THE ROLE OF PATIENT REPRESENTATIVE IN THE *MENTAL HEALTH CARE AND TREATMENT ACT*

by

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ABSTRACT

The *Mental Health Care and Treatment Act* of Newfoundland and Labrador introduced new provisions for patient rights, including access to a Patient Representative of the patient's choosing. This thesis explores the experience of one Patient Representative and the author provides an autoethnographic narrative using her experiences as a mental health nurse, manager and policy maker during the same timeframe. Themes of lack of empathy and respect for both the Patient Representative and the client as well as the need for advocacy and management accountability were identified by the Patient Representative and supported by the author through her autoethnographic narrative.

Recommendations include providing a Patient Representative role that is a paid independent advocate and creating a separate provision for families/caregivers to be involved in the treatment plan. This would support caregivers in their already full roles and allow a better balancing of the patient’s right to autonomy with the duty of care.

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I also wish to thank the lone participant for this study, who spent many hours in discussion with me as we journeyed together through his experiences as a Patient Representative and a caregiver. This thesis simply would not have happened without him.

Finally, to my husband Larry, my children Allison (Brian), Jeff and Hillary and my parents Tom and Theresa Lundrigan, my love and thanks for your constant and unconditional support, not just during my thesis but always.

This thesis is dedicated to the memory of Norman Reid, one of my first patients, who died as a result of untreated mental illness.

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LIST OF ABBREVIATIONS

MHCTA	Mental Health Care and Treatment Act
CRDP	Convention on the Rights of Persons with Disabilities
U.S.	United States
SSNL	Schizophrenia Society of Newfoundland and Labrador
CHANNAL	Consumer Health Awareness Network of Newfoundland and Labrador
ECT	Electroconvulsive Treatment
CEO	Chief Executive Officer

LIST OF APPENDICES

Chapter 1-Introduction

1.1 Purpose and Overview

About 500 times each year in Newfoundland and Labrador, a mentally ill person is detained against her/his will and brought to a psychiatric facility. On about 175 of those occasions s/he is hospitalized involuntarily under the *Mental Health Care and Treatment Act* (2006) and given psychiatric treatment without consent. Involuntary psychiatric hospitalization is coercive and usually includes detention in a locked facility. During hospitalization patients may be subjected to treatments such as potent psychotropic medication and/or electroconvulsive therapy or they may be placed in seclusion or restraints.

The Patient Representative is an individual who represents a person who is involuntarily hospitalized. Involuntary patients choose whether they have a Representative and who will represent them. Family members and/or caregivers are often asked to fulfill this role.

The purpose of this thesis is to review the role of the Patient Representative within the Newfoundland and Labrador *Mental Health Care and Treatment Act* (*MHCTA).* This will be done by examining one person's experience in the role of Patient Representative utilizing a case study approach within an autoethnographic narrative.

1.2 Study Objectives

The case study will concern a caregiver for a mentally ill person who has been in the role of Patient Representative for that person on two occasions and has been in the role of caregiver for about 25 years. During those 25 years I had employment roles as a mental health nurse, manager/administrator and policy advisor/maker in the mental health system. Therefore, I have chosen to examine this case study within an autoethnographic narrative.

My research questions are:

1. What is the experience of the Patient Representative role as outlined in the *MHCTA?*

2. What can we learn from this experience?

The specific objectives of my thesis are:

1. To examine the experience of one Patient Representative before and after the *MHCTA* (2006) came in force, using case study methodology.

2. To support the case study data with an autoethnographic narrative of my work experience before and after the *MHCTA* (2006) came into force.

3. To identify what has been learned from the data about the Patient Representative role.

1.3 Thesis Organization

This thesis is organized into 5 chapters. Chapter 2 will provide a review of literature on: mental health legislation and coercion; advocacy and involuntary hospitalization; procedural justice and human rights issues; and family and caregiver issues. Chapter 3 will provide an explanation of my methodology and methods for collecting and analysing the data. Chapter 4 covers my findings from the case study and autoethnographic narrative, including four themes identified from my interviews with the Participant. Chapter 5 discusses the data generated including: themes generated and issues associated with the Patient Representative role, the involvement of caregivers in the treatment plan, and human rights issues such as the right to autonomy vs. the duty to care. It also provides recommendations for policy related to the Patient Representative role; potential for future directions in legislation; limitations of the study and areas for future research.

1.4 Background

Mental health legislation acknowledges the need to provide psychiatric treatment to the relatively small number of acutely mentally ill individuals who do not seek care because of the symptoms of their illness. Such legislation exists throughout the world and in every province and territory in Canada. The World Health Organization reports the aim of mental health legislation is "to protect, promote and improve the lives and mental well-being of citizens" (World Health Organization, 2005, p.1). Mental health legislation exists in most countries and has been around for centuries, yet it has only been since the

United Nation's *Universal Declaration of Human Rights* in 1948 that it began to be informed by human rights (Kelly, 2011).

Gray, Shone and Liddle (2008) report that in Canada, the *Constitution Act* is the supreme law and all provincial legislation must uphold it. The *Constitution Act* contains the *Canadian Charter of Rights and Freedoms* (1982) which sets out fundamental rights and freedoms for all Canadians and requires individuals must be told their rights when involuntarily hospitalized (Gray, Shone & Liddle, 2008). Each province and territory has its own mental health legislation, which should be in compliance with the *Canadian Charter of Rights and Freedoms*, and could be challenged in the courts if not in compliance.

Newfoundland and Labrador is the most eastern province in Canada, with a population of about 527,000. On October 1, 2007, the Government of Newfoundland and Labrador proclaimed the *MHCTA* which replaced the *Mental Health Act* (1971). The *Mental Health Act* (1971) pre-dated the *Canadian Charter of Rights and Freedoms* and was silent on rights for involuntary patients. The *Mental Health Act* (1971) did include the right of the involuntary patient to appeal to a review board. However many patients did not know about the review board. There were no legislated procedural safeguards in place to inform them of their rights and no advocacy. New provisions in the *MHCTA* (2006) include a section on patient rights as well as timelines for patient appeals to the review board to be heard and decided upon and roles for a Rights Advisor and a Patient Representative.

In this province, to be involuntarily hospitalized according to the *MHCTA* (2006), two independent assessments of the person are required. The first may be done by a physician or nurse practitioner. The second must be undertaken by a psychiatrist, or by another physician if a psychiatrist is not readily available. Those completing the assessments must consider the following criteria:

> ... as a result of the psychiatric assessment, he or she is of the opinion that the person who is named or described in the certificate
>
> (i) has a mental disorder, and
>
> (ii) as a result of the mental disorder
>
> (A) is likely to cause harm to himself or herself or to others or to suffer substantial mental or physical deterioration or serious physical impairment if he or she is not admitted to and detained in a psychiatric unit as an involuntary patient,
>
> (B) is unable to fully appreciate the nature and consequences of the mental disorder or to make an informed decision regarding his or her need for treatment or care and supervision, and
>
> (C) is in need of treatment or care and supervision that can be provided only in a psychiatric unit and is not suitable for admission as a voluntary patient;
>
> *MHCTA*, 2006, section 17(1) (b)

The *MHCTA* addresses assessing a person's capacity to provide consent only indirectly. That is, embedded in the criteria for being certified in section 17(1)(b)(ii)(B) is the requirement that the person is "...unable to fully appreciate the nature and consequences of the mental disorder or to make an informed decision regarding his or her need for treatment or care and supervision." This would indicate the person's lack of capacity to provide consent. Hence patient consent is not sought. There is provision in the legislation for the attending physician, taking into account the involuntary patient's best interests, to diagnose and treat the patient without her/his consent (*MHCTA*, 2006, Section 35(1)). There are no provisions in this legislation for supported or substitute decision making.

The legislation provides, among other rights, access to a Patient Representative. The Representative, as defined in the *MHCTA* (2006),

> "means a person, other than a rights advisor, who has reached the age of 19 years and who is mentally competent and available who has been designated by, and who has agreed to act on behalf of, a person with a mental disorder and, where no person has been designated, the representative shall be considered to be the next of kin, unless the person with the mental disorder objects". (*MHCTA*, 2006)

There are no sections in the Act devoted specifically to the role of the Patient Representative, but in various provisions the Patient Representative is included when describing processes involving the involuntary patient. According to the *MHCTA* (2006), a person who is an involuntary patient shall not be denied access to their Representative (Section 12). The Patient Representative is to be informed of the person's rights under the Act and can apply to the review board on behalf of the involuntary patient for a review of the certificates of involuntary admission (*MHCTA*, 2006, Section12). The Representative is also contacted by the rights advisor and informed of the person's rights and the Representative may contact the Rights Advisor for assistance with an application to the Review Board or with obtaining legal counsel (*MHCTA*, 2006, Section 14). During the course of administering treatment, the physician and another health professional shall, where appropriate,

> (a) consult with the involuntary patient and his or her representative;
>
> (b) explain to the involuntary patient and his or her representative the purpose, nature and effect of the diagnostic procedure or treatment; and
>
> (c) give consideration to the views of the involuntary patient and his or her representative with respect to the diagnostic procedure or treatment and alternatives and the manner in which diagnostic procedures or treatment may be provided. (*MHCTA*, 2006, Section 35)

At the point of involuntary hospitalization patients are asked who they wish to have as a Patient Representative. This decision, one of the few decisions an involuntary patient may make associated with their hospitalization, is expected of the patient when they are acutely mentally ill and at what is likely to be a very stressful point in time. The legislation does not provide a process for becoming a Patient Representative, nor does it have a process for removing oneself from the role. Patient Representatives are often family members, however, they are not always family members and may not even know the patient well. There have been occasions when involuntary patients have "fired" their Patient Representative and named another person or a third or fourth individual to represent them.

Prior to the deinstitutionalization of persons with severe and persistent mental illness in the 1960s and 70s, they were cared for in psychiatric institutions. Since deinstitutionalizing persons with mental illness, families' roles have increased to providing housing, financial and other supports. In many instances, family members of persons with severe and persistent mental illness become their caregivers. A common concern that I have heard from families in my career as manager and policy maker has been that as family members, they have all the responsibility of providing care and support to their mentally ill family member, but do not get support from the system. Also, they are not included in the treatment plan while their family member is hospitalized, yet they are expected to provide the care and treatment after discharge.

The introduction of the *MHCTA* (2006) was a watershed moment in the history of mental health care for this province. Although various committees had been struck throughout the late 1970s and 1980s to develop policy directions for new legislation, none resulted in a new mental health act. Yet again in the late 1990s a stakeholder group met to update the policy directions to reflect the current best practice of the day. I am aware of this because I have worked in the mental health system since 1979, when I took a summer job at the local psychiatric hospital while I was a nursing student. My interest in the *MHCTA* stems from my experiences as a mental health nurse for the first 10 years of my career, and then as an administrator and policy advisor in mental health.

The new *MHCTA* (2006) resulted from recommendations of an inquiry into the shooting deaths of two men. In 2000, two men, in separate confrontations with police just 6 weeks apart, were shot to death by police in Little Catalina and Corner Brook, respectively. Little Catalina is a rural community of about 450 people on the east coast of Newfoundland in Trinity Bay. Corner Brook is a town of about 20,000 people located on the west coast of the island of Newfoundland. Both men had histories of mental illness and both were shot in front of their homes in the presence of family members. The judicial inquiry into their deaths recommended a new mental health act that would, among other things, review certification criteria, introduce community treatment orders, take a rights-based approach and include appropriate procedural justice (Luther Report, 2003).

Among other things the *MHCTA* provides procedural justice, including timelines, access to a Patient Representative and a Rights Advisor, and automatic reviews of the legislation by a provincial review board. This thesis focuses specifically on the role of the Patient Representative.

1.5 Rationale

In all instances of detainment and involuntary hospitalization, coercive measures are employed to keep the individual for assessment and/or admit the individual to hospital for treatment. As a mental health nurse, I have participated in many instances of forced treatment, and have witnessed the effects on the person coerced and also experienced personal effects from physically restraining and forcing medication on patients. As a manager, I have heard and investigated complaints from patients who were involuntarily hospitalized and coerced to take treatment. However, mostly, I have heard from family members and others who advocate strongly for their loved ones' right to treatment to be considered more in balance with their right for autonomy.

The coercive effects of certification, or involuntary hospitalization, on the patient should not be underestimated. The Patient Representative is the only legislated role that can advocate on behalf of the involuntary patient. It is therefore important to learn how that role is experienced.

It was a natural choice for me to pick this research because I have been immersed in this work and understood the significance of the Patient Representative role. I did not originally plan to do an autoethnography, and will explain that process later. I believe what we know socially is constructed and in the field of qualitative research, I have incorporated methods such as crystallization and writing-stories (Richardson, 2011), showing and telling and reflexive journaling (Ellis, Adams & Bochner, 2011) as ways to include my insider perspective. I believe having an insider perspective has provided some additional insights into what can be learned about the experience of the Patient Representative.

Chapter 2-Literature Review

2.1 Introduction

The purpose of this chapter is to review what is known and not known about the Patient Representative role, or similar roles, within mental health legislation. Mental health legislation is a broad term and depending on the context can include provisions in the Criminal Code, adult protection legislation and adult guardianship. For the purposes of this review, mental health legislation will focus on mental health acts which facilitate psychiatric treatment.

Embedded within the purpose of the current *MHCTA* is "to provide for the rights of persons apprehended, detained, restrained, admitted, assessed, treated and cared for and supervised under this Act" (*MHCTA*, 2006, Section 3(d)). The Patient Representative role, the subject of my study, is one of those rights.

These rights, including the right to a Patient Representative, are important provisions in this legislation because of the power provided in other provisions to physicians and treatment teams to force patients to undergo treatment that they have refused. In this province, families and caregivers are often the informal advocates who do not have a formal role once the patient is involuntarily hospitalized. Not only does the patient not have the ability to consent or refuse treatment, neither does the next of kin. The patient names the Patient Representative who may or may not be a family member or caregiver. Reviewing concepts such as coercion, advocacy and family/caregiver issues in relation to involuntary treatment are therefore central to the understanding of the Patient Representative role.

In this chapter I will provide literature on mental health legislation, factors associated with involuntary commitment, historical context for treatment of the mentally ill, coercion and its effects on involuntary patients, advocacy for those involuntarily hospitalized, procedural justice and patient rights, the Recovery movement, and family and caregiver issues. Reviewing what is known about these concepts will help position this study and will identify where this study is situated in the research, the gaps in the body of knowledge and how this study will attempt to address those gaps. My research questions are to explore the experience of the Patient Representative role in the *MHCTA* (2006) and determine what can be learned from this experience.

From this review of literature I will show that while there is evidence to support an advocacy role such as the Patient Representative for individuals involuntarily hospitalized, I was unable to find any studies of similar roles within mental health legislation. Terms searched in different combinations included "patient representative", "involuntary hospitalization", "civil commitment", "patient rights”, “coercion”, "mental health legislation", "advocacy", "human rights", "patient advocate" and "advocate role". Search engines included PubMed, PsycINFO, Sociological Abstracts, Sage Journals, Sociological Index and CINAHL. Studies described roles of caregivers, family members, or paid advocates not known or appointed by the involuntary patient. As such, my thesis will provide beginning information on an advocacy role such as the Patient

Representative role in mental health legislation, based on the case study of one Patient Representative's experience within an autoethnographic narrative.

2.2 Mental Health Legislation

Gray, Shone and Liddle (2008) report that to understand mental health law, one must have an appreciation for the effects of severe untreated mental illness, which can be devastating for individuals and their families/loved ones. Multiple testimonials of untreated mental illness reveal loss of job, home, friends and can lead to suicide, or in rarer instances, harm to others and homicide. Mental health legislation has been around in the U.K. and Canada since the mid 1850s, when it was first understood that mental illness was an illness that may require hospitalization and treatment. Mental health laws exist in most countries. China's first mental health law was passed in 2012 (Phillips et al., 2013).

One of the first mental health laws that provided involuntary treatment for persons with mental illness was the *British Lunatic Asylums Act, 1853*. Canada's provincial mental health laws had their roots from this legislation (Gray, Shone & Liddle, 2008). This statute provided for involuntary admission criteria and procedures, and community treatment with a leave of absence. There was no separation of admission and treatment, that is, if one was detained and admitted, one then received treatment. The legislation contained few rights and safeguards, other than the need for two physicians or a physician and judge to commit the individual to hospital and an established committee to ensure good care and hear and act on complaints. As a result, for dozens of years individuals who were committed to hospital "…lost many civil rights including the right to vote, to marry, to own property, to sue and other rights" (Gray, Shone & Liddle, p. 35).

Up until the mid 1970s mental health laws in Canada, the U.S. and the U.K. were similar in this approach. The humanistic perspective, also known as the need for treatment perspective, posits mental health laws are necessary because the person is ill. Those sharing this perspective believe the psychiatrist/team as clinicians are focused on the evidence of medical need for treatment, know medications are effective in treating symptoms, understand treatment follows admission, see admission as therapeutic; and believe individuals will get better, realize they needed treatment and will seek it in future.

Those with this ideology generally advocate for broad criteria for commitment to provide for "deterioration", that is, to provide for involuntary hospitalization when it is known that the person has previously deteriorated to a point of requiring involuntary hospitalization and will likely do so again if they have stopped treatment and symptoms have resurfaced (Schizophrenia Society of Ontario, 2013).

The U.S. began to introduce dangerousness criteria to state mental health laws which tightened certification criteria and abolished the criteria related to a need for treatment. These changes were referred to "…as the 'Magna Carta' of the mentally ill, promised to limit the number of people subject to incarceration and to save money at the same time. Such an appeal to fiscal conservative politicians and liberals concerned with civil rights violations was irresistible" (Gray, Shone & Liddle, 2008, p. 47). These provisions that restricted involuntary hospitalization made their way across the border to Canada where most provincial legislation, including that of Newfoundland and Labrador, adopted dangerousness criteria.

These restrictive revisions to mental health laws internationally were greatly influenced by civil libertarianism and the perspective that mental illness is not an illness but a social construction. In *Creating Mental Illness* (2002), Sociologist Allan V. Horwitz writes "In contrast to the disease model, the social constructionist view sees systems of knowledge as reflections of culturally specific processes. The central assumption of the constructionist tradition is that mental illnesses are inseparable from the cultural models that define them as such" (p. 6), whereas, the disease model regards diseases occurring naturally, regardless of any social meaning that may be attached to them (Horwitz, 2002, p.4).

Psychiatrist and theorist Thomas Szasz was a civil libertarian who took a different approach. He defined libertarianism as the rejection of using violence or threatening violence to impose will or point of view on a peaceful person; as well as being free of arbitrary government interference (Szasz, 2004). A common definition of mental illness includes alterations in thinking, mood or behavior brought on by a complexity of biological, genetic and environmental factors (Canadian Mental Health Association, 2002; World Health Organization, 2012). Szasz consistently and ardently challenged these fundamental understandings of mental illness. In his seminal book *The Myth of Mental Illness*, Szasz laid down the foundation of his theory on mental illness, or as he termed it, the “medicalization of disturbing or disturbed behaviours” (1974, p. 3). Szasz wrote numerous essays, articles and 25 books describing his argument that there are no mental illnesses, just physical illnesses, which include diseases of the brain; and that observing a cluster of behavioural symptoms and diagnosing a mental illness is a violation of human rights; and robs individuals of their responsibility to own their behaviour and make choices (Szasz, 1974).

Szasz was particularly critical of the practice of civil commitment and compared the history of civil commitment to the history of slavery and the practice of institutional psychiatry to the Inquisition (Szasz, 2010). He made it his life’s work to put forward the argument that psychiatry and mental illness have no place in medicine; that any brain disease with an organic cause is a physical illness and labelling people mentally ill is not diagnosis, but stigmatization (Szasz, 1974).

For Szasz, the most critical result of medicalizing mental illness is the power given to medicine through legislation to control behaviour through coercive means:

> Indeed, psychiatrists never tire of asserting and reasserting their right to deprive people of liberty. In 2005 Steven S. Sharfstein, president of the APA, reiterated his and his profession's commitment to coercion: 'We must balance individual rights and freedom with policies aimed at caring coercion.' The term 'caring coercion' would have fitted perfectly into the Nazi lexicon, along with Arbeit macht frei ('labor liberates') and Gnadentot ('mercy death'). (Szasz, 2006, p18)

Szasz's perspective, which was shared by some psychiatrists, psychologists and sociologists of the day, greatly influenced the changes made to U.S. and then Canadian mental health legislation.

Several authors believe mental health legislation is necessary to protect the rights of people with mental illness because they are vulnerable to stigma, discrimination and therefore rights violations (Kelly, 2011; Latif & Malik, 2012; Stylianos & Kehyayan, 2012). Others believe mental health legislation itself is stigmatizing. In Newfoundland and Labrador, mental health legislation is separate from the advanced health care directive legislation for individuals who lose capacity to provide consent due to medical illness. If a person is involuntarily hospitalized under the *MHCTA* (2006), the provisions of the *Advanced Health Care Directive Act* (1995) which provide for substitute decision making, do not apply to them.

Szmukler, Daw and Callard (2014) believe there should be a single unifying legislation for involuntary medical or psychiatric treatment, and only for persons incapable of decision making, regardless of the reason for the incapacity. Callaghan, Ryan and Kerridge (2013) agree and also argue there is a propensity to couple mental illness with incapacity.

> Autonomy should be considered the paramount right of all persons…the right to make self-determining decisions should be based on whether or not a person has decision -making capacity, *not* on whether a person has a mental illness or is considered to be 'vulnerable'…this remains the case even if the person is thought to be at risk of suicide. (p. 375)

Carney (2007) also questions whether specific mental health legislation is necessary and argues there is renewed support for "subsuming mental healthcare within the general laws governing consent to care or determinations of competence" (p. 482).

Others believe the opposite, that is, there is too much value placed on the right to autonomy for persons with mental illness and not enough emphasis placed on their right to treatment and that clinicians may overestimate patient's capacity (Gray, Shone & Liddle, 2008; Lepping & Raveesh, 2014; Owen et al., 2009).

> By putting most of our ethical eggs in the autonomy basket we have neglected other important principles. This has led to clinical situations in which basic needs of patients such as safety, food and social contacts can get neglected for the higher good of autonomy. (Lepping & Raveesh, 2014, p.1)

In recent years, international mental health law reform has drawn on the human rights movement. The 2008 *Convention on the Rights of Persons with Disabilities* (CRPD) has been considered by many as a new era in relation to how mental health laws should be reformed (Mcsherry & Wilson, 2011).

