's something new for me too, right? So then, that's when we work, actually I should say too we work with our mental health nurses and we have nurses that work with us too, so I'll just call them and say 'You know, this is happening with this person'…. They'll do a joint home visit with us and you know, just look at the whole situation and give us good ideas about how to deal with the person. – PH-FW-17

> I'm not a mental health expert, so I would try to work with a team of health care professionals and have some, we do have a mental health care unit here, so I don't know, some form of mental health special support for these guys put in place so that he's not left alone. – PH-FW-1

> So absolutely we either work with whatever psychiatric supports people already have or we try and get them psychiatric supports. – PH-DM-20

Participants from both groups describe the importance of trust, or establishing trust, between the client and the healthcare worker in situations where a client's liberty may be restricted or potentially restricted. The issue of *clients trusting healthcare workers* usually arose in the context of treating vulnerable persons. Participants spoke of the need to engender trust slowly with clients.

> You know, whether they are psychotic or not or paranoid or not, why should I trust you just because you're saying you're a nurse? Fair enough…. What I do a lot is I talk to them and I tell them, like, quite often a lot of them will ask about their medications and so on – 'Why are you giving me that and why aren't you giving me that one, this, this and this?' I pull their medications right up on the screen and show them, and I said that's what that's for, that's what that's for and that's what that's for… so what I can do as much as I can to sit and actually show them their treatment plan, it's bringing them into conferences and having a say with the treatment team, which can be very intimidating, but actually having a say – MH-FW-14

> And there are some people who are quite [mentally] ill and just wouldn't come near me. I was telling this story just the other day – there was one gentleman [at a local shelter where the participant was doing TB treatment and screening] who just, he would not ever give me a cough and spit or anything and then he just watched me. A lot. They have to watch you to make sure you're okay, you know? And one day there, this is months after I'd started and I was there every day, he walked by me and he said hey, ______ [makes clicking sounds to signal to come over] and I thought now I can get a sputum [Laughs]. From then on any time I asked him for a sputum [sample] he said sure [Laughs]. Yeah, sometimes it just takes time, you know they've got to make sure that you're okay, I mean they've got reasons why they're like that. – PH-FW-10

Note that in the first quote, by MH-FW-14, it seems that transparency is seen as a means of establishing trust, an idea that was echoed by some other participants, as well. In addition,

participants also described the need for *healthcare workers to trust that clients* will abide by treatment orders, especially in the community and away from an institutional setting.

> There may be people out in the community and they have case managers going out to see them and they refuse to open the door or they tell you I just took my medications before you came. You can't force them. Like you have no legal way to force them to show [you] so a lot of times it's on the honour system. – MH-DM-5

> Well, it's [DOT] seen either in a car or whatever, but we try to make it work for the patient as well as us. If it can't we will not jeopardize your job, we will not. We will say, we have to trust you to take your meds. – PH-DM-15

One participant noted that he or she never trusts that clients will comply with treatment; he or she assumes all persons with TB are untrustworthy.

> R: So then it's not a law that they have to take DOT unless you know, they're alcoholic and they've shown that they can't be trusted. Of course, we don't trust anyone, equally!
> I: Sorry, you don't trust everybody…
> R: Equally.
> I: So what does that mean?
> R: It means, they say you can't predict who are going to take their pills and who isn't, so yeah, that's why I say I'm never disappointed, I don't trust anyone. If they go ahead and take their medication and do what they're supposed to, oh, good for you, I'm happy and if they don't, it's like well, I didn't think you were anyways – PH-FW-17

One means of establishing or maintaining the client's trust throughout treatment that may involve liberty restrictions is to protect his or her privacy or confidentiality as best as possible. The issue was raised by participants in the TB group in the context of protecting a person's identity in the course of a contact investigation (although participants did not seem to make a distinction between 'privacy' and 'confidentiality').

> The nurses' absolute prime, prime, is confidentiality. We will never say to a workplace, a school or a friend who has TB who the person is that has TB. – PH-DM-15

> So we protect them, we never share the name and we will go to the n-th degree, but sometimes in the course of investigations, that anonymity is sometimes lost. – PH-DM-2

One participant noted that although the goal is to uphold the privacy of persons during contact investigations, a balance needs to be struck between protecting the privacy of the individual and the well being of others in knowing that they may have been exposed to TB.

> People are also concerned about their personal information and the protection of their personal information and we always kind of struggle in public health with the difference between you know, the public's right to know and protecting the public versus the individual's right and the individual's privacy. – PH-DM-2

Participants also noted that clients should be treated in a holistic manner when being treated for TB or SPMI. Both TB and SPMI were described as complex illnesses that require that other considerations, e.g., living situation, support systems, etc., be taken into account when treating the disease.

> You're not just treating the TB, you're treating the whole person as they're going through this experience which will end. – PH-FW-10

> You generally got to tackle TB cases in this situation as a package deal. Where someone who is very high functioning, you know, they'll generally be able to fit TB into the rest of their life, you play a minor supporting role and get them through treatment, but they are managing everything else. For people in that extreme situation, basically if you want them to be able to get through TB treatments safely you often have to deal with a lot of their barriers, which have nothing to do with TB and which are still going to exist after the TB has come and gone. – PH-DM-20

> A lot of it [recovery model] is in conjunction with the psycho-social model in a lot of ways, the resources that are available for them, it's teaching, it's the education with their disease, it's understanding medication administration management as part of that. It's understanding that what our progress that we think that they should be moving towards may not be what they're able to do at that time. – MH-FW-14

Finally, the main condition that justifies liberty restrictions, according to participants in the TB group, is that clients have a right to receive support while in isolation, i.e. public

health needs to apply some notion of reciprocity when treating individuals who have their liberty restricted or curtailed. The value of 'reciprocity' in public health means that when an individual is isolated for the good of others, on the basis of the harm that could arise if a given infectious disease spreads, then that individual should be given as many supports as possible and possibly compensated when discharging their public health obligations. To be clear, participants in the TB group never used the term reciprocity; however, one individual explicitly stated that "you know you have to keep them in isolation while they have the rights to have, you know, all the basic needs [met]" (PH-FW-19). Instead, participants described the many ways in which they provided the basic necessities of living for clients in isolation for TB.

TB healthcare workers provide many of the basic resources necessary of life while the client is in isolation, including food (whether actual food or access to food, e.g. bringing groceries).

> You know, for example the person has lost their income or whatever, they have TB and we provide food vouchers to them and we provide tokens to get to medical appointments and things like that. – PH-DM-12
>
> Some of them might have just had savings, but a lot of these people, they just struggle through that period and we do help them hook up with the food banks. – PH-FW-16
>
> They rely very heavily on the nurses the come to see them, so the nurses might be going to the food bank for them and pick them up some food or even some cases it's going to the library to get some books. – PH-FW-11

Given that there are many persons with TB that are also homeless, some public health units also provide access to a motel where persons can stay during isolation.

> We do have a motel that we sometimes will use, if somebody for example has been in _____ or they don't need to be in hospital any more, they're not acutely ill but we don't have the negative smear results back to indicate that they're not infectious any more, we have a motel or two – we have different ones that we can

> use where they would go there and we would still continue to visit them, the DOT worker would visit them there at the motel. – PH-DM-12

In addition to providing resources or access to resources during a client's time in isolation, participants noted that as healthcare workers, they were there to provide any and as much support as possible for their clients. Much of this support seemed to be psychological in scope, i.e., letting the person know that there was someone they could call upon for support and possibly companionship.

> I guess one of the challenges is to make sure that the person isn't isolated while they're on isolation, so we make sure that we visit them, we make sure that they have food, that they're alright, that they understand, you know, why they're on isolation, that we keep in touch with them, that we quickly get the sputum off to a lab, to make sure that they can be released from isolation as quickly as possible…. I think it's very important for the person to know that the nurse and the public health nurse and the DOT worker, that they care about them and that we're supporting them. – PH-DM-12

> When they realize that you'll go to that length, in terms of the family and having to establish, you know, help them get day care, and those are things that they'd be overwhelmed [with] at the time…. There's lots more social interventions that we do with TB persons, than we do with most of the other types of infectious diseases. – PH-DM-2

Sometimes the support provided by TB workers included advocating on behalf of their clients.

> And then the advocacy piece to make sure they have, whether that's a letter of support, whether that's, whatever it happens to be. – PH-DM-2

> We do advocate for our persons in that manner because there might be certain physicians that say 'No, no, no, this person needs to stay in isolation' but you know, we base that on the Canadian TB standards, so a lot of it, we do have a lot of advocacy for our persons in terms of you know, if someone is being too harsh or I don't know, unfair [with] persons. – PH-FW-11

Supporting persons with TB also means verbally encouraging them, trying to provide them with hope and acting as a kind of "cheerleader".

> Very often they're really sick in the beginning and they think they'll never be strong again. As soon as I see it, I point it out to them: 'Remember how you felt four weeks ago? Well, in another four weeks you're going to be feeling even better then this. You're gaining strength and stamina, you're sleeping better', you know and that makes them want to get better even more. – PH-FW-10

> It's one of the reasons why DOT works, because you have a relationship with the person who is showing up and saying, 'So still doing okay? Almost there, three months to go'. Often what we are really doing playing a cheerleader sort of a role. 'I know it's a hassle but don't give up.' And that applies just as much to people that have mental illness or are homeless or whatever. – PH-DM-20

While at times supporting client entails meeting them for DOT wherever is most convenient for them, at other times, the support that healthcare workers provide clients far exceeds the normal parameters of their job descriptions.

> We often go the extra mile. We've done, just recently, we moved somebody during the week, they were being evicted because they were in the hospital so the friend said you can store the stuff at our place but we have no way of getting it there, so the nurse has three cars, they went and emptied the guys apartment. That's what we do. We don't like it and the Region doesn't know about it. – PH-DM-15

> 'I have to go home, what am I going to do? I've got to go home, I've got to get stuff, I've got to make arrangements for my family and stuff like that' and the nurse met him on the 401 and gave him masks and said, 'Okay, if you have to go home, this is what you have to do for the weekend, you have to go home and the specialist will see you back here on Monday'. We were trying to arrange things with the _________ Unit because they were going to investigate all of the family members, but he was in a situation where he was well enough to drive. He drove, and we said, 'If you have to get out, you got to put the mask on' and he took stuff with him and she went in and she got supplies for him so that he could stop at the side of the road and do what he had to do to drive the 9 hours or whatever it was he was going up north, you know, stop for gas, he could pay with a credit card, I mean, we had everything, everything was worked out. – PH-DM-2

Another example of participants going beyond their job description was their willingness to spend their own personal money to support persons with TB.

> We do incentives, we do Timmy's cards if we have to. We don't have a budget for this stuff, but we do what we need to do. We do stickers for the kids, we do any – and the nurses buy this stuff, they buy little toys for the kids. – PH-DM-15

The need for healthcare workers to pay out-of-pocket for resources for their clients implies that there are possibly an insufficient amount of resources available for persons with TB during isolation. In fact, participants explicitly noted that there was a lack of resources available (material, more so than human) for those in isolation for TB.

> I: let's start with the income – what do you do in situations where there's the need for income?
> R: It's really sad – there is not much, depending on the employment of these people, there isn't much we can do. There is no extra subsidy. – PH-FW-16
>
> We don't have the funds to pay people's rent or jobs but we do get them Ensure if they're…a lot of our persons come in with a weight loss because that's part of the disease so we always…we have Ensure available for them which is a high protein supplement and we give that. – PH-FW-9
>
> The resources that I wish we had more of tend to be things like access to housing, support, specifically supportive housing. Access to respiratory isolation facilities that are more in the community. There are no single rooms even in the shelter system in Toronto. Thousands of beds and not a single one bed in one room in the shelter system. Stuff like that. So more not the social worker but the stuff for social worker to be able to put in place. – PH-DM-20
>
> Now, in an ideal world, you could manage, but I mean, it always comes back to resources and possible resources and you're not always able to give them everything that they need. – PH-FW-1

One participant in particular noted the need for mental health supports and programs for persons who suffer from TB and SPMI.

> The other piece that is, I said before that I wish I had more of by way of resources is psychiatric care for people who are infectious. So more psychiatrists, psychiatric nurses like ACT kind of stuff that are willing to see people who are infectious. That would, I mean it doesn't happen terribly often but when you need them boy you really need them, you really, really need them. – PH-DM-20

It is important to acknowledge that not all participants from the TB group described providing resources and supporting clients on the basis of reciprocity, but rather to ensure adherence to isolation so that TB does not spread to other persons.

> I guess in New York City in the mid 80s, they had, I don't know if you heard, the big problem with TB when they cut their funding, they had all these resistance strains, so I can see that coming. – PH-FW-16

Finally, the same participant stated that he or she did not feel the need to support his or her clients beyond their given job description.

> I don't drive them to their doctor appointment, I don't physically take them to get their CTs done. I don't pick up their medication for them, I don't do anything other than make sure that the medication is taken properly. That is my main focus. – PH-FW-16

Notable by its absence, the participants in the mental health group did not seem to discuss the idea of reciprocity vis-à-vis their clients; however, they did discuss the need to support persons with SPMI.

> It's the teaching around the disease process; it's the resources that are available to them, it's working with them in terms of programs and assistance they may need to acquire both in the hospital and outside of the hospital but not doing it necessarily for them, but giving them the resources and the tools to be able to carry on with that, if they either transfer from here or go into another setting – whether that be a group home or an apartment or what have you. – MH-FW-14

In particular, the need to support clients and provide the requisite resources for them to flourish in a community setting was repeatedly stated by many participants in the mental health group, but the support described relates *to the illness*, rather than *the observation/restraints or consequences of observation/restraints*. Perhaps given that the mental health group consisted of participants from mental health centres, and not community settings, the need to provide supports (and the resources this support would entail) is different than isolation for TB in the community setting. At best, one can only acknowledge the absence of discussions of reciprocity from participants in the mental health group, while speculating about the reasons for its absence.

To conclude, one should note that despite raising the need to build trust, treating people holistically, and espousing the value of reciprocity while persons are in isolation, none of the participants discussed the need provide a means of appeals mechanism when one's liberty is restricted to ensure the health and safety of self or others. Only one participant noted that "there are checks and balances to ensure that you know, civil liberties are not violated, that appropriate processes are followed and that there's legitimate use of anything that confines you know, human movement if you will, so that things like a threat to self, a threat to others, it has to be pretty serious" (MH-DM-4). However, despite referring to "appropriate processes" and "checks and balances", the participant never referenced the inclusion of the client in the decision-making process. The reason may be that the client, in a mental health setting, does not have the capacity to consent to treatment, hence staff have to act on behalf of the person. Regardless, even by participants in the TB group, where there are fewer issues related to capacity, the notion of an appeals mechanism was never introduced.

v. The consequences of liberty restrictions: Once the liberty of persons was restricted, participants described the consequences that might befall clients. Participants noted that the decision to restrict a client's liberty was not taken lightly; one participant noted that staff was always looking to increase a person's privileges.

> So that even though we may not present it as you know, let's talk about civil liberties today, there's always a dialogue about who needs to be here and who should be, continue to have this form renewed and who, you know, is doing better, who can now have their status reverted to a voluntary status and can go out on privileges and can resume a more normal life, if you will. – MH-DM-4

It is important to note that although participants would sometimes described the consequences associated with the illnesses themselves (e.g., the stigma related to TB and

SPMI), the consequences described in this section relate directly to having one's liberty restricted. The consequences include negative feelings about having one's liberty restricted, stress over finances, a client's sense of punishment, stigma, and the need to use force when a person refuses to accept an isolation or observation order.

To begin, participants described that clients whose liberties are restricted will often have negative feelings about these restrictions, which may manifest themselves in various ways including depression, low self-esteem, boredom, and paranoia.