The *Canadian Charter of Rights and Freedoms* (1982) prompted changes in provincial and territorial legislation to ensure mental health laws upheld Charter rights. However, most of the significant changes over the past two decades in Canadian mental health laws have concentrated on the way capacity and consent have been addressed as well as a broadening of involuntary treatment to include deterioration clauses in certification criteria and/or provision for community treatment orders. Newfoundland and Labrador is one of 5 provinces that currently has provision for community treatment orders. This province's *MHCTA* addresses capacity and consent issues by only providing for those without capacity to be involuntarily hospitalized or subject to a community treatment order. There are no decision making abilities such as a substitute decision maker. Neither the Patient Representative nor next of kin can engage in a process of supported decision making with the involuntary patient. There is no ability for the Patient Representative to sign consent or make treatment decisions on behalf of the involuntary patient and no ability for the involuntary patient to make treatment decisions, only to be given consideration for their views.

This province has chosen to provide the most direct route for involuntary treatment by leaving treatment decisions with the involuntary patient's psychiatrist (Gray, Shone & Liddle, 2008). The only other province that does this is Saskatchewan. New

Brunswick has a tribunal to provide consent for treatment. In British Columbia, consent for treatment decisions is provided by the director of the program and in Quebec the court provides authorization for treatment. Nova Scotia, Prince Edward Island, Ontario, Manitoba and Alberta have substitute decision makers, which are next of kin or if no next of kin, are appointed by the Court (Gray, Shone & Liddle, 2008).

Within the *Advance Health Care Directives Act* (1995), for persons who are deemed not competent, a substitute decision maker may be named to make health care decisions on behalf of the person, based on a gradation of next of kin. However, this substitute decision making only covers psychiatric treatment when the person is not certified under the *MHCTA*. The involuntary patient in this province is excluded in the provisions for an advanced health care directive and substitute decision making. In Canada, only Saskatchewan and Newfoundland and Labrador have mental health laws that do not provide a process for obtaining consent.

Newfoundland and Labrador is the only province in Canada that has a legislated role of Patient Representative, named by the patient, and a government appointed Rights Advisor. Other provincial mental health laws have a combination of substitute decision makers, rights advisors, paid advocates and formal roles for next of kin.

2.3 Factors associated with involuntary commitment

In any given year, epidemiologists have determined that 20% of the population has a diagnosable mental disorder and approximately 2.5% of those have an illness so severe, they may lose insight into the fact that they are ill (Kessler, Chui, Demler & Walters, 2005). A lack of insight into being ill is considered a significant risk factor for involuntary admission (Kelly et al., 2004). In other words, some individuals experience the symptoms of acute mental illness such as hallucinations or delusions and, because it is the brain that is affected by these illnesses, awareness and cognitive ability are affected. In some individuals, awareness and cognitive ability are affected to the extent they are unable to understand these are symptoms of being ill.

McGarvey (2013) identified what many in the mental health community report anecdotally, that is, a lack of intensive community treatment and support contributes to a significant amount of variability in the actions leading to involuntary admission to hospital. Other risk factors include having a diagnosis of schizophrenia (Ng & Kelly, 2012) or other psychotic disorder (Eytan, Chatton, Safran & Khazaal, 2013; Myklebust, Sorgaard, Rotvold & Wynn, 2012; van der Post et al., 2009); an involuntary status on a first admission (Fennig, Rabinowitz & Fennig, 1999; Kelly et al., 2004) or previous admission (Van der Post et al., 2009); being admitted as an emergency (Myklebust et al., 2012); risk of self-harm or harm to others (McGarvey, Leon-Verdin, Wanchek & Bonnie, 2013; Mulder et al., 2008); and substance abuse or dependence (Hustof et al., 2013; McGarvey et al., 2013; Mulder et. al, 2008). In several countries involuntary admission has been associated with socio-economic deprivation (Bindman, Tighe, Thornicroft & Leese, (2002) as cited in Ng and Kelly (2012)). Webber and Huxley (2004) found correlations between involuntary hospitalization and low social support.

2.4 Historical View of Persons with Mental Illness

A historical perspective can provide some context for the early treatment of those with mental illness. During the 17th Century, there was no conception that those then considered "mad" needed medical care. While people who were physically ill in the 17th century were treated in hospitals and at home by physicians, people with mental illness, or "madmen" according to French philosopher Michel Foucault, were signed into houses of confinement (Foucault, 1961). They were objectified, not seen as ill, not even seen as human beings. Foucault believed the mentally ill of the 17th Century were thought to be beast- like, and in need of neither punishment nor treatment:

> Madness here took its face from the mask of the beast. The men chained to the walls of the cells were not seen as people who had lost their reason, but as beasts filled with snarling, natural rage, as though madness at its furthest point was liberated from the moral unreason where its milder forms languished, and was revealed in all its immediate, animal violence. (Foucault,1961, p. 147)

Conditions in these houses of confinement were deplorable; people were kept in cages or chained to walls, often naked with just straw beneath their feet. The role of physicians was not for the care and treatment of those within these institutions of confinement but more to ensure the infections that were rampant inside the walls did not infect those outside.

The practice of confinement began to wane prior to the French Revolution and over time, legislation and financial support were provided for families to take care of their physically unwell, disabled and even poor family members. Foucault says during this time there was "...a moral rehabilitation of the figure of the Pauper" (p. 407); the poor had never been fully objectified, rather, poverty existed as a result of economics that affected some people. Thus, “...the great envelopment that made for the confused unity of unreason is now broken. Madness becomes individualized, strangely twinned with crime...they alone are that which merit confinement" (Foucault, 1961, p. 401).

Following the French Revolution, the monarchy, aristocracy and religion were overthrown by new enlightenment principles of equality, citizenship and inalienable rights (Foucault, 1961). The state of madness was still seen not as medical, but pitiable, and a decree was passed that madmen would be set free. However, the ensuing public concern of madmen being set free created further legislation that coupled the insane with dangerous animals that the public needed protection from. Once again, madmen returned to animal status (Foucault, 1961).

In 1792, large institutions in Paris such as Bicetre and the Salpetriere were named to take in the insane and in 1793, Dr. Philippe Pinel began removing the chains of the mentally ill (Foucault, 1961). Pinel holds a special place in psychiatric history and is often referred to as the founder of modern psychiatry. Indeed, it is at this place in history Foucault sees transformative changes in the conditions of the experience of madness, in terms of “forms of liberation", such as the suppression of confinement and the right of expression; and "structures of protection" such as the asylum as a form of confinement to regain truth (p. 459). However, within these structures of protection, Foucault describes a place for madness where it can be gazed upon subjectively, thereby completing its objectification:

> When the madness was recognized through the movement of separating from it, and measuring the distance from it in the reality of concrete institutions, the eighteenth century tension suddenly vanished...This possibility of grasping madness as something known and mastered at a stroke, in one single act of consciousness, was at the heart of the positivist experience of mental illness...this is not to say that knowledge entirely clarified it, but that starting from madness, and the status of object that had been conferred upon it, in theory at least, man could become entirely transparent to scientific investigation. (p.461)

During the 19th century there was a proliferation of asylums across England, France and North America. Pinel in France and Samuel Tuke in England heralded in what Foucault terms the "birth of the asylum" (1961, p. 463). Tuke, who was a Quaker, provided "moral treatment" through work. Asylums in England were deliberately built in the country to be close to nature and treatment consisted of being close or returning to nature, working the ground and being productive.   Foucault (1961) refers to Tuke's Moral Treatment as treatment that reunites man with reason in the form of nature, truth and morality. At the end of the "retreat" in the asylum, social morality is restored (p. 475).

For Foucault then, this marked a major transition in the social construction of madness, but not the liberation of those deemed insane. Rather, Foucault saw this as another form of confinement, this time, into the language and positivism of medicine and the beginning of internment of madness into medicine.   Horwitz (2002) states "For Foucault, mental illness did not exist until the seventeenth century...before then madness was linked with wisdom and insight, and since then it has been associated with alien forces that must be controlled by reason or by chains" (p.8).

The purpose of asylums was to restore those in them to moral living. People with mental illness were to be pitied and taken care of. Most people entering these asylums did not leave, until the advent of psychotropic medication in the 1950s. The asylum had become " ... a specialized, highly rationalized, bureaucratically-organized, state-supported asylum system, which isolated the insane, both physically and symbolically, from the rest of the community. It was, most agreed, a triumph for science and humanity" (O'Brien, 1989, p. 23).

As a colony of Britain at that time, Newfoundland was influenced by this experience. The local psychiatric hospital was originally built in 1855 as one of these asylums, at the time situated outside the city with farmland surrounding it. At the beginning of my career there were still elderly patients living there who had been "signed in" to the asylum by their relatives 50 or 60 years previous as either children or young adults. These patients referred to male staff at the hospital as "keepers". I witnessed great kindness but also great insensitivity to these patients.

Today's society continues to objectify those with mental illness, witnessed in stigmatization and discrimination. The Mental Health Commission of Canada (2012) reports some of the most stigmatizing experiences come from health care providers. Reynders, Kerkhof, Molenberghs, and Van Audenhove (2014) report stigma keeps people from accessing help and increases risk of suicide. Health care providers are therefore a target group for anti stigma initiatives, which have the best results if they include people with lived experience of mental illness telling their stories of recovery (Knaak, Modgill & Patten, 2014).

2.5 Coercion

According to Cambridge Dictionaries Online (n.d.), the term “to coerce” means "the use of force to persuade someone to do something they are unwilling to do". Coercion arises from a power imbalance. In medicine generally, this may be experienced by the patient through the physician's expertise and control of resources. In psychiatry, however, this power imbalance is magnified by the power to enforce treatment (Bingham, 2012; Zola, 1972).

In most countries, coercion plays a central but highly controversial role in mental health services and in mental health legislation (Myklebust et al., 2012; Pescosolido, Monahan, Link, Stueve & Kikuzawa, 1999; Salize & Dressing, 2005). Coercive interventions include "…restraints, locked units, quiet rooms, involuntary hospitalizations, and (in some cases) medications through which the will of clinicians and the power of institutions are enacted upon the bodies of psychiatrically defined individuals" (Lovell & Rhodes, 2014, p.618).

Formal coercion refers to the power given to clinical staff from legislation to force individuals to be psychiatrically assessed; and then detained, restrained, admitted to hospital and treated without consent. Informal coercion refers to the influence of family members and health care providers on the individual through ongoing reminders of appointments or warnings about consequences of not taking medication (Swartz, Swanson & Hannon, 2003); and persuasion by the person’s psychiatrist and family giving reasons why the patient would benefit from hospitalization (Monahan et al., 1995).

Lovell and Rhodes (2014) express concern that what is emerging today in psychiatry can be traced back to the era of confinement as described by Foucault. It has just been reconfigured and joined to not only hospitals but also community through the involuntary hospital and community treatment of the mentally ill.

The perception of coercion by the person and not those around the person is critically important. Coercion is a contextually dependant and moralized phenomenon

(Gardner et al., 1993). In other words, it is a social construction, dependant on the context of the situation and the person’s experience. Coercion may be experienced with persuasion, inducement (an exchange of something positive for agreeing to admission), threats, show of force (calling hospital security), physical force (restraint), legal force (involuntary hospitalization), giving orders, and deception (Lidz et al., 1997).

Rusch et al. (2014) studied 186 individuals who experienced involuntary hospitalization in four different psychiatric facilities in Zurich. They assessed for a number of negative emotional reactions resulting from involuntary hospitalization and found more self-stigma was predicted independently by higher levels of shame, self-contempt and stigma stress: "Shame and self-contempt as reactions to involuntary hospitalization as well as stigma stress may lead to self-stigma, reduced empowerment and poor quality of life" (p. 35). These findings remained significant after controlling for psychiatric symptoms, diagnosis, age, gender and the number of lifetime involuntary hospitalizations. The authors suggest that "because the number of lifetime involuntary hospitalizations was not associated with self-stigma or empowerment suggests that it is less the quantity of coercive experiences than their perceived emotional and cognitive quality that determines their impact" (p.40). This helps to further understand the subjective nature of the experience of coercion.

Hoyera et al. (2002) in their study on the use of coercion in the mental health system, state coercion may be justified insofar as involuntary treatment improves the individual's illness and outcome over no coercion (and thus no treatment), for individuals who are refusing: "The underlying belief is that patients suffering from serious mental disorders usually are unable to understand their need for treatment, thus justifying paternalistic interventions" (p. 93).

In mental health, coercion was originally believed to be only associated with involuntary treatment, however, a number of studies have shown that voluntary patients also report coercion (Hoyera et al., 2002). Furthermore, coercion is not limited to involuntary treatment in hospital. In community based settings Molodynski, Rugkasa and Burns (2010) identified through a review of research published in peer reviewed journals that informal coercion in community mental health treatment is prevalent and often used as a form of "leverage". Monahan et al. (1995) reviewed the literature on coercion and commitment and identified that while approximately 27% of psychiatric admissions in the U.S. were involuntary, some “voluntary” admissions included parents signing consent for a refusing child or a next of kin for an incompetent adult. They also report approximately 40-50% of certified patients aren’t aware that their hospitalization was involuntary; and approximately 50% of voluntary patients perceive themselves as having been coerced (Monahan et al.,1995).

Riley, Hoyer and Lorem (2014) reported on a study involving 11 participants under community treatment orders, a form of community based involuntary treatment whereby patients are required to take treatment or be assessed and possibly involuntarily hospitalized. Through using a narrative approach and a narrative analysis of interviews, the authors reported coercion was experienced as limits to freedom, excessive control and little influence of participation in their own treatment (p. 506), however, participants agreed to the community treatment because the alternative was an involuntary hospitalization (Riley, Hoyer & Lorem, 2014).

In several studies of patients who had been hospitalized following a psychotic episode, it was identified that the participants had symptoms of post traumatic stress disorder, not only from the psychotic episode, but also from the trauma of the coercive nature of their hospitalization (Meyer, Talminen, Vuori, Aijala &Helenius, 1999; Picken & Tarrier, 2011; Shaw, McFarlane, Bookless & Air, 2002).

Newton-Howes and Mullen (2011) did a systematic review of 27 studies of psychiatric patients' experiences of coercion and found most patients experienced forced treatment as dehumanizing. Gardner (1999) interviewed 433 patients after discharge from an involuntary hospitalization. While some believed they needed to be hospitalized, most had a negative experience with coercion and were not grateful for having been treated, in spite of believing they needed it.

Svindseth, Dahl and Hatling (2007) studied the experiences of 102 individuals undergoing either involuntary or voluntary psychiatric hospitalization. In 48 of those individuals, humiliation was reported. The two strongest factors that led to feelings of humiliation, that were found to be significantly higher among patients admitted involuntarily as opposed to those admitted voluntarily, were experiences of coercion and the conviction that "the admission was not right" (p. 47). Interviews with some of these patients supported the quantitative results; those with the most humiliation felt they were treated disrespectfully and as "inferior persons" (p. 50). The authors point to the evidence that identifies the experience of humiliation as a potential risk factor for mental disorder, in particular, depression (Svindseth, Dahl & Hatling, 2007).

Coercion was examined from the perspectives of patients themselves in a qualitative study of involuntarily hospitalized patients in Sweden. Oloffson and Jacobsson (2001) completed narrative interviews with 18 patients who had been hospitalized involuntarily. They were informed in advance that they would be asked whether they had been subjected to coercion and to narrate their experiences.

Participants described their perceptions of coercion as being taken by the police to hospital, coerced to stay on the unit, being converted from voluntary to involuntary, use of mechanical restraints and being coerced to take medication by mouth or by injection (Oloffson & Jacobbson, 2001). Further descriptions of perceived coercion included "…being 'threatened with sanctions' and 'not being listened to', and 'not being allowed to decide'. 'Bad attitude' and 'disrespect' on the part of the staff were also described as being associated with coercion" (p. 360).

Three recurring core themes were identified by Oloffson and Jacobson (2001) including: 1) Not being respected as a human being; 2) Being respected as a human being; and, 3) Respecting the staff. "Not being respected as a human being" included most of the narrated experiences: " 'Simply because I said I wanted to be discharged they extended my involuntary status…if you don't behave you will not have permission…you have to be good and docile' " (p. 360). The core theme of "Being respected as a human being" reflected participants' thoughts about how things should be. The third core theme "Respecting the Staff" was a need expressed by participants to understand and respect the staff’s work and try to relate to them and make a human connection: “Concerning the injection I did not say anything…you cannot …say ‘Why did you do that?’ because they think they did what they ought to do” (p. 363). In this core theme, the importance of “being respected as a human being” was stressed. Participating in treatment plans, being involved in care decisions and knowing one’s rights were narrated as being empowering and humanizing.

Katsakou et al. (2012) interviewed 59 certified patients in 22 hospitals across England using a grounded theory methodology and asked whether their involuntary hospitalization was right or wrong. From the resulting data, the researchers identified three distinct groups. One group understood the need for coercion to receive necessary treatment and a second group was ambivalent and thought while the treatment was needed, the coercion was unnecessary. The third group did not see a need for coercion or treatment. In a qualitative study of service users' experiences during psychiatric hospitalization, the theme of coercion by staff presented as a barrier to positive relationships (Gilburt, Rose & Slade, 2008). Swartz, Swanson and Hannon (2003) found experiencing coercion complicates and decreases the person’s ability to access services and creates a barrier to seeking future treatment.

Strauss et al. (2013) studied satisfaction levels of 240 voluntary and involuntary patients and found satisfaction with care was low for both voluntary and involuntary patients if they perceived coercion during their admission. Strauss et al. (2013) report these findings support prior studies that both involuntary admission to hospital and perceived coercion are negatively associated with patient satisfaction of their inpatient experience and suggests "...processes of decision making around hospitalization matter at least as much as outcomes" (p.463).

Deshpande, Morton, Haque and Oyebode (2008) studied all individuals certified under mental health legislation over a ten year period at a hospital in England and found those over age 65 were less likely to appeal their certification than those under age 65. In a similar study, Shah and Joels (2006) reported those under 65 are almost two and a half times more likely to appeal than those over age 65. Both groups of authors recommend additional advocacy and safeguards are needed for this population, along with a simpler appeal process (Deshpande et al., 2008). Kallert (2008) lamented the lack of knowledge and understanding of the effects of coercion in involuntary treatment for other specific populations that are certified, including those with acute psychosis, eating disorders, women, and youth.

Soininen et al. (2013) reported on a Finland study on secluded and restrained patients' perceptions of their treatment. Ninety inpatients between ages 18-65 years completed questionnaires on the perception of their treatment. They perceived they had received enough attention from staff and were able to speak their opinions, but their opinions were not taken into account. They did not believe seclusion and restraint had been necessary or helpful. From the group studies, women and older patients were more critical. The authors conclude "…that psychiatric treatment needs genuine dialogue between patients and staff, individual care should have alternatives and no routine decisions…the treatment culture must improve toward involving patients…and giving them a say" (p. 47).

O'Donoghue et al. (2014) interviewed 161 individuals who had been admitted either voluntarily or involuntarily to a psychiatric unit. 22 % of the voluntary patients had levels of perceived coercion similar to the perceived coercion experienced by the majority of involuntary patients. Kekewich (2011) questioned whether coerced voluntary treatment is ever appropriate and reviews literature that identifies what he refers to as the "voluntary conception of coercion (p.1). Examples of voluntary coercion include "…elements of persuasion, bargaining, begging, enticing, and threatening involuntary commitment" (Guarda et al., 2007 as cited in Kekewich, 2011, p. 1).

The deleterious effects of coerced treatment with involuntary hospitalization have been outlined. Coercion negatively impacts the involuntary patient's willingness to engage in follow up care with a treatment team and creates a barrier to seeking future treatment (Swartz, Swanson & Hannon, 2003).

Both Salize and Dressing (2005) and Kallert (2008) found research activities to be very few in numbers, especially considering the frequency throughout the world of involuntary commitment and coercive interventions generally and strongly recommended more research to support providing the least possible coercion with the least possible infringement upon civil rights. Kallert et al. (2011) states in depth studies are required to better understand the effects of coercion on psychiatric patients. In fact, almost all authors reviewed provided similar recommendations for more work in identifying how to reduce coercive practices to inflict minimum harm.

2.6 Advocacy

This dearth of knowledge in how to provide the least possible coercion during involuntary hospitalization implies a strong need for advocacy. Birnbaum (2010) provided a detailed account of the seminal work done by her father, psychiatrist Morton Birnbaum, who led advocacy for the right for quality treatment for certified patients. He advocated if a person is detained, they need a quality level of treatment or they should be released. The importance of systemic advocacy such as this is clear because of the powers given to clinical teams to force treatment. Forced treatment must be quality treatment, that is, it must result in positive outcomes for the patient. If, while involuntarily hospitalized, patients are not capable of making decisions; and no substitute decision maker is able to, as in the case of the *MHCTA*, then an advocate role, such as Patient Representative becomes very important.

I did not find any research on legislated representative roles within mental health acts, such as the Patient Representative role, that are appointed by the patient. However, there are examples of advocate roles with no personal relationship to the patient but are paid to meet with and advocate on behalf of involuntary patients. This type of advocate "…serves to promote the voice of service users, represent their interests and enable participation in decision making" (Newbigging, Ridley, McKeown, Machin & Poursanidou, 2014, p. 313). Stylanios and Kehyayan (2012), from the Psychiatric Patient Advocate Office in Ontario, report their advocacy model is based on empowering individuals through their narratives and opinions and facilitating collaboration with their mental health team. Advocacy, then is not advocating what we think is best for the person, but helping to raise their voice so that their perspective becomes part of decision making.

Kallert (2008) reported studies from the patient's perspective that revealed while certification may be associated with increased likelihood of feeling excluded from participating in treatment there was also expressed high satisfaction with a key worker, leading the author to conclude that this person could influence positive outcomes for the patient.

Srebnick and Russo (2007) examined files and completed interviews of 106 mental health outpatients with advanced psychiatric directives over a two year period to determine whether clinical interventions complied with the advance directions during 90 crisis events. Among other results, they report that those patients with a surrogate decision maker who accessed the directive were more likely to have compliance with the advanced directive. Of note is the authors' recommendation that patients appoint an informal advocate even if that person has “no standing as a surrogate decision maker” to increase the likelihood of their wishes being followed (Srebnick and Russo, 2007, p. 1183). This role sounds similar to the Patient Representative role in the *MHCTA* (2006).

Rosenman, Korten and Newman (2000) provide striking results in their study of outcomes for an experimental group of 53 involuntary patients who received ongoing advocacy throughout their hospitalization to a control group of 52 involuntary patients who received “routine advocacy and legal rights protection” on admission (p. 1034). Specifically, the advocate saw each patient every second day or more often and joined team discussions with and without the patient present. "The advocate would not argue against treatment but put forward the reasons for the patient's objections, report the patient's previous experience, and try to negotiate a treatment regimen acceptable to the patient." (Rosenman et al., 2000, p. 1031). Those who received ongoing advocacy throughout their admission had significantly more satisfaction with care, better follow up with after care and a significant reduction in rehospitalization (Rosenman et al., 2000).

In the United Kingdom, independent advocacy was available informally to involuntary patients if they requested it through the U.K Advocacy Network (Carver and Morrison, 2005). A qualitative study using semi-structured interviews with ten of these advocates revealed their strong focus on the client's wishes as opposed to their own opinions on what was best for the client; as well as difficulties engaging with clinicians who did not understand or respect their role (Carver & Morrison, 2005). Since then, with the enforcement of the U.K.'s *Mental Health Act* (2007), there are legislative provisions that stipulate that an "independent mental health advocate" must be available to involuntary patients. These advocates are paid employees of community agencies who may have professional designations or personal life experience, and must have appropriate training, be of good character, and be able to act independently of any person who requests they interview a patient or who is professionally attached with the patient's medical treatment (Steven & Symington, 2009).

Newbigging et al. (2014) evaluated England's independent mental health advocate services. A two phase qualitative study design defined quality and assessed the experience and impact of the independent mental health advocate service provision in eight study sites. Seventy-five focus group participants and 214 individuals were interviewed, including involuntary patients and advocates (p. 313). A robust study design took into consideration service users of all ages, in diverse communities and in varying levels of secure settings (from low to high). Their findings revealed that even with legislative provisions requiring advocates to be available and mental health staff to promote access to them, less than half of qualifying patients accessed the advocate's services.

These results are similar to the evaluation done of the *MHCTA* here in this province where 15 individuals who had been involuntary patients responded to a survey and only 6 (40%) indicated they had a Patient Representative; 5 refused a Patient Representative and the remaining 4 were unsure (Health and Community Services, 2012).The reasons why involuntary patients did not request advocacy services or a Patient Representative are not known, however, it may be related to how these roles are understood and promoted to patients by others as well as how much involuntary patients truly understand at the point in time when they are considered to be very ill.

2.7 Patient Rights

Throughout the literature on involuntary hospitalization, the use of coercion and the need for advocacy, is the foundational notion of individual human rights, specifically, the right to self-determination versus the duty of care. Concerns about human rights violations were described in the literature through analyzing patient narratives. These narratives revealed themes of rejection and humiliation/ punishment (Kogstad, 2009). Niveau and Materi (2006) reviewed 50 years of case law related to involuntary hospitalization that was heard by the Council of Europe's Convention for the Protection of Human Rights and Fundamental Freedoms. Rights protected under the Council of Europe's Convention were violated in 35 out of 40 cases of persons who were involuntarily hospitalized, including the right to liberty, security or a fair hearing (Niveau & Materi, 2006).

Canada's history of institutionalizing individuals with mental illness and/or intellectual disabilities included the practice of sexual sterilization, often without consent, as a precondition for release from the institution (McLaren, 1986). Debate on the merits of sexual sterilization flourished in the early decades of the 20th century in Canada. Sexual sterilization practices included vasectomies for men and tubal ligations for women and were part of a "mental health hygiene movement" that promoted eugenics as "a means of contraception for those unable to control their own fertility" (Dowbiggin, 2006, p. 179).

Those who were in favor of sexual sterilization included prominent psychiatrist Brock Chisholm, who served as Canada's deputy minister of health during World War 11 and was the first director-general of the World Health Organization (Dowbiggin, 2006). Chisholm believed that "the goal of psychiatry was to show how human beings could 'take the tension out of sexual development' and thus pave the way for 'effective social development'" (Dowbiggin, 2006, p.177). Chisholm also believed that "world peace and stability were being challenged by runaway population growth among the least intelligent groups of society" (Dowbiggin, 2006, p.177).

In 1933, the lieutenant-governor of Ontario, H.A. Bruce spoke publicly on his support for sexual sterilization. In a speech he gave he stated between 1871 and 1931 overall population numbers doubled but the mentally ill had increased six-fold with 50% of those produced by "feeble-minded parents". He believed if left unchecked, in 75 years one-half of the population would be institutionalized. "Since the segregation of the subnormal had clearly not restricted their multiplication, the only answer was to embark on a policy of sterilization" (McLaren, 1986, p. 127). While there were institutions such as the Catholic Church, and individual civil libertarians and mental health professionals who opposed eugenics, a large reputable group of like minded physicians across the country were in support, as was Tommy Douglas (before his tenure as Premier of Saskatchewan and founder of Universal Health Care) and the National Council of Women, including women's rights activist Nellie McClung (McCavitt, 2013).

Arguments for sexual sterilization included to prevent future mental illness and intellectual disability, to decrease costs of institutionalization into the future, to discipline what were perceived as moral deficiencies and also to provide greater liberty: "Sterilization would, it was claimed, result in greater liberty because it would permit the feeble-minded to leave their institutions and marry without running the danger of reproducing" (McLaren, 1986, p.138).

Provincial statutes to guide the practice were passed in Alberta (1928) and British Columbia (1933). The Alberta legislation authorized the sexual sterilization of 2,500 individuals (McCavitt, 2013). The British Columbia legislation was narrower in focus and as a result only " a few hundred" were sterilized in that province (McLaren, 1986, p. 145). These two provinces were the only ones that passed legislation permitting sterilization of the mentally ill without consent, however, the practice was carried out in other provinces with consent. These human rights abuses occurred within a global context of fear of population overtaking food and water supply. They were called into question when the atrocities committed by the Nazi party came to light and again in 1948 with the passing of the *Universal Declaration of Human Rights* (McCavitt, 2013). The practice of sterilization eventually stopped, however the Alberta law was not repealed until 1972.

The *Canadian Charter of Rights and Freedoms* (1982) provides for certain rights for all Canadians. All provincial, territorial and federal legislation, including mental health legislation, has to abide by these rights, which are part of the *Constitution Act* (1982). The *United Nations Convention on the Rights of Persons with Disabilities* (CRPD) was adopted in 2006. The CRPD does not contain new rights; rather, it brings together existing rights and highlights the needs and issues of persons with disabilities, including those with mental health disabilities (*Mental Health Commission of Canada*, 2013). Canada ratified the CRPD in 2010, which, according to Article 33(2), means that Canada shall promote, protect and monitor implementation of the Convention's principles for persons with disabilities (CRPD, 2006). Perlin (2014) states the CRPD positions mental health rights as disability rights, a clear distinction from the medical model, because it describes disability as a condition that occurs as a result of barriers that inhibit full participation in society.

Canada’s ratification of the *United Nations Convention of the Rights of Persons with Disabilities* in 2010 provided a new standard for mental health legislation, policies and regulations. The Mental Health Commission of Canada commissioned an external group to develop an instrument to evaluate the extent to which human rights are addressed in provincial mental health legislation. The instrument used incorporated standards found in the Convention for the Rights of Persons with Disabilities (2006) and pilot evaluations were conducted on mental health legislation in British Columbia, Manitoba and Nova Scotia (Mental Health Commission of Canada, 2013).

Recommendations arising from this evaluation included limiting the use of substitute decision making and promoting supported decision making as a preferred method (Mental Health Commission of Canada, 2013). Newfoundland and Labrador's mental health legislation was not evaluated, however, there is no supported or substitute decision making in this province's legislation, making it likely it would have scored poorly if evaluated with that instrument.

There is a section in the *MHCTA* (2006) devoted to patient rights. It requires that anyone detained under the legislation be informed of the reason for their detention and their specific rights (right to a lawyer and Patient Representative; access to a phone and privacy to consult). The detainee must receive a copy of the certification order, and rigid timelines must be adhered to regarding assessments and length of time to be detained. In addition a Patient Representative named by the patient should be called immediately and consulted on decisions affecting the patient. If fully certified and admitted to hospital, a Rights Advisor will contact the person within 24 hours and advise them again of their rights, including the right to appeal the involuntary hospitalization to a review board. The articulation of all of these rights, as well as the need for two physicians to independently assess the individual, provide procedural justice for those being involuntarily hospitalized.

In order to ensure a clear understanding of procedural justice, I will review Tyler's classic article (1988) in the construct of the concept. Tyler (1988) examined procedural justice through interviews with 652 citizens of Chicago who had involvement with police in the previous year. He considered whether the justice of the procedures influenced their satisfaction with outcomes and how citizens define “fair process”.

Tyler’s results were consistent with results of past studies which found procedural justice has a major influence on satisfaction and evaluation. He identified several criteria needed for citizens to assess a legal process as fair including “the degree to which the authorities followed ethical principles of conduct; the extent to which opportunities for representation were provided; the opportunity for error correction; and whether the authorities behaved in a biased fashion” (p. 103). Lind and Tyler (1988) suggest that using a process that appears fair and just will positively influence the satisfaction with outcome, even if the outcome is unfavorable.

Watson and Angell (2007) identified components of a framework for procedural justice between mental health and the justice systems to include “participation (having a voice), which involves having the opportunity to present one’s own side…and be heard by the decision maker; dignity, which includes being treated with respect and politeness and having one’s rights acknowledged; and trust that the authority is concerned with one’s welfare” (Watson & Angell, 2007, p. 787).

Kara (2014) reports that encounters between police and mentally ill persons have increased in Canada in recent years and applying a procedural justice framework to police interactions with the mentally ill can improve the nature of their interactions.

Wyder, Bland, Herriot & Crompton (2015) report on a qualitative study involving 25 participant interviews of people who were involuntarily hospitalized regarding how they felt about the process. They found that those patients who had little information about the involuntary process and did not know what was expected or the reasons for the admission, perceived it as arbitrary and harmful, whereas those who understood the process and reasons for being hospitalized saw it as a right that provided "guidance and protection" (p. 44). The authors conclude these experiences point to the importance of procedural justice and how staff and patients can work together to plan ways to meet the patient's needs, such as getting the involuntary status changed (Wyder et al., 2015).

O'Reilly et al. (2010) developed a position paper for the Canadian Psychiatric Association regarding principles for mental health legislation. They identify the principle of "appropriate procedural safeguards" must be available to citizens who are involuntarily hospitalized because of the "loss of liberty" or for those incapable of making a treatment decision because they "lose autonomy" (p. 2).

2.8 Families and Caregivers

The term "caregiver burden" is used regularly in the literature and refers to the "negative consequences to families related to their caregiving roles" (Reinhard, 1994 as cited in Rose, Mallinson & Walton-Moss, 2002, p. 518). Caregiver burden for families of individuals with severe and persistent mental illness includes subjective and objective distress (Crowe and Brinkley, 2015) with emotional, psychological, physical and economic impacts (Awad, Lakshmi & Voruganti, 2008).

A U.S. study using grounded theory methodology with 29 participant family members of persons with severe mental illness found that families experience life altering impacts: "…confronting the ambiguity of mental illness… managing crises, containing and controlling symptoms, crafting a sense of normal. Strategies were being vigilant, setting limits on patients, invoking logic, dealing with sense of loss, seeing patients' strengths, and taking on roles" (Rose et al., 2002, p. 516). Another grounded theory study with 19 participant family members of individuals with schizophrenia in the U.S. found that these mentally ill individuals were largely dependent upon caregivers, resulting in significant and negative impacts on caregivers' lives affecting both physical and emotional well-being (Gater et al., 2014, p. 1).

With the closure of psychiatric hospitals, care for individuals with severe and persistent mental illness has shifted from the formal mental health system to outpatient and community services, and most individuals with severe forms of mental illness live with family and friends (Chan & O'Brien, 2011; Gater et al., 2014; Veltman, Cameron & Stewart, 2002;). Although there have been advances in mental health care for individuals with severe mental illness, family members are still doing most of the care, providing practical support with activities of daily living, direct care and emotional support (Crowe and Brinkley, 2015).

Ostman, Hansson and Andersson (2000) conducted a longitudinal study of the quality of mental health services in Sweden between 1986 and 1997 when psychiatric beds were reduced and found that caregiver burden remained high and more family members experienced more obstacles getting access to treatment over time for their mentally ill family member and more needed mental health treatment for themselves.

Between 1965 and 1981, psychiatric beds in Canada were reduced by 70.6%, from 69,128 beds to 20,301 beds. In 1992, the last year national data was reported, bed numbers dropped further to 18,197 (Nichols, Driedger & Ballon, 1995, as cited in Chan and O'Brien, 2011). From my insider experience I know that psychiatric beds in Newfoundland and Labrador began to decrease in the early 1990s and again in 2000 with full psychiatric units closing and with bed reductions within units ever since.

Chan and O'Brien (2011) report the reduction of beds, along with a decrease in the average length of stay in hospital have not been supported by an increase in community support services. Therefore, the support and care once provided by long term stays in psychiatric hospitals have been passed to family members. Stuart (2005) as cited in Chan and O'Brien (2011) reported that in a survey of 534 members of the Schizophrenia Society of Canada, 32% of caregivers provided at least half day support each day to mentally ill family members in the past year. Estimates from caregivers in Australia reported an average of 104 hours per week in caregiving (Mental Health Council of Australia and Carers Association of Australia, 2000, as cited in Goodwin & Happell, 2007). One of the biggest challenges to family members is that while they are now the care providers, they experience feeling left out of the treatment plan in spite of evidence that involving family members in the treatment plan improves outcomes.

> With the greater responsibility for the care of mentally ill relatives thrust upon family members, caregivers often assume the role of nurse, counselors, advocate and crisis worker in addition to providing housing and financial support, maintaining treatment records, and providing clinical information to mental health professionals. In return, however, they receive little or no support in the form of respite/relief services, recognition, training, resources, peer support or the

> remuneration afforded to mental health professionals who provide similar and in most cases, less intensive support to mentally ill individuals. (Chan & O'Brien, 2011, p. 388)

Gray, Robinson, Seddon and Roberts (2010) studied the perspectives of mental health managers and clinicians on the social exclusion of carers using a methodology of reflexive storytelling. Sixty-five participants revealed 4 ways that carers are excluded:

> First, personal exclusions, including stigma…second, social exclusions, such as isolation; narrowing of social networks; and relating to education, training, employment and leisure; third, service exclusions …being taken for granted and having difficulties with access to appropriate services; and fourth, financial or economic exclusions that lead to carers paying for care. (p. 475)

Seeman (2009) traces the changes in how Psychiatry has viewed the mothers of mentally ill children: from the Schizophrenogenic mothers who caused mental illness in their children, through an era of being the "provocateurs" of illness, with expression of negative emotion and now as the burdened caregivers. Seeman, a psychiatrist, points out a compelling case for how families and in particular, mothers, provide care:

> Because psychiatric patients no longer live in asylums and no longer are prescribed first generation antipsychotics that used to render them effectively sterile, more and more women with schizophrenia are bearing children-children that their mothers, more often than not, raise. (p. 284)

The most common concern I have heard from family members and caregivers is the inability to access treatment, including involuntary treatment for their family member. I have heard this through my management and policy roles in mental health, in public and private consultations, and through community agencies such as the Schizophrenia Society of Newfoundland and Labrador.

Giacco et al. (2012) report that of the small number of qualitative studies done on caregivers' experiences with involuntary treatment, most expressed dissatisfaction with receiving too little information and not being involved in the treatment decisions and planning for discharge. They conducted a multicentre study in eight countries throughout Europe where a total of 336 involuntary patients and their caregivers were recruited and interviewed. Their results revealed that overall, families viewed involuntary treatment positively. This view was more positive than that of their ill family member and only moderately correlated with it. This led the investigators to conclude that "Caregivers may be more dissatisfied with the support and information they receive from clinical staff during the period of hospital admission than with the precise treatment that patients receive in the hospital" (Giacco et al., 2012, p. 489).

In the majority of provinces and territories across Canada, there are provisions in mental health legislation for substitute decision making for persons not capable of providing consent (Gray, Shone & Liddle, 2008). This is usually the next of kin, if one is available, which means families can have a direct role in treatment decisions. Exceptions are in Quebec where the court makes treatment decisions, New Brunswick where a tribunal makes treatment decisions for involuntary patients, British Columbia where the Director of the psychiatric facility makes the treatment decision, and Saskatchewan and Newfoundland and Labrador, where the treating physician makes the treatment decision (Gray, Shone & Liddle, 2008).

In this province, unlike any other, there is a Patient Representative role. That role may be filled by the next of kin, if the involuntary patient names that person to be her/his

Representative. If the patient does not name a Representative, the next of kin will be named unless the patient objects (*MHCTA*, 2006, section 2 (1) (t)). However even if the involuntary patient either names the family member or doesn't object to the family member being named the Representative, the family member as Patient Representative does not have the ability to provide consent for treatment decisions, as do next of kin in other provinces.

2.9 Recovery

The dominant post-positivist paradigm views illness as a specific reality that needs to be discovered, classified, diagnosed and treated by physicians with medicine. However, in the past 20 years a competing discourse of recovery has arisen. Adame and Knudson (2007), among others, identify an alternative narrative coming from those with lived experience that is focused on recovery. Will Anthony (1993), as cited in Perkins and Slade (2012) defines recovery as

> ... a deeply personal, unique process of changing one's attitudes, values, feelings, goals, skills and roles. It is a way of living a satisfying, hopeful and contributing life, even with the limitations caused by illness, recovery involves the development of a new meaning and purpose in life as one grows beyond the catastrophic effects of mental illness. (p. 29)

Tondora and Davidson (2006), as cited in Chen, Krupa, Lysaght, McCay and Piat (2013) describe the recovery process as the way in which a person with mental illness self manages their illness while taking back their life in the community. Services that are recovery oriented help facilitate that. Slade, Williams, Bird, Leamy and Le Boutillier (2012) report the recovery approach has evolved to a point where the wisdom developed from many narratives of individuals with personal experience is emerging as guiding principles for future mental health systems and wider society.

The focus of the medical paradigm is on diagnosis and treatment. The focus of recovery is an internal journey of "growing beyond" what has happened; not recovering from an illness but recovering a life (Perkins & Slade, 2012, p. 30). Services and access to professionals are not the most important or critical piece in recovery; rather it is "maximizing life chances" and making the most of one's life (Perkins & Slade, 2012, p. 29).

A systematic review of published frameworks and models of recovery revealed 97 papers from 13 different countries (Leamy, et al., 2011, as cited in Slade et al., 2012) that show recovery as a journey which is individual to each person. Themes of these journeys included concepts of "...connectedness, hope and optimism about the future, identity, meaning in life and empowerment" (p. 100).

The shift towards recovery has been happening nationally and internationally (Mental Health Commission of Canada, 2012) and is evidenced within Newfoundland and Labrador in a provincial recovery training program developed by people with lived experience; a music video of the arts community and mental health advocates calling on everyone that "we can do it", "we are not alone" and "fix the broken system" (Curran & Maunder, 2014); newspaper articles on empowerment, human rights and changing how we do things (Brake, 2014); and the creation of a grass roots movement called the "Community Coalition 4 Mental Health" (Brake, 2014).

Reducing and eliminating stigma and discrimination has to be one of the top priorities in order to foster a recovery oriented system. Individuals with mental illness experience significant stigma and discrimination. Those who have a mental illness identify stigma to be more disabling than the illness itself:

> (Erving)Goffman recognized that mental illnesses were among the most deeply discredited of all stigmatized conditions. In *Asylums*, Goffman was highly critical of the mental hospitals of the day for their antitherapeutic and stigmatizing effects. Along with contemporaries, such as Scheff and Szasz, these writers reinforced the concept that the negative and debilitating consequences of mental illnesses were more a result of the way in which psychiatry was organized rather than the illnesses themselves. (Stuart, 2012, p.455)

In my employment role I have been overseeing a social marketing awareness campaign, called *Understanding Changes Everything* (Government of NL, 2014). This campaign aims to challenge and ultimately change the way people think and act toward people with a mental illness or addiction and attempts to “normalize” mental illness and addictions by emphasizing that 1 in 5 of us will experience a mental illness or addiction in a given year. Through this campaign many people with lived experience of mental illness have shared their stories of recovery, an evidence based practice to reduce stigma (Knaak, Modgill & Patten, 2014).

Several authors have reported that inpatient settings are the most resistant to recovery focused services (Chen et al., 2013). There is ample evidence that rates of burnout exist among nurses in inpatient settings whereby they are unable to cope with the stress of caring for patients. In these instances, nurses may become unfeeling, disassociated and detach themselves from their clients to the point of dehumanizing them (Dickinson & Hurley, 2012; Singh, Cross & Jackson, 2015).

Chen et al (2013) interviewed patients, families, staff and managers to inform the development of recovery competencies for in-patient mental health providers. They identified that existing actions and practices of staff came from a medical model within a custodial framework, focused on risk control. Tensions associated with trying to deliver recovery focused services also came from providers (including competency level, insufficient knowledge, pressure, frustration, inadequate support), clients (including psychotic symptoms, emotional distress, medication side effects and cognitive impairment) and environmental tensions (including poor physical environment, inflexible routines, limited resources and hierarchical power structure) (Chen et al, 2013, p. 106). The authors report the competency set they have developed "strongly supports providers in overcoming clinical challenges in delivering recovery-oriented services…and can be useful in the development of focused education or training programs" (Chen et al., 2013, p. 115).

Dickinson and Hurley (2012) and Chen et al. (2013) both point to education for staff to address issues that create antipathy or inhibit staff from delivering recovery focused services. Chambers, Gillard, Turner and Borschmann (2013) point out that often, staff working in these complex acute care environments are junior staff with limited skills. This has been my experience with mental health nurses in particular, given these positions involve shift work. As nurses gain experience and seniority they apply for other positions with a regular Monday to Friday work week.

Chambers et al. (2013) evaluated a mental health staff practice development training program which was aimed at translating into practice "a deeper, more evidence-based understanding of service users detained under the Mental Health Act (p. 362) …with particular reference to those who had experienced seclusion, rapid tranquillization and/or control and restraint" (p. 364). Using an "action research paradigm", they developed a short, recovery focused education program based on the expressed needs of the involuntary patients. Among other needs, these patients' expressed needs included " to be treated with higher levels of dignity and respect by staff members; more involved in the decision making process regarding their care; given more information about their treatment plans; and to be 'heard' by staff members" (Chambers et al., 2013, p. 365). The positive findings have led to the program being implemented across other practice areas.