> No, like I don't think it's the nicest thing, as far as, I won't think it would be very, you know, for their self-esteem, I mean, they're all of a sudden in isolation room. – MH-FW-6
>
> She didn't socialize as well, so nobody was coming to her home and she wasn't going anywhere, so she found it really, I don't want to say depressive, but those terms, very lonely. – PH-FW-1
>
> Yeah, okay, so I guess it's very depressing too, if you can't talk, if you can't speak with people and I know for a lot of our persons that have come here [from other countries] let's say by themselves, it's scary. – PH-FW-11
>
> Some of them hate it [observation], they're very unnerved by it, to have somebody looking at you round the clock. Some persons, because of their impaired mental state probably don't even recognize that there's someone there and some you know, I find they just accept it, so I seen all levels of acceptance and non acceptance, yeah, yeah. Observing someone is intrusive. – MH-DM-4
>
> I think maybe they see it [DOT] as an intrusion into their life, like come on, I'm an adult, I know how to take medicine, I'm not an idiot. I can take it every day you know, who do you think you are with the city, big sister, big brother coming to see me and watching everything I do – PH-FW-17

Second, participants in the TB group described how isolation would negatively affect a client's ability to work and, therefore, would create financial stresses and an inability to provide for themselves and their families. Participants noted that since many of those with

TB are of a lower socioeconomic status, including new Canadians, their jobs often provided little to no social benefits (e.g. sick leave).

> The other challenge with isolation is the economic part of it; the economic part is the whole issue around we're taking away someone's livelihood…. We've had many times unfortunately, employees are fired because they don't show up, they lose their jobs. Many of our employees are contract and they're new immigrants so they're obviously at the bottom of the bottom in terms of rights…. Nannies in particular, they're just out of the house, no place to live and it's a question of how do you get them food because they can't get to a grocery store and they're new to the country and they don't know anybody - PH-DM-15

> I guess if someone is told that they have to stay in isolation, they can't go to work, so they might not receive any money if they don't have benefits, and most of our persons don't have benefits of any kind. – PH-FW-11

> Most people aren't prepared to be [in] isolation two, three or four months without work so they run out of cash very quickly when you have to pay rent or mortgages or whatever. – PH-FW-9

> Some of them just have a need to have an income. We could probably write a book on the reasons why you find people not obeying the isolation but those are some of the factors for sure. A lot of them are single income earners – PH-FW-16

Financial stresses did not arise in interviews with participants from the mental health group; it is unclear as to why this is the case.

A third consequence related to isolation or observation, as described by both groups of participants, was that clients often feel a sense of punishment by being in isolation or observation even though that is not the intended purpose.

> Especially long term chronic psychiatric patients will see any form of isolation, seclusion, you know, isolation precaution measures as a sense of punishment or punitive measures against them thinking they've done something wrong and that they don't see it as a benefit and a need for their health…. 'I'm in seclusion, oh my God, this is exactly where they put me when the police brought me here.' So you could, very easily, have someone relapse for that reason, thinking 'My God, this is where they put me before, the police threw me in here' this sort of thing, so it's engaging with them and letting them know this is strictly for medical reasons. - MH-FW-14

> They had escaped North Korea and unfortunately it was, it was a woman, she was the case and her husband, her husband was here, they had a baby and she ended up in the hospital and because she was infectious she couldn't leave, but I think they took that as, that she was imprisoned and they ended up just disappearing. – PH-FW-11

> We don't want to be seen also as punishing patients, because restraint could be construed as a punishment, even though we don't mean it that way – if you're on the receiving end [you might think] 'I just acted out and you locked me up.' – MH-DM-4

Stigma related to being in isolation was another consequence of restricting liberty. In particular, there was the stigma or potential stigma associated to being demarcated as different and potentially dangerous because of TB, both in a mental health centre and in the community.

> As far as Infection Control goes, you have to have like a sign kind of outside saying these are the precautions in this room, so another person could walk by and their fear, they don't know, especially when you're dealing with paranoid patients, some people are extremely paranoid and they see that someone's in a room, that there's isolation, so they may, you know, make comments to the other patient that's in isolation. – MH-FW-6

> With this particular case, it was mostly isolation and the fact that she's being isolated pretty much from the rest of the world and if she did want to go into the rest of the world, she would have to take precautions that would kind of, you know, wearing a mask which would kind of, it would draw attention from other people. – PH-FW-1

Finally, there may be occasions where a client refuses to abide by a restrictive measure. This was particularly the case with medication adherence in a psychiatric setting. The participants in the mental health group stated that if a person with SPMI is unwilling to voluntarily swallow their medications, and they were either placed on a community treatment order or involuntarily committed to the unit, then clients would be physically forced to take their medications.

> Sometimes if we have a patient who is non-compliant, like who doesn't want to take medications, sometimes we do what's called a depot injection; it's an

> injection of an anti-psychotic and it's usually given anywhere from two times a month. – MH-FW-6

> Okay, if the patient is unwilling to have psychiatric medication they apply for a treatment order, but the patient stays in the unit maybe for one or two months until they get the order. Once they get the order, the patient has to take the medication. They get the security guards, they do chemical restraints or physical restraints and they inject him, usually because they refuse to take oral medication. They give him mostly injections because there's one injection every two weeks or so and they get it [the psychiatric illness?] out of their head. When they improve, they agree to take the [oral] medication, usually. – MH-FW-8

Moreover, even in those cases when force was not used, participants suggested that persons with SPMI might be pressured to accept treatment.

> We always said that if we ever went into the General Hospital, like nurses who have been in this for a hundred million years, if we went into the General Hospital, we'd probably be fired because of how we can direct, and you know, there's a very fine line between firm redirection and verbal abuse and you have to have that, you need to have that in check. – MH-FW-14

Although not as prominent an issue as for participants in the mental health group, participants in the TB group also discussed how and whether to force those who refuse to take antitubercular medication or abide by isolation orders.

> You just have to be quite firm and let them know 'I appreciate how you're feeling, I would be feeling the same way but when you have TB in Toronto and you have this and this as part of your life, you're going to be visited by me every day because I want to be sure that you're taking your medicine because I know it's hard for you to remember to do it yourself'…. If they are resistant to the idea of meeting every day and so on, I just have to say 'I realize it is an imposition but you tell me what time is good for you. We can make this as short or as long as you like, but I will be coming in and I will watch you take your medication and I will observe you for side effects.' – PH-FW-10

> Because if they don't get treated, they'll be formed, like let's say a person's refusing to get the TB treatment, they get formed and they get it, whether they like it or not, they're going to get treated. – PH-FW-1

> At the end of the day, it's hard to mandate treatment on someone, like it's hard to force treatment on someone, like the [section] 35 you're mandated, you have to take treatment and you have to be isolated. The logistics of forcing treatment on

> someone though are you know, you'd have to physically restrain them daily and you know, give them their daily dose of medication or whether through and NG tube or IV, whatever you need, and the risks involved in doing that to the patient and to the staff and the trauma that that might create for someone, or potentially create for someone. – PH-FW-13

It seems that for participants in the TB group, it is unclear the extent to which TB treatment can be forced upon a client despite the permission to do under the *Health Protection and Promotion Act* in Ontario.

C. Discussions of Liberty, Control, and Choice

Throughout the interviews, participants from both groups discussed or mentioned 'autonomy', 'rights', 'freedom' and 'liberty' when discussing isolation and DOT in relation to TB, or observation and medication adherence in relation to SPMI; although the participants used these words, they did not define what they meant by them. However, participants discussed at length the concept of 'control' (or 'being in control') and 'choice'.

Some participants noted that despite having public health orders for isolation, in reality, the healthcare worker cannot be with the client at all times in a community setting. As such, *the client needs to choose* to remain in isolation and, as one participant (PH-FW-16) characterized the situation, the "will" to abide by the isolation order.

> Well, there's not much we can do. We do say you are welcome to spend some time in the TV room with the family, but the mask is required. So sometimes they make their own personal choices. Some people are not interested at all in masking properly so they would rather stay separate…. Well, it requires the patient has to be, have their own will to do it, because as I said, we're only there for the 15 minutes, so they have to have their own drive to want to protect others. – PH-FW-16

> You do have the right to eat there, I'm not saying you don't because this is a democracy and we do live in a country of freedom and of choice but I'm asking you to make the choice. I can tell you this and if I go out the door and you choose not to do it, these are the risks that are run for the rest of the people in

> your home so that needs to be your choice in the end but under my policies I'm required to advise you. – PH-FW-9

Some participants claimed that being in isolation for TB severely limited or restricted the client's choices. One participant, PH-FW-10, noted that it is not necessarily the isolation order that restricts the liberty of a client, but rather the presence of TB in the context of homelessness; thus, perhaps, an inference can be drawn that the material conditions prior to TB can affect the manner in which the client experiences the public health isolation order.[13]

> All of a sudden you have a person who's working, a person who is functioning normally, like, normally, going to work, going to school, going about their daily lives and all of a sudden they get diagnosed with TB and they get put in isolation and all of a sudden they're stripped off, you can't go here, you can't go there, you can't do this, this, this and this. So all of a sudden is that kind of sudden change from doing all of these things, now all of a sudden you can't go to work, you can't go to school, you can't really be involved into activities that you have been involved with prior to the diagnosis - PH-FW-1

> There's no shelter that you would be able to isolate somebody. I mean that would just be crazy putting somebody infectious into a shelter. Yeah, it's limited, the options of where they can go. – PH-FW-10

> If you're in _________, the choice is minimal because the medication is supervised and some of them are actually in the lock down unit there, like with police supervision, so the choices are down the drain, there is actually no choices except for the meal plan, like that's about it. – PH-FW-16

Despite the restrictions on choice, some participants note that 'less choice' is not the equivalent of 'no choice', i.e., that perhaps liberty exists along a continuum or range rather than functioning in a zero-sum manner. While some rights or liberties are restricted or curtailed, some are maintained even in times of isolation or observation.

> Yeah, that's a hard one because you know you have to keep them in isolation while they have the rights to have all the basic needs [met]. So I think when you first go in there you have to tell them that they're isolated and what that means, what's the scope of isolation, but at the same time we want you to eat, to still

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[13] This theme of the affects of material conditions on the experience of isolation is discussed in greater detail above in section *B.ii. Material condition*.

> have the freedoms that you had but you can't really go out and be with people, you have to stay inside. – PH-FW-19

Finally, participants differed about the extent to which a client has the choice to harm him or herself. Some participants stated that as along as the public is safe, the client has the choice to commit actions that could be harmful toward him or herself, while others seemed to hold the opposite sentiment.

> People refuse life saving treatment every day. Here's this treatment and it could save your life and people choose not to do it and they're allowed to make that choice, you know, that's fine. The difference with this is that by making this choice they put others at risk, so if they're in a place where they can be properly isolated, and not going to put the community at risk, then yes, they're allowed to make that choice about their own health. – PH-FW-13

> All you can do with people who have the tendency to want to harm themselves is give them, you know, let them know what the risks are with whatever they're doing. – PH-FW-10

> Always going back and making people aware of what their rights are in a scenario and stuff like that, that they do have rights, they have the right to refuse the medication, if they choose, but they'll end up at _______. You kind of paint the – they're limited rights but they're still choices and involving them, I think in those scenarios. – PH-DM-2

> Again, I can only speak for myself with 20 years, if it's [observation] necessary, it's necessary. I'd sooner see somebody put on a closer observation for a shorter period of time then to see somebody going through you know, a ream of medication that are not helping them and staying in that [psychotic] state for a longer period of time. – MH-FW-14

Notable by its absence, participants in the mental health group did not tend to speak of 'choices'; rather, those in the mental health group often spoke of a client's 'control' or lack thereof (although discussions of control were not limited only to those participants in the mental health group). Participants described how clients will, in times of liberty restrictions, try to establish control or alternatively, are encouraged to establish control as a mechanism for coping with their limited liberty.

> [Persons] go off their meds and part of it is yes, the symptoms associated with it sometimes and other times, it's like, 'I'm in control of my life now, they can't tell me what to do'. – MH-FW-14

> I try to stress to them that they're in this situation, they've got TB, they have to take this medication but the medication is going to do it's job but they have a big responsibility in their recovery too and that is to try to eat well, to get rest and to get exercise and that will help them get stronger quicker. When you get a disease, you feel like you have no control so you have to remind them: they do have some control, they have a lot of control. – PH-FW-10

One participant spoke of his or her control *as a healthcare worker*, in particular, the limited amount of control that he or she may have on a person in a community setting.

> When they're discharged, you have no control, you know, and even if you hook them up with an outpatient program, the program may only see them once a week and so a person goes to their own home, they can choose not to, or they can report that they're taking medication and not. – MH-FW-4

One might draw a conceptual link between a healthcare worker's sense of 'loss of control' and their discussions of persons having to choose to obey public health or mental health orders in a community setting (as described above). It appears that participants hold that in a community setting, their control as healthcare workers is dependant upon the choices made by clients. Given this tension, one participant went so far as to describe the need to limit the choices of persons with TB because he or she has as a healthcare worker a non-delegable obligation to protect the public.

> I think it would be difficult to give to any person, whether compliant or not, to give them that option of taking meds on their own, but that's personally me because I like to, I mean, it's your, the way I think it is, is this is my job and my license is on the line. – PH-FW-1

Despite some participants describing their lack of control as healthcare workers in a community setting, other participants described the manner in which they had the power to reduce the restrictions on a client's liberty, thereby bestowing or returning some control onto the client. Stated differently, some participants described their power, or being in position, to

'give back' some amount of control to clients by virtue of their position as healthcare workers.

> The other thing too is involving people in those choices and a really good example of that would have been that nursing mom, where from the time she was in hospital that we involved her in the care and let her make decisions. As much as possible, as sick as she was, she called and she set up those appointments. We gave her some control back. We could have done it all, but as much as possible, we tried to give her power back over those children, over the care. – PH-DM-2

> We will give them a set [of medication] for the whole week and then they take it themselves and they'll call in so you give a little bit more trust to the person and, that relationship, also by the time they're, you know, three or four months roll out, you have some, you form a relationship with your person and you kind of get to know them a bit better, even on a personal note and so then you give them a little bit back, they're in control, they'll call you daily and say 'I took my medication'. – PH-FW-1

Finally, some participants claimed that, for all the limitations, perceived or real, on the liberty of a client, the client still had an ability to advocate and enforce his or her rights and liberties. This ability of the person with TB or SPMI to uphold certain (unnamed and unidentified) rights or liberties was described by participants in what may be interpreted as antagonistic toward healthcare workers (perhaps bringing again into relief the tension between the control of the healthcare worker and the choices of clients).

> And I guess because with increased consumerism now, we're seeing persons that come in because they have access to the internet, they're exposed to much more than even we were, you know, ten years ago. They're asking more questions and they're challenging more, so that it behooves us to make sure that we're on top of rights, responsibilities and you know that people always threaten to sue. – MH-DM-4

> It happens where, sometimes if a patient is, if we're not letting them out on ground privileges because there's no order, sometimes they'll just say, that's it, I'm leaving, I want to go home, I don't want to stay here. But, if they're, how do I word this? If their behaviour is presenting as though they're really not, they probably shouldn't go out, it still becomes sticky – do you understand what I'm saying? Because they are here voluntarily, like, they could easily, if we kept them in, you know, they could call the patient advocate and stuff like that. – MH-FW-7

D. The Individual's Liberty and the Public's Health

During the interviews, participants were explicitly asked how to balance the rights and liberties of individuals in isolation or observation with the health and well being of the public. All the participants concurred that the protection of the public's health trumped the liberties of the clients; no participant erred on the side of protecting the liberty of the client when there existed a potential harm to the broader population. Of greater interest, perhaps, is the manner and kinds of responses given when asked how liberty and safety should be balanced.