LeBoutillier et al. (2015) investigated difficulties in implementing recovery focused services using a grounded theory methodology. Sixty five clinicians and managers were interviewed in ten focus groups. Results revealed that in order to provide recovery focused services, all policies, processes and priorities need to be recovery focused, otherwise, staff are unable to weave through competing and conflicting expectations. The researchers found that "Overall, there is a discrepancy between the organizational endorsement and expressed intent to promote recovery-oriented practice on the one hand, and the capacity of services and practitioners to operationalize the concept in day-to-day work on the other" (LeBoutillier et al., 2015, p. 437).

2.10 Conclusion

The literature reviewed has shown from the past to the present, the care and treatment of persons with mental illness has been complicated by issues of objectification and stigma. Involuntary patients have been significantly impacted by their perceptions of being coerced into treatment, which can have serious and negative effects on health outcomes and satisfaction with care. There is a strong need for advocacy for involuntary patients to ensure procedural safeguards are in place and adhered to, which has shown increased satisfaction on the part of involuntary patients and a decreased perception of coercion. Recovery oriented services can reduce stigma and increase patient satisfaction with services, however, staff stress and burnout need to be addressed with education and support.

Evidence shows that families and caregivers of individuals with severe and persistent mental illness are providing most of their care and treatment in the community, have trouble accessing treatment for their family member and once their family member is hospitalized, feel they cannot access information or influence treatment decisions. While there was no research on the role of Patient Representative within mental health legislation, there was support for an advocacy role similar to the Patient Representative role, particularly if it is formalized and framed within other procedural rights.

Chapter 3- Methodology

3.1 Introduction

My research questions are: How is the Patient Representative role in the *MHCTA* (2006) experienced and what can we learn from this experience? I chose these questions because in my former and current employment roles as mental health nurse, administrator and then Director for Mental Health and Addictions I have been involved in the enforcement of mental health legislation and in particular, in the rights provided within the legislation to patients who are involuntarily hospitalized. I will explain this in more detail later.

I decided early this would be a qualitative study, because I am interested in 'what' and 'how' questions, which have been characterized as the aims of qualitative research (Green and Thorogood, 2009). I ask these questions as they relate to the Patient Representative's experience, to examine it and to learn from it. I will also share my experiences working in the mental health system which will provide an insider perspective to data generation. I have chosen to do a case study within an autoethnographic narrative to answer these questions. In this chapter I will provide rationale for this choice, as well as methodological considerations and changes, and my methods for data generation and data analysis.

3.2 Social Constructivist Paradigm

According to Guba and Lincoln (1994), questions of method are second to questions of paradigm. That is, the world view of the researcher will determine how she sees the world and what form reality takes. A paradigm may be viewed as a "world view" or a set of "basic beliefs” that shows the "...nature of the 'world', the individual's place in it, and the range of possible relationships to that world and its parts..." (p. 107). Foster, McAllister and O'Brien (2006) write that “knowledge, understanding, and reality are socially constructed, rather than pre-existing, static and given" (p. 46). We develop a sense of what is real through interacting with and observing others. This is fluid and dynamic and "...people's perception and definitions of what is real frequently shift" (p.44). This is consistent with my worldview, that is, we construct reality through our experiences and interactions with others; therefore multiple realities and multiple truths exist. Within a post modern, constructivist paradigm, "realities exist in the form of multiple mental constructions, socially and experientially based, local and specific, dependent for their form and content on the persons who hold them" (Guba 1990, as cited in Lincoln, Lynham & Guba, 2011, p. 102).

There are many ways to approach my research question and several were considered, all within a postmodern social constructivist paradigm. I have chosen to do a case study of one Patient Representative and explore it within an autoethnographic narrative. The data for this study has been generated between the Participant and me though our sharing of information with each other and checking in with each other on our understanding of the information. The autoethnographic narrative was developed with the understanding that my reality is socially constructed and therefore influenced by social and cultural norms.

Very early in my career I made the decision to enter the mental health field and I have stayed with it for 33 years. I had a passion for this area even before I made a decision to become a nurse. The passion does not come from a place of lived experience either for me or for my family, and the system itself was unknown to me.

As a young child, I was deeply intrigued by the local psychiatric hospital and "what went on in there". Many years later, in 1979 I decided I wanted to work in mental health and started taking psychology courses in university. A friend who worked at the psychiatric hospital as an orderly told me about upcoming summer jobs. He told me they were looking for males but they might hire a female. After many calls and visits to the nursing supervisor, I was finally hired. While the staff members were in many ways very caring, what I witnessed and participated in disturbed me and ignited a passion that “somehow, we have to do better.” Those experiences will form part of my narrative.

At that time, the psychiatric hospital was a community unto itself: insular and isolated from the outside world. It was teeming with patients and staff and their routines and activities. There were arts and crafts, bingo, church services, and dances. A canteen area provided the daily gathering place for most patients who were permitted off their units. There was a patient's trust (bank), a barbershop and beauty parlour, a used clothing store and a dentist. The jukebox did not require money and played 20 year old songs. Going to work felt like entering a “time warp”. People were admitted to the hospital and stayed for months or years, moving from acute care to a gradation of units designed for various levels of psychiatric rehabilitation. I did not see many discharges. I did not see regular family visits either. Many patients had intellectual or developmental disabilities and were considered "residential", that is, they lived at the hospital with no plan for discharge. This would all change in years to come but at that time, it did not feel like we were on the road to change.

I was one of two women hired in a group of about 20 men. It would be another 20 years before a human rights complaint struck down the practice of specifying male gender when hiring, which was enshrined in one of the union's collective agreements. Males were preferred as a show of force or a "male presence" which, it was believed, would keep everyone safe. The male nursing assistant staff members outnumbered the female staff. They were needed for the running of emergency codes, paged overhead when it was determined that a patient needed to be placed in seclusion or needed to be physically restrained to receive an intramuscular injection of medication. These codes used to be called "Code 666 for male staff". In 2000 this changed to a multidisciplinary male and female team called the "Code White" team. Psychiatric emergency codes would also be called in the admissions area, when patients who were being involuntarily hospitalized refused to walk willingly to the ward. Or an emergency code could be called when a patient refused medication or struck out at unit staff in their refusal.

When I began work in 1979, the patients called all the female staff "Nurse" while all the male staff were called "Keeper". I was told this was because they kept the keys. Keys were (and still are) a show of power in the psychiatric hospital because everything is locked, including the doors to leave. The "keeper" name I believe went deeper than just a keeper of the keys and extended to keeper of almost everything related to patients’ lives, from what time they had meals to when they had baths and how they filled their days. When I began working at the hospital, the term "keeper" was only used by the patients who had been there a long time and over the years the name fell out of use. With such a strong focus on gender based staffing, we referred to each other as "male staff" and "female staff". That first summer I worked closely with nurses and realized I wanted to be a mental health nurse. I began nursing school that fall and when I graduated I went back to the psychiatric hospital to start my career. As the participant for this study journeyed through his role as Patient Representative and caregiver, I was working in the system as a mental health nurse, manager and policy maker.

3.3 Autoethnography

I had originally planned to take a social constructivist version of interpretive, hermeneutic phenomenology on the lived experience of the Patient Representative. This approach would have included interviewing several Patient Representatives on their lived experience. However two experiences altered this course, which I will explain.

The first occurred following my application to the Newfoundland and Labrador Health Research Ethics Board. They had questions for me on how I would handle potential conflict of interest between my employment role with the Department of Health and Community Services with the Government of Newfoundland and Labrador and my student researcher role. In a meeting with Board representatives, potential conflict of interest questions were clarified to their satisfaction by providing more detail on my current employment role, that is, I am not directly responsible for mental health services where patients are being involuntarily hospitalized. They were concerned with the ethical implications of a Patient Representative disclosing information that I would feel compelled to inform my employer about. Occasionally, however, individual client complaints are brought to the Minister's attention which might require my involvement. To avoid potential conflicts with study participants, it was decided to only accept participants who had not been Patient Representatives in the previous 6 months.

From my first shift in 1979 as a personal care attendant at a psychiatric hospital, I have found it deeply rewarding to work with people with mental illness, and in particular, those with severe and persistent mental illness. As a nurse working in acute psychiatry and forensic psychiatry units, I could directly support them, be a connection to reality for them, and show them kindness and compassion. As my employment changed to administrative and then policy roles, this type of work took on different forms such as providing funding for programs or revising policies. Making things better in the mental health system for these individuals and their families has been a career passion for me. However, for the small percentage of patients who require involuntary hospitalization, making things better within a mental health system from which they do not want to receive treatment has been challenging.

As a staff mental health nurse in the 1980s I regularly participated in forced treatment on involuntary patients. At the time I viewed these episodes of forcing treatment--such as restraining involuntary patients, placing them in seclusion rooms and administering intramuscular long acting medication--as a necessary part of helping them get better. However it deeply disturbed me. At the time I was not happy with how we did this and while I thought it could be done better, I didn't feel like I was in a position to do much about it. I will come back to this later.

Over the next fifteen years I had a series of senior leadership positions which included responsibility for patient care services at this hospital and others. Policies for responding to psychiatric emergencies, seclusion and other related policies that often included forced treatment, were revised to reflect better practices (although to this day, the process of forced treatment still involves emergency code teams who restrain involuntary patients, administer intramuscular medication and place these patients in seclusion). I investigated complaints from patients about these incidents. In my experience, most involuntary patients who were forced to receive treatment were experiencing psychosis and their perception of what was happening was likely terrifying for them. For example, there were complaints from patients that the medication they had been injected with was poison and that the staff were imposters. I also met with families of individuals with severe and persistent mental illness, however, I mostly heard from families advocating for their loved one to be admitted, either involuntarily or otherwise. Once admitted, the most common family complaint I received was that their loved one was being discharged too early.

In my experience (and this was also the participant's experience) many families of involuntary patients did not visit them regularly. I don't believe the environment at the psychiatric hospital is conducive to visitors; there are very few private rooms, practically no private space to visit and the unit doors are locked, requiring visitors to ring a bell to gain access. In some instances families live outside the region and are unable to travel. Some families are estranged from the involuntary patient because they were seen by the patient as responsible for calling the police and having them admitted involuntarily in the first place. I expect there are also instances whereby families used the time for respite while their loved one received treatment. If an involuntary patient was restrained by staff, medicated and placed in seclusion, visitors were generally not permitted. Thus, many of these coercive practices take place behind locked doors and out of view of family and friends.

In 2005, health care boards were restructured to four regional health authorities in Newfoundland and Labrador. At that time, I became the regional director for mental health and addictions within the eastern regional health authority. This health authority was the largest in the province and included St. John's. I was responsible for all government run mental health and addictions services in hospitals, treatment facilities and in community settings within the region.

When work in the province began that same year on new mental health legislation, I viewed it as an exciting opportunity to improve the process of involuntary hospitalization. My focus was on tangible changes. For example, under the former legislation, while involuntary patients had a right to appeal to a review board, there were no timelines and patients were often discharged before the review board met. My hope was to address such inefficiencies. I advised on the drafting of the legislation and then chaired one of many sub-committees that helped prepare the system for the changes the new legislation would bring.

Some of the significant changes that we focused on, such as timelines for the review board to respond to patients who appealed their involuntary status, could be tracked with ease. However, after the legislation was in force, I couldn't determine what was happening with the Patient Representative role. Was it effective? In my mind, the Patient Representative was the person who could advocate for the patient, although they were not able to make decisions for them. Were they having trouble in the role? Even when the 5 year evaluation of the *MHCTA* was completed, there still was not much information on the Patient Representative.

As a regional director I continued to hear about problems with the mental health system from families and caregivers. Most of the problems were still about trying to gain access to services or, particular to the objectives of this study, trying to get sick loved ones involuntarily admitted. However, once they were admitted, what then? In my current employment role I am responsible for policy in this area. What is the experience of the Patient Representative in this province?

As an insider to the system, I knew I had knowledge that could provide another context to the experience of Patient Representatives and perhaps enrich it. I was concerned reflexivity and journaling would not reveal enough of the influence my experience was bringing to this process and how critically important, from my perspective at least, the Patient Representative role is.

While I was sorting through these methodological issues, the second experience followed. Following ethics approval, I began recruiting participants. I originally sought participants through the Consumer Health Awareness Network of Newfoundland and Labrador (CHANNAL) and the Schizophrenia Society of Newfoundland and Labrador (SSNL). One participant joined my study. There was interest from several family members but they had not been Patient Representatives. I went back to the ethics board and received approval to expand my recruitment efforts to other community agencies and the regional health authority, however, no further participants were immediately forthcoming.

I interviewed the sole participant who had experience not only with the *MHCTA* as a Patient Representative, but also had experience informally advocating as a caregiver when the former legislation was in force. As such he could compare his experiences. In a discussion with my supervisory committee, the merits were explored of doing a case study (with this participant in mind) within an autoethnographic narrative. This approach appealed to me because my participant had extensive experience over time that he was willing to share. I could also then be as transparent as possible and fully explain my role in the process of data generation as an insider to the mental health system.

I then contacted the participant and met with him and reviewed all the changes, including my insider status and the fact he would be the lone participant, besides me. We discussed the increased measures I would put in place to protect his confidentiality, such as not revealing any specific details about his case, including the nature of the relationship he has with the patient he represented. He was agreeable to this and signed the amended consent. In the following sections I will provide detail on the methodology used and methods employed to conduct my research.

My original concern when considering a phenomenological approach involved how to position myself in the research. I believed my experiences and insider information would provide a different context and help provide a deeper, richer understanding of the

Patient Representative experience. Autoethnography seemed an appropriate methodology to help leverage these particular strengths.

Ngunjiri, Hernandez and Chang (2010) refer to autoethnography as a qualitative research method that combines ethnography, biography, and self-analysis to understand the connection between self and others. This methodology is rooted in ethnography, or the study of culture; it connects the researcher's personal experience to others and is context conscious. Ellis, Adams and Bochner (2011) say autoethnography is a methodology that describes and analyses personal experience to understand cultural experience. They say the "questions most important to autoethnographers are: who reads our work, how are they affected by it, and how does it keep a conversation going?" (p. 8). Richardson (2011) calls autoethnography a form of "evocative writing" in which the text is highly personalized and revealing; and the authors "tell stories about their own lived experiences, relating the personal to the cultural" (p. 931).

Other authors have described autoethnography as bringing into consciousness a personally constructed map of reality (Dyson, 2007); a valuable healing tool (Ettorre, 2006); or using self to reach culture (Pelias, 2003). Ellis and Bochner (2000) report that scholars turn to autoethnography when they want to focus on generating research grounded in personal experience on issues and experiences otherwise "shrouded in silence" which “...deepen our capacity to empathize with people who are different from us" (p. 2). This seems particularly relevant in this study, where the stigma of mental health is only beginning to lift but the stigma associated with severe and persistent mental illnesses and the practice of involuntary hospitalization is still, in my experience, entrenched and not openly talked about. I believe the words of Ellis and Bochner (2000) are particularly true for the experiences of Patient Representatives for those involuntarily hospitalized. They have been "shrouded in silence".

Some criticisms of the autoethnographic approach include: it is either not artistic or scientific enough; is insufficiently rigorous and too emotional; there is not enough time spent doing fieldwork; autoethnographers use biased data; and finally, autoethnographers are narcissists, not scholars (Ellis, Adams & Bochner, 2011). I was aware that doing autoethnography could be difficult, particularly after reading accounts of other beginning autoethnographers and their challenges with getting their work accepted as scholarly or publishable (Holt, 2003; Wall, 2008). I could appreciate the discomfort of having others reading your published autoethnography and wanting to engage in conversation about your personal reflections and experience (Dashper, 2015). However, as I read more and then became immersed in the writing and actual data generation, it seemed a natural fit for my nursing background.

I went into nursing to become a mental health nurse. When studying theories of nursing, Hildegard Peplau was a personal favorite because of her theory of interpersonal nursing. Peplau's theory focused on the therapeutic relationship between the nurse and the client and the nurse's use of herself as a therapeutic tool within that relationship (Peplau, 1952). Foster, McAllister and O'Brien (2006) point to the therapeutic use of self within the practice of psychiatric nursing as similar to the role of autoethnographer where the researcher shares her personal story and uses her own experience to increase understanding of the question being studied.

In reflecting on this, I also can draw similarities between autoethnography and using self as a therapeutic tool. I support the view of Richardson (2011) that making our personal experience more accessible to a wider public audience can also be empowering for persons with lived experience through provision of access to current knowledge in the mental health field. In my estimation, the common thread is using our experiences to help enrich understanding for others. This made autoethnography a more comfortable methodology for me when working with the participant.

3.4 Method

The methods I used for my study include semi structured interviews; a document review; memory writing; and a combination of showing and telling. I also did reflexive journaling as data generation was evolving because I wanted to be reflexive about the autoethnographical process itself.

It became clear to me early in the research process that writing my narrative was also a method that provided additional insights and generated data. Richardson (2011) states that writing is"...a method of discovery and analysis" (p.923) and that while we never completely capture this "worded world", to write means to "…find something out. I write in order to learn something that I did not know before I wrote it" (p. 924). I gained insights into past events in my career which I will share a bit later.

The document review included documents that I have in my possession because of my employment role. These include briefing notes and meeting minutes that were developed while implementing the *MHCTA* in 2007. I also found notes I had taken in a meeting with the participant in 2011. The use of these documents was approved by my employer. The executive team that I report to in my employment role is very supportive of this study. They hope the results will assist with the next legislated evaluation of the *MHCTA*.

3.5 Semi Structured Interviews

In keeping with a social constructivist paradigm, a constructionist view of interviewing was used whereby it is understood that both interviewer and participant produce knowledge within the interview together (Brinkman & Kvale, 2015). Brinkman and Kvale (2015) use the metaphor of the interviewer as a traveler on a journey who "enters into conversations with the people he or she encounters…. asking questions and encouraging them to tell their own stories of their lived world…. the journey may not only lead to new knowledge; the traveler might change as well" (p. 57-58). This was discussed with the participant and he understood and agreed with this method.

There were three interviews with the participant and all but the second session were taped and transcribed with reflexive notes taken. The second session occurred when I met with the participant to seek his amended consent for the change in methodology. We had spoken on the phone first and I expected a short meeting just to review the methodology changes and the form and have him sign it. However, we covered more so I took handwritten notes of our discussion and in our next meeting that I taped, I read the notes to him and received his concurrence that I had captured what we discussed.

The first interview was based on the participant’s schedule. We met in my work office at his request because it was close to where he lived. Subsequent interviews took place at a coffee shop. The following questions were prepared for this interview:

1. What has been your experience as a Patient Representative?
2. What do you believe the Patient Representative role is?
3. Did you receive any instruction on this role?
4. Were you satisfied with your experience as a Patient Representative?
5. What suggestions do you have for how this role may be improved?

Two interviews followed the first one, that were less structured and there was more sharing of information between us. I used constructionist thematic analysis as a method of text interpretation which is interpretive and recognizes that data or findings are co created between the researcher and participant and yield multiple perspectives of the same data (Lincoln, Lynham & Guba, 2011). Each transcribed interview was provided to the participant for his analysis and input.

About midway through the three interviews, I began writing my own narrative of working with involuntary patients, their families and the legislation from my experiences as a staff nurse, administrator, regional director and provincial director. I shared some of what I was writing with the participant.

3.6 Memory Writing/ Showing and Telling

Richardson (2000) describes postmodernist writing practices in qualitative work as occupying many different forms: "The ethnographic genre has been blurred, enlarged, altered to include poetry, drama, conversations, readers' theater, and so on" (p. 929). Richardson refers to these forms as "creative analytic practice ethnography, or CAP ethnography" (Richardson, 2011, p.929).

Another way of enhancing traditional research is moving from triangulation to what Richardson terms "crystallization" (p. 934). In crystallization it is recognized there are more than three sides to approach phenomena. Crystallizing the data means looking at it from many different non-linear perspectives and "…provides us with a deepened, complex, thoroughly partial, understanding of the topic. Paradoxically, we know more and doubt what we know" (Richardson, 2011, p. 934).

Ellingson (2009) provides 5 principles for crystallization in her book, *Engaging Crystallization in Qualitative Research.* Among these principles, Ellingson includes to "represent ways of producing knowledge across multiple points of the qualitative continuum, generally including at least one middle-ground (constructivist or postpositivist) and one interpretive, artistic, performative, or otherwise creative analytic approach" and "utilize more than one genre of writing (e.g., poetry, narrative, report)" (p.10).

The method of data generation within the case study interviews is constructivist. I include autoethnographic narratives that I have written from my own experience. In my narrative writing I used a combination of showing and telling. Ellis (2004) as cited in Ellis, Adams and Bochner (2011) explains showing, is designed to 'bring readers into the scene' (p. 3) to make events provocative, and engaging (Ellis, Adams & Bochner, 2011). Telling the story works with showing and provides some distance to allow the reader to process and think about the events (Ellis, Adams & Bochner, 2011). In my narrative I provide different points in time in my work life and describe incidents in which I was involved.

3.7 Analysis

Ellingson (2011) encourages researchers to consider "jumping and straddling multiple points across the field of qualitative methods" (p.595). I have done this with analysis, to ensure I gave the most rigorous attention to the various methods I was using to collect data. I needed to consider how to analyse my interviews with the participant and how to approach document review as well as how to analyse the various ways I tried to capture my own experience.

To do this I have used a combination of inductive and deductive methods. I transcribed the interviews with the participant without software and read them many times to become as familiar as possible and made notes on what I saw as emerging themes. The themes in this study came from the interviews with the participant. They were shared themes, that is, the themes generated came from his experience and then I shared my experience as they relate to these themes. I then reviewed some of the documents (for example, the notes I took of a meeting I had with the participant outside this study in 2011) to see if there were any consistent themes. I did reflexive journaling on my memory writing throughout my process of determining which methods to use and as the data was being generated.

3.8 Case Study

According to Flyvbjerg (2011), case studies are units of study that may be studied in a number of ways (qualitatively or quantitatively); are intensive and in depth (as compared to crossing over several cases); are developmental and evolve over time; and focus on "relation to environment" or are contextual (p.301). The unit to be studied for my thesis is the participant's experience as a Patient Representative in the *MHCTA* (2006). The time frame for this case study is from 1994 to the present time, which includes the full time frame for the participant's experience with the mental health system. This not only provides a description over time and allows for evolution of the case, it also gives context to the environment for the participant's experience as Patient Representative and includes the time before, during and after his experience as Patient Representative.

Case study methodology has been criticized as being limited. Yet, in studies of adult learning, there is a qualitative leap in the learning process from beginners to experts because experts have "intimate knowledge of several thousand concrete cases" (Flyvbjerg, 2011, p. 303). It is only because of experience with cases that one can move from beginner to expert, based on our learning process. This has been termed "engaged thinking-in-action" by nurse scholars who study how nurses not only use theoretical knowledge and apply it in practice, but how they become experts in nursing practice from continued practical application with individual cases, not from generalizing a few (Benner, Hooper-Kyriakidis & Stannard, 2011).

Furthermore, Flyvbjerg (2011) points out that a critical case, defined as "having strategic importance in relation to the general problem" (p. 307), may be generalized to some other situations in the sense that, if it is valid for this case, then it is valid for all or many cases.

My case study involves an educated man with financial means and resolve. He worked for many years in another government system and yet still had trouble in the mental health system trying to represent the Client, prior to the *MHCTA* (2006). He said, "If I had trouble, I'm sure others with lesser means than I would have difficulty as well". I believe this case study could be seen as a critical case in some respects but not all. His experience prior to the *MHCTA* generated meaningful data that highlights problem areas I expect others in the role may have had as well. However, in other areas it is unique unto itself. Variables in these situations include whether the client being represented is accepting of advice and support from the Patient Representative and whether s/he can make their needs known to the Patient Representative. Treatment teams are different and many individuals will only have had current experience as a Patient Representative since 2006 with the current legislation.

As mentioned earlier, I initially planned to interview several individuals who had been Patient Representatives so I could explore with them their lived experience. The first person I heard from was the sole participant. I will now refer to him as “John” , a pseudonym, for privacy reasons. I have known John through my various employment roles for many years. For confidentiality reasons, I will not reveal the nature of the relationship he has with the person he has been a caregiver and Patient Representative for, and will refer to the person who was involuntarily hospitalized as Jamie, a gender neutral name.

3.9 Meetings with the Participant

I became aware of John and Jamie approximately 20 years ago, during the time when Jamie had several long term admissions. I do not think I provided direct care to Jamie as a staff nurse and may have been involved from an administrative perspective with some dealing with Jamie but I cannot recall those details and neither can John.

However, I recognize and have met Jamie before and when I had my first meeting with John in 2003; I knew John and knew his involvement with the mental health system through Jamie.

In 2003, I met with John in a public engagement session for the province's first mental health strategy. I was conducting a series of sessions and John attended the session and provided very critical feedback on his experience with the mental health system and in particular the psychiatric hospital I was responsible for at the time. He did not recognize me and would not have known that was my employment role because I was doing this work on behalf of government as a special project.

In 2011, John requested a meeting with the Minister of Health and Community Services. By this time my employment role was Advisor to the Minister and I met with him on the Minister's behalf. In this meeting John shared personal observations on the mental health system and in particular, on one of the regional health authorities. He again was very critical of the mental health system.

Finally, in 2015 John contacted me to join my research study.

3.10 Ethical Considerations

Ethics approval for this research came from the Newfoundland and Labrador Health Research Ethics Board. I initially approached the Schizophrenia Society of NL (SSNL) which has family members and friends of persons with schizophrenia as members; as well as the Consumer Health Awareness Network of Newfoundland and Labrador (CHANNAL) which is an organization of individuals with lived experience of mental illness. Through informal contact and then written correspondence, I requested they assist me with participant recruitment by circulating to their respective memberships a poster I provided them that gave particulars about my study with my contact information so that interested individuals could then contact me directly.

John learned of my study this way and contacted me by phone. I heard from four other individuals. Three were parents of adult children with mental illness but none had been a Patient Representative. The fourth was a parent whose adult son was at the time involuntarily hospitalized. Because I could only accept participants who had not been in the Patient Representative role in the previous 6 months, I was not able to include this parent in the study.

Confidentiality and privacy are particularly relevant, given there is just one participant and the qualitative nature of the study. There are details of John’s story that will not be provided because it could lead to his identity or Jamie’s identity. Data was securely stored through encryption and I used codes instead of names; also names of hospitals and clinical team members are not included. Any information provided that might lead to an individual’s identity such as details of an inpatient unit, dates of admission or distinguishing details related to a person’s symptoms have been scrutinized to ensure privacy and confidentiality are protected.

In the interest of fully informed consent and voluntary participation, my roles were made very explicit to John. I provided my past, recent and current employment history. I was also clear about my role as a student and that this study is part of requirements for my thesis and participating in the study will not impact negatively or positively on any individual.

By fully exploring these research questions from a case study methodology within an autoethnographic narrative, with close attention to ethical considerations, I have attempted to provide the best opportunity to generate data and learn about the experience of the Patient Representative.

Chapter 4-Findings

4.1 Introduction

In this chapter I will explore the case study of the Patient Representative, John within an autoethnographic narrative. This chapter will begin with an introduction to John as well as some of Jamie's clinical history as told to me by John to provide some context for the discussion. The interviews with John will be briefly described, and then four themes from the interviews will be discussed. These themes, identified from reading and re-reading the interview transcripts, are as follows: a) lack of empathy; b) the need for respect and dignity; c) the need for advocacy for those admitted involuntarily; and, d) the need for more management accountability in the mental health system. John concurred with these themes. They come from his experiences before and after the Patient Representative role and are reflected strongly in the interview transcripts. These themes are meaningful to me as well and I will provide some of my experience.

4.2 John and Jamie

Within days of my recruitment posters being circulated, John called me. He indicated he would be happy to help in any way he could and thought the *MHCTA's* role of Patient Representative was an important area to be studied. As previously mentioned, we knew each other from previous meetings over the years regarding mental health services in the province.

John was a Patient Representative for Jamie on two occasions since 2007 when the *MHCTA* came into force. The most recent time that Jamie was involuntarily hospitalized under the legislation was in 2011. However, John has been providing care and support to Jamie since Jamie was first diagnosed in the early 1990s with a severe and persistent mental illness. According to John, the first time Jamie was involuntarily hospitalized was in 1993. Jamie was admitted several times following this, including a long term admission. During this time Jamie moved from an acute ward to a longer stay ward that provided psychiatric rehabilitation. Several involuntary hospitalizations followed. Since the current *MHCTA* was proclaimed in 2007, Jamie has been involuntarily admitted twice.

All admissions to hospital for Jamie were involuntary in nature, that is, to access treatment in hospital for Jamie, the legislation was necessary because Jamie had no insight that s/he was ill and was therefore refusing to see a physician. John shared with me some experiences he had trying to advocate for Jamie when there was no Patient Representative role and Jamie was involuntarily hospitalized under the former *Mental Health Act*. I could relate to some of these because I had experienced similar situations as a care provider. He was also able to then describe more recent experiences under the current *MHCTA* and comment on the differences.

John found the experience of Patient Representative to be an improvement from what he experienced during Jamie's previous involuntary hospitalizations. It is not known whether Jamie knew about the appeal process. This is one of the roles of the Patient Representative, as per the *MHCTA*, to act on behalf of an involuntary patient and appeal the certification to the Mental Health Care and Treatment Review Board. However, John strongly supported and advocated for each involuntary hospitalization to ensure Jamie received treatment, therefore, John did not wish to pursue an appeal and Jamie did not ask him to appeal.

John said he did not receive any instruction on the Patient Representative role. Yet, when asked if he was satisfied with his experience as a Patient Representative, he responded “Generally yes…generally and definitely, yes”. He attributes this good experience mostly to the positive experiences he had being included in team meetings about Jamie’s treatment and having his voice heard:

> *I'll tell you one of the things I noticed was remarkably different and definitely should be kept and that is this team approach that they have. And when Jamie was admitted, very soon after, we had this team meeting. I and the others, there were 5 others on the team. I don't remember their specific roles but you know, the psychiatrist, the recreation therapist, whoever else would be supervising Jamie’s progress. And we sat down and talked about all aspects of Jamie’s situation and we talked about the plan to stabilize and prepare Jamie for when s/he would be able to leave again. And I was able to tell them and they were prepared to listen to what I had to say about what would have to be done before Jamie came out.*

This represented a significant change from the earlier years when John felt he wasn't being heard and was disrespected by the psychiatrist. John went on to share with me a number of treatment issues, regarding Jamie's medication, sleep-wake cycle, reviewing the need for Electro Convulsive Therapy, and the need for supportive housing with respite workers for when Jamie was discharged. John believed these issues were reviewed thoroughly, suggested changes were made which improved Jamie's health and John was successful in arranging supportive housing and respite workers for Jamie. How the treatment team listened to John and considered his recommendations for Jamie's treatment were significant changes for John. While he was supportive of the Patient Representative role, he continued to have concerns about the treatment system and the experiences of individuals with severe mental illness who become involuntarily hospitalized. The following section on themes, generated from our interviews, illustrate his concerns, as well as my own from an insider perspective.

4.3 Lack of Empathy

On several occasions in different interviews with John, he referenced the lack of empathy he witnessed in staff working with Jamie and other patients. This deeply concerned and frustrated him, especially in the initial years when Jamie was involuntarily hospitalized:

> *People being recruited for these jobs are not sometimes very empathetic, you know? And a lot of them that are there are not empathetic…and in one of the worst instances I saw, there was a guy walking back and forth the corridor with his head in his hands moaning and groaning and one thing or another and obviously tormented right out of his poor head. After a while he walked over to the desk where this guy (nursing staff) was sitting down reading the newspaper. He'd been sitting at the desk there then for 20, 30 minutes. I was standing around out there with Jamie, just walking around with Jamie giving her/him a little walk and talk outside the TV room and this poor fellow walked over to the desk and started talking to the guy. He looks up from the newspaper... "Joe!" and shouted at him "you get out of my face!" Instead of saying "What's the problem?" you know? Or "tell me about it"...that's his job! Console!*

I asked John if he had seen changes in this over the years. He acknowledged he had not witnessed this in recent years when Jamie was admitted, however, he believed it was probably still happening. Generally, John believes there is "far less empathy for the condition of a mentally ill person than there is for a physical illness." He also said there needs to be "more acute screening of personnel who are empathetic."

As an insider to the system, I understand these comments from John. Over the years, I have investigated many complaints about the treatment individuals received. In almost all instances, people would repeat a phrase or two that they said the staff member had used, repeating it almost in disbelief. These phrases would be provided to me as evidence of the staff person's lack of empathy. I heard many times that people felt "disrespected" and "misunderstood". On several occasions, individuals have said to me that they weren't understood, or heard; that they were dismissed and that their own mental health concerns (or those of their loved one) were downplayed.

As a staff nurse there were times when I knew I was the only thing linking the person in front of me to reality and safety. Hearing someone describe a delusional thought can be profound. Some delusions are incredible and can even be amusing if one does not understand what the person is experiencing and feel empathy. I nursed a man who believed he was pregnant, another who believed he was Jesus Christ. I've witnessed incredible sensitivity on behalf of staff I worked with who could connect with individuals in the middle of these delusions and help them eat, dress, bathe, sleep. Other staff I would separate from these patients so as to avoid confrontation.

However, it was with individuals who were in emotional pain from childhood trauma, those who had been diagnosed with borderline personality disorder or as having "borderline traits", where I saw the most insensitivity and lack of empathy. As a young nurse 30 years ago, I was ill equipped to understand why these patients would hurt themselves over and over. I knew there was more to this than just "attention seeking" but was at a loss how to help. So I befriended them, was nice to them. In the words of one staff member at the time, I "let them walk all over me". One young woman in particular, who was admitted at age 16 and discharged at age 18, never to be readmitted, visited me 20 years later and told me how much those two years in hospital had negatively affected her. She told me that no one at the hospital for those two years understood the impact of the childhood trauma she experienced. It took 20 years of psychotherapy for her to heal from her childhood trauma and then the trauma she experienced on the unit where I worked. She described the disdain and derision she experienced from some staff. As a 16-year-old, the staff were parent figures, adults in authority. They belittled her, told her there was nothing wrong with her, that she was lazy and "attention seeking". She remembered me as someone who was kind to her but ineffective in helping in any meaningful way or in addressing how others treated her.

Where does this lack of empathy come from? In my experience, I believe some of the root causes are related to staff feeling stressed by their inability to deal with a situation, lack of resources in terms of staff numbers, staff burnout and the stigmatization and discrimination that people with mental illness and their caregivers or families experience from mental health services and health services generally.

I believe most staff who are attracted to the mental health system find their passion there and stay within the mental health field. Working in mental health provides a unique opportunity to help others who are deeply distressed, not through medicine and technology but by being another human to connect with. It is a fulfilling career for those with a desire for social justice and a passion for working with marginalized populations. However, it is also my experience that some people seek work in mental health because they are not confident about their competency in other areas of health care and think this area might be "easier". Others may have a physical injury and believe they can be easily accommodated in mental health. I have worked through these issues with human resources and union representatives who were trying to place physically injured staff in psychiatry settings simply because it was thought they would not have to do heavy lifting. Finally, my management experience has also informed my impression that working in inpatient psychiatric settings in particular can provide an environment for situations of power imbalances that can lead to abuse. On many occasions I have had to investigate allegations of abuse. Some of those investigations resulted in staff being dismissed and losing their professional licenses. Others were less clear: having the power to physically restrain a person, lock them in a room and force medication on them can leave that person feeling violated and abused, especially if their perception is they were not being understood and there was no kindness or empathy shown.

I do not believe we value our human resources in the mental health system as much as we should. I have made administrative decisions over the years that, in retrospect, unwittingly communicated this, such as setting up float teams for nurses to decrease replacement costs during sick leave, or filling positions with staff who did not have the best qualifications because I did not think I would get union support. Reducing staff numbers, not replacing them while sick, enforcing mandatory overtime, and refusing education opportunities all result in staff who feel undervalued. How can we expect staff to pass on messages of hope, support and caring when they are not receiving such messages themselves?

John’s example of the staff member shouting at the patient to “get out of his face” was similar to incidents I witnessed as a staff nurse and later investigated when families or individuals complained to management. In many of these instances, staff did not have the skills to intervene in these situations and reacted with frustration and anger. Sometimes staff experience their own mental health issues. I did not provide enough support for mental health staff and physicians when I was a director and I do not think enough support is being provided currently in the mental health system.

In so many instances of investigating these types of complaints, the recommendation was to provide education and skill development for staff. Ongoing education in the workplace to support staff, considered to be “discretionary spending” is often one of the first budget items to get cut during times of fiscal restraint. I recently participated in public consultations across the province with an All-Party Committee for Mental Health and Addictions. In each region, staff asked for more networking opportunities, on the job training and skill development.

4.4 Respect and Dignity

John recounted examples of how he felt disrespected as well as when he believed Jamie was disrespected. In his first interview with me, he indicated that persons being involuntarily hospitalized *had entitlements and one of the most basic ones is to be treated with respect.* He provided instances of the system being disrespectful to Jamie or to him. For example, he recounted a time in 1998 when he was reluctant to coerce Jamie in a vehicle to come to hospital, based on a previous occasion when he called the police and Jamie was placed by police in their car:

> *I was reluctant to coerce Jamie into, you know, getting into a vehicle, coming into St. John's because the time before, I did call the police. Our doctor recommended it. It was the only way I was going to get Jamie in. And from that time on Jamie never forgot. "The time the police came and took me away...they put me in a police car and brought me into a hospital and I'm no criminal." And Jamie was*

> *saying that for years after that..."and I'm no criminal". That was, you know, a person with a mental illness. That was an awful burden to be carrying.*

In another instance John spoke about the need to maintain the patient's dignity. We were again speaking about Jamie's reaction to being transported in a police car for involuntary treatment:

> *Jamie was reacting to that the same way as you or I would. You see? And that’s a big item for mental health rights. You treat them as far as possible and with the same dignity as with physical illness. I don't see that attitude is there.*

John's descriptions of Jamie's experience with the police deeply resonated with me. My personal experience with the two police forces in Newfoundland and Labrador has been positive over the years with regards to the services they provide detaining and transporting individuals under the *MHCTA*. However, their role is maintaining law and order and anyone detained in a police car is perceived as having done something wrong. Every day the police are at the local psychiatric hospital, bringing individuals in who are detained and who likely experience it similar to Jamie. Most times individuals are not combative, however, there are times when individuals who are ill become very aggressive, particularly if they believe staff or the police are going to hurt them.

When I was the regional director and worked at the psychiatric hospital, I witnessed many difficult situations involving police transport. Prior to 2004, when individuals were detained by the police under the mental health legislation, they were brought to the jail. Psychiatrists would see patients there because it was deemed unsafe to detain them in hospital emergency settings. I heard many accounts from families who called 911 for help with their adult child who may have been suicidal or psychotic and refusing help, only to have police respond to the 911 call and bring their loved one to the local jail. In 2004, a secure place was constructed within the psychiatric hospital where individuals could be detained safely and assessed. I recall watching police bring into hospital in handcuffs and shackles, a mother who had just given birth; a woman who was talked down off a bridge; and an elderly man who was evicted from his boarding room and was shouting in the street about the voices he was hearing. Many times, individuals were taken from their homes in pyjamas or with no shoes. They would always be handcuffed for security reasons.

Police transport individuals in crisis under mental health legislation to hospitals every day in this province and in other Canadian jurisdictions as well. In my experience, the safety of the individual and others involved in the detainment had been the primary consideration in transporting individuals. However, in 2005 when community agencies, formal mental health services, individuals/families with lived experience and the police came together in this province to plan for the new legislation, everyone had stories and reasons why the police should not be automatically involved in transporting everyone detained as they had been.

These stories were similar to John's: the indignity of being treated "like a criminal". Some individuals also experienced trauma by being involved with police, particularly when they were experiencing delusions that already involved law enforcement, spy agencies, and so on. The planning and implementation of mobile units of mental health staff who either ride along with police or work in partnership with them grew from that. However these arrangements are only in place in a couple of urban regions in the province.

John also spoke about how disrespected he felt by Jamie's psychiatrist prior to the *MHCTA.* Jamie had been involuntarily hospitalized following a lengthy period of increasingly bizarre and disturbed behaviour, and then discharged home with just medication and a follow up appointment. John was looking for a diagnosis and a plan that would help him to support Jamie, but did not receive either:

> *I just felt I was not respected as a spokesman for Jamie…What really put me beyond the tolerance point was being ignored. Well, the routine was I was coming in with Jamie for appointments with the psychiatrist, coming in all the way from (*names community*) and making appointments with this psychiatrist. And when we got here essentially, the doctor would say hello to Jamie and ignore me. And he would ask Jamie two or three questions and then take the cigarette out of his mouth and write a prescription for antipsychotics and good day to you. See you again in a few months. At that point I said to him "Just hold on there sir," because he was only asking Jamie and Jamie was saying everything was fine. It's not fine and it hasn't been. And so I wanted to tell him what the situation is. And so I described all that I had experienced that month at home. How difficult it was to persuade Jamie to come in to see him and I said now this has got to stop. At that point, I'm not sure if he had diagnosed Jamie or not. But the point was I had no answers to any of my questions at that point. At some point as soon as he had the diagnosis, he should have sat down and said 'Now, we diagnosed Jamie with (names diagnosis) and what it is and how to manage it you see and go from there. 'When Jamie is having delusions or seeing or hearing things, you don't argue, you don't try to tell Jamie no you are not hearing that, not seeing that, you go along with it; you're not going to convince Jamie of anything else.' Here I was trying to be rational, trying to be logical with Jamie. 'Do you understand that what you are seeing, I'm not seeing?' And it was making it very difficult for me and making Jamie upset and there was no need of it. I should have had some simple rules of thumb about how to manage the illness.*

John believed this particular psychiatrist was disrespectful to him. I understood why he would feel this way. Yet, I did not think this psychiatrist's behaviour was significantly different from others during that time and I shared that with John:

Colleen: I can't speak for that psychiatrist but when I was a staff nurse… it seems hard to justify this now, but we didn't tell patients their diagnosis. We didn't tell them.

John: You didn't tell them?

Colleen: We didn't tell them. The doctors didn't tell them the diagnosis, particularly if it was (names illness). If it was something like Depression yes, but something like (names illness), which clearly requires a lot of management, they weren't told. I don't know if it was seen as a difficult thing? I'm not really sure why.

John: So, if a person comes in to you with a physical disease, what is the argument against telling them that they have this physical condition? And helping them to understand. How can you justify that?

Colleen: No, you can't justify it.

John: I can understand not trying to tell that person he or she has (names illness), telling them what's wrong because they're not able to process the information anymore…but the people who provide the care who are responsible and able to monitor the care given…

Colleen: I think it has to do with the fact that our system, the mental health system, was never part of the health system traditionally. Back in the 17 and early 1800s mentally ill people were jailed (John nods) and then they were placed in long term asylums on the outskirts of town, away from people.

John: Yes, yes, that's right.

Colleen: The mental health system grew that way, separate from the rest of healthcare. All that time, the physically ill were in hospitals or at home. So, all the rules are different. The stigma is so deep. I've spoken to a number of people over the years who learned their diagnosis when they asked to see their chart or had a form filled out by a doctor for some reason and read it for themselves.

John: Really.

Following that interview, from my journaling for that day, I wrote the following reflection:

> *I reflected on this part of the conversation a bit more and realized I only shared with John a part of the reason, as I saw it, that we did not share the diagnosis. It is true the mental health system came from a different place, however at that point in time, when John was meeting with this psychiatrist, deinstitutionalization had not really commenced in this province and we were still keeping people in hospital for years at a time. Part of this psychiatrist's thinking may have been that he expected Jamie to end up in hospital anyway, that the trajectory for Jamie would be to only have short times outside of hospital that would occur less frequently over time so why bother doing a lot of education with John? We were so paternalistic then. I believe we felt hopeless in this system, we certainly didn't provide any hope. But we didn't want to dash any hope others may have about prognosis. Could we have been that arrogant? Jamie is doing so well now and we were so wrong.*

In addition to my reflection the day of the interview, I also wish to add that I experienced a system at that time that did not include families well. We took over from families, provided a complete institutionalization of their ill relative. Individuals were on acute care units for months at a time and if the illness was severe, they were then transferred to long term units; some moved into residential units and were never discharged. So at that time, we weren't teaching families about symptoms of illness or how to manage symptoms in their loved ones. We were managing their loved ones' illnesses along with most areas of their lives.