A few participants believed that it was 'clear' or 'obvious' that the public's safety trumps any liberties of the individual with TB or SPMI.

> I've always been a social liberal, all my life. However, I am a real right wing person when it comes to losing your rights when you're sick, when you can pose a public health risk. – PH-DM-15

> I: How do you balance the need to protect the community at large from being infected with TB with the needs of the actual tuberculosis patients as they go about their daily lives?
> R: Well, you don't have to balance it. If a person is infectious, you have to make sure that they are not putting anybody at risk including me right, that's a given so there's no, that can't be loose. As soon as they're no longer infectious, they can go back to their life and they can do what they want but while they're infectious, I'm sorry this is the way it has to be. – PH-FW-10

In addition, some participants espoused what may be characterized as a simplistic utilitarian calculus, whereby the good of the many, i.e., the public's health, should be ensured even at a cost to the individual, i.e., the liberty of the person.

> In keeping persons in isolation, that is protecting the public and if I felt that a person was breaking isolation and endangering other people, then I certainly would go forward to take the necessary steps to ensure that that wouldn't happen again – so like a section [s. 22 or 35 of the *Health Protection and Promotion*

> *Act*]. So you know, I certainly wouldn't turn a blind eye if somebody was breaking isolation…. In protecting the public you often, unfortunately you know, create suffering for your person. – PH-FW-11

> Somebody did have chicken pox; we had to isolate that person. The person was not allowed to move around and really because it was felt that it was too high risk in the general population. We just did not know which other patients were already immune, we were concerned about pregnant women, etc. So then it became the needs of the larger group rather than the individual. – MH-DM-5

> So are you risking, it's a greater loss if you have now ten people with TB or one person with TB. To me, it's always, I would probably lean on the side of protecting the health of the public, rather than the few rights of the individual…. If it was up to me I would have 24/7 surveillance, you know what I mean, but that's me, to ensure that nobody else gets sick, and potentially that way, because how other people are getting sick is by being in contact with someone who has TB. – PH-FW-1

Other participants, though still concluding that the safety of the public is paramount, did try to explain or give examples on the nuances of balancing the liberty of clients while protecting the public.

> But what ended up happening is because of that [a person with an infectious disease in a mental health centre] we had to shut down a part of the unit so there were no admissions there. It ended up kind of like there was an area of the unit that could be shut off so other people wouldn't be exposed to the infection but it ended up being a compromise in that a couple of other beds were closed down as a result of that to give her the space. So there's an example where in order to meet her needs, you know and to protect the rest of the people on the unit, she was given more space to wander but in the whole it means fewer people can be admitted there in general. It's actually closing off a couple of beds. So it's that dilemma around the resources and where do you put them and dealing with her quality of life, dealing with the resource issue, protecting the other people, you have to balance it all. I mean the only other option would have been to keep her in one little single room, which would have been really cruel I think for someone like her. I don't know that she could have understood that. – MH-DM-5

> You have to assess what their [persons'] needs are and try to assist them in being able to keep the isolation but at the same time not infect other people and being able to provide our service as far as DOTing, getting well and compliant again, but yeah, it's a very fine balance and I don't know if we're 100% at being able to do all that. Yeah, we try and that's the best I think we can say we do, you know, but it's a hard one. It's a hard one because here in Canada we do have a lot of different rights and whatever and freedom and people think they should have that

> and they should, but when it comes to protecting the public from an infectious disease, especially as one as serious as TB and you know, or others [like] SARS there, you have to follow the rules. – PH-FW-19

Both of these participants, MH-DM-5 and PH-FW-19, seem to suggest that a greater amount of resources may lead to a better opportunity of being able to provide the client with a greater range of choices, including more physical space or services such as DOT. The idea that reducing the limitations on a person's liberty may, in part, turn on the amount of resources available revisits the idea of reciprocity found in section *B.iv. How to restrict liberty*; in particular, it was noted above that participants described the need for resources to adequately support those persons in isolation. Perhaps one can infer, since the connection was never explicitly drawn by participants, that the resources needed to support client under some understanding of the value of reciprocity is seen as a means of respecting or protecting the liberty of persons as best as possible while still trying to ensure the health and safety of the public.

Finally, some participants did not seem to answer or know how to answer the question of balancing the liberty of clients with the protection of the public, even when asked explicitly during the interview; one participant, in particular, claimed that he or she simply did not know how to properly strike the balance between the values.

> I: What are some of the considerations when you think about having to balance the protection of the public versus the needs of the individual?
> R: Okay, one would be how infectious the person was, how credible of a historian were they, like if they can give us the names and the times that they worked and stuff like that, so all that background history, in terms of also the risk factors, the risk factors in terms of the population they may have exposed –PH-DM-2

> I: How do you balance, and maybe it's quite easily balanced, but how do you balance the needs of the individual with TB versus the need to protect the public from transmission?

R: Well, I think that just working with the person, getting them started on their medications as quickly as possible, letting the person know you know, what's going on, you're going to probably have to stay here in the hotel two or three weeks, until we get those results back to indicate that your sputum is now smear negative. You know, the DOT worker is going to come and visit you. PH-FW-12

I: One of the things that you touched on was the need to protect the public so the public health aspect of it. How do you, in your opinion, how do you balance that?
R: I don't know. I don't know. I have, as I mentioned before, I have no experience at all with TB and I mean, again, like looking at this [the scenario of TB in a person with SPMI], it's, I don't know. I don't know how you would; I don't know. I'm sorry. I don't know how to answer that. – MH-FW-7

E. Balancing the Goals and Values of Public Health and Mental Health

In addition to balancing the liberty of persons with the safety and health of the public, participants described whether or how to balance the goals and values of public health and those of mental health in the care of persons with TB and SPMI. Most participants from both groups acknowledged that addressing the care needs of those with TB and SPMI would be difficult. In particular, most of the participants in the mental health group noted that although balancing the interactions between a given psychiatric condition, antipsychotics and antitubercular medications would not be difficult, it would be difficult to provide satisfactory *psychosocial* care for a client while in isolation. Psychosocial activities, i.e., non-medical activities the goals of which are often to help persons with SPMI integrate with other people within a mental healthcare centre or community, may be disrupted if the person with SPMI is under a public health isolation order for an extended period of time.

It's sad because you realize you're isolating this person from the rest of the therapeutic community. The staff are interacting with them wearing personal protective equipment which has got to be kind of alien who someone who is cognitively impaired. – MH-DM-5

Well, I mean, as far as the person in isolation for a communicable disease, I mean, it shouldn't actually stop staff from actually giving the routine care and

> treatment…. So I don't think there's actually, the treatment of TB, you know, actually hinders their medical treatment of the patient's psychiatric illness…. The other group activities, like when they have to maybe cook together or maybe playing together, then it will. – MH-FW-3

> To someone who is relatively stable and is looking towards discharge and is doing well, suddenly think boom, 'I'm in seclusion, oh my God, this is exactly where they put me when the police brought me here'. So you could, very easily, have someone relapse. – MH-FW-14

> Having him go in respiratory isolation, depending on how long it is, I mean, it could cause him to maybe feel depressed or you know, he's away from, maybe he won't feel as confident when he goes back out into the community. – MH-FW-6

> I just think that being segregated like that and isolated could have a great affect on, like I said, on his mental health. Yeah, we get people have to go in isolation for the flu and we see how it affects them and it's awful for them, it's really awful for them. They have to you know, stay in their own room, they have their own bathroom and they feel like all the other patients are looking at them funny and looking down on them and they feel like they're full of germs and also can cause even more paranoia with themselves or with the other patients. – MH-FW-7

Despite acknowledging the difficulty in balancing the need for isolation with psychosocial care, no participant from the mental health group stated that the client's psychosocial care should trump the public health measures taken to arrest the spread of TB. Moreover, some participants from the mental health group spoke as if it were a given that the public health measures override psychosocial care, e.g., "But we certainly can't have the risk that it's [TB] going to, that these things [infectious diseases] are going to spread" – MH-DM-5.

Although some participants in the TB group also acknowledged that providing psychosocial care might be difficult while a client is in isolation for TB, many of these participants spoke at greater length about how the presence of a psychiatric illness may interfere with TB treatment, including adherence to isolation orders or medication regimens.

> I remember, we had one memorable psychotic patient years ago had fixed delusions about colours of pills. That was very, very tricky from a TB point of

> view because what she was wanting to do was take some of the TB meds but not others because of these fixed delusions that she was having. That's an example of a situation where her psychiatric condition was materially interfering with her safe TB treatment. – PH-DM-20

> It doesn't matter whether they have a diagnosed mental health illness or stuff like that, or not. I mean, that compounds the situation; you're looking at more issues around compliance and medication and is somebody's thought process rationale to begin with so that you can ration and reason, or if somebody is irrational, and already paranoid about taking stuff, it would make it much more complicated in terms of providing care, right? – PH-DM-2

> I've had people that some days they totally understand it when they're good and then some days when they're you know, not well and they don't understand it at all. They didn't even remember that they had TB, so there's such a scope that you know, as a spectrum that you're going from, it depends on that day sometimes with some people, so I don't know, it depends on where they are that day, whether they're understanding that they are sick and they have to take their pills, to other days when they're not sick at all and could care less whether they take the pills. – PH-FW-19

Participants from the public health group added that in persons with SPMI, TB is often not their primary concern since they often have to address other co-morbidities, including the psychiatric condition itself; as such, persons with TB and SPMI need to be treated holistically, i.e., a TB healthcare worker cannot merely treat the TB without treating the larger co-morbidities that may affect TB treatment adherence.

> Quite often, maybe they're [persons with SPMI] not on their psyche meds for example, or something like that. They're top priority isn't making sure they're seeing their DOT worker, their GP for treatment, right? Because they're dealing with other things. – PH-DM-12

> They may or may not, to greater or lesser degrees feel themselves [persons with SPMI] that TB is a serious problem in their lives but it's very rare that you can parachute in, deal with the TB and parachute out. You generally got to tackle TB cases in this situation as a package deal. Where someone who is very high functioning, you know, they'll generally be able to fit TB into the rest of their life, you play a minor supporting role and get them through treatment, but they are managing everything else. For people in that extreme situation, basically if you want them to be able to get through TB treatments safely you often have to deal with a lot of their barriers, which have nothing to do with TB and which are still going to exist after the TB has come and gone. – PH-DM-20

Finally, one participant made the following observation: that persons who are placed under s. 35 of the *Health Protection and Promotion Act* for failing to comply with treatment are generally persons who suffer from SPMI.

> Well the section 35's, they all have issues. So they have, they might be bipolar or schizophrenic, usually with an alcohol addiction as well. Sometimes they come from a jail setting. And they refuse any kind of psychiatric help. So who knows? Like they refused treatment initially till they get so sick that the disease has progressed a lot, until they finally agree [to treatment]. They refuse blood work, chest x-rays, fake the medication [intake]. So basically sitting in the room with a guard and just not accepting of treatment. Not accepting mental health help. And then after three months, they see themselves getting weaker, weaker, then the one person did accept treatment. – PH-FW-18

Given that s. 35 is arguably one of the most liberty restricting powers in Ontario (certainly in relation to health), it is important to note, in participant PH-FW-18's opinion, the characteristics of those persons who are subject to this section. An unanswered question remains about the general psychiatric makeup of those persons subject to s. 35 of *the Health Protection and Promotion Act* (or other similar provincial laws), what are the external circumstances that have led to the need to rely on law to enforce TB treatment, and perhaps what could be done to avoid having to resort to such measures.

F. Participants' Emotional Responses to Liberty Restrictions

Finally, some of the participants from both groups described their emotions toward liberty restrictions and those persons subject to restrictions. Although perhaps healthcare workers' emotional responses toward restrictions did not directly affect how they undertook their jobs vis-à-vis TB or mental health, it does seem to colour the participants' views on isolation, DOT, observation, and medication adherence. Participants often described the need to treat clients with respect and acknowledge the clients' sense of loss. Participants

most often described the empathy they felt toward persons with TB or SPMI whose liberty must be restricted for the good of self or others.

> I mean, every type of isolation, to me, I mean, should be considered an unfortunate situation. – MH-FW-3

> I think listening and understanding, just letting them know that you understand the issues, you definitely understand that it's a horrible position to be in, helps a little bit. – PH-FW-11

> Well no one particularly enjoys having to have someone be in restraints or seclusion or anything like that – MH-FW-6

> I have served orders, it's really tough. It's really easy when you work in government and you write the legislation. It's another thing when you're a police officer and you see the person being taken away and the children being taken away by Children's Aid because there's no one to look after them. Those are tougher. The reality is tough. You try to do it with heart. – PH-DM-15

> I do value people greatly and I do respect people greatly so I think that that comes through as well. It's not because I need to serve a purpose with them, like I'm not there because you know, 'Oh yeah, I'll be kind because I need to', it's, I really do want to know what's going on and if something is going on, I want to know, I do care, so I think that that empathy actually also helps to create a relationship of trust. – PH-FW-13

G. Conclusion

Participants from both the mental health and TB groups described various considerations regarding harm and liberty restrictions through discussions surrounding isolation, DOT, observation and restrains, and medication adherence. Overall, the participants seem to hold that protecting the safety and well being of the general public is more important that protecting the liberty of persons with TB or SPMI; however, it is clear that the need to restrict the various liberties of clients is not undertaken lightly by healthcare workers, at least not according to the participants. Participants provided a rich description of the reality and context surrounding restricting liberty on the basis of harm to self or others in

relation to TB and SPMI; most notably, participants argued that there was a need to support those clients that suffered through restrictions. The next chapter presents a comparison of the data from both the survey and the interviews in relation to the empirical literature on TB and persons with SPMI and the theoretical literature on the harm principle.

Chapter Seven: Discussion and Conclusion

In order to answer the research questions as articulated in *Chapter Four: Methods and Methodology*, I will first describe the theory that motivated my interpretation of the results in this discussion chapter. Second, I will compare the survey results and interview results, one in light of the other. The results will then be compared with reference to the empirical literature on TB and SPMI, as well as the theoretical literature on liberty and the harm principle. Third, on the basis of the results, I will begin to consider and suggest some generalizations and areas of future research in public health and mental health. I end with a discussion of the limitations of this study and some concluding remarks, including some policy and practice recommendations. The goal of this chapter is to provide answers to the study questions posed at the beginning of this thesis, namely, how do healthcare workers and decision makers in TB and mental health care conceptualize liberty, harm, and the harm principle and how can this inform public health and mental health more broadly.

A. The Relation Between the Results and Normative Theory

A theoretical and methodological question must be answered before analyzing the results relative to the political theory presented in *Chapter Two: Theoretical Background – Liberty and the Harm Principle*: what is the relationship between the views of participants on liberty, harm, and the harm principle and the theorists' understanding of liberty, harm, and the harm principle? Why should it matter if there are agreements or disagreements between the two groups, i.e., healthcare workers and theorists? One can give practical or instrumental reasons why it is important to solicit the opinions of non-theorists in matters of political philosophy. For example, some studies suggests that including members of the general

public in healthcare decision making processes can improve the quality of the policy decisions (Secko DM et al. ; Cox SM, Kazubowski-Houston M, and Nisker J ; Perhac R). Moreover, there may be democratic reasons to solicit the public's input into healthcare decision making, namely that it may help legitimize the decisions (Daniels N and Sabin J).