Furthermore, at that time, there were still references to "schizophrenogenic" mothers in the literature; an outdated theory with no evidence that suggests Schizophrenia occurs when individuals do not receive affection and approval from their mothers. As a professional community, while we may not have pointed the finger directly at loved ones, we held them in abeyance and with some suspicion until, in my experience, we could sort out what was happening with the patient and ensure the family hadn't contributed to the illness in some way.

It does not surprise me then, that the former mental health legislation had no role for a person, whether a family member or not, to help represent the patient. We, the formal mental health system, represented the patient.

However, now John's role is different. As noted earlier, John was invited to participate in meetings with the clinical team. Also, following discharge, while no longer in the formal role of Patient Representative (because Jamie is no longer involuntarily hospitalized), John's satisfaction continues:

> *She (psychiatrist) talks to Jamie and I take great pleasure in going in and sitting down and she understands the approach we take and she will start in, she will say hello to both of us and then she will start talking to Jamie. She will start asking Jamie questions you know? And of course I'm there listening and if there is a place where Jamie obviously doesn't understand the question or if Jamie is not giving the full picture and then I will say "Jamie, do you mind if I have a few words to say now?"... "No, no" you know? So then I will fill in the blanks and so on and the question that came up 6 months ago..."What about reducing ECT to every second week?" Now I knew that question was coming and I'd been asking Jamie for quite some time, you know, "How do you feel about that?" But I also knew from my own observations and the respite workers' observations; Jamie was always hearing voices in the past. But when s/he came out of ECT the voices were gone. Then three or four or five days later they were starting to come back. Wednesday is coming up, Wednesday is coming up. Tuesday night Jamie got everything ready for the next morning and was up an hour early for ECT. Most other patients when they came out of their treatment, after they had to rest for a half hour, they were tired and sleepy. Jamie came out you know hitting the ground running "Come on let's go for a coffee."*

John also spoke at length regarding the lack of appropriate community resources for those involuntarily hospitalized and he found this to be disrespectful:

> *This is the part of the program of integrating the mentally ill into the community and I remember the Minister of Health and so on......on TV or radio......lauding this marvellous approach to mental health for these people. This was supposed to be part of the program to restore their dignity. It wasn't doing any of these things...*

On several occasions, John compared the treatment of the mentally ill to treatment of the physically ill. In one instance, we were discussing the process of restraining involuntarily hospitalized patients and forcing medication by injection. While he saw the medicine as necessary, he wondered about the process for forcing treatment:

> *I would suggest that you would not treat a patient in other hospitals like that, in the sense that, you would say it's ok for a bunch of males to go in there and manhandle a person. In my view, there should be few exceptions to the idea where you treat a mentally ill person just as respectfully as you would treat a physically ill person. And at all times allowing them to maintain their dignity.*

While there are instances of voluntary patients being placed in seclusion for brief periods, most instances of seclusion involve persons who are hospitalized involuntarily. Until about 2000, staffing on the units at the local psychiatric hospital was gender based, due to a clause in the collective agreement for nursing assistants that required a certain number of male staff on all the units. In the 1970s, just before my career began, the hospital staffed the units with male nursing assistants and some female nursing assistants. Male staff from all over the building would respond to the overhead page for a psychiatric emergency. Male staff would then physically restrain both male and female patients and place them in seclusion rooms.

In 2000, when gender based staffing was eliminated, the process began to change. Because we could no longer rely on male staff to respond, all staff had to be trained in therapeutic crisis intervention, including social workers, occupational therapists, nurses and others. The response moved to a team approach, using beepers instead of overhead pages and included bringing the team in to help de-escalate situations so as to avoid having to place the individual in seclusion. Other changes included mandatory training in how to safely restrain, which also meant not restraining the chest area by placing the person face down and not holding the neck, to avoid breathing problems for the individual.

Up until the early 1990s, the practice of seclusion included the removal of the patient's clothing. Sometimes patients were given a hospital gown or blanket but only if staff believed the person was not at risk for self-injury. Each of these seclusion rooms was situated in the main corridor of the units. They each had a window and the patient could be seen by staff, visitors and other patients. On occasion, patients would be left naked; or they may have been provided a blanket but due to their psychotic state, they did not cover themselves with it.

In the past 15 years, these rooms have been reconstructed so that they are moved off the main corridor with a small area outside each for a staff person. Patients are placed on constant observation when in seclusion, meaning a staff member stays with them at all times, outside the room, so their safety is ensured. There is no longer any need to remove all their clothing. Yet, I am aware as an insider to the system, of instances when clothing is still removed for safety reasons, that is, the person's behaviour is believed to be impulsive and the person could inflict self harm.

4.5 Need for Advocacy

John believes the Patient Representative role is an advocacy role that is meant to "ensure the person you represent is receiving his or her entitlements under the act…and it is done in a professional and prompt way". The need for advocacy is a strong issue for

John and he recounted experiences where he felt more advocacy was needed. This was particularly so prior to the current legislation:

> *What I found before was that there was some reluctance of people providing services for Jamie... I found a reluctance to give ...to be cooperative I guess...in my discussions with them about Jamie's needs.*

Prior to the current legislation, John shared how he had to call police to bring Jamie to hospital and then because of the negative impact that had on Jamie, the next time, a few years later, he instead managed to convince Jamie to get in the car:

> *...the thing was that time when I brought Jamie...finally got Jamie in here and it was only you know...I, I, on a ruse more than anything else...I suggested that we go for a ride up to the arena because Jamie always liked hockey...you know. So, on a ruse I suggested we should go for a drive up to the arena… and Jamie agreed.*

Several years later, under the current legislation, Jamie's mental health once again deteriorated. S/he became very ill and refused to go to hospital or seek treatment. On this occasion, John called 911 expecting the police, but in addition a mobile crisis response team came to Jamie's home. This team was put in place to support people in mental health crisis, including those who may require involuntary hospitalization, shortly after the new legislation was proclaimed. John described his experience with the team as follows:

> *We had to call 911...and have...someone come in... people come in...and there was a police officer came with them. It was all done very...very well. It was handled very very well… but the thing was...to the point, I guess, the thing was that before that time when we brought Jamie...finally got Jamie in hospital, there was no help… and it was only you know...I, I, on a ruse more than anything else.*

As mentioned in Chapter 1, at the point of involuntary hospitalization patients are asked who they wish to have as a Patient Representative. This decision, one of the few decisions an involuntary patient may make associated with their hospitalization, is expected of the patient when they are acutely mentally ill and at what is likely to be a very stressful point in time. John believed Jamie would have been "too irrational" to express this and that John and Jamie were known by staff when they went to the hospital and John just introduced himself as the Patient Representative.

John shared several examples that occurred prior to the Patient Representative role, of working with psychiatrists and staff who, in his opinion, did not respect him and were "indifferent" to his advocacy efforts on behalf of Jamie. In the previous example described in 1998 in which he managed to get Jamie to the hospital "on a ruse”, John went on to describe the situation after he arrived at the hospital with Jamie. John believes this would have gone much differently if he had not been there advocating for Jamie.

> *So Jamie was there growling and grumbling and so on and saying "I'm not going to go" and "I'm not supposed to be in here today" and "I'm not going up there", you know? So, someone there called the red alert or whatever it is and maybe about 4 or 5 or 6 of the burliest of the staff came down and they were going to take Jamie up to the ward. So I wouldn't allow them and I said "Leave this alone for now...I think I will get Jamie up there without any manhandling" and so on and so I just went back talking to Jamie, giving a chance to unwind and so on...and I heard them saying...you know...basically what they said was..."We're not going to stand around here any more, we're going to take Jamie” you know? So with that I walked over and told them...I said “Forget that. Because I'll tell you now. If you're going to take Jamie you’re going to take me first" and I said "I'll get in a few kicks and punches before you take me. I'll decide when Jamie goes upstairs. You stand back as far as you can. And you can stay there as long as you like as long as you go away." So anyhow after more talking to Jamie, I made the comment ...now one of the caregivers up there is a fellow (identity has been disguised) who liked talking to Jamie about hockey. So I said "Jamie...Bob is upstairs there. He's on today. Why don't we go up and see what he thinks of the playoffs? Let's go up and see what he thinks of the playoffs and who is going to win the Stanley Cup this year?" "Alright!" So the two of us walked upstairs and went in, started talking to Bob. After a while he knew ...Bob knew what the situation was...and he nodded and I headed for the door to walk out, leaving them. Now Jamie saw me starting to go for the door and said "You're not going leaving*

> *me here?" and I said "No, Jamie, I won't leave you here for very long" and Bob said "He'll come back to visit you in a little while" and so Jamie was trying to get out through the door again but I just kept going, I was out and Jamie was in. No manhandling. You see? But if these guys had been left to themselves, this isn't the way it would have been done. And it would have set Jamie back God knows what again...you see?*

I understood this particular experience very well because I had experienced similar situations as a young nurse trying to be an advocate, many times over. I was 22 years old when I graduated and began my first permanent full time position at a psychiatric hospital on an acute care unit. For the first six months of employment, I was completely ostracized from the clinical team on the unit. I was excluded from coffee breaks, lunches, any kind of social talk. I was hired with a close friend who had graduated with me and we supported each other through those very difficult months. We were naïve and had no experience, and expected that because we were now Registered Nurses, we could implement changes. We were among the first nurses with degrees, the others were hospital trained and this caused some tension. Most of the men working on this unit were 15-20 years older than us. Just 6 years before this, there had only been one nurse (female) for the entire hospital. The units were run by (mostly) male nursing assistants.

The main trigger for the conflict we experienced was our attempt to change the way we handled forced treatment and psychiatric emergencies with involuntarily hospitalized patients. The way these situations were handled did not change until about 2000, when the requirement to have a minimum number of male staff was removed. Since then, a multidisciplinary team is used to respond to psychiatric emergencies, however, the basic protocol remains unchanged. In the following excerpt, John and I discuss what it was like when there was still a requirement to have gender based staffing:

> *Colleen: …Code 666 for male staff (Participant nods). We would page it overhead in the hospital.*
>
> *John: Yes*
>
> *Colleen: …and you'd hear thunder, you would hear the men running.*
>
> *John: Yes! I heard that. When I was there.*
>
> *Colleen: ... and they would be responsible for "running the code", for managing how it happened. And the nurse would be in some room somewhere drawing up the medication and when they had the patient restrained, the nurse would come inject the medication…it was upsetting, just being part of it.*
>
> *John: Just witnessing it*
>
> *Colleen: Just drawing up the medication*
>
> *John: Yes*
>
> *Colleen: Injecting somebody against their will*
>
> *John: Yes...this male...I'll call it "manhandling" females. That's part of your trauma as well, was it?*
>
> *Colleen: Yes. I think so.*
>
> *John: Yes.*

The following situation occurred in those first months of my employment with a young 24 year old man with schizophrenia. Eighteen years later he was living in a small community in a dilapidated house with no running water or electricity. He was floridly psychotic and died from complications related to untreated mental illness. However, when this story happened he was young, still optimistic about his future and anxious to be home and fishing with his uncle. He was very ill and did not believe he was ill. He was refusing medication and his psychotic symptoms were worsening. So eventually, the medication had to be administered in an intramuscular injection. I will call him Nathan.

> *It is early afternoon, just after lunch. Most of the patients are in the TV room, smoking. Nathan is in the corridor outside the nurse's station. He is chanting in what he considers to be a secret language. He believes he needs to do this to ward off the CIA who can hear his thoughts. He is becoming more agitated and the chanting is getting louder. So I am in the medication room preparing two injections for him. One is Haloperidol or Haldol, a neuroleptic to treat psychosis. The other is Benztropine, to treat the side effects of the Haldol, which are almost always experienced when given intramuscularly. I also measure out the dosages in liquid form to have on hand. The side effects are significant and can include stiffness, rigidity, restlessness, shuffling gait, drooling, neck and back spasms. Most patients don't like Haldol. Nathan hates it. But it is effective in treating psychotic symptoms and this is what is keeping Nathan in hospital against his will. Injecting him will create problems with trust and future engagement but he needs this to get better! He is so tormented by these delusions. But getting this medication intramuscularly into tensed muscle is painful. I am three months into my new job as a staff nurse. I am determined to do this the best way I can.*
>
> *The two male staff working today are in the main office, next to me. I glance out: one is removing his watch and glasses, humming along to a song playing softly on the radio. The other is on the phone, calling around to other units for male staff to help. We need five. This isn't an emergency so an overhead page isn't necessary. We don't talk to each other or plan for how this will happen. I know this is their domain. I hear each man entering the unit, the unlocking of the door, the buzzer, the re locking of the door. We end up with eight men. They all stay in case they are needed. They stand in the nursing station, socializing, laughing, making small talk. This is the ritual. They all remove eye glasses and watches. They don't speak about what they are going to do.*
>
> *The two men who work with me on the unit are in charge. They will find the patient and the others will follow behind. Nathan will be told he needs to go down to his room with them. Of course, everyone on the ward, Nathan included, knows what will happen. At that point it could go one of two ways. Nathan could walk down to his room and then they hold him steady and I would give the injections. Or he would start resisting. In that instance, they would grab his arms and around his neck in a chokehold (this was later not permitted), restrain him and move him into the seclusion room. I would come in, get into the tangle of arms and legs, give the injections and run out. Then one by one they would release a limb and back out of the room and Nathan would be locked inside. According to*

the policy, I would then require a physician to come to the unit and assess Nathan before he could come out of seclusion. It is this second scenario I want to avoid as much as possible. I feel traumatized every time I do this, so I reason, the patient must as well, much more than me. Nathan is now in the corridor calling out to me: "I'm not taking it Colleen! They can't make me take it! It's poison!" So I step out of the office, pass through the horde of men in the doorway and speak to him. I can feel the men watch us from the nursing station.

"Nathan, you want to get out of here, right?"
"Right".
"Well, taking this medication will help you get home."
"You're with the C.I.A. too".
"I'm trying to be helpful to you Nathan".
"You just want to poison me like the rest of them".
"You told me you want to go home. I'm trying to be helpful. This is the best way for you to get home".
"I don't need drugs that poison and I hate needles and I really hate Haldol!"
"Well, if you take it in liquid form, the side effects aren't as bad".
"It is still poison".
"I know you are really worried about taking this. I checked it very thoroughly and I believe it will be ok if you take it with some ginger ale in a cup. If you can do that, I can tell the men back there they can go back to their units".
"Get me the cup".

I quickly walk back into the station, grab the liquid medication and ginger ale and bring it back to him. He swallows it and begins chanting loudly and walks down the corridor to his room with his hands cupping his head. I feel triumphant! If we can get through this a few more times, his psychosis will settle and I can try to engage him a bit!

I walk back to the nursing station and the men are silent. They move out to the break room for a few minutes and then return to their units. The men working on my unit don't speak to me but that's not unusual. However, the other nurse working with me calls me into the medication room and closes the door behind us.

"Colleen, you shouldn't have done that, not after the men were all here."
"Why? Nathan took his medication in liquid form. I thought it went well."
"Yes, fine for Nathan. But you embarrassed the men on this unit. They called their friends down here for nothing. You need to be careful."
"Careful?"
"They protect us. I've been in pretty bad situations and they are the ones who make sure we are all safe. You want to be able to rely on them."

About a week later, I am in the elevator with a male staff and an involuntary patient bringing him up to the ward from the admitting area. The patient becomes agitated and says "I'm not going in there! I can't!" The male staff puts a chokehold on him. The patient turns red. "Be careful!" I say, "You're choking him!" With that the male staff releases his hold and pushes the patient on me as the elevator door opens. The patient gasps for breath and starts crying.

Nathan continues to refuse his medication. On this day, there is no time to arrange for extra men. Nathan is removing pictures from the wall looking for hidden cameras. He throws one of the frames on the floor. Patients peek out of their rooms to see what the noise is and quickly retreat. Staff try to speak to him and he begins chanting. One of Nathan's family members comes to the door to see if she can visit. The other nurse with me tells the male staff not to let her in right now, maybe later. The nurse calls the operator for an emergency code and we instantly hear overhead "666-male staff-1 west" repeated three times. I draw up the medication. We hear thunder rumbling and know it is male staff from all over the building running in the corridors and on the stairs. I hate that noise. We hear it almost every day, often more than once a day. I will never get used to it.

I go in the TV room and ask patients to stay there and one of the other staff goes in with them and they close the door. I see a teenage girl in the corner of the TV room crying and make a mental note to speak to her afterward. Patients are often too afraid to ask staff what is happening and why. They ask each other and advise each other what not to do to make sure this doesn't happen to them.

The first man unlocks the door and holds it open for others. Fifteen men respond. They approach Nathan and try to talk to him while they restrain him in the middle of the corridor. He is on his knees now chanting and they drag him into a seclusion room. The men pull off his belt, his shoes, his jeans, his shirt. He is left with his underwear. He is on his side, on a plastic covered mattress on the floor, still resisting, pushing back. Every inch of Nathan's body is held down. He is facing the inside, his back is facing the door. The men are straining from the pressure of trying to restrain Nathan. Nathan turns his head back and sees me. "Give me the liquid!" But too late now. I inject him twice in the buttock and am the first to leave. One by one the others back out of the room and the last one gives Nathan a blanket and leaves, locking the door. I peak in and Nathan doesn't move, lying on the mattress on the floor, his face turned to the wall.

As we walk back down the corridor, my hands start to tremble, my legs feel weak. One of the men says to me "See, you should have done that the first time, get it over with. I know you think it's kinder to try and talk them into it but it doesn't work and the quicker the better".

> *Nathan will spend most of the rest of his admission in seclusion, fighting us, being offered medication and then being given it by injection in seclusion. When he is no longer certified under the legislation, he discharges himself immediately and refuses follow up.*

Eight years later, following some other positions I had elsewhere, and still under the old legislation, I am back on another acute care psychiatry unit at the same psychiatric hospital. The collective agreement that requires a certain number of male staff hired into positions on each unit is still in place. In those eight years, very little has changed. It is 1990, just before I accepted my first management position. It was also about the time when Jamie first started experiencing psychotic symptoms and John was trying to get help for Jamie, although I did not know that then.

As the nurse in charge, I received a call that we had an admission coming from the lock up. This meant the person was picked up by the police for some reason and brought to the lock up. While there he was assessed by a psychiatrist who was on call for the lock up and now was being transferred to the hospital. I was informed the patient was enroute with the police and was being involuntarily admitted directly to seclusion. This meant that he was actively resisting and would need to be met downstairs by male staff and brought to the unit and placed directly in seclusion. Nursing assessment, history taking and the other routine admission protocols would have to wait. I phoned the unit psychiatrist who saw the patient being brought in and he gave me what we called a "verbal order" for Haldol and Benztropine either orally or by injection. I will call this patient Joshua.

> *It is 4 p.m. Admitting just called again, the staff and patient are on their way. I run down to make sure the seclusion room is ready, door unlocked, plastic covered mattress with no sheets on the floor, nothing else in the room. I*

encourage patients to go in the dining room and staff start making tea for them. The two syringes are ready and I also have liquid medication poured just in case. We hear them outside and I unlock the door. The male staff are restraining a young man by the arms. He walks in shouting "I don't belong here! This is all wrong!" They walk him to the seclusion room and I follow. He sees the room and begins to resist. "Not going in there!" The men speak to him in a casual tone, trying to calm him down "Come on now by, you won't get hurt in here. You'll get some medication and then have a nap, feel good as new". He struggles some more and starts shouting vulgar language at them. I take a closer look. Is he 18?

"Josh, how old are you?"
"16. What's it to ya?"
"I'm Colleen, I'm a nurse here. Can we talk for a minute?"
"I'm not talking to no one. I have nothing to say to anyone here."

The men tell Josh I have some medication to give him and he tries to bolt. Now he is being fully restrained on the floor. I help remove his boots, the men remove his jeans and Josh sees the needle. His face crumbles and he starts to cry.

"Please nurse, no, I'm afraid of needles. Please don't!"
"Josh, I can give you the medicine to drink instead, ok?"
(Sobbing) "ok".

One of the men says "Oh for Jesus' sake" as I run out of the room and down to the nurses' station to get the liquid medication. I come back and Josh drinks it and just lies on the floor crying. The men all walk out and we lock the door. As I'm walking up the corridor the unit phone is ringing. It's the psychiatrist.

"Is he in seclusion?"
"Yes".
"I'm coming up"

The psychiatrist, a young woman and not the same psychiatrist who saw Josh in the lock up, goes to the seclusion room and speaks to Josh for less than 5 minutes. She then asks the men to get him his clothes and let him out of seclusion. She comes in the nursing station with me and starts writing out the paper work for his discharge. As she writes, she tells me that Josh lives with his Mom who is addicted to alcohol. He has a part time job after school and had money hidden in his room. Mom found his money and got drunk. When Josh came home after school, he got angry with Mom, who in turn went into a rage. Josh called 911 and Mom then tore the phone from the wall. When the police arrived, Mom told the police Josh had torn the phone from the wall and that she was afraid of him. The police took Josh out of the home and to the lock up. They had a psychiatrist see him and Josh refused to speak to him and used a racial slur. The psychiatrist at *the lock up said "Send him to the hospital" and filled out the first certificate for involuntary hospitalization.*

I can't believe what the psychiatrist is telling me.

"That's it?"
"That's it. His Aunt phoned me and Josh just filled in the rest. I spoke to Dr. X who saw him in the lock up. This was just a mix up; he doesn't need to be here."

Joshua walks up the corridor, sniffling, holding his boots and belt in his hand.
"Can I use your phone?"
I give him the phone and he calls a fast food place where he works and tries to explain why he is late. He turns to me.
"I'm really sorry for shouting and giving you a hard time, ok?"

The unit doorbell rings. Joshua's aunt is there to drive him to work. She speaks very briefly to the psychiatrist at the door and then she and Joshua leave. I don't see Joshua again. It is 5p.m. Two hours before this, Joshua was in school. I feel absolutely shattered. We just used the full force of the legislation to detain, restrain, admit to hospital and force treatment on a teenager who is not even ill. How could this have happened?

The following evening around 5 p.m., I get a call from one of the city hospitals. Josh is in their emergency room with an oculogyric crisis, a side effect from Haldol. He can't move his eyes.

"He tells us he was in with you guys yesterday and you gave him medication".
"Yes, I gave him Haldol and Benztropine. He needs more Benztropine."

The next night the same thing happens. I get a call from the emergency, different staff, saying Josh is there with another dystonic reaction, what did we give him?

In the coming days I tell whoever I can about this incident. The psychiatrist doesn't want to talk with me about it and shuts down the conversation. The supervisor is sympathetic and shakes her head "tut, tut, tut". The other nurse who works with me is somewhat puzzled by my reaction: "Well, he was only here about half an hour and it got straightened up, right?"

About 6 months later, I describe the incident to a physician who is a resident in psychiatry and just joined our team. He says "There is no way that could have happened". Despite my attempts to convince him, he doesn't believe me.

John sees the Patient Representative role as an advocate. How would my experiences be different if there had been a Patient Representative with Nathan or Josh? The individual being admitted involuntarily is asked who they want their Patient Representative to be at the time they are being admitted. In Josh's case, it would not have helped at all. He had one certificate signed by one physician which is enough to detain and administer emergency treatment until the person can be assessed by a second physician. It is not until the second certificate is signed that the individual is an involuntary patient and then s/he gets a Representative. However Nathan had two certificates signed and he was admitted as an involuntary patient. We turned Nathan's relative away when we were preparing to give him intramuscular medication.

Having a family member present in the following situation did not help. As previously discussed, although the policy for seclusion at the local psychiatric hospital no longer includes the removal of a person's clothing, it still sometimes happens for patient safety reasons if it is believed the person may be at risk to self-harm. About three years ago in my current work role as provincial director, I received a phone call from a distraught mother. I have changed the name and some details for privacy reasons. The mother told me the day before, her 18 year old daughter Amy had been stripped of all her clothes in the mental health emergency unit by a number of staff after she took a pill from her pocket, swallowed it and then refused to empty her pockets. She was there for an assessment of suicidal ideation. Amy was restrained and her clothing was forcibly removed while her mother screamed at staff to stop and then she was given a hospital gown. Amy was locked in a seclusion room while waiting to see the psychiatrist because she had kicked and screamed while her clothing was removed and also because she wanted to leave. A few hours later, following the psychiatric assessment, Amy was released with no follow up. Her mother was told by a staff member that she had "spoiled" Amy and there was nothing wrong with her. The mother cried as she told me what had happened and she said Amy is now in bed crying and says she feels like she was raped and wants to die. The mother swore she would never bring Amy there again and was calling me to get Amy some help for the trauma she had endured at the mental health emergency.

This is not the first call of this kind I have received. It is clear to me these interventions inflict more harm than the self-harm staff were trying to prevent.

4.6 Management Accountability

In all of my meetings with John, including the ones outside of this study, he raised the issue of management accountability. John believed the health care system and in particular, the mental health system, was not accountable to the people it served and he believed the management of the system was at fault. In 2003, he presented to a small team I was leading that travelled across Newfoundland and Labrador seeking public input on the province's first mental health strategy. He spoke strongly about the problems he encountered with the care provided to Jamie at the psychiatric hospital and indicated he held management accountable for behavior of staff, which he found at times to be disrespectful of Jamie and lacking empathy.

In 2011, John requested a meeting with the Minister of Health and Community Services. I met with John on behalf of the Minister and took notes, which I kept. John believed in 2011 that an inquiry was needed into mental health. He stated there needs to be a management model that is more efficient. I read these notes to John in one of our interviews and he continues to hold that view. In another interview, when speaking about the Patient Representative role, John remarked that "the supervisors in the system should never have been removed" in the 1990s and that the health system was "headed for trouble".

In the early 1990s there was a recession in Canada and the Federal Government combined health and social services transfer funding to the provinces, calling it the Canada Health and Social Transfer. They reduced the overall amount of the Canada Health and Social Transfer going to the provinces and then required each province to divide the lesser amount between social services and health. All health and social services sectors in Canada received less money, resulting in service reductions and layoffs. Although discussions on regionalization had been happening at senior levels within the provincial health system prior to this, it was at this time that the 23 health boards in the province joined to become 7 regional boards, and the psychiatric hospital became part of a regional entity called the Health Care Corporation of St. John's.

Prior to the consolidation of the hospital boards, there were 33 managers working in psychiatry across the city. With the consolidation, those positions were cut by two thirds with one third remaining in a restructured mental health program. I was awarded the senior position for mental health. My first task was to hire the reduced number of positions and issue layoffs to many of my colleagues. We lost the entire executive at the psychiatric hospital, that is, the executive team which had been focused exclusively on mental health. Some moved on to other health positions, others retired. In 2005, we further amalgamated from 7 boards to 4 and the city's hospitals and community services became Eastern Health and I then became the Director for mental health and addictions services across the region, for community and hospitals.

Under the former structure, in 1994, I was a member of an executive team responsible for patient care services. Directors of Nursing, Social Work, Occupational Therapy and Psychology reported to me. Also on the executive team were two psychiatrists: one was a clinical director and the other a medical director. There was a chartered accountant responsible for all financial and support departments, a human resources position, a research and planning position and a communications position. We were all devoted to provincial psychiatric services and reported to a Chief Executive Officer who reported to a full Board of Trustees, just for the psychiatric hospital. There was also a Foundation Board for fundraising.

In the restructured 1995 mental health program, the director positions for Nursing, Social Work, Occupational Therapy and Psychology were all made redundant. Nursing units that each had a nurse manager were doubled up, in some cases one manager for three inpatient units. My position, Director of Mental Health, was the only senior position left for mental health. A Clinical Chief of Psychiatry also remained but was reduced to part time. The psychiatric hospital board and foundation board for fundraising and mental health awareness were both replaced with a regionalized board and foundation board for all city hospitals. This foundation board amalgamation excluded the children's hospital foundation board, to ensure the successful children's fund raising initiatives would continue. I reported to a Vice President, who had a business background and also had responsibility for all children's services, emergency services and other clinical programs and services.

Up until 1995, there had been a full executive team, senior management and unit managers at the Waterford Hospital with a dedicated CEO and board, all focused on mental health. The following year I was the single remaining (former) executive member, now a senior manager, with 12 managers for the psychiatric hospital and the two general hospital psychiatry units. I reported to a Vice President who had many other responsibilities besides mental health. This was the time when John experienced so many problems with the system and first became concerned with management accountability. When I shared this with John, he replied "…they went from one extreme to the other…" and "…there needs to be enough management positions to maintain accountability".

While things have improved since then and we were able to get more managers and more services back in the system, in some significant ways I believe we are still trying to catch up to where we were in 1995. In my experience, the health system is not focused enough on the person/client and instead, maintains a strong focus on the system. Furthermore, there is not a dedicated focus on mental health. Acute physical health services (cardiology, medicine, surgery, emergency and so on) appear to be the core lines of business and many policies and corporate strategies are designed for them with mental health managers often left to determine how these policies can best be fitted to mental health. They are also funded from the same budget which creates competition between programs for scarce resources and at the very least, a perception that funding is allocated with a bias toward acute physical health services.

This chapter reviewed four themes that evolved from data generated during interviews with John. In the final chapter these themes will be discussed and recommendations for the MHCTA and for provincial policy will be provided.

Chapter 5

Discussion, Recommendations and Conclusion

5.1 Introduction

Four themes emerged from the interviews I had with John: lack of empathy, respect and dignity, need for advocacy, and management accountability. In this final chapter I will discuss the theme of advocacy separately as it relates specifically to the role of the Patient Representative itself. I will discuss stigmatization and discrimination of those with mental illness, portrayed as lack of empathy and respect, as resulting from the objectification of persons with mental illness and will discuss addressing this through transforming the current mental health system with a recovery focus. I will then provide limitations to this study, recommendations for legislation and policy and areas for future research. I will conclude with answering my research questions: What is the experience of the Patient Representative role as outlined in the *MHCTA*, and what can we learn from this experience?

5.2.1 Need for Advocacy

John described the Patient Representative role as one that ensures the individual being represented is provided treatment in a “professional and prompt way". With John's involvement, major improvements were made to Jamie's treatment plan that promoted better sleep/wake cycle, social inclusion, reduced symptoms and an overall better quality of life. John also was able to access a house for Jamie with respite workers, during a time when substantial policies were not in place to support this. This was all done when he was Patient Representative. As a caregiver, John made a point of attending public consultations and providing input and made appointments over time with several Ministers of Health to share his views on how the system could be improved.

As outlined in the review of literature, there is strong support for advocacy. It could be said that John is a strong advocate not only for Jamie but also for change in the mental health system. In his interviews with me, John was always respectful of Jamie's wishes and often referenced how he had asked Jamie what s/he thought or wanted. However, John was not given any expectations or training on the role. John believed Jamie was so ill, that s/he would be "too irrational" to have named John as Patient Representative. It is therefore questionable how much advocacy could be done based on Jamie's wishes as opposed to what John thought was best for Jamie. Again, there is no ability for an advanced health directive to be enforced when Jamie is involuntarily hospitalized; the provisions of the *MHCTA* override the *Advance Health Care Directive Act.*

There is a provision in the *MHCTA* that the Patient Representative is to be informed of the involuntary patient's rights under the legislation and can apply to the review board on behalf of the involuntary patient for a review of the certificates of involuntary admission (*MHCTA*, 2006, Section 12). As well, the Patient Representative may contact the Rights Advisor, whose main role is to provide rights advice, for assistance with an application to the Review Board to appeal the involuntary hospitalization or with obtaining legal counsel (*MHCTA*, 2006, Section 14).

John believed Jamie needed hospitalization and treatment. It is not known whether Jamie wished to appeal her/his certification. In 2010/11, during the period of one of Jamie's involuntary hospitalizations, there were 155 involuntary hospitalizations (Health & Community Services, 2012) and 102 applications for appeal to the review board (Health and Community Services, 2015). It is possible Jamie may have either decided s/he did not want to appeal, did appeal without John's help, or did not know about the appeal process. John knows Jamie very well, appeared respectful of Jamie's wishes and in all likelihood, advocated in the best way possible for what he thought Jamie's wishes were.

John acknowledged he received no education or information on the Patient Representative role. He said he doesn't recall Jamie being asked who s/he wanted the Patient Representative to be, rather, the staff was familiar with John and he believes it was taken for granted. He also thought Jamie was too ill at the time to have been able to appoint one. In addition to this, the evaluation of the legislation reported only 40% of the involuntary patients who responded to their survey said they had a Patient Representative (Health & Community Services, 2012).

From my insider status I know that the original training for the legislation included “train the trainer” sessions for educators employed by the regional health authorities as well as education sessions for psychiatrists, staff and the general public. These sessions were done using a PowerPoint deck of slides, in which two of 22 slides were about the Patient Representative. The two slides simply quoted the legislation in terms of the definition of the Patient Representative and how they are appointed. There was no education aimed at families and caregivers of individuals with severe and persistent mental illness or for the individuals themselves.

In spite of the lack of education the system provided, the role of Patient Representative is considered one of the procedural safeguards, which is important when removing a person's right to liberty. The *Canadian Charter of Rights and Freedoms* (1982), section 7 states "Everyone has the right to life, liberty and security of the person and the right not to be deprived thereof except in accordance with the principles of fundamental justice" (O'Reilly, Chaimowitz, Brunet, Looper and Beck, 2010, p. 3). Courts have found involuntary hospitalization does not breach section 7 because it is in accordance with principles of fundamental justice (O'Reilly et al., 2010), meaning most of society would agree that there are sufficient procedural safeguards in place. Forced or coerced treatments happen regularly with involuntary patients and there is no substitute decision maker in the legislation in this province to provide consent. I believe more procedural support in the form of an advocate should be in place, either for the Patient Representative role or in another capacity.

John is Jamie's caregiver. I have not revealed his exact relationship to Jamie for privacy reasons. However, it is clear that he has had a long term supportive relationship with Jamie. Like John and Jamie, persons who are involuntarily hospitalized often choose close friends or family members to be the Patient Representative. Most family and friends want the person to receive treatment. Are we placing them in an impossible situation by expecting them to also be the advocate and present the patient's views on their hospitalization, which in many instances are contrary to their own?

I have many examples of family members from my insider experience who are already in this dilemma of trying to maintain a supportive relationship while at the same time, get treatment for their ill loved one who is refusing it. I have taken many calls, particularly from mothers of adult children with mental illness, who do their calling while their adult child is asleep or out of the house. This is also well documented in the literature (Giacco et al., 2012; Ostman, Hansson & Andersson, 2000).

John's experience is typical of someone trying to get help for a loved one when that person does not want help. He described trying to get Jamie to hospital by first relying on the police and when that experience traumatized Jamie, John described getting Jamie to hospital "on a ruse". This was also evident in John's description of early visits to the psychiatrist when, after experiencing very difficult times at home with Jamie, Jamie would tell the psychiatrist everything was fine. John wanted what was best for Jamie and in his estimation that was access to psychiatric treatment. Jamie however refused treatment. It is not clear exactly what Jamie wanted.

Without training, it is likely that Patient Representatives who are also family members are doing the best they can and continue to provide support and encouragement to their ill family member while cautiously advocating to the system for treatment. How fair is it for family members and loved ones to walk this balancing act of respecting the person's wishes and maintaining a relationship while seeking treatment without their consent? Should the formal system expect family members to fulfill this role, along with being the caregivers?

Other jurisdictions in Canada have paid advocates and the next of kin are substitute decision makers or at least still involved in the involuntary patient's treatment plan, but not expected to formally advocate on behalf of the patient. Stylianos and Kehyayan (2012) report that their Patient Advocate Office in Ontario has an advocacy model which supports the individual's empowerment through promoting their "own narratives and perspectives" (p. 117). Independent public advocacy services such as those provided to involuntary patients in the United Kingdom have requirements of appropriate training and experience, are all employed by agencies independent of the National Health Service, are knowledgeable about the mental health legislation and are able to attend meetings with or without the involuntary patient to advocate on their behalf (Steven & Symington, 2009).

5.2.2 Respect and Dignity; Lack of Empathy

John believed his experience as a Patient Representative was a positive one and when asked if he was satisfied with it he responded “Generally yes…generally and definitely, yes”. However, John had many concerns about staff and management that originated from his experiences prior to the Patient Representative role and in spite of good experiences as Patient Representative; he still had concerns with lack of respect and staff empathy as well as the accountability of management.

While John acknowledged that conditions had improved significantly, he believed if there continued to not be supervisors on the units, these problems would continue to exist. I understand John's concerns. When John described his experiences to me of witnessing the staff member shout at the patient to "get out of his face", and having to rely on police to get Jamie to hospital, among other experiences he had, I believe he was describing an environment significantly affected by stigma and possibly staff burnout. As discussed previously, stigma and discrimination have evolved from a long history of misunderstanding, fear and objectification of those with mental illness. Reducing stigma is difficult to do in inpatient settings and requires sensitivity to issues of staff burnout. Providing supportive staff policies, education opportunities and involving staff in decisions that affect them have been discussed earlier as ways to address burnout, thereby decreasing the depersonalization and apathy shown to patients.

Introducing recovery focused services should be considered to address these issues as well. However, as discussed earlier, transforming services to a recovery focus is difficult if the entire system does not support recovery (LeBoutillier et al., 2015). In Newfoundland and Labrador, a Recovery Network of approximately 180 formal and informal mental health leaders from ten community organizations, four regional health authorities and correctional services has been formed with support form the most senior levels in the provincial health system to lead the transformation to a recovery focused service. However, these efforts require sustained support from persons with lived experience, families, staff and senior leadership over a period of years to effect the necessary cultural change. It is not certain yet if the way the current system is structured will provide the support required for that type of long term change process.

5.2.3 Management Accountability

John spoke frequently about the lack of management accountability in the health system generally and the mental health system specifically. In early 1994, I oversaw the development of a one day workshop for all staff on acute care psychiatry units at the local psychiatric hospital. Prior to attending staff were asked to enter unlocked seclusion rooms on their own and take note of their thoughts and emotions. They were also asked to reflect (but not provide answers) on a series of questions about how they thought their patients experienced some of our interventions such as seclusion, restraint, locked units, and so on. The morning of the workshop focused on the impact of trauma and trauma informed practice. In the afternoon we had a panel of persons who had received treatment at the local psychiatric hospital and they shared their experiences directly with staff. Staff responded positively to the workshop at the time and from there a "Patient/Consumer Advisory Council" was established with consumer representatives who visited each unit, met with patients and provided some informal advocacy.

I believe these were beginning steps that, had they continued, might have evolved into a foundation for recovery focused practice. However, these initiatives did not get past the first round of regionalization of health boards in Newfoundland and Labrador, described earlier in this study. All the city hospitals were restructured under one board and significant management positions were lost in the mental health sector. I cannot recall how the workshop or the Patient/ Consumer Advisory Council actually ended, other than to say for about two years, regionalizing services and putting in place the new and much smaller management structure filled my time.

Goodall (2015) reports that settings with leaders who possess expert knowledge, are associated with better organizational performance and longitudinal studies that have shown universities with researchers as leaders make the best leaders. Goodall (2015) also cites several similar hospital studies with physicians as leaders. For example, in the United States, hospitals with physician-chief executives as opposed to executives with business or other backgrounds, achieved quality scores 25 % higher than the others (Goodall, 2011 as cited in Goodall, 2015). Goodall applies a theory of expert leadership to psychiatry and posits that the same would hold for psychiatric hospitals. She asserts however that "…a necessary prerequisite …is that expert leaders have direct executive power inclusive of budgetary and strategic oversight" (p. 1).

When I described what happened during this regionalization to John, which was the same time Jamie was back and forth to the hospital, he understood. John described what he believed to be the problem with management, that is, that we did not have clinical people as Chief Executive Officers in charge of our institutions; similar to Goodall's theory (2015). I have observed many advantages of a regionalized system and I do not recommend a return to full executive teams and boards for every hospital. However, specialty areas like mental health lost expertise in its leadership and the system lost a focus on mental health. I believe this may account for some of the problems that John experienced with management accountability. I also believe this could be an impediment to creating other long term systems change such as the move to a recovery focused system.

Transforming to a recovery focused system means the client holds an empowered position within the system to make goals and decide on a course of treatment. There will be times when an individual may be very reliant on services to get well. However even when involuntarily hospitalized, the individual should be supported in developing treatment goals as much as possible. To support a recovery focused system, policies and procedures will need to be revised to include client input and the involvement of significant others as requested. Hours of operation will need to reflect client need, that is, services cannot all operate only on weekdays, from offices. Services need to be accessible, inclusive and available after hours and weekends, and include self-help, peer support and online options. These changes will be difficult to implement and sustain over time within mental health services when they are part of a bigger regionalized system with regional policies and priorities that are not solely focused on mental health.

Yet, this transformative cultural change to a recovery focused system is needed to support staff, management and physicians to facilitate recovery for persons with mental illness. It is only if the system supports individual recovery will we be able to truly address issues of stigma and discrimination, objectification of those with mental illness and ensure appropriate procedural justice is available for anyone detained under the *MHCTA*.

5.3 Recommendations for Legislation

Section 6 of the *MHCTA* states: "The minister shall, every 5 years, conduct a review of this Act and the regulations and the principles upon which this Act is based and consider the areas in which improvements may be made and report his or her findings to the Lieutenant-Governor in Council" (2006). The full legislation was not in force until 2007, when community treatment orders were introduced. The first evaluation was completed by the Newfoundland and Labrador Centre for Health Information in 2012 and the second one will be due in 2017. The first three recommendations from the knowledge generated by this study are framed with this legislated evaluation in mind.

1. **The role of Patient Representative needs more clarity**. While it may not have been intended as a full advocate role, there is a need for an advocate within the legislation that is independent of families and caregivers. The role of Rights Advisor could be reviewed and amended to not only advise on rights but also to advocate on behalf of the wishes of the involuntary patient. Or, a completely new role could be developed similar to Ontario's Patient Advocate's Office, referenced earlier. This would also remove the need for the patient to appoint a Patient Representative during her/his most ill hours and days. Rights advisors are currently on contract with the Department of Health and Community Services. If rights advisors are considered for this expanded role, part of the review for this potential amendment would need to include a review of where Rights Advisors should be employed to ensure their independence as advocates.

2. **Consider a specific role within the *MHCTA* for caregiver/next of kin.**

There is current provision in Section 35 of the *MHCTA* for the Psychiatrist and another team member, where appropriate, to consult with the Patient Representative and the involuntary patient, explain the treatment plan and give consideration to the views of the Patient Representative and involuntary patient. If the Patient Representative becomes a paid independent role and/or is merged with the role of Rights Advisor, the involvement of next of kin should still be considered, particularly for those next of kin who are caregivers. A role for next of kin need not be as a substitute decision maker if it is deemed appropriate for this to continue to be the attending psychiatrist. However, views of caregivers need to be heard to ensure the individual's needs are fully understood by the treatment team. Furthermore, caregivers need to be informed about all the aftercare needs in order to support the individual on discharge. If a paid advocate role was in place along with a legislated role for caregivers, John could focus on providing care and support to Jamie and Jamie would have a formal advocate to ensure her/his voice is heard and rights are protected.

3. **Provide education on roles within the *MHCTA***

More education is needed for families and individuals on the roles within the legislation. Webinars for the general public should be posted online on Government and regional health authority web pages and promoted through organizations such as the Community Health Awareness Network of Newfoundland and Labrador, the Canadian Mental Health Association and the Schizophrenia Society of Newfoundland and Labrador. While some printed material is available now for individuals, more should be available to place in the hands of interested individuals when they need it.

5.4 Recommendations for Policy

The Minister of Health and Community Services has committed to bringing in a new provincial mental health and addictions strategy. The following three recommendations generated from this study's data are made with a new provincial mental health and addictions strategy in mind.

1. **Transform the mental health system with a recovery focus**

The transformation to a recovery focused mental health system should be supported by the most senior officials of Government, administrators of regional health authorities and community agencies, and staff and physicians. This will ensure involuntary psychiatric treatment in Newfoundland and Labrador is nested within a system that values and supports patient autonomy and choice while recognizing the need for involuntary treatment at times that assists the person to recover and resume living a life with meaning.

2. **Develop provincial policy on patient transportation while detained under the *MHCTA.***

Provincial policy is needed for transportation of individuals who are detained under the provisions of the *MHCTA* for assessment or treatment. While John's experience with the mobile crisis response team was positive, he regretted the use of police and the effect it had on Jamie prior to the current legislation. Even today, mobile crisis response is only available in the city of St. John's. While it may not be feasible for mobile crisis response to cover all areas of the province, policy direction is needed that provides for alternatives as opposed to entirely relying on police transport.