I would like to propose and briefly defend an epistemological reason why there may be a political imperative to try and understand the perspective of non-theorists in the politics and policy of public health and mental health. There has been much written about value pluralism in political philosophy, i.e., the idea that different people from different social, cultural, and racial groups will espouse different, often incompatible, values. Western political philosophy has, to a large extent, centered on understanding what follows from this supposed truism, including developing competing arguments as to what kinds of reasons should matter in public debates (Rawls) or arguing that some values are, indeed, shared by all human beings and can serve as a foundation to developing shared political values (Raz J ; Powers and Faden). There may be, however, reasons to believe that there exists *experience pluralism* among human beings, i.e., every person will have different life experiences that will shape his or her values, including political values. The nascent idea of experience pluralism stems from Iris Marion Young's argument against the political conclusions of (a) being impartial to life experiences (e.g., Rawls' 'veil of ignorance', a thought experiment whereby persons decide what is politically valuable without knowing what is their actual social positions) and (b) 'reversing positions' (i.e., the idea that it is politically expedient in a free and egalitarian society for agents to consider the potential consequences of decisions from the viewpoint of other agents). For Young, it is not only impossible to disassociate

oneself from one's experiences, but it is also dangerous to believe that one can ever know what it is like to be another person. Young writes:

> Who we are is constituted to a considerable extent by the relations in which we stand to others, along with our past experience of our relations with others. Thus the standpoint of each of us in a particular situation is partly a result of our experience of the other people's perspective on us. It is hard to see how any of us could suspend our perspective mediated by our relations to other, in order to adopt their perspectives mediated by their relations to us. The infinity of the dialectical process of selves in relation to others both makes it impossible to suspend our own positioning and leaves an excess of experiences when I try to put myself in the other person's place (Young).

For example, I, Diego Silva, as a 29-year-old white Canadian male of Uruguayan heritage living in Toronto in 2012, have a certain set of experiences that are unique to me and me alone. Moreover, my experiences have been, and continue to be constructed, relative to my interactions with my environment and with other people with their own experiences that are shaped by their relationships with their environments and interactions with others. For Young, it is impossible to suspend one's experiences in order to either adopt an impartial position or to try to reverse positions with others for any purpose, including trying to establish common political values.

The political repercussions of taking seriously the plurality of human experiences cannot be evaluated here. Although experience pluralism may seem, perhaps, a simple or even simplistic truism, assuming that it is true, many questions arise, perhaps most importantly, what does it mean for collaboration and cooperation between individuals in the political sphere? For the purposes of this thesis, one might argue that taking seriously experience pluralism means that political theory that ignores the experiences of non-theorists risks making inappropriate assumptions about the reality of how theory is applied. More concretely, any notion of liberty, harm, and the harm principle ought to be informed by the

experiences of those healthcare workers, including those working in TB care and mental health care, since Mill, Feinberg, Raz, and Kant will not have had the experiences of those healthcare workers. The different versions and counters to the harm principle provide a preliminary justification for legislators and policy makers in addressing important challenges related to the treatment of TB and SPMI, but the application of the harm principle must also be informed by the realities of those who must execute the laws and policies and those who are subject to the laws and policies grounded in the harm principle (i.e., the TB patients and persons with SPMI). This study ventured to begin to understand the viewpoints of some of those people who are responsible for executing policy and legislation grounded in the harm principle in Ontario.

Finally, assuming that for whatever reasons, one takes seriously the role of empiricism in answering political questions and challenges, one might approach an analysis of results in either a descriptive or prescriptive manner; the former tries to answer the question 'How can one understand group *x's* perspective relative to theory *y*?', while the latter tries to answer the question 'From the perspective of theory *y*, what needs changing in the perspective of group *x*?' I will try to only provide a descriptive analysis of the repercussions between the results and theory, and venture to give prescriptions only in places where I feel there are clear conclusions that are defensible by arguments from both the perspective of theory and the study's results.

B. Comparing the Survey and Interview Results

i. Comparing the results: A mixed-methods study is intended, in part, to use different forms of data in order to best answer a given research question. Qualitative data from semi-

structured interviews allows for more in-depth analysis of a topic that is often context-dependent; however, the researcher may be limited in his or her ability to generalize the findings given the small numbers of interviewees. Quantitative surveys most often capture data from a larger number of participants and the data, depending on the research design, are more likely to be generalizable. However, the quantification of beliefs and ideas can fail to capture nuance and depth on particular topics or themes (Creswell and Plano Clark 2007).

For the purposes of comparing across the qualitative and quantitative results of this study, the six scales and three non-factored questions described in the survey results section served to anchor the comparison with the themes that emanated from the semi-structured interviews. Although all the scales and non-factored questions are used in this comparison, not all the themes from the interviews could be compared to the survey, i.e., there were more themes than there were types of questions in the survey. Possible reasons for the discrepancy include that one can derive a greater amount of information from interviews than surveys; one can also explore new themes that emerge, as they emerge, unlike in a survey. Moreover, given that this survey was distributed via email to professionals with limited free time within organization, the survey needed to be brief in order to gain approval from the partner organizations, as well as to maximize the response rate and completion rate. Finally, while the bulk of the survey items were designed to understand the perspective of respondents vis-à-vis the concept of harm and the harm principle, the interviews provided enough time to look more in depth to the how the participants in mental health and TB care conceptualize liberty and the context surrounding restrictions on liberty.

Tables 7.1 and 7.2 provide a starting point for the comparisons of the survey and interview results. First, Table 7.1 provides a definition and explanation of the various scales

and non-factored survey items; the information in Table 7.1 is described in greater detail in *Chapter Five: Results – Online Survey*.

Table 7.1: Definition of Scales and Other Survey Items
DOT (Directly Observed Therapy) – The greater the score, the more likely the respondent will answer that DOT is necessary for TB treatment.
Risk – The greater the score, the more likely the respondent will answer that it is okay to interfere in the life of x if x poses a risk of harm to community.
Public Health (PH) Orders – The greater the score, the more likely the respondent will answer that public health orders must be obeyed despite the consequences to the individual.
Harm to Others – The greater the score, the more likely that the respondent will answer that an individual cannot harm others.
Harm to Self – The greater the score, the more likely that the respondent will answer that an individual cannot self-harm.
Kant – The greater the score, the more likely the respondent will answer such that what is "wrong" is a separate and distinct idea from "harm".
Force Medications – "If he does not voluntarily comply with tuberculosis drug treatment, he should be physically forced to take antitubercular medications" (Questions 4 and 8).
Why Stop Harm to Self or Others – Reason respondent believes that spread of TB should be stopped (Question 9); Reason participant believes that a person with schizophrenia should take meds and receive psychosocial support (Question 10).
Percentage of Acceptable Risk of Harm – "If there is a _____ chance that an individual's action may accidentally harm another person, then that action should not be allowed" (Question 16).

Second, Table 7.2 provides a comparison between the two data sets. Four points of clarification on how to read the table: first, 'MHP' refers to 'mental healthcare worker participant'; 'TBP' refers to 'tuberculosis worker participant'; and 'FHP' refers to 'family health program worker participant'. Second, the first vertical column on the far left of the

table represent the six scales and non-factored questions re-described in Table 7.2, while the top row refers to the themes emanating from the interviews that either cohere or differ from the survey scales. Third, within each cell, the first bullets refer to data from the interviews; the subsequent bullets refer to data from the survey. For example, in the first cell 'DOT-Goal of Care/Treatment', the sentence "TBP [TB participant]: DOT to help client with side-effects of TB drugs" is derived from the interviews, while "TBP/MHP [Mental Health participant] v FHP [Family Health participant], p=.000; TBP v MHP, p=.000" refers to data from the survey (meaning that there was a statistically significant difference between the survey respondents of those groups in the DOT scale, as articulated in *Chapter Five: Results – Online Survey*). Finally, a blank cell signifies that there was neither an accordance nor discordance between the scales and the themes.

Table 7.2: Comparing the Qualitative and Quantitative Results

	Theme and Sub-themes from Interviews							
Scales from Online Survey	Goal of Care/ Treatment	Why Restrict Liberty	Concept of Harm	Assumption: Risk of Harming Others	Assumption: Default to Law	The Need to Use Force	Individual Liberty vs. Public's Health	Values of Public Health vs. Mental Health
DOT	- TBP: DOT to help clients with side-effects of TB drugs - TBP/MHP v. FHP, p=.000 - TBP v. MHP, p=.000							
Risk				- The greater exposure to risk of harm x, the lessening that x will be viewed as 'grave' risk - TBP think SPMI 'risky'; MHP think TB 'risky' - TBP v. MHP, p=.041				
Public Health Orders					- To uphold PH & MH law and policy - TBP/MHP v. FHP, p=.000			
Harm to Self	- MHP: protecting client from self-harm - No statistically significant	- To protect client from self-harm - No statistically significant						

	difference b/w groups	difference b/w groups						
Harm to Others	- TBP: Isolation to protect others from infection - No statistically significant difference b/w groups	- To protect others from harm - No statistically significant difference b/w groups					- The public's health & safety trumps individual liberty - No statistically significant difference b/w groups	
Kant	- MHP: reestablishing independence of clients - TBP v. MHP, p=.011							- MHP: Must maintain psychosocial care, the goal of which is reestablishing independence of clients - TBP v. MHP, p=.011
Other Items								
Force Medications						- MHP: okay to use force as last resort - TBP: unclear whether one can force TB meds - Bimodal distribution within groups as to whether to force meds		
Why Stop Harm to Self			- Harm as primarily					

or Others			physical - 76% of participants 'TB physically harms' - 48% of participants 'Schizophrenia interferes with ability to provide for oneself' - 40% 'Schizophrenia reduces future options'					
Percentage of Acceptable Risk of Harm				- The greater exposure to risk of harm x, the lessening that x will be viewed as 'grave' risk - TBP= SPMI 'risky'; MHP= TB 'risky' - 52.7% of participants agreed that 20% chance of harm to others warrants prohibition of act				

MHP= 'mental healthcare worker participant'
TBP= 'tuberculosis worker participant'
FHP= 'family health worker participant'

ii. Participants' understanding of harm: To begin, it seems that harm to self or others justifies interference from the perspective of both the interviewees and the survey respondents. As one participant from the TB group noted, "[w]e basically deal with compliance, making sure they take their medications for tuberculosis so that they don't infect other people" (PH-FW-19); a similar kind of response was evident from the mental health group participants: "[i]f it's a psychiatric problem because you know, you've already tried to hit a number of other patients and so to keep you safe and the other patients safe, we need to seclude you in this room" (MH-DM-4). The participants interviewed in both the TB and mental health groups often seem to equate harm with physical harm, i.e., harm as "violence", "aggression", or "not exposing others" to TB. Moreover, the mean scores for the harm to self scale (TB, M=14.82; Mental health, M=14.00) and the harm to others scale (TB, M=17.45; Mental health, M=18.10) reveal a potentially similar disposition to using physical harm to self or others as a justification for restrictions on liberty from the perspective of both TB and mental health workers. This view of harm as a physical threat that justifies limitations of liberty is also present in some of the literature surrounding TB care and mental health treatment, e.g., s.20(5) of the *Mental Health Act* 'harm' is described as "physical harm".

However, there exists reason to believe that participants in both the survey and interviews had at least some conceptualization of harm beyond that of harm as merely physical. In the survey, when respondents were asked what kind of reason they felt best described their justification for preventing the spread of TB, 76% answered because 'TB physically harms a person'. In contrast, when respondents were asked why a person should take their antipsychotic medications and receive psychosocial support, approximately 48%

answered that 'Untreated schizophrenia interferes with a person's ability to provide for him or herself' while approximately 40% responded that 'Untreated schizophrenia reduces a person's future life options or opportunities'. This result seems to suggest that respondents differed regarding their understanding of TB as a kind of harm (i.e., physical harm) versus schizophrenia as a kind of harm (i.e., interference with ability to care for oneself and reducing future options). One may tentatively interpret these results to indicate that the kind of harm may differ depending on the type of disease; a question remains, however, whether this logic can be extended beyond discussions of the harmfulness of diseases. The interviews suggest that harm may also mean something more than merely physical harm for the participants. For example, the mental health participants discussed the psychological harm that might occur if a client is left in observation or restraints too long, or the emotional toll of being in isolation for a respiratory infection rather than due to aggressive actions caused by a psychiatric illness (i.e., the sense of feeling punished for doing nothing wrong). The participants in the TB group discussed at length about the negative consequences that arise from being in respiratory isolation (e.g., not being able to work and care for one's family or the stigma associated to being in isolation for TB). However, despite the participants discussing the negative aspects of having and being treated for TB or an SPMI, one cannot firmly conclude that the participants would classify such negatives aspects as 'harm'. At most, there is reason to believe that the survey respondents and the interview participants potentially conceptualized harm as something beyond merely physical harm, which would be in keeping with the nuanced notions of harm as articulated by Mill, Feinberg, and Raz.

In addition to implicit or explicit articulations of what is harm, the results also revealed the participants' understanding of *risk* of harm to self or others. From the

interviews, one TB group participant and one from the mental health group noted that what is considered 'risky' may depend on whether one is accustomed to working with persons with SPMI or persons with TB; therefore, those working in TB may find working with persons with SPMI as 'risky' or posing a risk of harm to others, while those who work primarily in mental health will view infectious diseases, such as TB, as posing a risk of harm due to their unfamiliarity with different infectious diseases. Other TB interview participants also noted that the general public, who do not often encounter persons with TB, might overreact when confronted with TB during contact tracing. The risk scale from the survey seems to corroborate the findings from the interviews. When respondents were asked whether they considered the character in the vignettes with TB and TB/schizophrenia, a risk to transmit TB to the rest of the community, respondents from the mental health group were more likely agree than those in the TB group (TB, M=10.88; mental health, M=14.60, p=.041). In addition to considering the evaluation of risk of harm from the different professional perspectives (TB v. mental health) and a professional as opposed to a member of the public, there are also legal interpretations of risk of harm. For example, it was the judge's evaluation of the risk of harm to the general public posed by Mr. McKay's TB infection that lead the judge to uphold the application of s.35 of the *Health Protection and Promotion Act* relative to Mr. McKay (Toronto (City) Associate Medical Officer of Health v. McKay). In the case of Mr. McKay, the judge provided a legal interpretation of risk of harm as the probability of *x* occurring and the gravity of *x*; the conclusion was that Mr. McKay's XDR-TB posed a sufficiently grave threat to the community and that it was at highly probable that Mr. McKay would not comply with the isolation order. The judge's decision was based on all the evidence presented in the trial; presumably the evidence as to the gravity of Mr.

McKay's TB was put forth by public health experts, which raises the question of what counts as evidence of risk and the use of science to help adjudicate risk of harm in law. As one participant from the TB group noted: "[w]e'll get these smear results back and the smears will be negative and then in fact, the culture comes back positive; the person really does have it, right?" (PH-DM-12).

iii. Participants' understanding of liberty: Although the survey did not ask questions that related to ideas of liberty directly, there may be indirect evidence as to the respondents' conceptions of liberty in the survey. Question 10 of the survey, which asks, "[w]hich of the following answers best describes the reason why persons with schizophrenia should take antipsychotic medication and receive psychosocial support" and where 48% respondents answered "[u]ntreated schizophrenia interferes with a person's ability to provide for him or herself" and 40% of respondents answered "[u]ntreated schizophrenia reduces a person's future life options or opportunities", may indicate that the respondents, across all three arms, might be amenable to Feinberg's and Raz's ideas about liberty. One might extrapolate from these answers and posit whether Feinberg's notion of interests to care for oneself or Raz's notion of autonomy as being constituted, in part, by one's options, might resonate with healthcare workers in TB and mental health.

The interviews, however, may give a better sense of what the participants' understanding of liberty or what liberty entails. Recall that participants rarely used the words 'liberty' or 'freedom' but rather discussed at length about choice(s) and control. The participants from the TB group spoke about the choices that persons with TB have and do not have while receiving antitubercular medications and while in isolation; in particular, the participants noted that the choices TB clients can make in their day-to-day lives are reduced

(e.g., "going to work, going to school, going about their daily lives and all of a sudden they get diagnosed with TB and … you can't go here, you can't go there" – PH-FW-1) but they still have some choices to make, including the choice to self-harm by not abiding by antitubercular drug regimens (e.g., "[a]ll you can do with people who have the tendency to want to harm themselves is give them, you know, let them know what the risks are with whatever they're doing" PH-FW-10). The participants from both the mental health and TB group also spoke about control, either being in control or lacking control as a client. The participants spoke about giving control back to clients (e.g., "[a]s much as possible, as sick as she was, she called and she set up those appointments. We gave her some control back." – PH-DM-2) and clients asserting control and their freedom (e.g., "[t]hey're [clients in mental health] asking more questions and they're challenging more, so that it behooves us to make sure that we're on top of rights" – MH-DM-4). It remains unclear what is the conceptual link, if one exists, between the notions of 'choice' and 'control' for the participants. Regardless, the language of 'choice' and 'control' resonates with different theoretical articulations of liberty. For example, the notion of being in control espoused by the participants may or may not be similar to Kant's idea of self-mastery as an expression of freedom, or perhaps the idea of choice and control is already present in Mill's three domains of liberty, namely, liberty of consciousness; tastes and pursuits; and assembly. Most explicitly, however, the participants' discussion of 'choice' and 'control' coincides with two of Raz's three conditions of autonomy, namely an "adequate range of options" (i.e., having a range of both important and trivial life choices) and "independence" (i.e., the ability to pursue one's choices).

The results from the survey and interviews suggest that the participants believe the following with respect to liberty and harm: first, participants conceptions of harm and liberty may be nuanced and may coincide with the various articulations of liberty, harm, and the harm principle found in the literature. This suggests that there may be differences in how various healthcare workers in public health and mental health interpret these values and moreover, how these differences may alter the application of the harm principle in practice. Second, in future research, it would likely be beneficial, either via survey or in interviews, to directly ask participants what they understand by such terms as 'liberty' and 'harm' or, in particular, what it means to them in the context of their professional responsibilities. Being able to gain clarity on what healthcare workers in public health and mental health understand by such concepts could validate the theoretical concepts themselves and allow for more nuanced policy by explicitly citing the various articulations of liberty and harm that may be similar or conflict in practice.

This study's results also seem to suggest that perhaps those working in mental health, at least those who participated in the survey and in the interviews, are more likely to place a greater emphasis on protecting the liberty and rights of the client relative to the community, or at least, that the willingness to sacrifice an individual's liberty for the good of the broader community to stop the spread of TB may not be as strong than those working directly in TB treatment or may require that certain provisions are met (e.g., ensuring psychosocial care at all times). The empirical literature related to TB seems to suggest that the liberty of the individual are superseded in cases where there is a threat of transmission of TB; arresting the spread of TB is the primary purpose of TB care from a public health perspective. For example, as noted in *Chapter Three: The Empirical Background – TB and Person with*

SPMI, the WHO maintains that "the benefits of using this drug [cycloserine] may outweigh the potentially higher risks of adverse events" and that even though cycloserine is contraindicated for persons suffering from psychosis, cycloserine should be discontinued "if this can be done without compromising [the TB] regimen"(World Health Organization). One of the conclusions that Kant and Kantians draw is that no individual may be sacrificed for the benefit of others, i.e., no one can be permissibly compelled to forego self-mastery and be a slave to another. As such, it is unclear that a Kantian would be sympathetic to the logic of the WHO, i.e., even if a Kantian would justify restricting someone's liberty via isolation for the good of the others due to the reciprocal understanding of freedom, it is unlikely that a Kantian would allow for the psychiatric sacrificing of an individual for the good of the community if it meant that the person with SPMI cannot retain their self-mastery. The Kant scale in the survey was built upon a series of questions that intended to distinguish between harming and wronging, whereby someone is wronged if their liberty is interfered with even if no harm occurs. The Kant scales suggests that respondents from the mental health group (M=18.80) are more likely to view harming and wronging as distinct concepts than those working in TB (M=16.55, p=.011). Although even if the mental health group respondents distinguished between harming and wronging, it does not follow that they would necessarily disagree with the WHO's conclusion (and like conclusions, which call for the extreme sacrificing of individuals for the greater good in order to arrest the spread of TB); however, some passages from the interviews suggest that there may, in fact, be some link between a higher mean score on the Kant scale and opposing cases of interfering with an individual's liberty without providing psychosocial support. For example, the participants from the mental health group noted that not only was the goal of treatment the psychiatric

improvement of the client, but also establishing the client as a independent member of their community. Moreover, the participants from the mental health group seem to be aware, to a greater extent than those working in TB, that although addressing the adverse psychiatric side-effects of antitubercular medications may not be difficult, it would be difficult to maintain adequate psychosocial care during a period of isolation. As Fagerhaugh's ethnographic studies from the late 1960s suggest, it may be that those working in TB view their job as providing *treatment* (or clinical treatment) whereas those in mental health view their role as providing *care* in a more holistic sense (Fagerhaugh ; Fagerhaugh SY). The study of Bender and colleagues on 'welcomed intrusions', along with some of the other themes emanating from this study (e.g., the participants from the TB group who noted the extensive social care that is involved with assisting a client to overcome TB) suggests that the difference between whether or not mental health workers view their clients in a more holistic manner than those working in TB treatment may not be so clear.

iv. TB care versus SPMI care: There may exist other differences in how each group of healthcare worker interprets the standard actions and course of care in the others' field. Participants interviewed from the TB group seem to conceptualize DOT as being primarily about assisting the clients with their TB treatment, including ensuring the minimization of any drug side-effects. This viewpoint is in keeping with Bender and colleagues' results that suggest that part of the notion of DOT being a 'welcome intrusion' means not only providing medical care for clients, but also providing psychological support, especially during times of respiratory isolation (Bender et al. 2011). As participant PH-DM-20 noted, there is a kind of 'cheerleader' role that TB workers provide their clients often times during DOT visits. Unlike much of the TB treatment literature and policy documents, however, those TB

workers interviewed did not describe the primary role of DOT as being one of ensuring medication adherence in order to prevent TB transmission (World Health Organization 2006; Public Health Agency of Canada 2007; Bayer and Dupuis 1995; Coker 2000). The statistically significant difference in the DOT scale in interpreting the role of DOT between TB workers/mental health workers and family health workers, as well as the statistically significant difference in the DOT scale between TB workers and mental health workers, may have at least two divergent explanations: it may be that DOT is taken for granted among TB workers as a standard of care they must provide clients, whereas the notion of DOT is unfamiliar to those working in mental health and family health programs. In other words, watching clients swallow their medications may not be among the primary activities in the jobs of some healthcare workers who work in mental health or family health programs. However, in the interviews, those working in mental health discussed at length the challenges associated to medication adherence, including the need to be mindful of 'cheeking', i.e., when clients do not swallow their medication by keeping pills in their cheeks and disposing of them afterwards. According to mental health interviewees, cheeking, in turn, leads to workers making sure medication is swallowed, not unlike the purpose of DOT as presented in policy. Perhaps this may lead to a second understanding of the statistically significant difference between the interpretations of the importance of DOT via the DOT scale, namely, those survey respondents in mental health and family health programs did not understand what is DOT and thus, were more likely to give a 'neutral' response to the questions regarding DOT (i.e., not because they were ambivalent about the use of DOT in TB treatment but rather perhaps over a misunderstanding of the term 'DOT').

v. Adherence to law: Another point of convergence between the survey and interview data is the role that laws play in the professional lives of those working in mental health and TB care. To begin, the laws that govern the treatment of TB and SPMI seem to differ from the other laws that govern health and healthcare. Specifically, those working in TB and mental health have the discretion to use coercion in ways that seem unique relative to other domains of healthcare. While this is not a legal thesis, it is rare to see legislation that overrides the *Health Care Consent Act* in Ontario, yet, both the *Mental Health Act* and the *Health Protection and Promotion Act* allow for the divergence from the *Health Care Consent Act* in certain instances. Moreover, the main coercive sections of the legislation (ss. 22 and 35 of the *Health Protection and Promotion Act* (*Health Protection and Promotion Act, R.S.O. 1990, Chapter H.7*) and ss. 20 and 33 of *the Mental Health Act* (*Mental Health Act, R.S.O. 1990, Chapter M.7*)) are grounded in the harm principle, including prohibiting harm to self. As described in *Chapter Six: Results – Qualitative Interviews*, participants from both the TB and mental health worker groups assumed, and did not seem to question, the need to follow law. As participant PH-FW-9 stated, "[m]y job is to ensure the person complies [with] the legislation, public health legislation for the province of Ontario". The Public Health Orders scale seems to corroborate the interview data; the mean score on the scale was significantly higher for those working in TB and mental health than the respondents from the family health programs, which suggest that those working in TB and mental health are more likely to defer public health orders than those in family health programs (TB/Mental Health, M=20.57; Family Health, M=17.93, p=.000).

Perhaps the most unique and controversial section of the *Health Protection and Promotion Act* is s.35(c), which reads "that the person [with a virulent disease, e.g., TB]

place himself or herself under the care and treatment of a physician" (*Health Protection and Promotion Act, R.S.O. 1990, Chapter H.7*). Moreover, as described in *Chapter Three: The Empirical Background – TB and Person with SPMI*, the judge in Basrur v. Deakin upheld s.35 on the grounds that Mr. Deakin would continue to pose a threat to the community and the high costs related to housing someone not receiving treatment indefinitely (Basrur v. Deakin). The legal ruling in Basrur v. Deakin, however, run counter to the WHO's primary ethics policy on TB treatment, which states that no one should be forced to receive treatment because if patients "…do not accept [treatment], their informed refusal should be respected, as the isolated patient no longer presents a public health risk" (World Health Organization). The survey data suggest that there is disagreement *within* the three groups of workers. Questions four and eight asked whether the character from the vignettes should be forced to receive antitubercular medications if he does not voluntarily comply; all three groups clustered rather evenly among the strongly disagree/disagree (approximately 48% for question four, 47% for question eight) and agree/strongly agree (approximately 42% for question four and 49% for question eight) ends of the Likert scale. The discordance within the groups was not as evident from the interviews; however, some of the TB interviewees stated that it is difficult to determine whether or not someone should be forced to receive either antitubercular medications, while those in the mental health group were perhaps somewhat more comfortable with forcing medication intake (e.g., depot injections) but only as a last resort and in clear cases of threat of harm to self or others.

In summary, the comparison of the survey and interview results suggest the following:

1. Both TB and mental health workers and decision-makers espoused an understanding of harm as not only physical, but also as a reduction of future options or opportunities. The kind of harm being considered at a given moment in time may be dependent on the whether one is discussing the case of a person with TB or a person with SPMI.
2. There is reason to believe that the mental healthcare worker participants placed somewhat of a greater emphasis on protecting a client's liberty than the TB worker participants.
3. There may be a misunderstanding between the participants as to the role or jobs of the other participants from other fields (i.e., TB care versus mental health). This may or may not lead to a misunderstanding of the measures taken to reduce the risk of harm as part of the work of others in different fields (e.g., the role of DOT in TB care).
4. Both group of participants from TB and mental health seemed to defer to law to guide their actions in relation to their work.

C. Theoretical Observations and Questions for Future Research

In this section, I will discuss three themes that relate to both to the study and the theory that motivates the project. First, I discuss the need to seriously consider the role of perception in the application of the harm principle, i.e., that the various perceptions of what is a risk of harm and the extent to which it is a risk colors how the harm principle is applied in practice. Second, I discuss how the participants described the context in which the harm principle is applied and how that shapes the understanding and future application of the harm

principle, especially since similar conclusions are drawn in the theoretical literature itself (i.e., that the notions of liberty and harm are complex, defy simplicity and may alter depending on how and when they are applied). Finally, I present the idea of reciprocity, which may serve to compliment the application of the harm principle and is in keeping with participants who described in the interviews the need to support those individuals whose liberties are curtailed for the benefit of the general public through acts such as isolation orders. I believe that these three themes can serve as a springboard for future research in public health and mental health ethics.

i. Potential political ramifications of perceptions in public health and mental health: If experience pluralism is true, then there exists the need to develop fair procedures for addressing the effects of experience pluralism in public health and mental health. Discussion about the perception of 'reality' or 'what is the case' permeates the interviews and raises questions about the role of perception in how the harm principle is applied in the context of TB and persons with SPMI, and more broadly, the political implications of perception in public health and mental health. But moreover, considerations about the perceptions of the participants may give credence to the plausibility of experience pluralism. For example, as discussed above, there may exist differences regarding how risk of harm is perceived between the TB and mental health group of participants, both in the survey and the interviews. Moreover, from the interviews, there are discussions about how workers might predict whether or not a client will abide by treatment orders. For example, for some of the participants in the public health group, teenagers cannot be trusted to abide by public health orders because they are teenagers, or persons who ask too many questions about isolation are considered unlikely to abide by isolation orders. Participants in the mental health group

discussed how deterioration of a client's symptoms might be a sign that the client is not swallowing his or her medications. It seems that the participants, based on their previous experiences with clients, will try to deduce how current clients will act in terms of treatment adherence. But several of the participants noted the difficulty in trying to predict a client's future behaviour: "[b]ut even, I've been wrong. People that I thought there's no way that guy is going to take the meds, and they've been fine, so…I can't tell you!" (PH-FW-17). The differences in perceptions of what is 'risky' or what constitutes a risk of harm, coupled with descriptions about how to predict human behaviour in the context of treatment adherence, is critical to the application of the harm principle in practice. The ability to predict who will adhere to TB drug regimens and isolation orders will help fix a healthcare worker's perception of what clients pose a risk of harm to the community precisely by not adhering to their treatment orders, i.e., in order to *prevent* a harm from occurring, namely the transmission of TB, part of the considerations that healthcare workers undertake, will include the evaluation of whether the client will abide by treatment orders. However, the very evaluations of behaviour for the purposes of predicting the client's future behaviour may itself be subject to the particular healthcare worker that happens to be with a particular client. A similar story can be told of healthcare workers in mental health vis-à-vis persons with SPMI. The subjective judgment of whether or not *A* believes that *B* will behave in manner *x* is not a revelation or unique to the context of TB care or care for persons with SPMI; however, there exist few examples in the public sphere where there is the potential to limit someone's liberty (include freedom of movement and personal security) in the manner that is legally obligated in the case of care of persons with TB or SPMI.

Another issue related to perception that may affect the harm principle, or at least articulations of the harm principle that extend to harm to self as a potential justification for interference with liberty, are the participants' discussions of 'best interests' in the interviews. The views of the participants from the mental health group is particularly relevant given that harm to self is used as a justification to interfere in the context of persons with SPMI who pose a risk to self-harm. Participants from the mental health group often referred to trying to understand the viewpoints of persons with SPMI in order to ascertain what is in the client's best interest: "I create that space where I can meet them where they are, or try to meet them where they are, try and understand where they are and where they're coming from" (MH-FW-13) and "[w]e all seem to come up with a team decision and say okay, this is what we have to do, what's best for the patient and what do we have to do" (MH-FW-6). This viewpoint of being able to discern, or trying to discern, what is best for an individual may be in keeping with Raz's articulation of the harm principle, whereby it may be that certain actions are prohibited if said actions pose a risk of harm to an individual and their future options and opportunities. Feinberg provides a potential counter to Raz's position, who as described previously, noted that it is difficult to distinguish between persons suffering from 'neurosis' (or some kind of mental illness, e.g., SPMI) and their very conditions, i.e., the condition of a person with an SPMI may be part of what constitutes the person. If the person's mental states are part of what the self is, then it is unclear the extent to which the choices taken *because of* a person's SPMI must be taken into account when deliberating about a client's best interests. There is reason to believe, therefore, that the perceptions of mental healthcare workers regarding what is the 'best interests' of those with SPMI may shape the promotion or interference with the liberty of someone with an SPMI, which may

also depend on whether or not, or the extent to which, a psychiatric condition is taken as constitutive of a person's personality.

Deliberations on the role of perception, and what can be known and how it is known, suggest that the idea of 'perception' plays an important, though perhaps underappreciated or implicit role, in the application of the harm principle. I would argue that of the four theorists and versions of the harm principle (or objections to it) covered in this thesis, only Feinberg seems to consider the role of perception in how the harm principle may apply in practice in his discussion of the role of mental illness as part of a person's self in considerations of soft-paternalism. Moreover, none of the theorists explicitly mention or explain in any detail the role that perception of risk of harm and best interests might play in evaluations of harm to self or others. However, if the idea of a plurality of experiences, as described above, is true, what role might this epistemological uncertainty play in the application of the harm principle in practice, in the public sphere? At the very least, it may suggest that there exists the need to consider the multitude of possible best interests and harms that may exist in a given application of the harm principle. Moreover, there may be reason to believe that it is not enough to merely consider the possible viewpoints of the interested party, but to include the various parties in the deliberation process, and to establish a fair procedure for deliberation. There exists, for examples, procedures for public deliberation vis-à-vis priority setting in health care (Daniels N and Sabin J 2002) or theorists who have concentrated on the role of dialogue and discourse in politics (e.g., Jurgen Habermas); perhaps similar procedures can be established when the harm principle or other political decisions need to be applied in the context of public health and mental health. Although it is beyond the scope of this thesis to describe what that process might entail, the results of this study seem to suggest the need to

consider more careful the reality of the various perceptions of harm, risk of harm, and best interests in future applications of the harm principle in public health and mental health.

ii. The context surrounding the use of the harm principle: One complaint among theorists is that notions of liberty and the harm principle have been overly simplified when applied in fields such as bioethics or in legislation and policy. For example, Powers and colleagues argue that the current understanding of liberalism and Mill's articulation of the harm principle are "misguided" (Powers, Faden, and Saghai), while Krom argues that the harm principle applied in the field of infectious disease control without any reference to its theoretical foundations is impoverished (Krom A. 2011). In keeping with the critique of some authors, but from a practical perspective, one might argue that the survey and interview results present the complexity of applying the harm principle when treating TB and SPMI. In the interviews, participants from both the TB group and the mental health group noted many contextual features that they consider, either explicitly or implicitly, when justifying interference on the grounds of harm to self or others and in the application of the restrictions themselves. Recall that participants described the need to work with individuals (as best as possible) during times of isolation, the need to protect the privacy and confidentiality of clients, and the need to support clients throughout their time in isolation or observation (which will be discussed further in the next section on reciprocity).

One contextual feature about persons with TB or persons with SPMI that was noted by participants in interviews were the often socioeconomic obstacles facing individuals *before* their liberty needed to be restricted for the public good. Participants from the mental health group noted the poverty and stigma that those with SPMI face on a day-to-day basis, irrespective of the presence of any infectious disease. As PH-DM-20 noted, "[y]ou generally

got to tackle TB cases in this situation [of persons with SPMI] as a package deal…. basically if you want them to be able to get through TB treatments safely you often have to deal with a lot of their barriers, which have nothing to do with TB and which are still going to exist after the TB has come and gone" (PH-DM-20). The participants from the TB group noted that those who are at greatest risk of TB infection are persons of lower SES, as well, and in Toronto this would include new Canadians who have jobs with fewer or no benefits and little access to resources to be able to subsist, along with their families, through isolation and time away from work. Stated simply, those who are most likely subjected to interference on their liberty as justified by the harm principle are likely to be from a vulnerable population, at least more vulnerable relative to those who are less likely to have TB or suffer from an SPMI.

It is important to note, however, that the vulnerability of persons with TB or SPMI, and their susceptibility to being disproportionately subject to the use of the harm principle, is not a new discovery; for example, as noted in *Chapter Three: The Empirical Background – TB and Person with SPMI*, Coker discusses at length how the moves toward restricting liberty through isolation and DOT disproportionately affected vulnerable populations during the epidemic in New York (Coker 2000). The WHO also described TB as a "disease of poverty" (World Health Organization 2009). Moreover, Mill himself believed that the vulnerability of a population must be taken into account when applying the harm principle; recall that Mill argued against the *Contagious Disease Acts of 1866 and 1869* on the grounds of equality, namely that the law did not protect and promote the liberty of women, including sex workers, in the same manner as that of men (*The Evidence of John Stuart Mill Taken Before the Royal Commission of 1870, on the Administration and Operation of the*

Contagious Diseases Acts of 1866 and 1869. 1870). Therefore, combining the preexisting epidemiological data and historical analysis of TB and SPMI with the data from this study's survey and interviews, one can argue that the harm principle disproportionately affects vulnerable persons when applied in the context of TB and mental health. Moreover, that in keeping with theorists such as Mill, the inequality among groups must be taken into consideration when applying the harm principle (a conclusion that would not seem *prima facie* antithetical to either Feinberg's or Raz's accounts of the harm principle). The need to protect the community or others from the risk of TB infection, or violence from a person with SPMI, requires a careful consideration of the context in which the need to protect arises; in other words, further consideration needs to be given about what role, if any, egalitarian ideals should balance the need to protect the community when the burden for 'protection' disproportionately falls onto some social groups rather than others on the basis of *prima facie* morally irrelevant criteria (e.g., differences in SES).

iii. Reciprocity: Despite the need to consider fair processes when applying the harm principle, and in addition to taking into account that the harm principle is disproportionately applied toward members of vulnerable populations, the participants seemed to overwhelmingly agree that the general public must be protected from harm, whether TB or potential harmful acts due to someone suffering from an SPMI. Moreover, all three versions of the harm principle, and the Kantian objection, would seem to support enforcement of isolation or the temporary interference of liberty for the protection of the general public from harm. It is conceivable that TB and some kinds of harms that are the product of psychotic episodes, violate Mill's three domains of liberty, or wrongfully harm the interests that a person might have (i.e., Feinberg), or reduce future opportunities and one's independence

(i.e., Raz). Even a Kantian perspective would allow for interference with an individual's movement in the form of isolation for TB or observation during a psychotic episode, since the individual with TB or an SPMI are threatening the ability of others to be self-masters (recall that freedom is mutually reinforcing for Kant). Each situation and client is unique, and therefore it is difficult to make generalizations; however, *prima facie*, all the theories seem to support some level of interference with the liberty of a person with TB or an SPMI if he or she poses a risk of harm to self or others.

The participants, as noted in *Chapter Six: Results – Qualitative Interviews*, spoke about the need to support individuals during times when clients' liberties were restricted. The support of DOT workers toward TB clients took on several forms, including psychological support (e.g., encouragement, positive reinforcement), providing books or ways of linking to their communities, going to the food bank to procure food, and paying out of pocket (when possible and necessary) to provide the client and their families with the means to survive an extended period of time in isolation (e.g., Tim Hortons gift cards as incentives). Some of the mental health participants described, for example, trying to include clients who were on the ward in decision-making as much as possible, in order to try to reestablish a sense of control. The idea that the healthcare workers, as agents of the state, need to provide support for their clients may be best captured by reference to the notion of reciprocity.

Reciprocity may be an external and complementary notion to the harm principle. Viens and colleagues describe reciprocity as a condition for legitimizing the use of restrictive measures in the context of infectious diseases, broadly speaking. The authors begin by distinguishing between moral justification and moral legitimization. An act is morally

justified if one can demonstrate that it is the morally right act given the circumstances; an act is morally legitimate if the justified act "is performed in a morally acceptable manner" (Viens, Bensimon, and Upshur). Several conditions need to be present to legitimize a morally just act (e.g. in the case of infectious diseases, the state has the authority to isolate or quarantine, if the isolation or quarantine is necessary from a scientific viewpoint). Viens and colleagues (along with other authors) argue that reciprocity is one such condition for legitimatizing restrictions (Upshur ; Holland S ; Viens, Bensimon, and Upshur).

Reciprocity "demands an appropriate balancing of the benefits and burdens of the social cooperation necessary to obtain the good of public health" (Viens et al. 2009, 211) and "that we compensate those disproportionately burdened by complying with restrictive measures and making restitution to those individuals wronged by being subjected to unfair or intolerable treatment" (212). Reciprocation, then, is not merely a unidirectional relationship, but bidirectional, whereby the individual owes society and the state for the goods he or she obtains as part of a collective, and the state and society owe individuals for their particular input of goods toward the public or collective pool. Moreover, reciprocity seems to entail some kind of *quid pro quo*, whereby if a person's liberty is removed or curtailed, they then deserve compensation. If compensation is owed to individuals, then reciprocity "grants individual and societal interests equal and supporting weight as goods" (212). In other words, if restrictive measures need to be applied to protect the public good, the right or liberty curtailed does not cease to exist, i.e. the liberty is upheld as inalienable. I would argue that the justification for this feature of reciprocity, the justification for why compensation is necessary, is at the crux of legitimizing restrictive measures. The harm principle, whether that of Mill, Feinberg, or Raz, may be thought of as a method of trading

off goods or interests (including an interest in upholding one's liberty in the public sphere); but since the liberty does not cease to exist merely because it may require interference in certain circumstances, the legitimization of the curtailment depends necessarily on upholding some notion of reciprocity.

Viens and colleagues conclude by stating "we also need to pay attention to the circumstances that allow us to fulfill our reciprocation obligations" in particular by removing barriers that may hinder discharging obligations (213). I would argue that one should expand the understanding of how "circumstances" affect reciprocation by explicitly considering the context of the liberty restriction (e.g., the particular use of the harm principle at a given moment in time) and background conditions of the individual or the populations subjected to the application of the restrictive measure. If reciprocity is designed to compensate or restore individuals who are disproportionately burdened by having to comply with restrictions that are justified via the harm principle, then the disproportionate burden may occur during the act of restriction (by virtue of the very restriction itself), but it may also precede the act of restriction (e.g., due to socioeconomic differences between populations). When restricting on the basis of the harm principle, preexisting conditions of vulnerability should not be exacerbated (e.g., by ensuring that a client with TB does not lose their home because they cannot go to work, or that a person with SPMI have all their basic needs met while having to remain in observation on a ward). The state needs to be sensitive to not continually and overly disadvantaging the same group when the liberty of clients clashes with the protection of the public from harm. The *historical context* of the parties subject to liberty restrictions needs to be considered, not only when curtailing liberty, but also when compensation is sought via reciprocity.

What reciprocity is and what role it might play in public health and mental health remains to be developed. Important questions will remain unanswered in this thesis; for example, how much compensation is a person owed under the notion of reciprocity? I would argue that if one were to take seriously and contemplate what goods, interests, or liberties are being sacrificed in a given situation, then the need to compensate fully might be equally high (e.g., the state owes a great deal to individuals if it asks individuals with TB to remain in respiratory isolation for extended periods of time). What might be the differences and similarities in the application of reciprocity when a person's liberty is restricted to protect *others* from harm, as opposed to those instances when the person is restricted so as not cause *self*-harm? Although the notion of reciprocity and how it might be applied in practice requires much greater consideration, reciprocity seems to support the actions and beliefs of the participants as presently described in the interview results.

Briefly then, how might reciprocity align with the various political theories described in *Chapter Two – Theoretical Background*? There are *prima facie* reasons to suggest that reciprocity would compliment the harm principle, as well (or, at least, that the use of the harm principle to justify interference does not preclude the application of some notion of reciprocity). Beginning with Mill, there may be, at least, two means by which he could argue in favor of incorporating reciprocity within his broader defense of liberty. First, a Millian might argue, as Mill did himself in the context of the *Contagious Disease Acts*, that the three domains of liberty (i.e., freedom of consciousness, freedom of tastes and pursuits, and freedom of assembly) ought to be applied in an egalitarian fashion; moreover, when the harm principle is used to curtail freedoms that are guarded under one of the three domains, then there exists an obligation for the state to rectify the curtailments so as to protect Mill's

broader egalitarian liberal framework. A second possible line of argumentation for Mill might be to justify reciprocity by reference to his theory of utilitarianism, which he claims grounds his broader political liberal philosophy. Under Mill's theory of utilitarianism, one might argue that upholding reciprocity, or codifying the value of reciprocity in law, would increase the amount of aggregate happiness (broadly construed).

The value of reciprocity might also fit with Feinberg's and Raz' theories of liberty and legitimate coercion. For Feinberg, reciprocity might provide a fourth consideration when balancing independently valuable and rightful interests. Recall that for Feinberg, when two agents have competing and mutually exclusive interests, one ought to consider the vitality of the interests, the degree to which other interests are at stake in the trade-off situation, and the interest's 'inherent moral quality'. A fourth consideration for Feinberg might be that since the interest lost is still an important interest to protect, that reciprocity has an ability to act as compensation that might mitigate the amount of loss for any given individual. Under Feinberg's theory, it is unclear who has responsibility for reciprocity, but it would conceivably be a responsibility of the state. A similar line of argumentation might be possible for Raz, as well, except the argument might be made in terms of opportunities and independence (the foundation of Raz' notion of autonomy), insofar as reciprocity might be a means of increasing future quality opportunities for individuals in light of necessary restrictions.

All three preceding theories that justify the use of reciprocity, however, are subject to the following objection: all hold reciprocity as *a good* to be considered *in addition to* the harm principle. Although reciprocity might be supported in each instance that the harm principle is used to restrict a freedom, it does not follow that it ought to be used in all

instances; other factors might come into consideration due to the consequentialist nature of all three theories (to varying degrees). The clearest example might be that under Mill's utilitarianism, there may be instances when states should not reciprocate for restricted liberties if there were to be a decrease in the overall amount of happiness in the world (e.g., if it costs too much to support individuals while in isolation for TB given broader governmental resource constraints, e.g., modern-day 'austerity measures'). Again, it is likely the case that reciprocity can be incorporated and used to complement all three versions of the harm principle; however, an additional argument would have to be provided that is independent of the harm principle and that may not apply in all instances where liberties are restricted.[14]

Perhaps the strongest defense of reciprocity can be provided by Kant's notion of equal (or reciprocal) freedom. Recall that for Kant, freedom is not about the amount or consequences of choices, or choices at all, but rather with the ability to choose and to shape one's own life, i.e., to have self-mastery. Moreover, this notion of freedom must be compatible with everyone else's freedom, i.e., the state and all persons must value each person's liberty as the same; no one should be more free than another person. As such, restrictions on actions are permissible under a Kantian notion of freedom, if restricting someone's movement, for example, helps maintains everyone else's freedom. For example, isolation might be permissible so as to ensure that others are not infected with TB and remain self-masters. However, it also follows that the state ought to promote actions that ensure or enhance self-mastery;[15] as such, reciprocity might be one of the values that the state ought to

[14] One might counter by arguing that the goal should not be to have a theory accommodate the notion of reciprocity, but rather, that one should choose what political theory they think is best and then see if reciprocity can be defended. I will leave this important issues aside in this thesis.

[15] For example, Kant's argument for some amount wealth redistribution, i.e., why the state needs to ensure that everyone has the basic material resources necessary for life, is so that everyone is free and not dependent on the charity of others (6:326).

promote because it is in keeping with the protection of individual freedom. If this kind of argumentation is sound, then it might be that reciprocity ought to be promoted regardless of economic considerations, i.e., if a range of choices is curtailed, in a justified manner, such that it affects the person's self-mastery (e.g., not being able to buy food while in isolation for TB), then the state has a duty to protect the individual to the best of its ability regardless of cost.

As stated previously, the manner in which reciprocity does or does not cohere with the various political theories and notions of the harm principle requires greater and more careful consideration; the preceding are merely preliminary thoughts that require further development.

D. Limitations

This study has several limitations that fall within two broad categories: limitations that stem form the design of the study and those limitations that arose as the study progressed beyond the design phase.

The first limitation that stems from the design of the study is that the study limited participation only to those public health units and mental health centres within the geographic confines of the Greater Toronto Area (GTA); therefore, there are issues related to the generalizability of results beyond this region, including the possible legal differences between Ontario and other jurisdictions and the unique demographic composition of the GTA as an urban centre with a high percentage of Canada's new immigrants. Given the need to keep the design feasible relative to the budget and human resources, restricting participation to public health units and mental health centres in the GTA was reasonable.

Moreover, since there are no other studies of its kind, any information ascertained can be used to further future research on the same or similar subjects. As well, the problem encountered in the GTA regarding liberty restrictions related to TB and SPMI is not unique to the region and might apply many other liberal democratic jurisdictions. Second, the study was designed so as to exclude consideration of persons with addictions, despite their suffering from high rates of TB (Oeltmann JE, Kammerer JS, and Pevzner ES), as well as the increasingly common integration of addiction studies into the field of mental health research more broadly. The reason for the exclusion of persons with addiction from the study was that given the novelty of the study and the complexity of design, the history and sociology related to addictions (e.g. questions of responsibilities for one's addictions) added further complexity that would make analyses more difficult and convoluted. However, future studies should evaluate what role addictions might have in healthcare workers and decision-makers' understanding of liberty and the harm principle. Third, despite sampling from public health units and mental health centres, the study did not sample from the four TB clinics within the GTA. The reason that TB clinics were excluded is because they are much more clinically focused (i.e. treatment is about the TB patient only), while public health units are charged with clinical responsibilities, as well as public health responsibilities, such as enforcing isolation and treatment.

There also exist several limitations that stem from the execution the study design and survey instrument that were not evident prior to data collection. First, the survey instrument focused on evaluating respondents' conceptualization of 'harm' rather than 'liberty', i.e., most of the items addressed issues of harm rather than liberty. Since one of the main motivating factors for the study was understanding how the harm principle was applied in

practice in public health and mental health, coupled with the need to keep the survey short in order for it to be completed in a timely manner, the survey centered on the concept of harm rather than liberty; as such, it remains unclear how the respondents' ideas about liberty may or may not coincide with the different articulations of liberty as presented in *Chapter Two: Theoretical Background – Liberty and the Harm Principle.* Second, the order and content of the two vignettes may have affected the answers of the respondents. Recall, in the first vignette, the case centered on a character with TB and the second vignette centered on a character with TB and schizophrenia. Four of the eight questions related to the two vignettes (i.e., questions two, three, six and seven) constitute the Risk Scale. The results of the Risk Scale found that mental health workers scored higher than those working in TB units (with a higher score indicating a greater likelihood of finding the character of the vignette as posing a higher risk of harm to the community). It may be conceivable that the order of the vignettes may have affected whether or not one group of respondents found the character a risk to the community. In the future, it may be worthwhile to give additional vignettes trying to ascertain the respondents' perception of risk of harm with a character that only has schizophrenia (or some other SPMI) prior to the introduction of a character that has both TB and schizophrenia. Third, the biographical questions on the survey were placed at the end of the survey to encourage respondents to participate by hopefully beginning the survey with interesting questions that would resonate with the potential respondent, as per the Tailored Design Methods (Dillman 2000); however, since the biographical information (most importantly, the question asking them whether they worked in a TB, mental health or family health team) were the independent variables, the answers to questions at the beginning of the survey where the respondent did not finish the survey and did not answer the biographical

questions were subsequently removed from the data. The placement of the biographical questions remains an area of debate in the development of survey instruments (Aday and Cornelius 2006).

Fourth, the research ethics board (REB) at Ontario Shores did not allow the researchers to contact participants directly to invite them to participate in the survey citing privacy and confidentiality concerns (although they did allow me and the organizational point person to contact people directly for the interviews). It was never clear to the me and the thesis committee that contacting workers at Ontario Shores with an invitation to participate in the survey would jeopardize privacy, especially since all invitees were given a unique code that disassociated them with their names and email addresses. The REB at Ontario Shores recommended procuring respondents via flyers distributed to the units; however, given that this would change the carefully considered recruitment strategy, we decided to forgo collecting survey responses from this organization. As a result, it may be that a bias was introduced into the mental health group survey population since all mental health worker respondents were from the Schizophrenia Program at the Centre for Addictions and Mental Health (CAMH). Fifth, not all the organizations were as punctual in replying to emails vis-à-vis the logistics of the project. In particular, CAMH proved to be challenging when trying to ascertain a population from which to sample for the survey (e.g., there was confusion as to who within the organization I needed permission to disseminate the survey). In order to not delay the data collection process, the survey dissemination proceeded with the public health units before all administrative matters could be dealt with at CAMH. It is not clear whether the difference in when the survey was administrated could have affected the difference in response rates between the various groups. Sixth, in keeping with Dillman's Tailored Design

Method for surveys, and in particular trying to engender a sense of reward and trust in the potential respondents as per the method, the survey was presented to potential respondents as a survey about TB and persons with SPMI, i.e., the word “TB” preceded the words “SPMI” or “mental health”. The idea was to tie the survey to the actual jobs of the potential respondents, rather than what I felt were more abstract ideas like ‘liberty’ and ‘harm’. It is unclear, however, that given the small number of TB patients in the mental health system, whether this strategy may have failed to attract mental health respondents; it is possible that the idea of TB in their client populations did not seem as important and hence that responding to the survey was not deemed worthwhile or of interest. When considering the three preceding post-design limitations (i.e., the REB at Ontario Shores, the logistical problems at CAMH, and whether framing the survey as having to do with TB and SPMI rather than liberty and harm), it may be that these factors lead to a final limitation, namely the small sample size and poor response rate from mental health respondents for the online survey. To reiterate, there were only 10 respondents from the Schizophrenia program at CAMH for a 13.7% response rate. The data from the survey is insufficient to draw any strong conclusions or inferences due to the small sample size and those who responded may be non-representative of the study population. However, despite the small sample size, statistically significant results emerged, and coupled with the themes and patterns found in the qualitative interviews, it suggests that it is worthwhile to reproduce the study and continue this line of inquiry in the future.

E. Conclusion

The participants' conceptualizations of liberty, harm, and the harm principle appear to be as nuanced and diverse as the theories of the harm principle itself; although the detail and level of argumentation of the theorists was not evident in the survey or interviews, at the very least, when the theory and the results of this study on the harm principle are considered in tandem, it belies any oversimplification in the understanding and the application of the harm principle in public health and mental health.

Returning to the four research questions articulated in *Chapter Four: Methods and Methodology*, the answer to the questions could be summarized as follows:

1. How do frontline TB healthcare workers and decision-makers conceptualize liberty, harm, and the harm principle?

   Answer: Those working in TB care conceptualized liberty and harm in a nuanced fashion. Through the interviews, liberty was described as consisting of 'choosing' or 'having choices'. The interview and survey results suggest that harm, although often conceptualized in terms of physical harm, was also conceptualized as consisting of reduction of options or ability to care for oneself under certain circumstances. There is some evidence to suggest that those working in TB viewed SPMI as a greater risk to self and others than those working in mental health. The harm principle was used to justified liberty restrictions but the notion of reciprocity was introduced as a necessary corollary of applying the harm principle in practice.

2. How do frontline mental healthcare workers and decision-makers conceptualize liberty, harm, and the harm principle?

Answer: Those working in mental health also conceptualized liberty and harm in a nuanced fashion. Through the interviews, liberty was described as consisting of 'control' or 'having control' over one's life. The interview and survey results suggest that harm, although often conceptualized in terms of physical harm, was also conceptualized as consisting of reduction of options or ability to care for oneself under certain circumstances. There is some evidence to suggest that those working in mental health viewed TB as a greater risk to self and others than those working in TB care. The harm principle was used to justified liberty restrictions but the notion of reciprocity was introduced as a necessary corollary of applying the harm principle in practice.

3. How do the study's empirical findings align with common ethical and political arguments justifying the use of the harm principle?

   Answer: The findings generally cohere with the theorists' views on liberty and harm, and the use of the harm principle to justify limitations. Liberty was viewed both in terms of 'control' and 'choices', while harm was not only viewed as physical harm, but also as consisting of other types of harm depending on the circumstances (e.g., being treated for TB versus an SPMI). Moreover, the participants seemed to justify the use of the harm principle by arguing that those whose liberty is curtailed need to be supported. The support of those whose liberty is restricted is in keeping with the burgeoning articulation of reciprocity in public health and mental health.

4. How do the study's empirical findings elucidate one's understanding of the application of the harm principle in public health (in particular related to TB treatment) and mental health (in particular related to SPMI)?

Answer: In keeping with both the theoretical literature, the empirical results suggest that a simple and straightforward application of the harm principle is not possible in practice, in either public health or mental health. 'Harm' is a nuanced notion that may be used differently by not only members of different healthcare worker groups (e.g., public health as opposed to mental health workers) but also may differ in its application within a group of workers (e.g., different TB workers will understand harm, and the consequences of using the harm principle, differently). Policy and legislation should reflect, and not obfuscate, the inherent difficulty in the application of the harm principle in public health and mental health practice.

In addition to answering the research questions set forth at the beginning of the thesis, I believe that based on the results, three recommendations can be made that could have potentially important practice and policy implications:

1. The various understandings of liberty and harm, both within and between the groups of participants, suggest that how liberty and harm is understood is context-dependent. As such, decision-makers must be aware that there is no 'one-size-fits-all' application of the harm principle, whether in public health or mental health. What harm means for the individual with TB will be dependent upon the particular detail of that individual's life (e.g., does she have a family? What is her employment situation?); likewise for persons with SPMI (e.g., does he have a family for support? How does he manage co-morbidities?) Being sensitive to the context in which the harm principle is applied, and the various understanding of 'harm', is particularly important in complex situations where multiple state actors must cooperate to find

solutions (e.g., when a person with an SPMI, who is also homeless, contracts TB).

2. The state must do a better job preventing the need to use the harm principle in the first place, especially as it relates to TB and SPMI. In order to reduce the number of times restrictions on liberty must be applied and justified by reference to the harm principle, there needs to be a concerted effort to ameliorate the conditions that lead to persons acquiring TB, or reducing the social triggers that lead to harm of self or others on the part of persons with SPMI. This recommendation is not novel, but merely a reiteration of one of Frieden's assertions (that applies equally well to dealing with SPMI, as it does TB): "While these patients must accept responsibility for their actions, society must also accept responsibility for creating and allowing to flourish the conditions for non-compliance: poverty, homelessness, drug abuse, lack of access to medical care, and mental illness" (Coker 2000). Ameliorating the background conditions, however, will require cooperation beyond public health and mental health toward other Ministries of Provincial and Federal governments (e.g., Immigration, Correctional Services, etc).
3. Interference of the various liberties (e.g., the right of mobility and security of the person as protected by the Canadian Charter) of persons for the protection of others, as justified via the harm principle, requires that the state support persons' whose liberties are limited. In other words, when liberties are restricted for the good of others, the state has an obligation to help these persons discharge *their* obligations to others; this is justified through the

notion of reciprocity. However, the obligation to support individuals whose liberties are restricted cannot fall upon the various levels of kindness of the public servants (e.g., in the case of TB or SPMI, the frontline healthcare workers); it is the state's responsibility to ensure there are reliable mechanisms in place to support persons whose liberty are restricted as justified on the grounds of the harm principle.

There are several topics that require future conceptual and empirical research, which will likely have important policy and practice ramifications. First, although the results of the study are suggestive, drawing more concrete conclusions requires replicating the study with more rigour and greater response rates (in particular, as it relates to the survey), possibly in a new setting, in order to test the generalizability of the findings herein. Second, some theoretical questions have arisen that require greater conceptual and empirical deliberation, in particular, as they relate to the application of the harm principle. The role of deploying reciprocity along with the harm principle or other means of justifying restrictive measures, the possible egalitarian application of the harm principle, and the fair and legitimate processes in executing orders on the basis of the harm principle all need greater consideration and evolution of thought. Finally, greater attention and inquiry needs to be given to the role of epistemology in the politics of public health and mental health; it may be worthwhile to consider more carefully Iris Young's epistemological arguments and whether they prove persuasive in matters related to delineating between value and experience pluralism, and the political ramifications of such lines of inquiry.

Regardless of the particular research objectives and questions, moving forward, it is imperative that researchers and policy makers in public health and mental health pay close

attention to the context in which values, such as the harm principle, are utilized in practice and the how the perceptions of the healthcare worker, those charged with executing legislation and policy, fundamentally shape the application of values in practice.

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Appendix One – Introductory Email to Potential Interview Participant

Dear _____________,

You are being invited to participate in an interview to discuss key ethical issues related to tuberculosis (TB) and persons with severe and persistent mental illnesses (SPMI – i.e. persons with schizophrenia, schizoaffective disorders, bipolar disorder). The University of Toronto is conducting a study about how frontline healthcare workers and decision-makers address ethical challenges related to TB and persons with SPMI. You have been identified as someone who is knowledgeable and interested in the subject matter. As a member of _______, your participation is important and will contribute to research that is intended to affect public health and mental health policy and practice.

The interview will last approximately between 45-60 minutes. I have attached a copy of the consent form, if you'd like to read it. I will also be bringing a copy of the consent form to the interview. If you have any questions, please feel free to contact me at diego.silva@utoronto.ca or at 647-225-5287.

**Please note that participation is completely voluntary; there is no penalty for declining this invitation and no one will be made aware, if you decline.

If you'd like to participate, please suggest some dates and times that work best for you.

Thank you for your time and assistance. I look forward to speaking with your soon.

Sincerely, Diego Silva

Appendix Two – Consent Form: Interviews

Participant Consent Form

Project Title: Exploring Conceptualizations of Harm: The Case of Tuberculosis and Persons with Severe and Persistent Mental Illnesses

Principal Investigators: Diego Silva, MA
PhD Candidate, Dalla Lana School of Public Health
Collaborative Program in Bioethics, Joint Centre for Bioethics
University of Toronto
155 College Street, Suite 754
Toronto, ON M5T 1P8
Email: diego.silva@utoronto.ca
Phone: 647-225-5287

Co-Investigators: Ross Upshur (Supervisor), Jennifer Gibson, Carol Strike

Sponsor: Canadian Institutes of Health Research

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Preamble:
You are being invited to participate in an interview to discuss key ethical issues related to tuberculosis and persons with severe and persistent mental illnesses (SPMI). Before deciding whether or not you wish to participate, it is important that you understand the project. This consent form describes the purpose, procedures, and potential harms and benefits of this project. It also describes your right to refuse to participate or to withdraw from the interview at any time without penalty. Please ask the interviewer to explain any terms you do not understand and make sure all your questions are answered to your satisfaction before signing this consent form.

Background:
This study focuses on how frontline healthcare workers and decision-makers address ethical challenges related to the case of tuberculosis (TB) and persons with severe persistent mental illness (SPMI). For the purpose of this study, SPMI entails schizophrenia, schizoaffective disorders, and bipolar disorders.

You are being invited to participate in this project because you have been identified as someone who is knowledgeable or interested in the subject matter given your role at [NAME OF INSTITUTION]. Your participation is important and will contribute to research that is intended to affect public health and mental health policy and practice.

Procedures:
If you agree to participate, you will be asked about your opinions on ethical questions related to TB and persons with SPMI. The interview will take approximately 45-60 minutes. The interview will be digitally recorded and transcribed. Only the research team identified above will have access to the
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transcript. All digital files will be kept in a password-protected computer; all paper copies of the transcripts will be kept in a locked cabinet and shredded at completion of the study. Your decision to participate or to not participate will be kept in strict confidence. All personal information will be removed from the transcripts and you will not be identified in any reports, publications, or presentations.

Potential Harms and Benefits:
There are no physical risks associated with participating in this project. If any of the questions make you feel uncomfortable, you may choose not to respond. You may stop participating in the interview or withdraw from the project at any time. Withdrawing from the project will in no way affect your employment at [NAME OF INSTITUTION].

This project will not benefit you directly; however, it has the potential to improve pubic health and mental health policy and practice. You do not give up any of your legal rights by participating in this project. Your privacy and confidentiality will be respected throughout the project. Your employer will not have access to the data you provide. Your name will not be attached to any comments you make during the interview so there will be no way for anyone to attribute your comments to you. There will be no financial incentive for participating in the project.

Publication of Research Findings:
The results of these findings may be published in academic journals, presented at academic conferences and used for education purposes to the extent that this would further an understanding of these issues. Your identity will not be revealed in any publication.

Contacts:
If you have any questions or concerns, please contact Mr. Diego Silva by e-mail at diego.silva@utoronto.ca or by telephone at 647-225-5287. You will be provided a copy of this consent form at the interview. If you have questions about your rights as a research participant, please contact Daniel Gyewu in the Ethics Review Office at the University of Toronto (e-mail: d.gyewu@utoronto.ca or telephone: 416-946-5606).

Consent:
I understand that my participation in this project is voluntary and that I may withdraw at any time without penalty. I have received a copy of this signed consent form. I have read and understood the above information and agree to participate in this project.

____________________	______________________	___________________
Participant Name	Signature	Date

……

I have explained the project and obtained the informed consent of the above-named participant.

____________________	______________________	___________________
Investigator Name	Signature	Date

Appendix Three – Interview Guides

Interview Guide – Mental Health

1. Can you please briefly describe your role here at ___________?
2. What are some challenges related to isolating an individual in a psychiatric hospital?
3. Monitoring medication adherence through direct observation is when a healthcare worker watches a client swallow the necessary medications. What are some challenges related to monitoring medication adherence through direct observation in psychiatric care?
4. Sergei arrived in Canada from Russia three years ago. He is 27 years old and has been recently diagnosed with active pulmonary tuberculosis. His English is good and he has been working part-time as a janitor at a local high school for six months. He lives in a two-bedroom apartment with a roommate who is also a recent immigrant to Canada from Russia. Sergei's roommate has tested negative for TB. It is unclear how Sergei caught TB. Moreover, Sergei also suffers from schizophrenia. He was diagnosed when he was 21 and since then, he has received medications for his psychiatric condition. With proper drug treatment, Sergei has managed to keep the symptoms from schizophrenia to a minimum with only two psychotic episodes since diagnosis. He is currently in intensive case management; he is having success in the program and he is integrating well into the community. Public Health has considered ordering Sergei to remain in respiratory isolation for the duration of treatment. It is unclear whether the antitubercular medications will lessen the effectiveness of his antipsychotic medications.
    a. What is your initial responses to this situation? What is your gut reaction?

b. What are the features of this case that you find the most compelling? In your opinion, what are the most important things to consider?

c. In your opinion, what, if any, are the ethical challenges in the scenario?

5. How should we balance the needs of protecting the community or the person with an SPMI from harming others or self-harm, with the need to help empower the person with an SPMI to function as an individual within his or her community?
6. Anything else you'd like to share? Are there any other questions you think I should ask? Are there any other comments you'd like to make?

Interview Guide – Public Health

1. Can you please briefly describe your role here at ___________?
2. What are some challenges related to isolation of tuberculosis patients?
3. Directly observed therapy is when a healthcare worker watches a patient swallow the necessary medications. What are some challenges related to directly observed therapy in tuberculosis care?
4. Sergei arrived in Canada from Russia three years ago. He is 27 years old and has been recently diagnosed with active pulmonary tuberculosis. His English is good and he has been working part-time as a janitor at a local high school for six months. He lives in a two-bedroom apartment with a roommate who is also a recent immigrant to Canada from Russia. Sergei's roommate has tested negative for TB. It is unclear how Sergei caught TB. Moreover, Sergei also suffers from schizophrenia. He was diagnosed when he was 21 and since then, he has received medications for his psychiatric condition. With proper drug treatment, Sergei has managed to keep the symptoms from schizophrenia to a

minimum with only two psychotic episodes since diagnosis. He is currently in intensive case management; he is having success in the program and he is integrating well into the community. Public Health has considered ordering Sergei to remain in respiratory isolation for the duration of treatment. It is unclear whether the antitubercular medications will lessen the effectiveness of his antipsychotic medications.

a. What is your initial responses to this situation? What is your gut reaction?
b. What are the features of this case that you find the most compelling? In your opinion, what are the most important things to consider?
c. In your opinion, what, if any, are the ethical challenges in the scenario?

5. How should we balance the needs of protecting the community from being infected with tuberculosis with the rights of tuberculosis patients to go about their daily lives?
6. Anything else you'd like to share? Are there any other questions you think I should ask? Are there any other comments you'd like to make?

Appendix Four – Introductory and Follow-Up Emails to Potential Online Survey Participants

Dear Participant -

You are being invited to participate in an online survey to identify key ethical and policy issues related to the treatment of tuberculosis (TB) in persons with severe and persistent mental illnesses. The goal of the survey is to find out how frontline healthcare workers and decision-makers conceptualize harm to self and others in public health and mental health. Your participation is important and will contribute to research that is intended to affect public health and mental health policy and practice.

Please click here to access the survey. The survey will only take approximately 10 minutes to complete. If you have any questions, please feel free to contact me at diego.silva@utoronto.ca or by phone at 647-225-5287.

Please note that participation in this study is completely voluntary. Your responses will not be made available to management.

Thank you for your time and cooperation.

Sincerely,
Diego Silva
PhD Candidate
Dalla Lana School of Public Health
University of Toronto

REMINDER

Subject: Reminder to take TB and mental health survey

Dear Participant -

We haven't heard from you, but your opinion is important to us. Please consider taking the time to fill out our survey here.

You are being invited to participate in an online survey to identify key ethical and policy issues related to the treatment of tuberculosis (TB) in persons with severe and persistent mental illnesses. The goal of the survey is to find out how frontline healthcare workers and decision-makers conceptualize harm to self and others in public health and mental health. Your participation is important and will contribute to research that is intended to affect public health and mental health policy and practice.

The survey will only take approximately 10 minutes to complete. If you have any questions, please feel free to contact me at diego.silva@utoronto.ca or by phone at 647-225-5287.

Please note that participation in this study is completely voluntary. Your responses will not be made available to management.

Thank you for your time and cooperation.

Sincerely,
Diego Silva
PhD Candidate
Dalla Lana School of Public Health
University of Toronto

FINAL REMINDER

Dear Participant -

We haven't heard from you, but your opinion is important to us. Please consider taking the time to fill out our survey here.

This is a final invitation to participate in an online survey to identify key ethical and policy issues related to the treatment of tuberculosis (TB) in persons with severe and persistent mental illnesses. The goal of the survey is to find out how frontline healthcare workers and decision-makers conceptualize harm to self and others in public health and mental health. Your participation is important and will contribute to research that is intended to affect public health and mental health policy and practice.

The survey will only take approximately 10 minutes to complete. If you have any questions, please feel free to contact me at diego.silva@utoronto.ca or by phone at 647-225-5287.

Please note that participation in this study is completely voluntary. Your responses will not be made available to management.

Thank you for your time and cooperation.

Sincerely,
Diego Silva
PhD Candidate
Dalla Lana School of Public Health
University of Toronto

Appendix Five – Consent Form and Online Survey

Tuberculosis and Persons with SPMI

Page #1

Tuberculosis and Persons with Severe and Persistent Mental Illnesses

Persons with severe and persistent mental illnesses (SPMI – i.e. schizophrenia, schizoaffective disorders, bipolar disorders) suffer from a higher prevalence of tuberculosis (TB) than persons without mental health challenges. The reasons for this situation are likely due to higher rates of co-morbidities, socioeconomic factors, and substandard or transient housing.

In light of this situation, researchers at the University of Toronto (Dalla Lana School of Public Health and the Joint Centre for Bioethics) are conducting a survey on the ethical issues related to TB and persons with SPMI. One of the goals of the survey is to find out how frontline healthcare workers and decision-makers conceptualize harm to self and others in public health and mental health. Given your position as a frontline healthcare worker or decision-maker, your opinions are important in shaping future policy and practice in public health and mental health.

Your privacy is of utmost importance; your survey will be kept confidentially. All raw data will be de-identified and seen only by the research team at the University of Toronto and no one within your organization. Completing this survey is voluntary and you can stop at any time without penalty.

The survey should take approximately 10 minutes to complete.

I consent to participating in this survey.

- Yes
- No

Page #2

Section One: Please read the case below. Then indicate your level of agreement with each statement.

Case 1:

A 27 year old male presents with active pulmonary tuberculosis. He recently immigrated to Canada from Russia. His English is good and he has a part-time job as a janitor at a local high school. He lives with a roommate in a two-bedroom apartment. He is on no other medications. He does not have any contraindications toward the antitubercular drugs he must take.

1. He should receive directly observed therapy for his tuberculosis treatment (whereby a healthcare worker watches him swallow the tuberculosis medication).

- Strongly Agree
- Agree
- Neutral
- Disagree
- Strongly Disagree

2. He should be treated for his TB in a specialized environment (e.g. a hospital with a tuberculosis unit), away from the broader community.

- Strongly Agree
- Agree
- Neutral
- Disagree
- Strongly Disagree

3. He is a high risk client likely to spread tuberculosis.

- Strongly Agree
- Agree
- Neutral
- Disagree
- Strongly Disagree

4. If he does not voluntarily comply with tuberculosis drug treatment, he should be physically forced to take antitubercular medications.

- Strongly Agree
- Agree
- Neutral
- Disagree
- Strongly Disagree

Page #3

Case 2:

A 27 year old male presents with active pulmonary tuberculosis. He recently immigrated to Canada from Russia. His English is good and he has a part-time job as a janitor at a local high school. He lives with a roommate in a two-bedroom apartment. He also suffers from schizophrenia, which is currently under control. He receives antipsychotic medications and is responding well to community psychosocial support. It is unclear whether the antitubercular medication may lessen the effectiveness of his antipsychotic medication.

5. He should receive directly observed therapy for his tuberculosis treatment (whereby a healthcare worker watches him swallow the tuberculosis medication).

- Strongly Agree
- Agree
- Neutral
- Disagree
- Strongly Disagree

6. He should be treated for his TB in a specialized environment (e.g. a hospital with a tuberculosis unit), away from the broader community.

- Strongly Agree
- Agree
- Neutral
- Disagree
- Strongly Disagree

7. He is a high risk client likely to spread tuberculosis.

- Strongly Agree
- Agree
- Neutral
- Disagree
- Strongly Disagree

8. If he does not voluntarily comply with tuberculosis drug treatment, he should be physically forced to take antitubercular medications.

- Strongly Agree
- Agree
- Neutral
- Disagree
- Strongly Disagree

Page #4

Section Two: For each question, please select the answer that best describes your opinion.

9. Which of the following answers best describes the reason why the spread of tuberculosis should be stopped:

- TB interferes with a person's ability to provide for him or herself.
- TB reduces a person's future life options or opportunities.
- TB physically harms a person.
- TB interferes with an individual's personal freedom.

10. Which of the following answers best describes the reason why persons with schizophrenia should take antipsychotic medication and receive psychosocial support:

- Untreated schizophrenia interferes with a person's ability to provide for him or herself.
- Untreated schizophrenia reduces a person's future life options or opportunities.
- Untreated schizophrenia physically harms a person.
- Untreated schizophrenia interferes with an individual's personal freedom.

Page #5

Section Three: For each statement, please indicate your level of agreement.

11. An individual should obey a public health isolation order even if it causes him or her psychological distress.

- Strongly Agree
- Agree
- Neutral
- Disagree
- Strongly Disagree

12. An individual should obey a public health isolation order even if it makes him or her psychiatrically ill.

- Strongly Agree
- Agree
- Neutral
- Disagree
- Strongly Disagree

13. An individual should obey a public health isolation order even if it worsens a preexisting psychiatric illness.

- Strongly Agree
- Agree
- Neutral
- Disagree
- Strongly Disagree

14. Public Health should have the power to order people into quarantine during infectious disease outbreaks.

- Strongly Agree
- Agree
- Neutral
- Disagree
- Strongly Disagree

15. If someone is given a quarantine order by Public Health, they should follow it no matter what else is going on in their life at work or home.

- Strongly Agree
- Agree
- Neutral
- Disagree
- Strongly Disagree

Page #6

16. If there is a _____ chance that an individual's action may accidentally harm another person, then that action should not be allowed.

- 20%
- 40%
- 60%
- 80%
- 100%

Page #7

17. It is wrong for an individual to harm innocent bystanders by causing them physical pain.

- Strongly Agree
- Agree
- Neutral
- Disagree
- Strongly Disagree

18. It is wrong for an individual to harm innocent bystanders by causing them psychological pain.

- Strongly Agree
- Agree
- Neutral
- Disagree
- Strongly Disagree

19. It is wrong for an individual to harm innocent bystanders because it interferes with the bystanders' ability to provide for their own basic necessities.

- Strongly Agree
- Agree
- Neutral
- Disagree
- Strongly Disagree

20. It is wrong for an individual to harm innocent bystanders because it interferes with the bystanders' ability to achieve their life goals.

- Strongly Agree
- Agree
- Neutral
- Disagree
- Strongly Disagree

Page #8

21. Individuals with a psychiatric diagnosis should not be allowed to physically harm themselves.

- Strongly Agree
- Agree
- Neutral
- Disagree
- Strongly Disagree

22. Individuals without a psychiatric diagnosis should not be allowed to physically harm themselves.

- Strongly Agree
- Agree
- Neutral
- Disagree
- Strongly Disagree

23. Individuals with a psychiatric diagnosis should not be allowed to act in such a way as to reduce opportunities later in life.

- Strongly Agree
- Agree
- Neutral
- Disagree
- Strongly Disagree

24. Individuals without a psychiatric diagnosis should not be allowed to act in such a way as to reduce opportunities later in life.

- Strongly Agree
- Agree
- Neutral
- Disagree
- Strongly Disagree

Page #9

25. Trespassing on another person's property is wrong even if the owner never finds out.

- Strongly Agree
- Agree
- Neutral
- Disagree
- Strongly Disagree

26. Trespassing on another person's property is wrong even if it does not disturb the property.

- Strongly Agree
- Agree
- Neutral
- Disagree
- Strongly Disagree

27. Silencing an individual's freedom of speech is wrong even if that individual never finds out.

- Strongly Agree
- Agree
- Neutral
- Disagree
- Strongly Disagree

28. Looking through an individual's bag is wrong even if that individual never finds out.

- Strongly Agree
- Agree
- Neutral
- Disagree
- Strongly Disagree

Page #10

Section Four: Demographics

For each question, please select the response best represents you.

29. At what type of organization do you work?

- Public Health Unit - Tuberculosis
- Public Health Unit - Family/Maternal/Child Health
- Mental Health Facility

30. Please select the response that best describes your current position.

- Frontline Healthcare Worker
- Administrator/Decision Maker
- Other ___________________________

31. How long have you worked in your current position?

- Less than 1 year
- 1-5 years
- 6-10 years
- 11-15 years
- 16-20 years
- Greater than 20 years

32. Please provide the year of your birth (e.g. 1973).

____

33. Do you identify as:

- Woman
- Man
- Transgendered

34. Were you born in Canada?

- Yes
- No

35. Thank you for taking the time to participate. Do you have any questions or comments for us?

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Should you have any questions or comments, please feel free to contact Diego Silva, PhD Candidate, at diego.silva@utoronto.ca.