3. **Develop provincial policy on the use of chemical and physical restraints**

The practices of chemical (medication) and physical restraints and seclusion are currently guided by policies and procedures within regional health authorities. Seclusion is used frequently in this province and as reflected in the experiences of Joshua, Nathan and Amy, can have deleterious effects. A provincial policy that is recovery focused and includes the collection of data on use and outcome is recommended to provide more procedural safeguards associated with these forced interventions.

5.5 Limitations to the Study

A limitation of this study is that interviewing Jamie about his experiences with the Patient Representative and interviewing others such as psychiatrists and other team members, were not part of the approach to this research. It was important to focus on the experience of the Patient Representative, however, the experiences of others may have enriched the data. A different methodology may have provided different insights into the role of Patient Representative if other Patient Representatives and staff had been interviewed, particularly those staff who work directly with involuntary patients and their Representatives on a day to day basis.

Also, memory writing relies on memory and so some of my experiences, while they became very vivid for me again in recounting them, are memories nonetheless and have been shared as I have remembered them.

5.6 Areas for Future Research

Although mental health legislation has been in place for over a century, there are still many knowledge gaps. Future studies on the role of Patient Representative should consider focusing on the perspectives of persons with lived experience of involuntary hospitalization, their service providers and their families/caregivers.

According to Gray, Shone and Liddle (2008), people in this province and Saskatchewan are "…usually promptly treated. This tends to reduce the length of admission" (p. 23). While this may be so, it places an increased onus on this province to ensure appropriate procedural justice is in place. Therefore, the impact of having a substitute decision making role for families is an important area for future research.

Combining a case study with an autoethnographic narrative worked well in this study. In particular, I believe my autoethnography enriched and supported the experiences of the Patient Representative. Most autoethnographic narratives in health literature that I reviewed came from individuals who had experienced the health issue themselves. My insider status was not from a place of lived experience of having mental illness or being a caregiver or Patient Representative. Rather, it was from my experience working in the system with them. I believe this methodology generated meaningful data and provides a deeper understanding of complex human issues. This methodology should be considered by other qualitative researchers.

5.7 Conclusion

The experiences of a Patient Representative within the *MHCTA* (2006) were explored in this thesis by utilizing a case study methodology within an autoethnographic narrative. While the Patient Representative was generally satisfied with the role, he had many concerns dealing with the mental health system that provided services to the patient he represented. Issues of lack of empathy and respect for both the Patient Representative and the client as well as the need for advocacy and management accountability were identified by the Patient Representative and supported by the author through her autoethnographic narrative.

Policy recommendations include separating out an advocacy role from the Patient Representative role. Providing a Patient Representative role that is a paid independent advocate and creating a separate provision for families/caregivers to be involved in the treatment plan would support caregivers in their already full roles and allow a better balancing of the patient’s right to autonomy with the right to treatment.

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Appendix A

Consent to Take Part in Research

TITLE: Exploring the Experiences of Patient Representatives under the Newfoundland and Labrador Mental Health Care and Treatment Act

INVESTIGATOR: Colleen Simms

You have been invited to take part in a research study. Taking part in this study is voluntary. It is up to you to decide whether to be in the study or not. You can decide not to take part in the study. If you decide to take part, you are free to leave at any time.

Before you decide, you need to understand what the study is for, what risks you might take and what benefits you might receive. This consent form explains the study.

Please read this carefully. Take as much time as you like. If you like, take it home to think about it for a while. Mark anything you do not understand, or want explained better. After you have read it, please ask questions about anything that is not clear.

The researcher will:

- discuss the study with you
- answer your questions
- keep confidential any information which could identify you personally
- be available during the study to deal with problems and answer questions

1. **Introduction/Background:**
   Patients in hospital under the *Mental Health Care and Treatment Act* can choose someone to act on their behalf. This is a very important role because the patient does not want to be in hospital. It is not known if this role is helpful and doing what it should.

2. **Purpose of study:**
   This study will explore the experiences of people who act on behalf of those patients in hospital under the Mental Health Care and Treatment Act. It will review whether the role is seen as helpful by those who have been in that role.

3. **Description of the study procedures:**
   You will be asked to meet twice with the researcher. The first time, she will ask you questions about your experience as a patient representative. The researcher will have

a tape recorder and will tape what is said. Later she will type it out and organize into topics. She will then meet with you once more to review the information from the interview to make sure you are okay with it.

4. Length of time:

Your two meeting times will be scheduled at a place and time of your convenience. Each may last up to one hour.

5. Possible risks and discomforts:

- Emotional Risks- You may experience some discomfort talking about events during the time the family member or friend was in hospital. If this occurs, the researcher can assist to get help as needed.
- Risks related to the researcher's dual role- The researcher is conducting this research as a Masters student. She will only use this information as part of data collection for this study. Every effort will be made to maintain confidentiality. Any information that might identify you or others you may refer to during the interview will be removed from the data. However, the researcher is also the Director for Mental Health and Addictions with the Provincial Government. If you are aware of a patient being physically or sexually assaulted, this would be considered a very serious event. If a serious event such as this has not been reported to anyone in authority, it is possible the researcher will feel she has to report the event if she feels strongly that to not report it may result in harm to other patients. You are advised to report this event to the appropriate manager in the hospital where the incident occurred and not tell the researcher about this type of event. That way, she will be able to maintain your confidentiality. If you have questions or concerns related to the patient that you may wish to discuss with the researcher because of her other role, these issues need to be discussed at another time when she is in her working role as Director.
- Inconveniences- There may be some inconvenience related to taking 2 one hour time periods. The researcher will do as much as possible to schedule times and locations which will be best for you.

6. Benefits:

It is not known whether this study will benefit you.

7. Liability statement:

Signing this form gives us your consent to be in this study. It tells us that you understand the information about the research study. When you sign this form, you do not give up your legal rights. Researchers or agencies involved in this research study still have their legal and professional responsibilities.

8. What about my privacy and confidentiality?

Protecting your privacy is an important part of this study. Every effort to protect your privacy will be made. However it cannot be guaranteed. For example we may be required by law to allow access to research records.

When you sign this consent form you give us permission to
- Collect information from you
- Share information with the people conducting the study
- Share information with the people responsible for protecting your safety

Access to records
The Researcher, Colleen Simms will see study records that identify you by name. Other people may need to look at the study records that identify you by name. This might include the research ethics board. You may ask to see the list of these people. They can look at your records only when supervised by Colleen Simms.

Use of your study information
The researcher will collect and use only the information that is needed for this study.

This information will include
- information from your interview

Your name and contact information will be kept secure by the research team in Newfoundland and Labrador. It will not be shared with others without your permission. Your name will not appear in any report or article published as a result of this study.

Information collected for this study will kept for five years.

If you decide to withdraw from the study, the information collected up to that time will be destroyed. This information will only be used for the purposes of this study.

Information collected and used will be stored in a locked location in the researcher's home, located in Torbay, NL. Colleen Simms is the researcher responsible for keeping it locked and safe.

Your access to records
You may ask the researcher to see the information that has been collected about

you.

9. Questions or problems:

If you have any questions about taking part in this study, you can meet with the investigator who is in charge of the study at this institution. **That person is:** Colleen Simms

Principal Investigator’s Name and Phone Number

Colleen Simms
437-7690

Or you can talk to someone who is not involved with the study at all, but can advise you on your rights as a participant in a research study. This person can be reached through:

Ethics Office

Health Research Ethics Authority

709-777-6974 or by email at info@hrea.ca

10. Declaration of conflict of interest

The researcher is a Master's student with Memorial University of Newfoundland. Her paid job is Director for Mental Health and Addictions with Government of Newfoundland and Labrador. She is conducting this study as part of her Master's program and not as a government employee.

After signing this consent you will be given a copy.

Appendix B

A Letter with New Information

Title: Exploring the Experience of Patient Representatives in the Newfoundland and Labrador Mental Health Care and Treatment Act

Protocol Title:

Addendum # 1 to the Patient Informed Consent, Version February 16, 2015

You have signed consent to take part in this study. This letter provides new information that we have learned since this study started.

I wish to change my approach to this study by including only your experience as patient representative (instead of up to 10 patient representatives) and as well, include my own experience as someone working in the mental health field. So, instead of having a second meeting to just review your interview transcript, the meeting will also include explaining the difference in my approach to the study. Given you are the only participant, extra effort will be made to ensure your privacy. In addition to omitting all names of people, towns, hospitals, diagnoses, and units, I will also not reveal your relationship to the person you were patient representative for.

This change was brought about due to the difficulty recruiting new participants and also because I am in a unique situation where I have worked at a senior policy and administrative level with the Mental Health Care and Treatment Act.

All other information from the main consent remains unchanged.

By signing this form, you are indicating that you have read and understand this information, and that you agree to continue to take part in this study.

Signature of Patient	Printed Name	Date
Signature of Witness (if applicable)	Printed Name	Date

I believe that the person signing this form understands this new information and voluntarily agrees to continue to participate.

________________________________	____________
Signature of Investigator	Date

Appendix C

Semi Structured Interview Script-Patient Representative

1. Can you tell me about your experience as a patient representative?

2. Can you explain to me what you believe the patient representative role is?

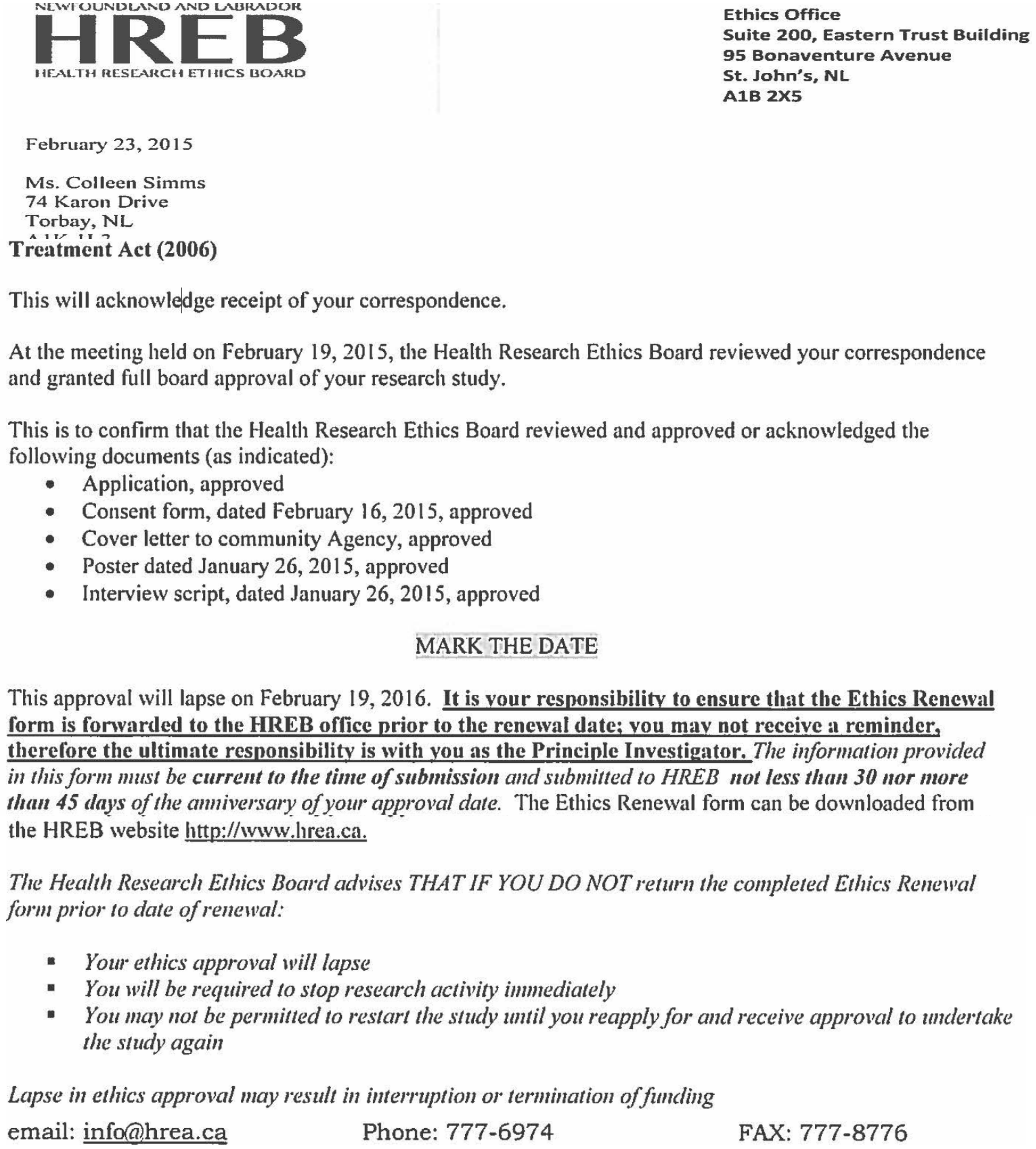
3. Did you receive any instruction on this role?

4. Were you satisfied with your experience as patient representative?

5. Do you have any suggestions for how this role may be improved?

Appendix D

Ethics Approval



NEWFOUNDLAND AND LABRADOR
HREB
HEALTH RESEARCH ETHICS BOARD

Ethics Office
Suite 200, Eastern Trust Building
95 Bonaventure Avenue
St. John's, NL
A1B 2X5

February 23, 2015

Ms. Colleen Simms
74 Karon Drive
Torbay, NL

Treatment Act (2006)

This will acknowledge receipt of your correspondence.

At the meeting held on February 19, 2015, the Health Research Ethics Board reviewed your correspondence and granted full board approval of your research study.

This is to confirm that the Health Research Ethics Board reviewed and approved or acknowledged the following documents (as indicated):

- Application, approved
- Consent form, dated February 16, 2015, approved
- Cover letter to community Agency, approved
- Poster dated January 26, 2015, approved
- Interview script, dated January 26, 2015, approved

MARK THE DATE

This approval will lapse on February 19, 2016. **It is your responsibility to ensure that the Ethics Renewal form is forwarded to the HREB office prior to the renewal date; you may not receive a reminder, therefore the ultimate responsibility is with you as the Principle Investigator.** *The information provided in this form must be* ***current to the time of submission*** *and submitted to HREB* ***not less than 30 nor more than 45 days*** *of the anniversary of your approval date.* The Ethics Renewal form can be downloaded from the HREB website http://www.hrea.ca.

The Health Research Ethics Board advises THAT IF YOU DO NOT return the completed Ethics Renewal form prior to date of renewal:

- *Your ethics approval will lapse*
- *You will be required to stop research activity immediately*
- *You may not be permitted to restart the study until you reapply for and receive approval to undertake the study again*

Lapse in ethics approval may result in interruption or termination of funding

"This is your ethics approval. Organizational approval may also be required. It is your responsibility seek the necessary organizational approval from the Regional Health Authority or other organization as appropriate. You can refer to the HREA website for further guidance on organizational approvals.

You are also solely responsible for providing a copy of this letter, along with your application form, to the Office of Research Services should your research depend on funding administered through that office.

Modifications of the protocol/consent are not permitted without prior approval from the Health Research Ethics Board. Implementing changes in the protocol/consent without HREB approval may result in the approval of your research study being revoked, necessitating cessation of all related research activity. Request for modification to the protocol/consent must be outlined on an amendmen form (available on the HREB website) and submitted to the HREB for review.

This research ethics board (the HREB) has reviewed and approved the research protocol and documentation as noted above for the study which is to be conducted by you as the qualified investigator named above at the specified site. This approval and the views of this Research Ethics Board have been documented in writing. In addition, please be advised that the Health Research Ethics Board currently operates according to *Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans*; ***ICH Guidance E6: Good Clinical Practice*** **and applicable laws and regulations. The membership of this research ethics board is constituted in compliance with the membership requirements for research ethics boards as defined by** ***Health Canada Food and Drug Regulations Division 5; Part C.***

Notwithstanding the approval of the HREB, the primary responsibility for the ethical conduct of the investigation remains with you.

We wish you every success with your study.

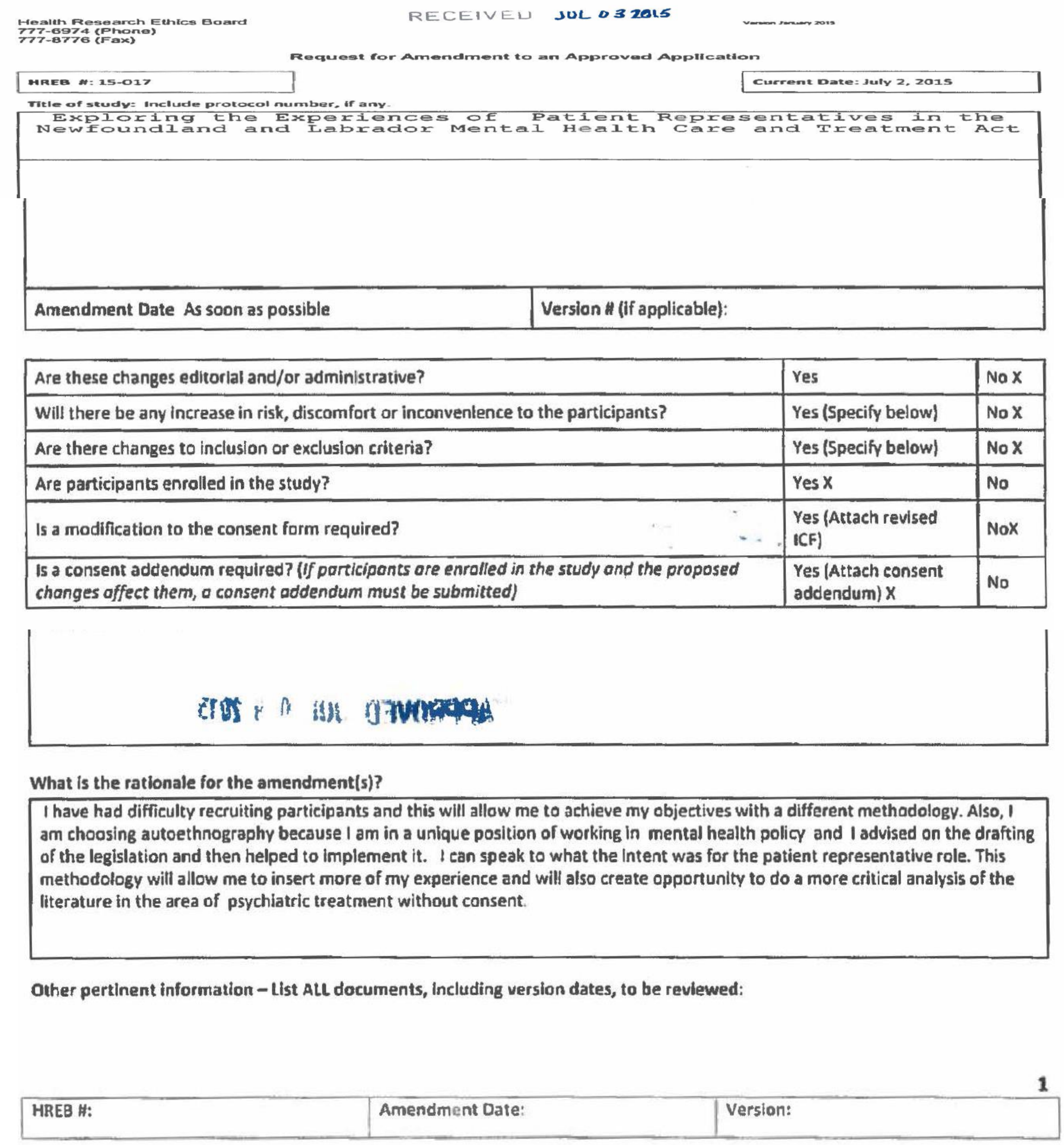
Sincerely,

Dr Fern Brunger, PhD (Chair Non-Clinical Trials)
Ms. Patricia Grainger, (Vice-Chair Non-Clinical Trials)
Health Research Ethics Board

Cc: Dr N. Beausoleil
Dr V. Maddalena

Appendix E

Amendment Approval



Health Research Ethics Board
777-6974 (Phone)
777-8776 (Fax)

RECEIVED JUL 03 2015

Version January 2015

Request for Amendment to an Approved Application

HREB #: 15-017

Current Date: July 2, 2015

Title of study: Include protocol number, if any.

Exploring the Experiences of Patient Representatives in the Newfoundland and Labrador Mental Health Care and Treatment Act

Amendment Date As soon as possible	**Version # (if applicable):**

Are these changes editorial and/or administrative?	Yes	No X
Will there be any increase in risk, discomfort or inconvenience to the participants?	Yes (Specify below)	No X
Are there changes to inclusion or exclusion criteria?	Yes (Specify below)	No X
Are participants enrolled in the study?	Yes X	No
Is a modification to the consent form required?	Yes (Attach revised ICF)	NoX
Is a consent addendum required? *(If participants are enrolled in the study and the proposed changes affect them, a consent addendum must be submitted)*	Yes (Attach consent addendum) X	No

What is the rationale for the amendment(s)?

I have had difficulty recruiting participants and this will allow me to achieve my objectives with a different methodology. Also, I am choosing autoethnography because I am in a unique position of working in mental health policy and I advised on the drafting of the legislation and then helped to implement it. I can speak to what the intent was for the patient representative role. This methodology will allow me to insert more of my experience and will also create opportunity to do a more critical analysis of the literature in the area of psychiatric treatment without consent.

Other pertinent information – List ALL documents, including version dates, to be reviewed:

HREB #:	**Amendment Date:**	**Version:**

Colleen Simms — Colleen Simms — July 3/15

Printed Name of Principal Investigator — Signature of Principal Investigator — Date

This Health Research Ethics Board (the HREB) has reviewed the amendment as noted above for the study which is to be conducted by you as the qualified investigator named above at the specified study site. This approval and the views of this Research Ethics Board have been documented in writing. In addition, please be advised that the Health Research Ethics Board currently operates according to Tri-Council Policy Statement (TCPS2) and applicable laws and regulations. The membership of this research ethics board complies with the membership requirements for research ethics boards defined in TCPS2.

***Full Board** Review and Approval granted at* ______________________ *Meeting*

______________________ ______________________

Signature Chair (Dr. Fern Brunger) *Date*

______________________ ______________________

Signature Vice-Chair (Patricia Grainger) *Date*

OR

***Reported** to Full Committee at* July 9, 2015 *Meeting*

Approved by:

______________________ APPROVED JUL 0 8 2015

Signature Chair (Dr. Fern Brunger) *Date*

______________________ ______________________

Signature Vice-Chair (Patricia Grainger) *Date*

HREB #:	Amendment Date:	Version: