# "Experience is the Best Teacher." Community Treatment Orders (CTOs) among Ethno-Racial Minority Communities in Toronto: A Phenomenological Study

by

# Magnus Mfoafo-M'Carthy

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

Factor-Inwentash Faculty of Social Work

University of Toronto

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#### Abstract

Since de-institutionalization, numerous community based treatment modalities have been implemented to provide treatment for individuals diagnosed as seriously and persistently mentally ill. CTOs are a recent addition to the community mental health care system designed to provide outpatient mental health services to seriously mentally ill clients and using legal mechanisms to enforce a contractual obligation to participate in those services. Although there is a growing body of literature on CTOs and other mandated outpatient treatment programs for people diagnosed with mental illnesses, the research predominantly focuses on the perspectives of service providers and family members. Little attention has been given to how clients view the experience of receiving the treatment and no attention has been given to the experience of clients who are of ethnoracial minority background.

As Ontario is a racially and ethnically diverse environment in which many people of minority backgrounds are placed on CTOs. This study, utilizing a phenomenological methodology, interviewed twenty-four participants of ethno-racial minority background who are either on CTOs or have been on a CTO in the past. The focus of the study was to explore the views and lived experience of the participants regarding the treatment.

The outcome of the study showed that the participants did not experience the treatment as racially motivated but felt it was necessary and beneficial. The participants discussed the impact of power in the treatment process.

Implications of the study were that it would enhance the mental health literature by providing an understanding of serious mental illness among individuals of ethno-racial minority background. The study would provide insight for policy makers and practitioners on providing effective support for the marginalized.

## Acknowledgements

For everything there is a season, and a time for every purpose under heaven:

A time to be born, And a time to die; A time to plant, And a time to pluck up that which is planted;

A time to kill, And a time to heal; A time to break down, And a time to build up;

A time to weep, And a time to laugh; A time to mourn, And a time to dance;

A time to cast away stones, And a time to gather stones together; A time to embrace, And a time to refrain from embracing;

A time to seek, And a time to lose; A time to keep, And a time to cast away;

A time to tear, And a time to sew; A time to keep silence, And a time to speak;

A time to love, And a time to hate; A time for war, And a time for peace (Ecclesiastes 3:1-8)

And a time to commence a doctoral study and time to bring it to a successful end<sup>1</sup> I would like to give glory to God for His faithfulness through this journey.

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<sup>&</sup>lt;sup>1</sup> Author's rendition

the importance of education. THANK YOU! My siblings: Leslie (Shabash)<sup>2</sup>, Joycelyn, Johnnie, Maud, Samuel, Shanti, Alpha, Omega and BenEben. My in-laws, Samuel Tutu Dankyi (who did not live to see this day) and Comfort Asante, deserve recognition

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<sup>&</sup>lt;sup>2</sup> Deceased

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## **Chapter 1: Introduction**

This study examines Community Treatment Orders (CTOs), an agreed form of outpatient mental health treatment for the mentally ill, from the lived experience and perspective of ethno-racial minority clients in Toronto, Canada. The first chapter of this study provides a historical background and overview of the outpatient mental health system, including the genesis of other forms of outpatient mental health treatment such as CTOs. The advent of deinstitutionalization in the Western world is explored to better understand community-based mental health treatment, and to gain insight into factors that influenced the change in treatment focus and eventual establishment of CTOs. The context of the study establishes the purpose and justification for the investigation.

In concert with escalating health care costs, the need to provide support for individuals diagnosed with mental illness in a less structured environment led to the deinstitutionalization of mental health care services, a movement initiated more than fifty years ago (Burnham, 2006; Durbin, Goering, Streiner and Pink, 2006; Fakhoury and Priebe, 2002). Over the past century, the Western world cared for the mentally ill in state or government funded hospitals, albeit, without the provision of adequate services or treatment. Over time, governments and institutions heeded the call from advocates and mental health consumers that the mentally ill would be better served in the community-close to their family and loved ones - than in institutions (Clarke, 1993; WHO, 1953).

The 1960s saw a shift in paradigm as activists and members of the community became empowered, advocated for increased support, and promoted the rights of the mentally ill. Advocates focused on the conditions of the mentally ill and the impact of the lack of continuity of care on their lives. The move to implement changes emanated

from reforms over time aimed at humane and responsible treatment; this culminated in deinstitutionalization, that is, the downsizing or reduction in the number of hospital beds by releasing patients - in particular, the mentally ill - into society for community-based treatment (Fakhoury and Priebe, 2002; Goering, Wasylenki and Durbin, 2000; Hadley, 1996; Lamb and Bachrach, 2001; Peele, 2000). The goal of deinstitutionalization was to provide services and resources to individuals diagnosed with mental illness, together with community rehabilitation programs and early intervention services, in the least restrictive treatment setting (Goldman, Foley, and Sharfstein, 1985).

According to one school of thought, the trend towards deinstitutionalization emerged not in response to new medical knowledge or therapy, but out of fiscal and legal necessity (Sealy and Whitehead, 2004; Talbott, 2004); others, however, believe that newer psychopharmacological medications, such as phenothiazine, and derivatives like chlorpromazine, reduced symptomatology in the mentally ill making deinstitutionalization possible. Advances in psychosocial treatments, as well as legal, judicial and legislative actions also contributed to deinstitutionalization (Kelly and McKenna, 2004; Talbott, 1979), as did the increasing consensus that the seclusion of the mentally ill in institutions infringed upon their civil liberty, and did little to improve their condition (Foucault, 1965).

This shift from psychiatric institutions to community-based agencies and programs took place throughout much of the Western world in the 1960s (Fakhoury and Priebe, 2002; Nelson, Lord and Ochoka, 2001; Spencer and Munch, 2003). The deinstitutionalization of mental health treatment encompassed three major goals: first, to shift the dependence of patients, physicians, professional resources and society away

from institutions; second, to increase the number of mental-health beds in general hospitals, and third, to expand community-based outpatient services (Bachrach, 1996).

The focus switched from an emphasis on clinical and management orientation, towards 'strengths-oriented' and collaborative approaches to assist individuals to integrate to the community with the provision of appropriate treatment, training, education, work and housing (Devers et al. 1994; Goldman, Thelander & Westrin, 2000; Konrad, 1996; Randolph, et al. 2002).

Deinstitutionalization in the Western world began with the introduction of case management support, and by the 1990s it had become the acceptable norm (Burnham, 2006). Together with assisting clients to find employment and housing, the aim was to ensure the adequate provision of community support and resources for outpatients to avoid re-hospitalization (Durbin, Goering, Streiner and Pink, 2006; Johnson, Prosser, Bindman, and Szmukler, 1997); as a result, "the discourse and language in the treatment of the mentally ill changed from medical discourse to include a rehabilitation discourse, with patients now being referred to as clients" (Nelson, Lord and Ochoka, 2001, p. 14). Research has proven that such methods were successful in reducing clients' psychiatric symptoms and hospitalization, and increasing their satisfaction (Kopelwicz and Liberman, 2003).

The success of deinstitutionalization, however, was impeded by the absence of adequate and prior establishment of the necessary resources and services to facilitate community rehabilitation. The United States responded early to these concerns by funding the development of community mental health programs and services (Scott & Lammers, 1985). In the late 1970s and early 1980s, however - even though community

care was recognized to be a more humane, effective and cost-effective alternative - financial support was curtailed due to budgetary constraints, and the mentally ill were significantly impacted despite the progress made (Lamb and Bachrach 2001; Scott, 1985).

Deinstitutionalization, while beneficial, could entail serious detrimental outcomes for the mentally ill, such as homelessness, where many find themselves living on the streets and vulnerable to becoming victims of neglect and exploitation (Burnham, 2006; Grob, 1991; Isaac and Armat, 1990); the community's inability to sustain the significantly large number of individuals diagnosed with mental illness, and coordinate multiple care and support programs, have been cited as contributing factors to these conditions. Furthermore, although long-term hospitalization is now the exception, patients receive little assistance in preparation for discharge or pre-arranged community care (Telias, Fronsky and Umansky, 2000).

Other consequences of deinstitutionalization include the lack of treatment after discharge, social isolation, incarceration and poor quality of life for outpatients (Hadley, 1996; Lamb and Bachrach, 2001; Peele, 2000). The difficulty of many to adjust to community living further exacerbated the segregation and exclusion experienced by patients due to the stigma associated with mental illness (Kelly and McKenna, 2004; Konrad, 2002; Nelson, Lord, and Ochoka, 2001). Lamb (1997) challenges this notion, however, and argues that some patients accustomed to the institutional form of living preferred long-term facilities because of their lack of initiative, apathy, withdrawal, tendency of submissiveness to authority, and dependence on institutions.

Furthermore, the prevalence of violence within the mentally ill population is well documented in literature (Swanson, et al. 2002; Shaw et al. 2006; Steadman, 1998) and identified as a consequence of deinstitutionalization. Although the incidence of violence by persons with mental illness is lower than the general population, it is often accorded higher profile in the media - reports are replete with accounts of the mentally ill murdering loved ones or 'innocent victims', usually during periods of non-compliance with medication and treatment; these clients invariably end up in the criminal justice system (Torrey and Zdanowicz, 1998). In addition, research suggests that outpatient mental health clients are more likely to fall prey to victimization, taken advantage of due to the nature of their illness, and at many times, are more susceptible than the general public to robbery, assault, sexual assault and rape (Teplin, McClelland, Abram and Weiner, 2005).

In light of the prevailing conditions, governments in the Western world began to explore ways by which problems associated with de-institutionalization could be curtailed in a responsible and efficient way.

## **Responses to Deinstitutionalization**

To facilitate deinstitutionalization, governments and mental health professionals initiated community-based programs, including case management and psychiatric rehabilitation in the provision of community support; these treatment modalities emphasize clients' involvement in the development and realization of personal care and goals. Case management and psychiatric rehabilitation provide treatment and support to assist clients with managing their symptoms and building on their strengths. Clients were

also provided with supportive housing and case management services (Anthony, Cohen and Farkas, 1990; Burnham, 2006; Solomon, 1992).

Other programs like the Assertive Community Treatment Teams (ACTT) were later introduced to assist mentally ill clients to access appropriate mental health treatment in the community. ACTT evolved from the work of Arnold Marx, Leonard Stein and Mary Ann Test on an inpatient unit in Madison, Wisconsin, in the 1960s. They noted that on returning to the community following an inpatient stay, clients often lost the gains they achieved in hospital. The team observed that the around-the-clock services provided by hospitals alleviated many of the symptoms exhibited by their clients, and based on this finding, recommended similar outpatient care in the community (Stein & Test, 1985).

The Assertive Community Treatment Team (ACTT) offer comprehensive, community-based psychiatric treatment, rehabilitation, and support to persons with serious and persistent mental illnesses, such as schizophrenia (Krupa, et al., 2004; Ontario ACTT Association, 2004). Their activities include case management, assessment, psychiatric services, employment and housing assistance, family support and education - all of which help individuals to live comfortably and successfully in the community. The ACTT provide individualized treatment and other support services through a multidisciplinary team comprised of physicians, social workers, nurses, occupational therapists and other clinicians. The ACTT model is most suitable for persons with persistent and severe mental illness, with a history of numerous hospitalizations (Boust, Melody, Kuhns & Studer, 2005; Krupa, et al., 2004).

Despite the government's attempts to address the problems created by deinstitutionalization, a large number of individuals continued to fall through the cracks of the mental health system as evidenced by several incidents of violence in public arenas, which precipitated a concentrated focus in this area. This led to the establishment of Community Treatment Orders (CTOs) to provide more intensive community-based care and treatment for the persistently mentally ill with a legal backing.

In Ontario, the murder of Brian Smith, a popular newscaster in Ottawa, on August 1, 1995 by Jeffrey Arenburg, an individual diagnosed with paranoid schizophrenia, precipitated the establishment of CTOs (under the auspices of Brian's Law) in Ontario (Canadian Broadcasting Company, 2000; Mallan and Boyle, 2000; Walker, 2008). The legislation was put in place following recommendations from the public, legislators, and investigators to integrate mandated outpatient treatment into the mental health care system. For more than a decade, CTOs have been utilized as a model to provide support and treatment to the severely and persistently mentally ill who otherwise would not have access to treatment. CTOs may be likened to other forms of community-based mental health treatment, however the difference is that CTOs have legislative backing requiring that failure to comply with the conditions of the treatment mandates legal intervention. This means a physician could issue a form (an order for examination, often referred to as form 47) for the police to apprehend and present a CTO client to the hospital for evaluation.

A review of literature identifies a dearth of information on CTOs within ethnoracial minority communities. This is a significant gap in knowledge because a large body of research shows that ethnoracial minority clients bear the brunt of inadequate care, inadequate access, and racism within the health care system in the Western world (Bhui, et al. 2005; Noh and Kaspar, 2003; Ojed and Bergstresser, 2008; Wamala, Bostrom, and

Nyqvist, 2007; Wang, et al. 2005; Williams, 2001). Even though it has been over 20 years since the institution of CTOs, and numerous studies have explored various aspects of the treatment, none have investigated CTOs from the perspective of ethno-racial minority clients. This is the first study in Canada to seek a clear understanding of clients of ethno-racial minority backgrounds and their lived experience with CTOs. Thus, viewing CTOs through the lenses of ethno-racial minority clients who have intimate knowledge of the treatment provides insight and direction on how this intervention best serves the interests of these clients.

The majority of studies on CTOs is quantitative in nature and primarily explores this treatment option from the perspective of the dominant culture<sup>3</sup>. The purpose of this study is to understand the impact of CTOs from the perspective of these clients identified within ethno-racial minority communities. The decision to utilize a qualitative study is based on the consideration that this is a subject about which little or nothing is known. In addition, the phenomenological method is used in this investigation because the focus of the study is to capture the participants' point of view.

This study will contribute to mental health literature by providing a deeper understanding of mental health treatment of persistently and seriously mentally ill clients of ethno-racial minority backgrounds, particularly in the case of mandated outpatient treatment. This study may serve to increase and enhance treatment modalities by social workers as the profession explores ways to more effectively work with marginalized clients from different ethno-racial minority backgrounds. Furthermore, it may provide

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<sup>&</sup>lt;sup>3</sup> It refers to the majority group of the population. The majority group could be considered as the group that has power, social status and privilege. The dominant group has the power / ability to discriminate against the minority group. In Canada, the majority group refers to Caucasians. In the US, the majority group is often referred to as WASP – White, Anglo-Saxon protestant. Thus, anyone not considered White / Caucasian other than aboriginal people falls within the category of ethno-racial minority group.

insights for policy makers and practitioners into the treatment of the persistently mentally ill, particularly those from ethno-racial minority communities.

"Experience is the best teacher", was selected as the title for this thesis based on the fact that people tend to learn by observing and relating to their environment and circumstances, whether positive or negative. In the case of CTO clients of ethno-racial minority backgrounds, the experiences, both positive and negative, is used to educate and inform others about the treatment. By using a phenomenological research methodology, these clients are given a voice to articulate their views and experiences regarding CTOs. They become the conduit through which the ethno-racial minority phenomenon of community treatment orders (CTOs) is communicated.

## Justification for the study

Following the inception of CTOs in Ontario, the Ministry of Health and Long-Term Care mandated the Centre for Addiction and Mental Health (CAMH) with the responsibility of monitoring CTOs in jurisdictions within the Greater Toronto Area (GTA) in Ontario, Canada. CAMH, therefore, is the employer of CTO coordinators in the Greater Toronto Area. As a CTO Coordinator with more than nine years experience, the researcher works closely with psychiatrists to ensure CTOs are effectively implemented, and has had the opportunity to work with a number of clients, including those of ethno-racial minority backgrounds. Over the years, there have been questions by

<sup>&</sup>lt;sup>4</sup> This quotation was initially used by Julius Caesar (52 B.C) "Experience is the teacher of all things." Pliny (AD 77) made reference to "Experience is most efficient of all things. Tacitus (c. 203) stated "Experience teaches." "Experience is the best teacher" was used in the Widow Bedott paper (1856) by Frances M. Whitcher, Wise words and wives tales: The Origins, Meanings and Time-Honored Wisdom of Proverbs and Folk sayings Olde and New by Stuart Flexner and Doris Flexner (Avon Books, New York, 1993).

practitioners and stakeholders with regard to whether CTOs meet the needs of ethnoracial minority clients. Also, research has shown that clients of ethnoracial minority background have not been fairly treated within the health care system; this study is an attempt to get answers to those questions.

On a personal note, the researcher embarked on this study based on curiosity about how clients feel about CTOs and its impact on clients of ethno-racial minority communities. This focus of interest was further precipitated by the researcher's own ethno-racial background and the desire to explore an alternative perspective of CTOs.

Chapter two of the study gives the background and context of CTOs. It explains the importance of the international context of CTOs, and explains what could be learned from the international perspective and how this has influenced CTOs in Ontario.

Chapter three explains the theoretical frameworks in relation to the study and literature review. The theories describe the intersection between the empowerment, anti-oppressive and post-colonial frameworks and their relevance to this study.

Chapter four of the thesis examines the existing empirical literature on CTOs.

Related studies from varying professional points of view are explored to identify gaps in the literature. The relevance of the research question to the body of the literature is also examined.

Chapter five explores the significance of the phenomenological methodology and the justification for its application in the study. Detailed methodology of the research process is also provided.

Chapter six presents the research findings, analysis of participants' responses and in-depth exploration of the emerging themes.

The final section, chapter seven discusses the study and the outcome of the investigation. Contributions, implications and application to practice are discussed. The limitation of the research study is further discussed. Recommendations for future research will also be discussed.

## **Chapter 2: Background and Context**

This chapter describes the implementation and utilization of Community

Treatment Orders (CTOs) in Western countries, including Canada. The utilization of

CTOs in other jurisdictions has been given a special attention in this study due to

Canada's interest in exploring these experiences to ensure the success of the treatment.

Reference to the international context of CTOs is important due to consultations that

precipitated its implementation in Ontario. Reference to most of the jurisdictions shows

the similarities in the circumstances leading to the introduction of this mandatory

outpatient treatment; a number of the CTOs - for instance, in New York and California 
were motivated by violence perpetrated by a mentally ill person.

A Community Treatment Order (CTO) is an outpatient mental health care treatment option for the severely and persistently mentally ill. A CTO may be described as an extension of community-based mental health treatment and an offshoot of the deinstitutionalization of mental health treatment that commenced in the Western world more than four decades ago. CTOs are a form of legally mandated outpatient treatment or commitment, where the provision of mental health treatment for the severely and persistently mentally ill is provided in an outpatient setting with the support of service providers, which include physicians, case managers, and in some cases, care providers. It differs from conventional case management, however, because a CTO legally mandates a person to follow through with the established treatment plan, or "risk sanctions for non-compliance such as potential involuntary hospitalization and treatment" (Torrey and Zdanowicz, 2001, p. 337).

According to the Ontario Mental Health Act (2000), the purpose of a Community Treatment Order is "to provide a person who suffers from a serious mental disorder with a comprehensive plan of community-based treatment or care and supervision that is less restrictive than being detained in a psychiatric facility" (MHA 33.1(3)). A CTO constitutes a legal contract between a client and his/her physician that outlines the specific treatment, care and supervision to be provided in the community. This form of treatment is often regarded as an extension of inpatient hospital care with the legal mechanisms in place to encourage adherence (Monahan, et al. 2001).

CTOs were introduced to provide treatment for mentally ill patients deemed "hard to treat." These individuals are typically those who are less likely to maintain the gains achieved in hospital. While their condition is stabilized during hospitalization, upon discharge most do not follow through with the proposed treatment recommendations, frequently resulting in the deterioration of their illness and re-hospitalization (Hiday and Scheid-Cook 1991).

In Ontario, the enactment of Bill 68 in December 2000 led to amendments to Ontario's Mental Health Act and the introduction of CTOs as a prescribed treatment option for the persistently mentally ill. Prior to Ontario, Saskatchewan was the only province in Canada to offer CTOs (O'Reilly, Keegan, and Elias, 2000; O'Reilly et al, 2006). In October 2005, Nova Scotia's House of Assembly passed the Involuntary Psychiatric Treatment Act, which became law in July 2007. CTOs have also been implemented in most jurisdictions in Australia, New Zealand, Israel, the United States (42 states and the district of Columbia), Scotland, Norway, Switzerland, Portugal, Sweden, the Benelux countries (Belgium, Netherlands, and Luxemburg), the United

Kingdom and Wales (Bonnie and Monahan, 2005; Churchill, 2007; Gerbasi, Bonnie, and Binder, 2000; Kisely, et al. 2005; Lawton-Smith, 2005; Preston, Kisely, and Xiao, 2002; Salize and Dressing, 2004; Swartz, Swanson, Kim and Petrilla, 2006).

CTOs are described using varying terms in different jurisdictions: Mandatory Outpatient Treatment (MOT), Outpatient Committal (OPC), Involuntary Outpatient Commitment (IOC), Leave Certificates and Assisted Outpatient Committal (AOC), Supervised Discharge and Compulsory Community Treatment (Bonnie and Monahan, 2005; Gerbasi, Bonnie and Binder, 2000; Kisely, Campbell, Scott and Preston, 2007; Segal and Burgess, 2006; Trueman, 2003). The question often asked by stakeholders is whether CTOs and other outpatient committal mechanisms are a panacea for ineffective outpatient mental health treatment, or whether other treatment options are more appropriate and in the best interests of individuals with mental illness.

CTOs have received controversial reviews with as many opponents as supporters (Swartz, Wagner, Swanson, and Elbogen, 2004). It has been described as a coercive and unethical treatment, allowing health care practitioners to infringe upon the rights of clients. CTO opponents argue it is a form of forced treatment that removes clients' autonomy to make their own decisions (Mallan, 2000; Szigeti, 2001; Weitz, 2000). Others profess that CTOs discourage mentally ill persons from seeking help at hospitals for fear of being placed on this treatment. Despite the resistance to, and criticisms directed at CTOs, advocates argue that this treatment option is a humane way of providing support, treatment and resources for mentally ill individuals. Furthermore, it reduces encounters with the criminal justice system frequently experienced by this client population (Swanson, et al. 2003). CTOs are also seen as a way to offer much needed

help to individuals who are mentally ill and considered a danger to themselves or others in the absence of intervention (Lamb, 1999; Mallan and Boyle 2000). It should be noted, however, that there are studies that have found CTOs have no direct impact on treatment outcomes for clients (Kisely, et al. 2007; Kisely, Smith, Preston, and Xiao, 2005).

# **International Comparisons of CTOs**

Figure 2:1

<u>Summary Table</u>

Place	Year CTO	Illness	Status on	<b>Client Consent</b>	Length of contract
	Instituted	Criteria	admission		
Australia	1986	Immediate	Involuntary	Unable to consent if incompetent	3 months prior to 1997.  Currently, 6 months renewed multiple number of times
New Zealand	1992	Danger to self / others	Issued by courts	Unable to consent	6 months – Indefinite after 1 year
USA – Majority of the States (42 +) (New York)	1999	Medication non- compliance or history of violence	Court mandated	Unable to consent	6 months
Scotland	2005	Danger to self	Court mandated	Involuntary	6 Months
England and	2006	Mental disorder	Physician implemented		6 Months after a year, yearly intervals

Wales		Treatment			
		necessary			
		prevent			
		suicide or			
		serious self			
		harm			
Israel	1991	Danger to self	Issued by	Voluntary or	6 months
		and others	psychiatrists	involuntary	
Canada					
Saskatchewan	1995	Suffer from	Physician	No consent needed	3 months
		mental		from patient or	
		disorder		substitute decision	
				maker (SDM)	
Nova Scotia	2007	Suffers from	Physician		
		mental			
		disorder			
Ontario	2000	Suffers from	Physician	Voluntary /	6 months - after 1 year
		mental		Involuntary	mandatory review
		disorder		Consent from client	
				or SDM	

Irrespective of the fact that CTOs are considered an international phenomenon, they have only been implemented in countries in the Western or developed world. CTOs are therefore exclusively utilized as treatment in places that adhere strictly to the Western

medical model and could be said to be "White dominant"; despite the similarities in concept, different approaches are employed in different countries.

#### Australia

CTOs are currently operative in all jurisdictions of Australia. Victoria was the first state to introduce outpatient psychiatric care in 1986 (Dedman, 1990), and following five years of consultation, the New South Wales Mental Health Act was enacted in 1991 (Power, 1999). The purpose was to reduce re-hospitalization rates of mentally ill patients with a history of deterioration due to medication non-compliance on discharge from hospital (Vaughn, et al. 2000). CTOs were implemented in Western Australia in November, 1997 with the enactment of the new Mental Health Act (McIvor, 1998) which legislated that an order must be made by "a qualified mental health specialist, who must specify which medical practitioner is to supervise the patient's treatment or care, where the patient is to receive care, the frequency at which the medical practitioner is to report to the specialist, and the duration of the order which must not exceed three months in the first instance" (Preston, Kisely, and Xiao, 2002, p. 2). Eventually, all six Australian states and two territories implemented CTOs (Power, 1999).

The criteria for issuing CTOs in Australia are:

- The person referred for CTO must be mentally ill.
- The illness requires immediate treatment or care, both of which could be obtained by admission to a psychiatric in-patient service.
- The person is an involuntary patient, admitted and detained for their own safety and that of the community.

• The patient has refused or is unable to consent to the necessary treatment or care for the mental illness (Dedman, 1990).

Victoria comprises a population of approximately 5 million and as of 2003, 2,700 CTOs were issued. In New South Wales, with a population of about 6.6 million, 2,000 to 3,000 CTOs were issued within the same time frame (Dawson, 2005).

#### **New Zealand**

The Mental Health Act (1992) of New Zealand legislated CTOs to provide outpatient treatment to all persons considered "mentally disordered." Treatment, including medication, is provided by the health professional responsible for supervising the CTO and who is empowered to "enter a patient's residence at reasonable time for proper purposes" (i.e., for the administration of medication) (Gibbs, Dawson, et. al. 2004). Prior to 1997, the duration of a CTO was three months, but subsequently was extended to six months and is renewable through an appeal to the Mental Health Tribunal in the respective jurisdiction. If renewed after a year, it becomes indefinite, with no future date for review.

In New Zealand, the courts do not have the power to rule against legislation consistent with human rights norms. Consequently, CTO clients under involuntary hospital care are instead granted "trial leave", or leaves of absence, from the hospital. The conditions of the treatment pertain to medication compliance and community-based support.

The criteria for CTOs or involuntary outpatient treatment are:

1. The individual referred to CTO must have a serious mental illness.

- The individual poses a serious danger to the health or safety of self or others, or demonstrates seriously diminished capacity for self-care.
- 3. Availability of appropriate outpatient care and support.
- 4. A CTO may only be issued by a district court following a hearing.

CTOs in New Zealand are for six-month periods and renewable by the district court.

#### **United States**

In the United States, outpatient treatments along the concept of CTOs have been introduced in 42 states, including the District of Columbia. However, the standards for outpatient and inpatient commitment differ from state to state. In New York for instance, it is called Assisted Outpatient Treatment (AOT), often referred to as Kendra's law, named after Kendra Webdale, a young lady who was pushed in front of an oncoming train in New York City by Andrew Goldstein, a mentally ill individual (New York State OMH, Kendra's law, 2005). The criteria for Assisted Outpatient Treatment (AOT) include:

- Individuals who have a mental illness and a history of hospitalization or violence.
- Clients must be over 18 years of age.
- Individuals who, based on clinical determination, are unlikely to survive safely in the community without close supervision.
- Individuals who have a history of medication non-compliance with treatment (New York State OMH, Kendra's law, 2005).

A review of the AOT program in New York shows that between November 1999 and December 2004, 3,766 applications were granted petition by the courts to participate in the treatment program for the first six months, of which 3,493 were eligible for renewal of their treatment agreement - however, only 2,236 were eventually renewed. The review found that the AOT program improved accountability and clients' access to services, as well as the development of treatment plans and discharge planning (New York State OMH, Kendra's law, 2005).

Laura's law was introduced in California in 2001 where CTOs are issued after a court assessment following petition. The patient must be 18 years of age or older, suffer from a mental illness and likely to deteriorate in the community without support. Such a person should have a history of non-compliance with treatment/medication and relapse would likely affect the client and others. CTOs are issued for a six-month period and renewable for another six through a procedural review (Appelbaum, 2003). Florida introduced CTOs in 2005 with conditions similar to that in California.

North Carolina introduced outpatient treatment in 1977 as the least restrictive alternative to hospitalization, and subsequently introduced the statute in 1985 as a preventative measure. The criteria stipulate that the individual has a mental illness and would likely survive in the community with the support of family, friends and service providers. The goal of the outpatient treatment is to prevent relapse and harm to self or others; it recognizes that the nature of the mental illness inhibits the individual from making an informed decision. CTOs are effective for 90 days and renewable for another 180 days through procedural review (Miller & Fiddleman, 1984; Hiday & Goodman, 1982). Other states in the US have a similar involuntary outpatient treatment.

#### Scotland

CTOs were introduced in Scotland in October 2005 with analogous criteria, including proven mental disorder and the expectation that medical treatment will potentially reduce deterioration of illness and threat of harm to self or others (Churchill, 2007). Professionals involved in the application of CTOs include mental health officers, medical officers and members of the Mental Health Tribunal of Scotland. The criteria for the issuance of a CTO in Scotland are as follows:

- The treatment is ordered by the courts
- A person referred to the program must exhibit symptoms of a mental disorder
- Medical treatment should be available that prevent the disorder from worsening, alleviating the effects of the illness.
- Prove that the lack of treatment will worsen the individual's condition.
- Fact that the mental condition has impaired the patient's ability to make treatment decision.

A community treatment order in Scotland is for six months. It could be renewed for another six months and thereafter there will no more renewal (Churchill, 2007).

## **England and Wales**

Supervised Community Treatment (SCT) was introduced in England and Wales in March 2006 - following amendments to the 1983 Mental Health Act - to allow patients with mental illness to live independently in the community, subject to the provisions in

the Act. The goal of the supervised community treatment is to treat patients in the least restrictive alternative setting to hospitalization, avoid the "revolving door" syndrome, and protect severely mentally ill individuals from suicide or serious self-harm (Churchill, Hotopf, and Singh, 2007). Treatment recommendations such as psychosurgery and ECT, however, require approval from a tribunal.

Criteria for establishing the supervised community treatment is as follows:

- Client suffers from mental illness
- The client's condition requires medical / psychiatric treatment
- There is appropriate treatment available
- The purpose of treatment is to ensure that it prevents the deterioration of the client's condition, and protects the client from suicide and be able to provide safety and protection of others. (Churchill, Hotopf, and Singh, 2007)

Supervised community treatment in the UK and Wales is for six months.

#### Israel

Outpatient compulsory community treatment was legislated in 1991 as part of changes to the Israeli Mental Health Act (Ajzenstadt, Aviram, Kalian and Kanter, 2001; Durst, 1999; Silfen & Levy, 1995) and mandates recommendation by a psychiatrist, usually for a six-month period; patients may be re-hospitalized for treatment non-compliance. This outpatient mandated treatment is referred to as involuntary outpatient commitment (IOC). IOC is an order for individuals suffering from mental illness to

involuntarily receive treatment outside the hospital environment and viewed by clinicians as a condition of release from hospital or an alternative to hospitalization.

Clients benefit from this treatment by avoiding unnecessary institutionalization and receiving suitable treatment and care. Conditions for determining a person's eligibility include a diagnosis of mental illness and deemed a danger to either to self or others. There is no court involvement in IOC treatment, neither is there an outside review of the treatment and participants do not have the right or ability to challenge a physician's decision. Critics describe IOC as "a control mechanism extending State and professional powers beyond the hospital and into the community" (Ajzenstadt, Aviram, Kalian and Kanter, 2001, p.653).

#### Canada

In Canada, Saskatchewan was the first province to introduce CTOs in 1995 however they are effective for a three-month period, as opposed to six months in Ontario. The majority of health practitioners report this form of treatment to be very beneficial, though physicians rarely use them (O'Reilly, Keegan, & Elias. 2000). Nova Scotia formally implemented CTOs on July 3, 2007.

#### CTOs in Saskatchewan

As the first province to implement CTOs, the conditions under which CTOs are established are as follows:

- A diagnosis of mental illness and the need for treatment
- Past two years the person has experienced the following:

- 2 months / 60 days as an involuntary patient in a psychiatric facility
- Previously been the subject of a CTO
- The likelihood that without treatment in the community, the person may
  be a danger to him/herself or others, and substantial mental or physical
  deterioration due to the disorder.
- Mental health services are available in the community
- The person lacks insight to make informed decisions regarding their condition, treatment and care in the community.
- The person must be capable of understanding and complying with the requirement of the treatment as stipulated in the CTO (O'Reilly, Keegan and Elias, 2000).

In Saskatchewan, clients referred for CTOs are required to be examined by two physicians. Neither the Substitute Decision Maker (SDM) nor client is required to give consent regarding the treatment; the physician makes the assessment and implements the treatment.

#### CTOs in Ontario

CTOs, as the name implies, facilitate community-based treatment for individuals who fit the criteria of the "revolving door syndrome" (Hiday & Scheid-Cook, 1991). It is a contractual agreement between the client, his/her Substitute Decision Maker (SDM) and

the service provider, where both parties are required to commit to fulfilling their obligations as specified in the treatment plan. The physician who issues the CTO may request the patient to present for examination if, in his/her opinion, the client is not complying with treatment; if the patient refuses, the physician may issue a Form 47 (an order for examination) which authorizes the police to apprehend and bring the patient to the issuing physician for examination. A CTO is effective for a six-month period unless terminated earlier, and may be renewed by the patient's physician at any time during the six months and up to one month following its expiry. After every second renewal, a review by the Ontario Consent Capacity Board (CCB) is required however the client has the right to apply to the CCB at any time to appeal the proposed treatment.

CTOs in Ontario do not legalize forced treatment in the community, forcible administration of medication in a person's home, or immediate hospital admission of clients who fail to comply with the conditions outlined in the treatment plan; CTOs do, however, authorize examination of the person by the issuing physician; the decision to hospitalize the client is based on that examination and cannot precede it (Ontario Mental Health Act, 2000).

A Substitute Decision Maker (SDM) (if a client is deemed incapable) and community support workers (involved in the clients' care) are often named in the treatment plan attached to the CTOs, in which their specific roles and obligations are clearly outlined. The Community Treatment Plan (CTP) is a proposal that outlines the prescribed recommendations by the psychiatrist and community mental health workers, and includes medication dose and frequency. The CTP is a separate document, but forms

the crux of the treatment with consideration for the patient's ability to comply with the plan.

As part of the agreement to establish CTOs in Toronto, Ontario, the provincial government funds the Centre for Addiction and Mental Health (CAMH) for the provision of coordinators to integrate CTOs in "schedule one" facilities in the City. The role of CTO Coordinators includes providing CTO education to physicians and psychiatrists, stakeholders and patients. They also liaise with community partners on behalf of CTO clients for case management services, assess patients for CTO eligibility, develop treatment plans, and advocate on behalf of clients.

## Criteria for issuing a CTO in Ontario

The utilization of CTOs in other Western countries has had a tremendous impact on outpatient mental treatment, generating many discussions among supporters and critics alike; in the midst of these arguments, it is believed to be an effective treatment for the seriously mentally ill. In Canada, the lesson learned from other countries is that CTOs are the last resort for outpatient treatment, after other forms of intervention have failed.

In accordance with mental health legislation, a physician may only issue a Community Treatment Order if an individual meets the following criteria:

 The individual has a diagnosis of a severe and persistent mental illness based on the Diagnostic and Statistical Manual of Mental Disorders (DSM);

- The individual has had more than one inpatient stay in a psychiatric facility within the past three years;
- The person has been hospitalized for a cumulative period of thirty days within the past three years, or has previously been a subject of a CTO;
- The person meets the Form 1 criteria outlined in the Mental Health Act.

Prior to the issuance of a CTO, the CTO Coordinator develops a Community

Treatment Plan (CTP). The CTP is developed in conjunction with the client or his/her

SDM, the issuing physician, and any other party involved in the patient's treatment or

care.

In addition to a diagnosis of a severe and persistent mental disorder, the physician must also establish that the absence of continuing treatment or care, as well as supervision in the community, will likely effect the patient, causing serious bodily harm to himself/herself or others, suffering substantial mental or physical deterioration, or serious physical impairment (Ontario Mental Health Act, 2000). Upon the issuance of the initial form (Form 49- notice of intention to issue or renew the CTO), the patient or SDM should consult with a rights adviser. While the patient may refuse rights advice, the SDM cannot. In accordance with the Health Care Consent Act, 1996, the client or designated SDM must consent to the Community Treatment Plan.

The debate concerning CTOs, however, is an international issue that numerous countries are grappling with. Issues regarding coercion, human rights and the ethical implications of the treatment, are still being explored (Snow & Austin, 2009). CTOs or mandated outpatient treatment, therefore, were introduced as a legal mechanism to curb the perceived dangerousness of those deemed seriously mentally ill. It could be argued

that CTOs are not a random approach to treatment, but rather a political machinery set in motion to protect "innocent victims"; this raises questions about social justice that requires to be addressed in developing a theoretical framework for looking at CTOs.

A review of CTOs in the different jurisdictions shows the intent of establishing a system of providing treatment to the mentally ill deemed to fall through the cracks of the mental health system without appropriate support. Though the duration of the treatment is different in different jurisdictions, the ultimate purpose of the legislation is the treatment of the severely mentally ill. For instance, the difference in CTOs in Ontario and other jurisdictions is the fact that the duration of the treatment varies from one jurisdiction to the other. In Ontario, the initial contract is six months and after twelve months, there is an automatic review. In Australia for instance, the treatment becomes permanent after one has been on it for a year. In Saskatchewan, the treatment is for three months. In the US, it varies from three months to six months.

The shooting death of Brian Smith, an Ottawa Sportscaster in August 1995 by Jeffrey Arenburg, an individual diagnosed with paranoid schizophrenia in 1995 was the catalyst that precipitated the introduction of CTOs in Ontario (Walker, 2008). At the time of Mr. Smith's death, Mr. Arenburg was delusional and hearing voices. The death led to an inquest by the Ontario government, which resulted in the establishment of Brian's law in commemoration of the sportscaster and in order to prevent future death. The focus of the legislation was to reduce the hospitalization rates of the mentally ill and to mitigate incidents of violent behavior (Walker, 2008). This legislation resulted in changes to the Ontario mental health act and the health care consent act.

The introduction of CTOs in Ontario is important to the ethno-racial minority community in Ontario, particularly Toronto. As the ethno-racial minority population in Toronto increase, it is important for treatments like CTOs to reflect the diversity of the populace. However, as reported by the evaluators of CTOs in Ontario, the perspective of the ethno-racial minority of Ontario was ignored (Dreezer, Bay, and Hoff, 2005). In the report the following observations were made:

- Individuals from cultures that maintain high respect for authority have proven to follow through with the expectations of the treatment.
- 2. There are those who view this treatment with suspicion and are likely to be traumatized by it. This is based on the exposure and experience of abuse by authority figures in their countries of origin.
- 3. CTOs serve as an effective way of obtaining needed services which, due to barriers, would otherwise not have been received.
- 4. Family members' negative perception of mental illness and other forms of illnesses deter individuals from seeking professional help.
- 5. Inadequate culturally sensitive mental health resources play a significant role in the lack of effective treatment for individuals from ethno-racial communities.

These, therefore, make it necessary to explore this treatment, (CTO), and the voice of individuals from diverse communities who have participated in this treatment.

Overall, it could be argued that the utilization of CTOs in most developed countries is expedient as it provides support for the seriously mentally ill, who otherwise may not benefit from treatment in the community. Though, its implementation is based

on the Western medical approach, it serves clients of all races including those of ethnoracial minority background.

## **Chapter 3: Review of Theoretical Literature**

### Theoretical Foundations

As the social work profession is committed to diversity, cultural competence, and inclusion, it is imperative to recognize the significance of culture in the treatment of the mentally ill, particularly individuals from ethno-racial minority communities (Davis 2007; DePalma, 2006; Keatings & Robertson, 2004). Despite numerous studies on the impact of culture on treatment, individuals from minority, immigrant and racialized communities continue to experience inadequate support and treatment geared toward their socio-cultural beliefs. This inadequate support may be attributed to a number of factors, including racism and oppression (Anderson & Armstead, 1995; Anderson et. al., 1991; Essed, 1990; McKenzie & Bhui, 2007; Tinsley – Jones, 2003; Tsang, Bogo, & George, 2003; Williams & Collins, 1995).

Describing the terminology - race, ethnicity and culture, according to McKenzie and Crowcroft (1996), can be daunting due to the difficulty reaching an agreement on classifying individuals of different races involved in a study. The authors therefore suggest that in an attempt to classify race, ethnicity and culture, it is imperative that a range of information that describes the groups be gathered to identify those being studied. For the purpose of this study however, an attempt will be made to succinctly describe ethnicity and race in a way that will identify ethno-racial minority clients in the Canadian context.

To engage in meaningful discourse on this subject necessitates discussion of the term ethno-racial minority<sup>5</sup> as used in this study, as well as a definition of ethnicity and race. According to Isijaw (1999) ethnicity or ethnic group is defined as a group of people with a distinct belief system or culture, or people who identify themselves as descendants of those who share a distinct culture and identify with their ancestors; it refers to persons who share a cultural commonality. James (2003) postulates that ethnicity "gives individuals a sense of identity and belonging, based not only on their perception of being different, but also on the knowledge that they are recognized by others as being different" (p. 51).

Race on the other hand, refers to a group of people, family, tribe or a nation that belongs to or identifies with the same genetic heritage. Race is described as "the socially constructed classification of human beings based on the historical and geographic context of individual experience" (James, 2003, p. 40). The term 'ethno-racial' recognizes the configuration of a group that belongs together because of the assumed shared ancestry and also because of some shared culture. The use of the term minority refers to a subset of a larger group or a group / individuals deemed unimportant or inferior based on their race, culture, beliefs or level of education (Isijaw, 1999; James, 2003). Thus, for the purpose of this study, making reference to ethno-racial minority refers to groups or individuals from different ethnic backgrounds, particularly immigrants, other than the dominant race.

Based on the definitions of ethnicity and race, access to power and resources, and their inequitable distribution, is germane to the understanding of CTOs among ethno-

<sup>&</sup>lt;sup>5</sup> In Canada reference to ethno-racial minority communities include new comers as well as people whose roots go back more than one generation. Relevant to this study, many of the people in these groups originate from countries with histories of colonial rule by European nations.

racial minority communities. Accordingly, the conceptual frameworks that inform this study are: empowerment, anti-oppressive, and post-colonial frameworks.

## **Empowerment Framework**

Historically, individuals diagnosed with mental illness bear the brunt of society's mistreatment and this includes those from ethno-racial minority communities. Over the years, a diagnosis of mental illness has been associated with powerlessness (Linhorst 2006). More often, people diagnosed with mental illness have found themselves enduring varying forms of inhumane, physical, emotional and psychological treatment. In addition, they have to deal with the stigma associated with mental illness. Stigma is described as the negative attitude or belief that causes people to fear, avoid, reject or discriminate against those with mental illness (Ibid). In concert with the inhumane treatment, the mentally ill are faced with other forms of social control that render them powerless. They are either forcibly hospitalized against their will, or forced to undergo treatments as a means to "foster and maintain order and conformity" (Aviram 1990, p. 82). The sense of powerlessness renders clients of ethno-racial minority background helpless and deprived of support and resources, creating multiple systems of oppression where they find themselves victimized on multiple fronts.

Powerlessness could be described as the product of several factors; these include: economic insecurity, inexperience in the political process, a lack of education, training and access to information, physical and emotional stress and learned helplessness. Also, aspects of a person's emotional or intellectual make up and ailments relating to mental illness prevent them from actualizing possibilities (Cox, 1989, cited in Lee, 1994).

Helping clients deal with the challenging issues associated with mental illness calls for the utilization of the empowerment framework which provides clients with skills and the ability to overcome the social consequences of their diagnosis / illness.

Empowerment has been described as the process of gaining power or autonomy by the less fortunate and the marginalized, for the purpose of improving equity and quality of life (Askheim, 2002; Gutierrez, 1990; Hasenfeld, 1987; Nutbean & Harris, 2004; Parsons, 1991). Linhorst (2006) defines empowerment particularly for people with severe mental illness as "the meaningful participation of people with severe mental illness in decision making and activities that give them increased power, control, or influence over important areas of their lives" (p. 9). Among the numerous attempts to define empowerment as a theory, there is the suggestion that the marginalized are encouraged to engage in activities that reduce and/or eliminate the powerlessness created by negative valuations of members of a stigmatized group (Solomon, 1995, cited in Busch & Valentine, 2002).

The empowerment theory accentuates self-determination; this has been an essential social work practice guideline utilized by pioneers of the profession, from as early as the nineteenth century in addressing issues of social control among the poor and the marginalized (Parsons, Gutierrez & Cox, 1998; Simon, 1990). "Empowerment processes are the mechanism through which people, organizations, and communities gain mastery and control over issues that concern them, develop a critical awareness of their environment, and participate in decisions that affect their lives" (Zimmerman & Warschausky, 1998, p.5). In this situation, any process that engages people to participate in an activity that enhances their power, control, or influence, could be described or

deemed empowering. For those with serious mental illness, empowerment may be described as the ability to have control over their treatment. That is, being able to decide on treatments without any form of coercion or fear of repercussion. It could be thus explained that having control over ones treatment is empowering because it provides individuals with the tools/ skills to make decisions that have a tremendous impact on them.

The empowerment framework argues that having the power and ability to make decisions leads to outcomes that positively affect those involved in the treatment. These include

"increased confidence, improved social skills, greater knowledge of resources, stabilization of psychiatric symptoms, having decision-making power in a particular situation, or any other outcome that facilitates individuals' ability to exercise power and influence over their lives" (Linhorst, 2006, p. 6).

Implementing the empowerment approach is not based on forcing or cajoling others, however, those holding power or position of authority can play a vital role in empowering the vulnerable. Simon (1990) describes this process as being "a reflexive activity, a process capable of being initiated and sustained only by the agent or subject who seeks and sustained only by the agent or subject who seeks power or self determination" (p. 32). The framework refutes unresponsiveness to treatment as the basis for "hard to treat" individuals in the mental health system, and suggests instead that community resources are not modeled to meet their specific needs (Cummings, 2001; Finfgeld, 2004).

The marginalized, including those of ethno-racial minority background are, by definition, engaged in relationships with persons or groups that have power over others.

The power structure often makes it difficult, or even impossible, for the marginalized to assert or extricate themselves from some forms of domination. The social work profession considers the marginalized as a population at risk due to their limited access to resources and their exclusion from positions of power (Busch & Valentine, 2000). The empowerment theory provides the guidelines needed to inform practice with the marginalized. For people to empower themselves, they must be able to avail themselves of the services the community provides. Social work activities and processes focus on increasing individuals' access to control over their lives and promote self-confidence, clearer self-perception, knowledge and skills. Thus, based on the empowerment approach, mental health clients are expected to be able to "emancipate" themselves from the domination of the mental health care system through support, knowledge and self-reflection; as they are able to make progress, it significantly impacts their communities (Carling, 1995). This, however, is not exactly what is happening with CTO clients of ethno-racial minority background.

When considering the use of CTOs among clients from ethno-racial communities, an empowerment orientation raises questions about whether CTOs are considered a tool of empowerment, and whether or not this legally mandated outpatient treatment for the severely mentally ill enhances the development of resilience, assertiveness, self healing and mutual aid networks. Thus, exploring treatment from the client's perspective by asking what they want and what their true aspirations are engages them in the treatment process and also enhances their self-esteem. Even though clients may have access to case management and community support – which can be empowering - the coercive nature of the treatment, and the fear of apprehension for treatment non-compliance, could be

disempowering. This creates a form of power imbalance where the marginalized in the mental health system, especially ethno-racial minority clients, who are particularly marginalized, are compelled to be dependent on the system. Dependence on the mental health system creates a 'learned helplessness', where clients feel disempowered to make their own decisions or advocate on their own behalf.

The empowerment theoretical framework, by its definition, emphasizes self-determination, releasing power to the disempowered, and the capacity to enhance their well being; it enables individuals to gain greater control over their personal lives.

However, an empowerment-based analysis of CTOs and their use among clients of ethnoracial minority background suggests that the intervention can create dependency rather than independence and can be disempowering to clients instead of empowering.

The empowerment theoretical framework raises many questions regarding the impact of CTOs that can be applied to clients of ethno-racial minority communities - its failure to directly address the specific issues associated with race-based oppression of these clients necessitates the exploration of other theoretical frameworks, such as the anti-oppressive and the post-colonial frameworks that can address the struggles and difficulties faced by ethno-racial minority communities in accessing the mental health care system for treatment.

### **Anti-oppressive and Anti-racist Frameworks**

Anti-racist theory embedded within the anti-oppressive frameworks, focuses attention on marginalized ethno-racial minority communities and the impact of racism on these communities. Anti-racist theory addresses issues of race in ways "that make

racialized power relations explicit, deconstructs the social construction of race, and analyzes interlocking systems of oppression that serve to marginalize and exclude some groups while privileging others" (Carr & Klassen, 1996 cited in Hassouneh, 2006 p. 256). Both anti-oppressive and anti-racist perspectives would point toward the interlocking effects of racism, ableism, ageism and stigma against mental illness in marginalizing ethno-racial minority clients in the mental health care system. This perspective is reinforced by research clearly demonstrating that ethno-racial minority clients in the mental health system experience institutionalized racism, interpersonal racism and direct exposure to race-based abuse and exclusion (McKenzie & Bhui, 2007); anti-racist and anti- oppressive perspectives raise questions regarding the extent to which CTOs perpetuate or challenge racism in the system and experienced by ethno-racial minority communities.

According to Schiele (1996), oppression is a deliberate effort or system put in place to suppress the power and potential of a certain group of people: "legitimizing and institutionalizing in-humanistic and person – delimiting values such as materialism, fragmentation, individualism and inordinate competition" (p. 286). Oppression creates a system of exploitation in a climate of inequitable distribution of resources (Miley & DuBois, 2007).

The anti-oppressive framework is based on the premise that power is used by the privileged to oppress the marginalized; thus, the marginalized, including those from ethno-racial minority communities, are at the mercy of the powerful (dominant culture) (Garcia and Melendez, 1997; Pollack, 2004; Preston-Shoot, 1995). Its view is for a world characterized by freedom from all structures of domination and privilege, and anti-

oppression works to create equity for all social groups (Bishop, 1994; Campbell 2003; Dominelli, 2002; Mullaly, 2002). The framework, according to Payne (1997), is derived from a variety of theories, including the critical, feminist, anti-racist, post-structural and post–modernism theories. It attempts to work with individuals to eliminate problems that arise from problems originating in the wider social contexts of their lives through the support of certain professions such as social work, as well as community organizations, who assist the marginalized to address issues of oppression.

The anti-oppressive framework is also based on the notion that the marginalized are oppressed in every area of life. The suggestion is that the "use of power is three dimensional since it acknowledges structural inequality and exploitative legal, social and economic relationships and seeks a fundamental realignment of power relationship in wider social context" (Braye & Preston, 1995, p.107, cited in Miley & DuBois, 2007). It seeks to assist those impacted by the oppressive social order, to redress inequality within the system, as well as the consequences of racism, oppression and marginalization within various segments of the population (Mullaly, 1997). To cite an example, Dalyrymple and Burke (1995) note that:

Black women are treated different from white women, lesbians are treated different from heterosexual women, disabled women are viewed different from able-bodied women, older women are viewed differently from younger women (p. 8).

In a similar context, the mentally ill population is treated differently from the dominant non-diagnosed society, and the interlocking effects of racism and ableism means that those from ethno-racial communities rate low on the structural ladder. This racialized oppression is also experienced in the mental health system, where marginalized clients can be either mistreated or controlled as part of the proposed treatment.

The focus of the social work profession is to actively explore avenues to contribute to the liberation of the vulnerable and oppressed with the ultimate goal of promoting their social inclusion (Mclaughlin, 2005). When exploring issues of oppression, in some cases, professionals charged with the responsibility of working with the marginalized tend to be individuals who are not subjected to the matrices of oppression that affect their clients. They are usually a representation of a system responsible for perpetuating inequality. This creates another system of oppression where clients of ethno-racial minority backgrounds find themselves oppressed and marginalized again based on the treatment and the lack of understanding of their culture. The successful alleviation of oppression is therefore undermined if those charged with addressing the issues are part of the larger system that perpetuates such practice.

Racism affects individuals from ethno-racial minority communities more than the dominant race, and this is portrayed in various ways, including the disproportionate involuntary treatment of racial minority, especially Black people. A study in England surveyed 32,023 patients in the mental health system and found that 21 % of the respondents were of Black descent even though Blacks account for about 7% of the total population. Furthermore, the rate of admission to psychiatric institutions tends to be lower than average for White British, Indian and Chinese groups, whereas Black Africans, Caribbeans and those of mixed race (White and Black) were 19% to 39% more likely to be admitted involuntarily (McKenzie & Bhui, 2007). The prevalence of racism is evident not only in the UK, but around the Western world (Agyeman, 2007). Racism creates mistrust, fear, and wariness of Blacks, and this is further fuelled by prejudice, misunderstanding and the misconception by those of the dominant culture (Tinsley –

Jones, 2003). Racism has implications for health care in the Western world as it also contributes to disparities in the form of inequitable provision of resources in the community (Anderson & Armstead, 1995; Anderson et. al, 1991; Essed, 1990; Williams and Collins, 1995). Other reports also speak to racial oppression and its consequences for the people of ethno-racial communities. Research has shown that the physical and mental health of individuals from minority communities is impacted by a health care system that is shaped around the needs of the dominant culture (Thompson-Miller & Feagin, 2007).

Mental health professionals' lack of awareness of cultural issues, displays of bias or prejudice, and their inability to understand clients' languages and the clients' fears and mistrust of treatment, further diminishes the capacity for ethno-racial minority clients to benefit from the mental health care system (U.S. Surgeon General's report, 2001, p.14). These problems between clinicians and clients have several consequences. Studies show that mental disorders are on average more prevalent among Blacks than Whites and that treatment options are influenced by race and socio-economic disparity; for example, mentally ill individuals from ethno-racial backgrounds are more likely to be prescribed antipsychotic medication and less likely to be offered psychotherapy (McKenzie, Semele, van Horn, et al., 2001; US Department of Health and Human Services – Mental Health, 2001). Moreover, persons from ethno-racial backgrounds have a higher rate of drop out or non-compliance with mental health treatment compared to those of the dominant culture due to adverse experiences in the mental health system and the cultural incompetence of service providers (McKenzie and Bhui, 2007; Williams, 2002). They have less access to services than Whites, and they have the tendency to enter the mental

health system later and are misdiagnosed more often, resulting in lower likelihood of receiving adequate treatment (Nelson, 2004; Shavers & Shavers, 2006).

Ethno-racial minority communities would be better served and service delivery more effective with specialized training of health care providers in ethnic and cultural issues. Cultural competency is a very important consideration in the treatment of the marginalized, as it contributes to the success of effective treatment modalities and promotes sensitivity towards this client population (Hollar, 2001; Ridley, Chih, Olivera, 2000; Williams & Morris, 2000, Williams, 2005), however, the oppressive nature of the dominant race makes it almost impossible to embrace

The anti-oppressive theoretical framework is therefore a means of deconstructing a systemic approach to the way the marginalized, and people of ethno-racial minority background, are perceived and treated by the dominant culture. Providing meaningful services to the marginalized, particularly those from ethno-racial minority background calls for cultural awareness, sensitivity and competence. Regarding CTOs, clients of ethno-racial minority background more often than not, find themselves in a position where service providers lack cultural competence and sensitivity to provide efficient service that will enhance their recovery.

The paucity of expectation for cultural competence in mainstream institutions is a reflection of the systemic marginalization of ethno-racial minority groups. This makes it necessary for service providers to utilize the anti-oppressive and anti-racist framework to effectively work with this client population.

### Post-Colonial Theoretical Framework

Post-colonial theory is based on the analysis of the process of colonization which in part involved Western European nations conducting a "civilizing mission" in Asia, Africa, the Caribbean, South America and other parts of what was then the third world. This mission sought to transform the colonized (referred to as "primitive people") into quasi-Europeans under the control of the colonizers, and maintained with lower social status. In the application of CTOs to ethno-racial minority population in White-dominant contexts, it can be argued that this civilizing mission continues. Through the process of treatment, the system exert social control by identifying those who deviate from dominant expectations for functioning as disordered and abnormal and transforming them through treatment (mandated involuntary treatment) into civilized, compliant occupiers of the patient role (Bhui, et al. 2005; Noh and Kaspar, 2003; Wamala, Bostrom, and Nygvist, 2007; Williams, 2001). Ethno-racial minority clients may in turn experience these interventions as an extension of the civilizing mission experienced in their homelands or where they may have received similar western-based treatment. The application of post-colonial theory raises questions about the transformation of identity, denigration of non-dominant ethno-racial minority ways of being, and power relationships that play out in a system where the ethno-racial majority often has control over ethno-racial minorities (Qureshi, Collazos, Ramos and Casas, 2008; Rodney, 1974; Williams, 2003).

Ethno-racial minority communities in Canada are comprised mostly of immigrant populations from countries of origin that were once colonized by the European nations. For example, the 2006 population census identifies South Asians as the largest visible minority in Canada (Statistics Canada, 2008); the British colonized most of the countries

in Asia. As the name implies, post-colonialism is a criticism of the past and contemporary actions of colonial powers in the Third World and focuses on the consequences for countries that were under colonial power, and their citizens. Post-colonialism addresses issues of dominance by a strong nation over the colonized by means of force, taking advantage of the colonized through trade and the exploitation of manpower, and resources of raw materials. The colonialists, while committing these atrocities against the colonized, placed themselves on high moral ground (Adu-Boahene, 1987).

The post-colonial framework and its impact on the colonized lend insight into consequences of the application of CTOs among ethno-racial communities. The goal of civilization was achieved through whatever means necessary - including war and propaganda - to impress upon the colonized the superiority of the colonialist. The colonized were considered a danger to themselves and the civilized world, and therefore colonialists impressed upon them the need for exposure to civilization (Fanon, 1961). The colonialists.

..sought to incorporate Africans into institutions which would simultaneously provide more productive labour and consolidate colonial rule. The development of the African colonies was believed to reside in restructuring the interface between the state and society (Kelemen, 2007, p. 76).

The superiority of the colonialists touted Whiteness as the will of God, and Whites from the Western world felt they had the inalienable right to dehumanize the 'Other' - that is, people of other cultures, particularly racialized groups (Adu Boahene, 1987, Said 1978). They also believed that the colonized were "lost" and needed direction and redemption. Although post-colonialism has emerged from analysis of the

relationships between former colonies and the dominant Western world, it has applications to a wide range of relationships that exist between groups that are stratified to designate rich versus poor, political majority versus political minority, and powerful versus disempowered. Although nations like the United States and Canada did not participate in the overseas colonization, as nations that benefited from that colonization through slavery, and also benefited from their own colonial campaigns against the native peoples of North America, the political arrangements in both nations reflect contemporary continuities of the colonial enterprise (Askelan and Payne, 2006).

Fanon (1961) talks about the "systematized negation of the other, a frenzied determination to deny the other any attribute of humanity; colonialism forces the colonized to constantly ask the question: Who am I in reality?" (p. 182). This refers to a system that denies the rights of individuals, eventually rendering them helpless in the face of the "powers that be." The concept of colonialism may be extended to the marginalized and disenfranchised of society, such as those of ethno-racial minorities communities diagnosed with mental illness. This practice of domination can manifest in psychiatry when ethno-racial minority clients are involved in interventions like CTOs, and are legally obligated - or covertly coerced - to participate in their civilization into obedient, compliant clients dependent on the care and benevolence of a system governed by the dominant group (Corbie-Smith, Thomas, & St. George, 2002; Williams, 2005).

In addition, clients of racialized communities are expected to believe that Western medication is far superior to other treatments they may prefer and are obligated to adhere to medication at the risk of experiencing the consequences of non-compliance. Thus, notwithstanding clients' background or belief system regarding treatment, they are

compelled to follow medication regimen prescribed by physicians and are seen as problematic if they are not in compliance.

When the post-colonial framework is applied to the treatment of CTO clients of ethno-racial minority background, we are made aware that these clients may lose their identity and their autonomy as individuals when diagnosed with mental illness. Some are judged unable to make treatment decisions for themselves, so others, such as family members or the Public Guardian and Trustee (PGT) in Ontario are appointed to make treatment and /or financial decisions for them. Like the colonized, the freedom to decide what is in their best interest and /or to make choices is removed. Moreover, the implementation of CTOs was based on input from the dominant culture to the exclusion of ethno-racial minority communities (Dreezer, Bay, and Hoff, 2005), thus precludes consideration of the cultural appropriateness of this treatment option. The CTO legislation was passed despite concerns about autonomy.

The far reaching effects of post-colonialism on identities, attitudes and practices extend beyond colonies to a much broader area as evidenced today in society's treatment and social control of the marginalized, including the mentally ill, whose affairs are directed or controlled by the dictates of the system.

CTOs may also be viewed as a form of social control, where clients are obliged to adhere to the treatment agreement and contract enshrined in the Community Treatment Plan (CTP), despite their discomfort or being controlled by a treatment modality that lacks cultural sensitivity.

A further parallel may be drawn between the colonized and the treatment of the mentally ill. Despite attempts to impose education and culture on the colonized, they

were never wholly accepted or embraced as part of 'civilized society'; similarly, despite the significant education, advances and progress in the treatment of mental illness, this marginalized population has yet to be accepted as part of the "able bodied" community without the associated stigma.

Exploring CTOs in conjunction with these theoretical frameworks provide a broader perspective on the impact of this treatment among clients, and the lived experience of individuals from ethno-racial minority communities. The utilization of the empowerment, anti-oppressive and anti-colonial frameworks, sheds light on how the subjectivity of the individual clients is construed. The frameworks give perspective to what we know about their needs, circumstances, wants, aspirations and how that impacts their treatment. The frameworks therefore provide the foundation on which this study will be developed. However, a full argument cannot be made for this study without also looking at the empirical literature that has been produced on CTOs and identifying the gaps and the issues that suggest the need for this particular investigation. The frameworks will be used as the lens to evaluate the literature on CTOs and its impact on ethno-racial minority clients.

Thus, the frameworks (empowerment, anti-oppressive, and post-colonial) generated from the review of relevant theoretical research context, informed utilization of the phenomenological study. This will be a study that will explore the voices that are missing in the debate from the perspective of ethno-racial minority clients.

# **Chapter 4: Review of Empirical Literature**

## **Descriptive Studies of Community Treatment Orders (CTOs)**

An extensive literature search to develop the conceptual frameworks and the examination of major databases such as the Web of knowledge, PsychInfo, Medline, Scholars Portal, Sociological abstracts, Scopus and Google scholar for the period 1980 to 2010, yielded numerous articles related to CTOs. The following key words were employed in the search: Community Treatment Orders (CTOs), Mandatory Outpatient Treatment, Outpatient Committal, Involuntary Outpatient Commitment, Leave Certificates, Assisted Outpatient Committal and Outpatient Treatment. The results yielded numerous articles related to CTOs, the majority of which were conducted in different countries and were quantitative in nature. Most explored the effectiveness of CTOs from the perspective of service users (clients), family members, caregivers and service providers, while some explored CTOs from the perspective of admissions to hospital and the coercive nature of the treatment. All the studies were reported in English language journals and based in Western English –speaking countries. It was noted there were no CTOs in developing countries.

With a few exceptions, literature in the area of CTOs does not reference issues of empowerment, oppression or post-colonial theories. Empowerment is central to and an increasingly important consideration in the treatment of mental illness, while the influence of the anti-oppression and post-colonial theories, which have deep historical roots, are also critical in the evolution of mental health treatment. These gaps in literature therefore necessitate further exploration.

## **Perception of stakeholders toward CTOs**

Given the recent developments in the field of community mental health, it is imperative that feedback on the impact of CTOs from those directly involved in providing support and treatment (including family members, clinicians and other stakeholders) be evaluated. Moreover, as this discussion seeks to explore the ethno-racial impact of the treatment, an opportunity to view CTOs through the lens of a culturally diverse client population will enhance the discourse on CTOs.

Feedback from a survey of clinicians in New Zealand revealed that CTOs were considered to be time consuming and cumbersome, irrespective of the fact that they facilitated community treatment (Currier, 1997). In other New Zealand studies, however, clinicians expressed contrary points of view, with respondents portraying a positive perception of CTOs (Dawson and Romans 2001; Romans, Dawson, Mullen and Gibbs, 2004). Dawson and Romans (2001) carried out a retrospective study to explore the use of CTOs in Otago in Australia among psychiatrists and clients involving clients' records between 1992 – 1998 and a survey of psychiatrists. Findings of the study showed reduced rates of hospital readmissions for clients on CTOs, and psychiatrists reported CTOs useful for patients considered severely mentally ill and in need of long-term care.

Romans, Dawson, Mullen and Gibbs (2004) carried out a comparative study involving a postal and national survey of psychiatrists, and regional survey of non-psychiatric community mental health professionals. The psychiatrists reported that CTOs enhance clients' priority for care and that it provided structure for treatment support and stability. In line with other studies, the respondents believed that CTOs enhanced clients'

care structure for treatment and also lent support for continued contact and stability (Currier, 1997; Dawson and Romans, 2001). The majority of respondents, however, also noted that CTOs affect the therapeutic alliance between clients and their practitioners. The other study (Romans, Dawson, Mullen and Gibbs, 2004) had limited response, primarily from physicians, and thus likely portrays bias, as the feedback was mostly from physicians.

A study in Australia found clinicians viewed mandatory CTOs as a viable treatment option for a specific group of severely mentally ill patients (Rolfe, 2001). In a Canadian study in Saskatchewan, O'Reilly, Keegan and Elias (2000) surveyed 69 licensed psychiatrists to determine the pattern of use and the satisfaction of CTOs among this profession, similar outcomes were identified where all respondents felt CTOs were very effective and helpful for those severely mentally ill who were unlikely to utilize treatment services without a form of outpatient committal. The majority of psychiatrists also considered CTOs as satisfactory and a very useful treatment tool for clients deemed hard to treat. The primary concern of the respondents was the limited three-month duration of CTOs. There was no clear explanation for the reluctance of physicians to utilize CTOs, despite supporting their usefulness.

In Israel, on the other hand, clinicians rarely utilized CTOs; they were viewed as a "policing function," where treatment compelled them to monitor their clients (Ajzenstadt, Aviram, Kalian & Kanter, 2001). A number of psychiatrists and patients reported CTOs had a negative effect on clients, which further prevented clinicians from providing effective treatment. The authors also explored the extent to which outpatient committal met the goals of preventing hospitalization and safeguarding the rights of the mentally ill

and found it to be ineffective. Although this was a mixed method study, the analytic process was not discussed.

The study by Ozgul and Brunero (1997) on the benefits of CTOs received a higher rating from family members and case managers. They applauded the role of CTOs in reducing family conflict and client distress through enhanced medication compliance and prompt treatment, as well as promoting a safer environment. Mullen, Gibbs and Dawson (2006) similarly reported positive findings where family members believed CTOs lessened stress, reduced the burden of monitoring and improved clients' quality of life.

Clients' view of CTOs varied; some regarded CTOs as an effective tool, while others expressed apprehension and felt CTOs infringed upon their rights and did not allow them the liberty to make their own decisions (Mullen, Gibbs, & Dawson, 2006). The authors interviewed 27 individuals whose relatives had been on CTOs for more than 6 months. The family members were in favour of CTOs and viewed it as a positive influence on their relatives, themselves and their relationship with the clinical team. It could be argued that the study's limitation of the low number of participants (n-27) encompassed an over representation of those in favour of CTOs on account of the consent process.

In a qualitative study, Gibbs, et al, (2004) explored the impact of CTOs on Maori patients and their extended family, and the views of mental health professionals. 39 individuals, of whom eight were Maori patients, were interviewed using a semi-structured tool. Overall, the health professionals, family members and majority of clients reported CTO treatment to be beneficial, helpful and safe. Physicians in the study expressed concern, however, over the conflict they experienced in reconciling traditional beliefs with the medical model regarding treatment of mental illness. A number of

professionals acknowledged the importance of providing treatment to a population considered hard to control. CTOs were considered an effective community-based support for mentally ill individuals who would otherwise fall through the cracks of the health care system. Although the health professionals, family members, and most clients found the treatment beneficial, helpful and safe, some clients complained about stigma and weight gain, and the restrictions associated with CTOs. A notable limitation of the study was the sample of size of only eight Maori patients, which precluded generalization of the findings to the entire Maori community.

The fact that Gibbs, et al, (2004), in their study focused on the Maoris; an ethnoracial population which is not a member of the dominant racial group raises other questions. Though the eight Maori respondents do not represent the entire Maori community, they reported the Eurocentric treatment approach to be beneficial. This brings to the fore the post-colonial theoretical framework which explores the imposition of colonialism among colonized countries. Like the colonized, the Maori's in the study reflect a system that imposes what is deemed right on the marginalized; this therefore further necessitates exploration of CTOs among ethno-racial minority communities.

The Maori study illustrates the ambivalence of CTOs among clients and clinicians, unlike their family members who fully appreciated and embraced the treatment, which is reflective of the relevance of culture in understanding the Maoris.

Though arguments for and against CTOs were clearly articulated, the missing link was the impact of the treatment on ethno-racial minority communities - none of the studies identified in the literature review attempted to explore CTOs from the perspective of the cultural influence of the participants involved.

# Quality of life

Quality of life is the improvement in an individual's life based on the support and resources provided by service providers in the community. It denotes the degree of contentment and satisfaction in an individual's life, and must take into consideration individuals' subjective wellbeing.

Phelan and associates (2010) followed a group of mandated outpatient commitment clients and recently discharged mental health clients who both attended the same outpatient mental health program. The study looked at psychotic symptoms, suicide risk, serious violence perpetration, quality of life, illness related social functioning, perceived coercion and stigma. Though there were differences between the two groups regarding illness and related social functioning, quality of life did not significantly differ between the two groups. This may be attributed to the availability of resources to both groups at the program. This is similar to the outcome reported in the study by Steadman, et al. (2001).

A longitudinal study by Link, Castille and Stuber (2008) in New York City involved 184 individuals with serious mental illness, of whom 76 were court ordered for outpatient treatment. The outcome of this study showed improved social functioning and quality of life among the court ordered outpatient clients.

Swanson and associates (2003) followed involuntary hospitalized participants discharged under outpatient commitment for a year and reported similar findings; a higher increase was noted in the quality of life of the mandated outpatient participants together with greater adherence scores.

Ingram, Murhead and Harvey (2009) explored whether CTOs reduced problem behaviours and improved social functioning. Using a naturalistic retrospective mirror image study of case notes and utilizing each case as its own control, the researchers found CTOs contributed to increased treatment outcomes, including quality of life.

Overall, the studies supported CTOs or mandated outpatient committal in improving the quality of life of the seriously mentally ill. However, none explored outcomes of the treatment from the perspective of ethno-racial minority clients.

# Coercion

Exploring coercion among ethno-racial minority clients raises awareness of empowerment and oppression issues associated with CTOs, though it has rarely been dealt with directly. Research on coercion explores issues of power and oppression and how it affects the powerless and marginalized in society. In the mental health system, coercion is viewed by many as a legitimate way of treating individuals who otherwise may not benefit from treatment intervention.

Coercion is described as the act of dominating by force, enforcing or being compelled to make a decision contrary to one's desire. The process of coercion could result in disempowering and oppressing others. Mandated community-based mental health treatment in particular CTOs, have been described as coercive (Diamond, 1995; Elbogen, Swanson, & Swartz, 2003; Swartz, et al. 2002). The coercive aspect of this treatment option is explored to determine its impact on treatment efficacy.

Research shows that CTOs and other outpatient mandatory treatments violate client rights in their interaction with clinicians (Chodoff, 1984; Geller, 1986; Mfoafo-

M'Carthy & Williams, 2010). The argument is between the medical model that focuses on compliance with treatment and civil liberties that address the rights and protection of clients under the law. Chodoff (1984) clearly articulates this distinction: "dangerousness versus medical necessity and the relative role of right versus obligations and of autonomy versus paternalism." Allen and Smith (2001), caution that the coercive treatment of the mentally ill is likely to undermine and discourage clients from seeking help from within the mental health system. This line of argument is supported by Diamond (1995) who argues that coercion interferes with clients' autonomy in making treatment decisions, and that clients are capable of determining what is in their best interests when they are supported, rather than coerced.

Brown (2003) posits the essence of involuntary outpatient committal and use of coercion, as a tool for compliance, is to correct the notion that the current outpatient system has failed to serve the severely mentally ill. The author questions the effectiveness of mandatory outpatient treatment, which alienates clients, and concludes that a voluntary form of service provision may be more effective for the mentally ill. Brown (2003) did not, however, address the viability of severely mentally ill clients voluntarily seeking help without any form of coercion. Everett (2007) explored the potential and likelihood of both overt and covert forms of coercion and recommends approaches that least exhibit any form of coercion, or coercive treatment.

Swartz and associates (2003) explored the long-term effects of coerced outpatient treatments on deterring voluntary participation. The study involved 104 individuals with schizophrenia and spectrum disorders and 85 mental health professionals in Piedmont, North Carolina. The questionnaire for the study employed the MacArthur perceived

coercion scale (Gardner, Hoge, Bennett, et al. 1993). The majority of the professionals viewed legal pressures and coercion as effective tools in promoting persons with schizophrenia to seek help and remain in treatment; according to the clients however, the coercive nature of the treatment deterred them from seeking help.

Swartz, et al. (2002) in an experimental study examined self-reported coercion among individuals with severe mental illness. A multivariate analysis of the study showed a significant level of coercion associated with longer periods of mandated outpatient treatment among the participants, particularly African-Americans who identified as single, lived independently, had substance abuse issues and poor insight into their condition, and exhibited severe symptoms. Why African-Americans tend to be coerced into outpatient committal and whether there is a link to institutional racism, as observed in the mental health system warrants exploration of CTOs from the cultural and racial points of view. While this study is one of the few that addresses treatment issues affecting minority clients, no consideration is given to major influences such as racism, which is of particular relevance to ethno-minority clients.

In another study, Steadman, et al. (2001) attempted to evaluate the effectiveness of a three-year pilot program in New York City. In the study, 142 clients were randomly assigned; 78 to court ordered outpatient treatment and enhanced case management services and the remaining 64 to enhanced case management services only. The outcome measures explored were: hospitalization rates, number of arrests, quality of life, symptomatology, treatment non-compliance and perceived level of coercion. There were no statistically significant differences in outcomes between the two groups; the number of hospitalization days during the follow up period, and perception of the participants'

quality of life and level of coercion were about the same for both groups. The participants reported a high level of coercion with regard to the court ordered outpatient treatment.

In a study by Swanson, et al. (2003), involuntarily hospitalized clients awaiting discharge to outpatient commitment were randomly assigned to continue with the outpatient commitment or released; both groups were followed for a year. Study outcome showed improvement in the quality of life for the participants under outpatient commitment; however, the perceived coercion moderated the effect of the outpatient commitment.

McKenna, Simpson and Coverdale (2006) in a cross-section comparative study attempted to determine the level of coercion perceived by those under outpatient commitment compared to discharged outpatients. The researchers matched 69 outpatient commitment clients with a sample of voluntary outpatients. The outcome showed that though the level of coercion for involuntary outpatient was relatively low, it tended to be higher than that experienced by voluntary outpatients. The effects of clients' perception of coercion on clinical outcomes beyond one year were not addressed.

On the other hand, Elbogen, Swanson, and Swartz (2003) examined the effect of involuntary outpatient commitment and representative payeeship on perceived coercion, as well as treatment adherence in severely mentally ill patients. Findings revealed that respondents with involuntary outpatient commitment and representative payee both perceived their mental health treatment to be significantly more coercive than subjects without these legal interventions. Swartz and associates' (2002) experimental study involved self-reported coercion in randomly assigned subjects with severe mental illness

released on either involuntary outpatient treatment or no outpatient commitment. They found a significantly high level of reported coercion among subjects on outpatient commitment, in particular, pressure from case managers regarding medication compliance.

In another study, Swartz, et al. (2003) compared the views of four stakeholder groups regarding outpatient commitment: individuals receiving treatment for schizophrenia and related disorders, their family members, clinicians treating these individuals, and members of the general public. Respondents were presented with vignettes depicting potential outcomes associated alternatively with involuntary outpatient commitment and voluntary treatment. The findings of the study showed that family members in particular were willing to accept the coerciveness of outpatient commitment to realize improved outcomes for persons with schizophrenia and related disorders.

The coercive nature of mandated outpatient treatment is clearly associated with both positive and negative elements, however, only the study by Swartz, et al. (2003) identified the impact of coercion on African-American clients; most investigations did not report on ethno-racial minority groups in their samples, thus contributing to the gap in the literature and necessitating study of ethno-racial minority groups.

### **Effectiveness of CTOs: Hospitalization and utilization of health services**

To gauge the effectiveness of CTOs requires review of hospitalization rates, the availability and utilization of community resources for patients discharged from hospital, and its impact on clients' quality of life in the community. Studies that have explored

these factors will be examined to determine whether CTOs stem the tide of the "revolving door syndrome."

Preston, Kisely, and Xiao (2002) examined whether being on a CTOs reduced clients' utilization of health services in comparison to a control group. The researchers utilized an epidemiological study in Western Australia with a population of about 1.7 million; 228 subjects were placed on a CTO and matched with an equal number in the control group. Outcome measures for the study were inpatient admission, bed days, and outpatient contacts one year after the implementation of the CTO. The results reflected reduced hospital contacts for both groups; however, CTO clients had more outpatient contact on account of the mandated treatment. In another study, Kisely, Xiao, Preston (2004) examined whether CTOs reduced hospital admission rates by utilizing survival analysis of CTO cases and controls from Western Australian database. The researchers concluded that CTO clients had higher hospital admission rates, and that lower rates could not be achieved by CTOs alone. The findings also showed that clinicians promptly intervened on behalf of CTO clients rather than allowing them to remain in the community and consequently further deteriorate.

In another study, Kisely, et al. (2005), examined the psychiatric admission rates of CTO clients in Australia and non- CTO clients in Nova Scotia. In this comparative study, the authors employed a population-based record linkage analysis of an inception cohort. They utilized a two-stage design of matching and multivariate analyses to control for socio- demographics, clinical features and psychiatric history. The outcome of the study a showed a statistically significant number of re-admission rates among CTO clients. A logistic regression of patients on CTOs, however, showed a reduction in length

of stay among CTO clients. This outcome supports early intervention in the treatment of CTO clients to reduce their lengths of stay in hospitals.

A study by Hunt et al. (2007) utilized a comparative study of clients on CTOs and a control group. They examined participants' socio-demographic and clinical variables, including hospital use and engagement with health services on exit from case management services. The study revealed that CTOs and case management support reduced the hospitalization of clients. CTO was viewed as a support for those who otherwise would have refused services. The epidemiological study by Burgess, et al. (2006) on the relationship between CTOs and the frequency and duration of hospitalization rates was inconclusive; however, the authors found that greater community involvement in client care reduced subsequent inpatient stays.

Whether compulsory treatment orders for psychiatric patients reduce subsequent health service use when compared to control groups matched on socio-demographics, clinical features and previous psychiatric history has been extensively explored. Studies that reviewed inpatient admissions, bed days and outpatient contact prior to being placed on CTOs and one year thereafter for both groups found no significant difference between groups and concluded that CTOs alone do not reduce admissions of the mentally ill (Kisely, Campbell, Preston & Xiao 2000; Kisely, Preston, & Xiao, 2001; Kisely, Xiao & Preston, 2004). The study by Segal and Burgess (2006), on the other hand, found that mandated community treatment reduced hospitalization and increased community treatment days. Swartz, et al. (1999) supported these findings; the researchers concluded that mandated outpatient treatment combined with intensive case management, reduced re-hospitalization rates among the severely mentally ill.

The study by Segal and Burgess (2006) found that the administration of depot medications enhanced outcomes for patients whose mental health would otherwise be compromised by poor adherence to treatment. It concluded that CTOs increased the number of service contacts for participants, decreased the number of hospital admissions, and reduced length of inpatient stays. A similar study concluded that CTOs reduced hospitalization, particularly among those treated with depot antipsychotic medication (Muirhead, Harvey & Ingram 2006). Another study examined the readmission rates of CTO clients within a four-year period, supported CTOs as an effective tool to improve treatment outcomes for individuals with schizophrenia and other serious mental illnesses (Vaughn, et al. 2000).

Empirical studies show that CTOs reduced the risk of violent behaviour and increased clients' participation in mental health services while also improving adherence to treatment and decreased hospital admission, recidivism and arrest rates (Swanson et al., 2001; Swartz et al., 2000; Swanson, Van Dorn, Monahan, & Swartz, 2006). It lowered the risk of violent behaviour in persons with severe mental illness and improved their quality of life (Swanson et al. 2003).

Two randomized controlled studies in New York (Steadman, et al. 2001) and North Carolina (Swartz, et al, 2001) were conducted to test the effectiveness of CTOs. The New York study did not report any statistically significant differences between the court-ordered treatments and enhanced case management services. The North Carolina study, on the other hand, revealed that patients subjected to sustained outpatient commitment had fewer hospital admissions and inpatient days, and were more likely to adhere to community treatment. It further showed that sustained outpatient commitment

order exceeding 180 days tended to increase treatment adherence and reduce outcomes such as relapse, violent behaviour, victimization and arrest; intensive mental health treatment facilitated monitoring of patients for a longer period of time (Swartz, et al. 2001).

The literature shows that CTOs, when implemented under the right conditions with appropriate supports, enhances the condition of clients. Despite the extensive research on CTOs within this complex treatment environment, negligible attention has been paid to the lived experiences of clients on CTOs, and the impact of CTOs on clients from ethno-racial minority communities. Although the studies generated vital information on CTOs, none have explored it from the angle of ethno-racial minority clients or from the perspectives of the empowerment, anti-oppressive and post-colonial theoretical frameworks. This gap in literature supports exploration of CTOs as a treatment option from the perspective of clients from ethno-racial minority backgrounds.

#### **Issues Relevant to Ethno-racial Communities**

A report on ethno-racial minority communities in Ontario cited that in 1971, non-European ethno-racial groups in the Toronto metropolitan area accounted for 5% of the population; by 2001, however, the number of ethno-racial minority groups had ballooned to almost 40% (Ornstein, 2006). In 2006, Toronto was considered home to 8% of the country's population, 30% of all recent immigrants and 20 % of all immigrants; 47% of Toronto's population self-reported as being part of a visible minority (City of Toronto, 1998-2010). These accelerating rates increase the likelihood of individuals from ethnoracial minority groups being placed on CTOs or receiving treatment from community-

based mental health programs; there is a need, therefore, for more studies and treatment interventions tailored to individuals of ethno-racial minority backgrounds in Toronto and Canada as a whole.

An extensive review of the literature revealed numerous studies on CTOs from divergent perspectives. A number of studies explored the impact of CTOs among stakeholders (Ajzenstadt, Aviram, Kalian & Kanter, 2001; Currier, 1977; Dawson & Romans, 2001; O'Reilly, Keegan, & Elias, 2000; Romans, Dawson, Mullen & Gibbs, 2004), while others investigated the coercive nature of CTOs (Allen & Smith, 2001; Everett, 2001; Elbogen, Swanson & Swartz, 2003; McKenna, Simpson, Coverdale, 2006; Steadman, et al. 2001; Swartz, et al. 2002) and the utilization of health services and hospitalization by CTO clients (Burgess, et al. 2006; Hunt, da Silva, Lurie & Goldbloom, 2007; Kisely, et al. 2007; Kisely, Campbell, Preston & Xiao, 2005; Kisely, Xiao & Preston, 2004; Muirhead, Harvey & Ingram, 2006; Segal & Burgess, 2006; Swanson, et al. 2001; Swanson, et al. 2003; Swartz, et al. 1999; Wagner, Burns & Hiday, 2001; Van Dorn, et al. 2006).

In all the studies, however, the perspective of ethno-racial minority communities on CTOs is largely absent. Of the few articles that address the cultural impact of CTOs, only one in particular focuses on the Maori population in New Zealand (Gibbs, Dawson, Forsyth & Mullen, 2004). The article cited the importance of timely intervention in clients' treatment and also noted that continued communication efforts with clinicians and family members, as well as reconciling traditional beliefs with the medical model, could significantly improve the provision of efficient care. The authors recommended further in-depth study of CTOs among clients from diverse ethnic communities. As

previously noted, there is a dearth of literature on the nature of mandatory communitybased treatment programs among individuals from ethno-racial minority communities.

It is critical that the views of clients be given due consideration as their contribution is vital to the current knowledge base. Research that has focused exclusively on the dominant culture (or included minority groups in peripheral ways), although important, has precipitated an initial understanding of the impact of CTOs on clients; significant limitations are evident, however, with regard to their impact on ethno-racial marginalized clients. This study therefore concentrates on the lived experience of clients from ethno-racial minority communities to provide an alternate perspective on CTOs.

# **Context for the Study**

A better understanding of the relationship between CTOs and ethno-racial minority communities in Ontario necessitates a clear definition of what constitutes an ethno-racial minority community. According to Statistics Canada, ethno-racial minority communities include new immigrants and those whose roots go back more than one generation. They encompass ethnic origins that exclude the French, English and Aboriginals.

The concept of ethnicity is somewhat multidimensional as it includes aspects such as race, origin or ancestry; identity, language and religion. It may also include more subtle dimensions such as culture, the arts, customs and beliefs and even practices such as dress and food preparation. It is also dynamic and a constant state of flux. It will change as a result of new immigration flows, blending and inter marriage, and new identities may be formed (Statistics Canada, 2004).

According to the Statistics Canada 2004 census, 20% of Canada's population is foreign-born and comprised of more than 200 ethnic groups; in contrast, the 1901 census

identified only 25 different ethnic groups. In 2001, immigrants accounted for more than two-thirds of Canada's population growth (Statistics Canada, 2003b) and between 2001 and 2005; approximately 80% of new immigrants were from Asia, Africa and the Middle East. Prior to the 1960s, most immigrants originated from Western and Southern Europe, but since 1980, migration from other countries has steadily increased and now surpasses the traditional sources (Statistics Canada, 2004). In light of declining birth rates among the Canadian-born population, immigration significantly influences the demographic mosaic. According to research predictions, by 2017 one in five Canadians will belong to an ethno-racial minority group (Statistics Canada, 2005).

# Problems faced by ethno-racial communities

Research shows that persons from ethno-racial minority communities are more likely than those of the dominant culture to face numerous problems, including language difficulties, poverty and poor health ((Oxman-Martinez, Krane and Corbin, 2002; Kazemipur and Halli, 2003; Jackson & Smith, 2002).

Bowen (2001) describes language as "medicine's most essential technology," referring to the means by which individuals are able to articulate their concerns and their ability to pursue appropriate avenues of support. The percentage of people whose mother tongue is not English is expected to rise from 17% in 2001, to 21-25 % in 2017 (Statistics Canada, 2005). The inability of health care professionals to communicate in different languages, as well as cultural misunderstandings, is of primary concern among ethnoracial minority communities.

Language constitutes a crucial aspect of an individual's culture. It is common for persons from ethno-racial minority communities to view their culture as part of themselves, thus making it difficult for them to assimilate into the Canadian culture. Cultural beliefs and practices promote and protect good health among certain communities (Oxman-Martinez, Silva, Lach and Poulin de Courval, 2004), however, the gap between the services required and those that are offered highlights the need to review the current working definitions of health and health practices to incorporate the increasing cultural diversity of Canada's landscape. There is a need to embrace the practices of other traditions and cultures and avoid the homogenous 'Eurocentric' approach to this changing phenomenon.

References have been cited to the "healthy immigrant effect", which suggests that new immigrants are healthier than the general Canadian population on account of the medical examination necessary prior to admission to Canada (Newbold and Danforth, 2003; Hyman and Guruge, 2002; Visandjee, Desmueles, Cao, Abdool and Kawanjian, 2004). However, research reflects a change in this phenomenon as immigrants settle down, and this may be attributed to a number of factors such as poverty, racism, lack of employment or low paying jobs (Oxman-Martinez, Krane and Corbin, 2002; Kazemipur and Halli, 2003; Jackson and Smith, 2002; Visandjee, Desmueles, Cao, Abdool and Kawanjian, 2004).

Statistics Canada (2005) reports that 97% of new immigrants to Canada rated their health as very good or excellent six months after emigration, compared to 88% of the general population. A longitudinal study based on the National Population health survey between 1994/95 and 2002/2003, found that non-European immigrants were twice

as likely to report deterioration in health over an eight-year period; in addition, they were more likely to increase body weight index by about 10% or more and adopt an unhealthy lifestyle as they assimilated into the Canadian culture (Statistics Canada, 2005).

The concept of ethno-cultural differences is brought to the fore as practitioners recognize that treatment practices are Eurocentric, homogenous and one-dimensional. The demographic shift in major cities over the last few decades raises the importance of ethno-cultural diversity faced by practitioners (George, Shera, and Tsang 1998; Tsang, Bogo and George, 2003).

One notable complexity arising from cultural diversity is that an individual of ethno-racial minority origin may not necessarily be attached to his/her community or cultural values, or for that matter, the dominant culture. The potential exists for those seeking care to misunderstand health care practitioners and service providers regarding the appropriateness of a required treatment, and thereby undermine adherence. The terminology employed by health practitioners may also create misunderstanding, so that the meaning of the illness could become a bone of contention between service providers and recipients of service (Oxman-Martinez, et al. 2004).

These factors, which result in the under utilization of health care resources among people from ethno-racial minority communities may be further exacerbated by the lack of familiarity with the Canadian health system (Elliot & Gillie, 1998) and being unaccustomed to seeking professional help for mental or emotional health problems; these individuals tend to depend upon their own cultural interpretation of the ailment and seek help from within their own community.

A better understanding of the cultural relevance of CTOs necessitates comprehension of cultural competence in working with this marginalized population. Cultural competency has been variously defined with no consensus on one single specific definition (Davis, 2007). For the purpose of this study, cultural competence is defined as "the capacity to work across multiple paradigms to find ways to engage with clients" (Williams, 2006, p. 209). Cultural competence facilitates the provision of quality services to underserved ethno-racial communities in a manner that respects their differences and integrates their cultural attitudes, beliefs and practices into all aspects of care (Davis, 2007; DePalma, 2006). To be effective, community-based programs and organizations must meet the needs of increasingly culturally diverse North American communities (Davis, 2007; Williams, 2006).

In addition to culture, the literature also cites other problems encountered by ethno-racial minority clients, including systematic racism, oppression and disempowering practices, on a regular basis.

Though numerous studies have greatly contributed to the significance of CTOs in the Western world, the same cannot be said about CTOs among ethno-racial minority clients in Canada. In light of these discussions, it is imperative that the lived experience of CTOs among ethno-racial minority communities be explored. The next chapter details methodology of the study.

# **Chapter 5: Methodology**

### **Design and Methods**

The objective of this study is to explore the lived experiences of individuals from ethno-racial minority communities who have participated in the CTO program. The primary focus of the study is to determine whether CTOs meet the needs of ethno-racial minority clients. The specific questions are:

- How are CTOs experienced in comparison to other experiences in the mental health system?
- As ethno-racial minority individuals, what are their perspectives on how a
   CTO serves them and others like them?
- What effects do CTOs have on ethno-racial minority clients and how do they perceive the treatment and how do they see themselves?

The study utilized qualitative research methodology to explore the experiences of the participants, specifically, a phenomenological approach, to capture the "lived experience from the perspectives of those who live it and create meaning from it" (Padgett, 1998, p. 8). Creswell (1998) asserts that a phenomenological study "describes the meaning of the lived experiences for several individuals about a concept or phenomenon" (p.51). A phenomenological study facilitates a methodology that probes the human experience, sheds light on the complexity of individual perceptions and offers ways of gaining insight and understanding into people's experiences. In contrast to the positivist method, phenomenology uses both narrative and interpretive approaches, such as the ability to utilize the metaphor of life as narrative, and also, shift from personal experience to situating it socially and culturally. For the purpose of this study, the

"individuals" being referred to are clients from ethno-racial minority backgrounds, and the "phenomenon" is the CTO process. The study attempts to describe the phenomenon as accurately as possible, without the influence of any preconceived framework.

According to Mouton and Marais (1990), individual researchers engaged in such studies "hold explicit beliefs" (p.12), however, in a study of this nature, it is important that the perspective of the participants are taken into consideration. This study seeks to understand the social and psychological phenomena from the perspectives of the participants and therefore their responses are of primary importance.

Among the different qualitative approaches, this researcher found the phenomenological methodology particularly appealing on account of its exploratory design that is more likely to restrict biases. The focus of a phenomenological-oriented research is to gather fundamental knowledge on a subject about which little is known, as in the case of CTOs among ethno-racial minority clients within the Canadian context.

A phenomenological study addresses how people experience their world, this epistemological process originated from the thinking of Edmund Husserl. According to Dostal (1993), Husserl believed that phenomenology allowed philosophy to reach a level where truth is undisputed. He therefore developed the idea of suspending what was believed to be true about the world in order to arrive at what was deemed to be pure consciousness, which could be likened to pure experience. Heidegger expanded Husserl's ideas by shifting the attention from knowledge to determining what it means to be a person. Heidegger's major contribution focused on the notion of how one is viewed in the world.

After Heidegger, other philosophers like Merleau-Ponty more broadly explored phenomenology. Merleau-Ponty's approach was to combine Husserl's approach with an existential orientation generated by Heidegger (Madison, 1999). He describes objects of consciousness as they reveal themselves to direct experience. He sought to persuade his readers that objective thoughts distort lived experience.

Phenomenology presents two strands of thought with distinctive approaches: eidetic or descriptive and the hermeneutic approaches. The eidetic phenomenology seeks to explore the significant structures of a human experience, and describes the experience from the perspective of the participant. Phenomenological description attempts to create a synthesis to bring together the different dimensions and components of the issue being explored, into something coherent (Kvale, 1996; Moustakas 1994; van Manen, 1997). The eidetic phenomenology also utilizes "bracketing", which consists of the researcher holding his/her presupposition about the phenomenon, in order to discover the truth and describe it as objectively as presented in the consciousness of the participants (Cohen, 1994; Kvale, 1996; Moustakas, 1994; van Manen, 1997).

The hermeneutic phenomenology originated from Martin Heidegger, a student of Husserl. The hermeneutic approach is based on the interpretation of texts. This approach discovers the meanings of the phenomenon being studied that are not clearly evident to the researcher.

Van Manen (1997) explores a blend of the eidetic and the hermeneutic phenomenology referred to as the Utretch or the Dutch school. This is intended to bridge the descriptive and the interpretive approaches of the study. Van Manen (1997) describes phenomenology as the ability to:

.....transform lived experience into a textual expression of its essence in such a way that the effect of the text is at once a reflexive re-living and a reflective appropriation of something meaningful: a notion by which a reader is powerfully animated in his or her lived experience (p.36).

The utilization of a phenomenological approach was effective in exploring the lived experience of the participants. The study blended the approach as described by Van Manen (1997) (the eidetic and hermeneutic phenomenology) with the aim of both describing and interpreting the phenomena of CTOs among ethno-racial minority clients in Toronto. As previously described, the integration of the three theoretical frameworks – empowerment, anti-racist and post-colonial approaches fits within the social work framework. These models will therefore inform the phenomenological inquiry.

### Ethics Approval

Before embarking upon this study, consent was obtained from the Ethics Review Committee at the University of Toronto and the Centre for Addiction and Mental Health (CAMH). The researcher is employed at the latter as a CTO coordinator. As per the research protocol, initial consent for the study was sought from CAMH before an application was submitted to the University of Toronto for ethics review.

#### Sampling and recruitment

In a phenomenological study, reference is made to 'participants' or 'coresearchers' rather than 'subjects' or 'respondents.' The purpose of making reference to "participants or co-researchers" in a phenomenological study is based on the subjective experiences of the individuals involved in the study, thus, making them feel connected and part of what is being studied. Participants in a study are considered experts of their

own experience, and the role of the researcher is to engage them in conversation and gain insight into their experience (Kvale, 1996). According to some researchers, the numbers of individual participants in phenomenological investigations are not as important as the quality and variety of the descriptions they provide in the interview (Polkinghorne, 1989). Phenomenological researchers suggest that an appropriate sample size ranges between six and twelve persons on the grounds of thematic redundancy (Thomas and Pollio, 2002). Other phenomenological researchers suggest saturation is reached with lengthy interviews involving 5 to 25 persons (Boyd, 2001; Creswell, 1998). Creswell (1998) recommends lengthy interviews in this form of study. The number of participants selected for this specific topic ensures that the themes derived from the interviews will be maximized (Padgett, 1998). The main criterion utilized to select participants was clients who had relevant experience and were willing to talk about their experience (Pollio, Henley and Thompson, 1997).

For this study, the researcher interviewed a total of 24 participants. Initial consideration of recruiting a specific number of people from each ethno-racial minority group was aborted as an extremely difficult venture (see Appendix 1). The reason being that some racial minority groups were more willing to volunteer than others, perhaps a reflection of their fluency with the English language and willingness to have their voice heard. In this study, a greater response was received from one ethno- racial minority group (Blacks). For the purpose of recruitment, purposive sampling was employed because it is an effective non-probability sampling that aids in the identification of participants (Welland and Kruger, 1999).

To date, more than 1000 clients have been issued CTOs in the City of Toronto since its inception; approximately 40% of the clients on CTOs are of ethno-racial minority backgrounds (TREAT – CAMH database – accessed on November 2, 2009). The predominant ethno-racial minority groups in Toronto that have been issued CTOs are Blacks (Canadians of African and Caribbean descent), South Asians (including clients of Indian, Bangladeshi, Pakistani and Sri Lankan background), and East Asians (including clients from China, Japan, Vietnam, South and North Korea). Other ethno-racial minority communities with limited representation are Hispanics, Middle Easterners and West Asians (TREAT - CAMH – CTO Data – accessed on November 2, 2009).

Participants were recruited through flyers (Appendix E) with information on the study, which were given to CTO coordinators and case managers for distribution to clients. Flyers were also left at the offices of doctors who treat CTO clients. Prospective participants were identified at the following hospitals: the Centre for Addiction and Mental Health (CAMH), The Scarborough Hospitals (the General and Grace campuses), North York General Hospital (NYGH), Humber River General Hospital, Toronto East General Hospital (TEGH), Rouge Valley Hospital (Centenary Site) and St. Joseph's Hospital. Potential referrals were also received from the Canadian Mental Health Association (Toronto Branch) and a number of Assertive Community Treatment Teams (ACTT) in Toronto. Interested clients who met the eligibility criteria were asked to contact the researcher by telephone, at which point the study was explained in more detail and a mutually convenient appointment was arranged for an interview. Participants with no access to a telephone were directed to contact the researcher through an intermediary, either a CTO coordinator or case manager. On a number of occasions the researcher

worked closely with CTO coordinators and case managers to arrange an interview with the participant.

The prospective participants for the study were provided with a letter that clearly outlined the background, purpose and objectives of the study (Appendix A). It also contained contact telephone and e-mail information for the researcher and the researcher's supervisor. Participants in the study were assured of confidentiality, and that personal information or any data that revealed their identity would not be published in the findings of the study.

Prior to arranging interviews with the participants, the researcher explained in detail the criteria for selecting participants, the methods, the estimated duration of interviews (between one hour to one and a half hours), and the risks and benefits of the study. Participants were assured that their participation was voluntary and they could withdraw from the interview at any time without jeopardizing their treatment or access to services. They also had the option of not responding to questions if they felt uncomfortable. Study participants were assured that there were no risks to their participation, and that their input would provide insight into CTOs as experienced by people of ethno-racial minority backgrounds.

Participants were assured that all identifying information would be properly secured. All electronic files would be secured with password security and all information gathered stored in a secure and locked cabinet in the researcher's office for a period of seven years, after which the information would be destroyed. Prior to the commencement of the interview, the researcher reviewed the consent forms (Appendix B) with the participants and obtained their signature. Participants were also informed that

if they experienced any distress they had the option of withdrawing from the study and would be offered clinical intervention. Prior arrangements had been made with Rouge Valley Health System (RVHS- Centenary site) to accept such referrals. Participants were advised that the researcher would have no recourse but to intervene if they expressed thoughts of hurting themselves or others. An honorarium of \$20.00 was provided to each participant for participating in the study.

#### Selection Criteria

Selection criteria for this study included individuals who were:

- a) Aged 18 years or older and diagnosed with an Axis I mental illness based on the Diagnostic and Statistical Manual of Mental Disorders (DSM IV).
- b) Either currently on, or had previously been on a Community

  Treatment Order.
- c) Of ethno-racial minority background.
- d) Able to provide informed consent.

#### Data Collection

Phenomenological research traditionally discourages structured interviews and formalized questions; rather, the interview should adapt the form of a conversation based on the questions asked, thus generating discourse (Morse and Richards, 2002). As part of the process, a semi-structured interview guide (Appendix C) was created to provide guidelines to the interview process. The interview flowed with participants answering

questions, and based on the responses, the researcher was able to probe further with follow-up queries. The interviews ranged from 30 minutes to one hour, and were held at mutually agreeable locations. Thirteen of the interviews took place in the homes of participants; five interviews occurred at the Rouge Valley Health Systems – Centenary Site, one at the North York General hospital, one at the Centre for Addiction and Mental Health – Queen Street site, one at CMHA – Toronto office, one at a Tim Horton's coffee shop, one in a coffee shop of a shopping mall, and one in a group home.

In total, there were over 18 hours of interview time. All the interviews were audio taped and transcribed verbatim with the assistance of an external transcriptionist. Participants in the study were not identified by their real names; pseudonyms in the form of letters and numbers were assigned to the participants; this was to protect their identity regarding the study. Field notes and memoing were documented immediately following the interviews and as new ideas emerged.

The interviews were semi-structured and respondents were encouraged to emphasize issues of particular relevance in their individual narratives. The interview involved informal interaction and the employment of open-ended questions. To create a relaxed and trusting atmosphere, interviews began with a social conversation in an attempt to break the ice and engage with the client; this helped create a climate in which the participants felt comfortable and willing to respond honestly and comprehensively (Moustakas, 1994).

A demographic questionnaire was developed to gather demographic data from participants (Appendix D), which included diagnoses, employment status, source of income, relationship status, the number of years diagnosed with illness, involvement with

other services, race/culture and level of education. This data was utilized to create a descriptive socio-demographic summary of the participants.

The interviews were open-ended and directed by the participant; the interview guide served to ensure focus was maintained on the research topic. According to Moustakas (1994, p. 114),

The phenomenological interview involves an informal, interactive process and utilizes open-ended comments and questions. Although the primary researcher may in advance develop a series of questions aimed at evoking a comprehensive account of the person's experience of the phenomenon, these are varied, altered, or not used at all when the co-researcher shares the full story of his or her experience of the bracketed question.

The following areas were explored in the interview: CTO as a treatment option, day-to-day activities under a CTO, experience of racism, relationship with case manager and psychiatrist/physician, and other forms of community-based treatment. Subquestions probed for clarification, elaboration and additional information from the participants.

At the commencement of each interview, the researcher again explained to the participants the purpose of the interview and reminded them of their option to refuse to respond to questions they felt uncomfortable with, or to terminate the interview if necessary. Participants were required to sign two consent forms, a copy of which was given to them. They were also given the option of requesting a copy of the interview or the transcript. The structured demographic questionnaire was administered after consent was obtained. At the conclusion of each interview, the researcher afforded the participant with the opportunity to ask questions, or request additional information pertaining to the

research topic. The researcher requested participants' permission to contact them should the need arise for additional information or further clarification.

The audio-recorded interviews were sent to a professional who specializes in transcribing audio interviews into typewritten text. The researcher verified accuracy of the transcribed material by reading the transcripts and listening to the taped interview.

The audio-recorded interviews were identified by assigning each interview with a number, for example, the participant identified as Client AB would be assigned a number beginning with 001 and progressing to 024. The date of the interview was inscribed on the tape. All taped interviews were locked in a secured cabinet in the researcher's office to which no one else had access. All electronic files for the study were password-protected and accessible solely by the researcher.

### **Data Analysis**

The current investigation embraced Moustakas' (1994) approach to a phenomenological study: the epoche, horizonalization, textual descriptions, structural descriptions and the essence of the experience.

According to Moustakas (1994), Husserl's epoche is described "...as the freedom from suppositions, the epoche, a Greek word meaning to stay away or abstain..." (p. 85). This is explained as a process during which the researcher's "prejudgments, biases, and preconceived ideas about things" (p. 85), are set aside for the purpose of the study. In this process, the worldview or perception of the researcher is bracketed, that is placed out of action – "cleared of ordinary thought and present before us as phenomenon to be gazed upon, to be known naively and freshly through a "purified" "consciousness" (p.90). The

phenomenon epoche does not necessarily require the elimination of every thought in the mind of the researcher, but "biases of everyday knowledge" that pertains to the study (Moustakas, 1994). With epoche, "we are challenged to come to know things with a receptiveness and a presence that lets us be and lets situations and things be, so that we can come to know them just as they appear to us" (p. 86).

The process of "refraining from judgment", where the researcher holds off or shelves any pre-existing assumptions or knowledge about the topic or participants in the study is referred to as bracketing (Creswell, 1998; Moustakas, 1994). In this study, the epoche referenced the researcher; despite his years of experience in this area of study, a concerted effort was made to suspend or conceive any judgments or views on the findings of the study. As the phenomenon was further explored, various structures were defined and analyzed (Moustakas, 1994; Patton, 2002). Bracketing enabled the process, and data from the participants was utilized to identify emerging themes, which were further explored in other interviews.

Horizonalization is another dimension of the phenomenological reduction. The terminology is derived from the word horizon, which is described as never ending process (Moustakas, 1994). "Each horizon as it comes into our conscious experience is the grounding or condition of the phenomenon that gives it a distinctive character... When we horizonalize, each phenomenon has equal value as we seek to disclose its nature and essence" (p.95). In the horizonalization of the data, particularly significant statements from the interviews relevant to the issues being explored were employed to develop a list of themes; overlapping themes were purged (Moustakas, 1994).

Coding of the data was undertaken using NVivo 8 (QSR International) software to sort and organize the data. NVivo is a software program developed for the purpose of aiding in the organization and management of qualitative data. Data for this study was organized using free nodes to identify statements and themes, and tree nodes to organize the data into categories and subcategories.

The themes and meanings derived from the analysis from the study were utilized to develop the textural descriptions of the experience of the participants. The textural descriptions and structural descriptions of the study are integrated "into the meanings and essences of the phenomenon" (Moustakas, 1994, p.119).

#### **Trustworthiness**

During the research process, which involved research design, data collection and analyses of the study, the researcher maintained a journal to document data collection and decisions regarding the study (Erlandson, et al, 1993; Padgett, 1998). The journal served as a source of information to refresh the researcher's memory regarding subjective impressions of the interview responses, issues, observations and concerns during the interview process. Quality control was achieved by maintaining a reflexive journal and an audit trail that detailed the progress of the study, which also allowed scrutiny by anyone who wished to trace the investigator's steps. Credibility of the research was established through prolonged engagement with the data analysis, constant observation of the phenomena under study, referential adequacy and regular debriefing with the supervisor of the study. The investigator's broad experience with CTOs, as well as the population of interest, lent further credibility to the study.

As suggested by Padgett (1998), the researcher maintained regular contact with other CTO coordinators and case managers, on average once per week. Peer CTO coordinators and case managers were familiar with the larger study and research interview methods and provided useful input. Ongoing debriefing with CTO Coordinators also proved to be a source of support (other than the research supervisor and members of the thesis committee) for the discussion of ideas and aspects of the research.

#### Chapter 6

#### **FINDINGS**

#### Introduction

This section presents the findings of the study in three main parts. The first part addresses the socio-demographic description of the participants. In the second section, cultural review/reflexivity is discussed and the third section focuses on the findings of the study.

#### SECTION 1: DESCRIPTION OF THE STUDY SAMPLE

The study comprised of twenty-four participants, all of whom were from the City of Toronto. Toronto is the largest census metropolitan area in Canada. The 2006 census cited the population of Toronto as 2.48 million (Demographic information for the City of Toronto, 1998-2010). Although the participants for the study were from different ethnoracial minority groups, the sample was not, nor intended to be, statistically representative of the ethno-racial minority community in Toronto. Utilizing purposive sampling, participants were selected for the study based on their common experience of being, or having been, on a CTO. Furthermore, the participants were willing to discuss their experiences on this treatment in an open and forthright manner with the assurance that what they shared would not be held against them, nor impact their treatment. Their experiences offered insight into CTO as treatment, particularly from the perspective of ethno-racial minority participants. The age group of the participants situates them within the context of the larger mental health system.

## Age

The age of the participants ranged from 18 to over 58 years (table 6.1). The mean age of the participants was 37.8 years.

Table 6.1

Age Groups	Number of Participants	Percentage
18 years -25 years	3	12.5%
26 years - 33 years	4	16.7%
34 years - 41 years	8	33.3%
42 years to 49 years	4	16.7%
50 years to 57 years	4	16.7%
58+	1	4.2%

The majority of participants fall within the 34-41 year age range, while participants in the 18-25 and over 58 age groups registered the smallest number. The relatively small sample size precludes generalization; however, the single participant aged 58 years or over may be explained by the fact that clients within this age category are typically referred to seniors programs, rather than mandated outpatient treatment like CTOs. It is worth noting that though one or more age groupings may have high representation, CTOs are not limited to any specific age group.

#### Gender

As shown in table 6.2, study participants were predominantly female, representing 62.5% (15) of the sample and almost double the number of male participants.

**Table 6.2** 

Gender	Number of Participants	Percentage
Males	9	37.5%
Females	15	62.5%

# **Ethnicity**

Participants were identified by their race and also region of origin. For the purposes of this study, participants were categorized as Blacks, West Asian, South Asian, East Asian and Middle Eastern. The majority of participants were from the Black community and further differentiated into three groups based on the region from which they hailed: Black Canadian (self-identified as born in Canada); Caribbean-Canadian (the majority from Jamaica); and African-Canadian (Africans who immigrated to Canada). Participants as identified by ethnicity illustrated in table 6.3.

**Table 6.3** 

Ethnicity	Number of Participants	Percentage
Black Canadian	3	12.5%
Caribbean Canadian	8	33.3%
African Canadian	3	12.5%
West Asian	1	4.2%
South Asian	6	25.0%
East Asian	2	8.3%
Middle Eastern	1	4.2%

# **Immigration**

The immigration data of the participants looked at their length of stay in Canada as immigrants. Of the 24 participants, eighteen (75%) reported immigrating to Canada as adults, thus, they have been in the country between five to fifteen years. The remaining six (25%) participants reported they were brought to Canada as children between the ages of three to ten.

**Table 6.4** 

Immigration data	<b>Number of Participants</b>	Percentage
Migrated as adult	18	75%
Migrated at young		
age	6	25%

#### **Marital status**

As illustrated in table 6.4, of the twenty-four participants, fifteen (62.5%) were single. Only 2 were married at the time of the study; the remainder were either divorced or separated.

**Table 6.5** 

Relationship Status	Number of Participants	Percentage
Single	15	62.5%
Married	2	8.3%
Separated	2	8.3%
Divorced	5	20.8%

## Education

The level of education attained by the participants is shown in table 6.5 and reflects that over 50% had post-secondary education, while the remaining participants had either high school education or trade school training.

**Table 6.6** 

Education	Number	Percentage
High School	4	16.7%
Trade School	4	16.7%
College	7	29.2%
University	8	33.3%
Graduate School	1	4.2%

### **Employment**

As reflected in table 6.6, most of the participants were unemployed at the time of the interview (79.2%). Only 16.6% of the participants held either full-time (8.3%) or part-time (8.3%) employment. One participant reported as being self-employed (4.2%).

**Table 6.7** 

Employment	Number	Percentage
Full Time	2	8.3%
Part Time	2	8.3%
Unemployed	19	79.2%
Self Employed	1	4.2%

#### Income

The primary source of income for majority of the participants (83.3%) was from the Ontario Disability Support Program (ODSP) which grants income to disabled persons whose disability prevents them from maintaining gainful employment. Only 12.5% of the participants were in paid employment. The participants' source of income is presented in table 6.7.

**Table 6.8** 

Income source	Number	Percentage
Paid Employment	3	12.5%
ODSP	20	83.3%
СРР	1	4.2%

#### Diagnosis

All study participants had a diagnosis of mental illness (table 6.8), the majority of who had schizophrenia (16 or 66.7%). The second largest category of mental illness was bipolar disorder (20.8%). The CTO data reflects that most individuals referred to this

treatment program have a diagnosis of schizophrenia and this likely explains the predominance of this diagnosis within the study sample.

Table 6.9

Diagnosis	Number	Percentage
Schizophrenia	16	66.7%
Schizoaffective	1	4.2%
Depression	2	8.3%
Bipolar	5	20.8%

#### **Length of Illness**

The length of illness was relatively short, from 1 to ten years, for the majority of participants (18 or 75%). Five (5) participants (20.8%) had been diagnosed between 11to 20 years, and the remaining 2 participants from 21 to 40 years (table 6.9).

Table 6.10

Length of Illness	Number	Percentage
1 - 10 years	17	70.8%
11 - 20 years	5	20.8%
21 - 30 years	1	4.2%
31 - 40 years	1	4.2%

## **Length of Treatment**

It is an accepted fact that a diagnosis of mental illness does not necessarily entail treatment. Participants in this study, however, portrayed a similarity between length of illness and length of treatment. As illustrated in table 6.10, 18 (75.0%) participants had received treatment for their condition between 1 to 10 years and 4 (16.7%) of the participants reported being on treatment for more than 10 years (between 11 to 20 years). Only 2 (8.3%) of the respondents reported length of treatment that exceeded 20 years.

Table 6.11

Length of Treatment	Number	Percentage
1 - 10 years	18	75.0%
11 - 20 years	4	16.7%
21 - 30 years	2	8.3%
31 - 40 years	0	0.0%

# **Length of Time on CTO**

As the study seeks to explore the lived experience of individuals of ethno-racial minority background on CTOs, length of time on this treatment modality was an important consideration (table 6.11). Ten (10) (41.7%) of the participants reported being on a CTO for six months, followed by 9 (37.5%) between 7-12 months, and 3 (12.5%) exceeded 19 months. Of the twenty-four participants, two reported being on a CTO for more than 2 years.

Table 6.12

Length of time on CTO	Number	Percentage
1 -6 months	10	41.7%
7 - 12 months	9	37.5%
13 - 18 months	0	0.0%
19 - 24 months	3	12.5%
2 years +	2	8.3%

#### Frequency of Visits with Case Manager

CTOs require the involvement of case management as part of the contract/agreement. The community treatment plan for the CTO is developed in conjunction with case management, and while clients may not opt for case management, in most cases it is a treatment component. In this study, just over half of those surveyed (13 or 54.2%) reported case management involvement. Of the 24 participants, 10

(41.7%) reported meeting with a case manager once a week as part of the treatment agreement, and 3 (12.5%) met bi-weekly. Frequency of visits with case manager is illustrated in table 6.12.

Table 6.13

Frequency of Visits with Case Manager	Number	_	Percentage
Once a week	1	0	41.7%
Twice a week		3	12.5%

### Frequency of meeting with psychiatrist

The primary purpose of CTOs is to ensure that individuals with persistent and serious mental illness do not fall through the cracks of the mental health system. The focus is to ensure that these individuals are provided with adequate support in the community, and as part of their treatment, they are expected to meet with a psychiatrist whose responsibility is to ensure that clients and their medications are frequently evaluated. Seventeen (17) (70.8%) of the study participants reported meeting with their psychiatrist/physician on a monthly basis, five met twice a month, one client met his/her psychiatrist once every two months and one every six months (table 6.13).

Table 6.14

Frequency of Visits with Psychiatrist	Number	Percentage
Once a month	17	70.8%
Twice a month	5	20.8%
Once every 6 months	1	4.2%
Every 2 months	1	4.2%

#### **Consent to CTO treatment**

As part of the CTO process, individuals are either expected to consent to their own treatment or have substitute decision makers (SDMs) making decisions on their behalf. For the purpose of this study, sixteen of the participants (66.7%) consented to their own CTOs and eight (33.3%) participants reported having a substitute decision making (SDM) consenting on their behalf.

Table 6.15

Consent to CTO	Number of Participants	Percentage
Self	16	66.7%
SDM	8	33.3%

The data provided by the participants suggests subgroups among those interviewed for the study. For instance, the immigration data showed two groups of participants – there were those who immigrated as children and those who moved to Canada as adults. It should be noted that these may contribute to different experiences, even regarding CTOs.

# **Findings – Section Two**

The research employed bracketing to effectively articulate the lived experience of the CTO participants of ethno-racial minority background. The focus was to describe the meaning of the experience from the worldview of individuals who have *had* the experience and attached meaning to it (Cohen & Omery, 1994, p148). Epoche, or suspension, in theory, allows for reduction, which will enable the access to grasp the phenomenon in question. Epoche is an attempt by researchers to withhold their presuppositions and "reflect" on the experiences being described by the participants.

This is part of the phenomenological description that is not only the subjective point of view of a person's experience, but also fundamental and necessary to the experience (Cohen & Omery, 1994; Van Manen, 1990). Effective bracketing necessitated reduction. Reduction is the ability to put aside all that goes on with interpretation in order to see the phenomenon as it is; it requires clearing one's mind of all biases, preconditions, concepts, prejudices, ideas and theories pertaining to this treatment, so that participants are approached with a "blank slate".

The researcher spent time reading through the text to have an idea of what was being articulated by the participants. Though phenomenological researchers recommend putting aside biases and approach the subject with a blank slate, there was some difficulty based on the researcher's experience as a CTO coordinator.

Without bracketing, the potential exists to approach the participants as an expert (based on the level of knowledge) and thereby risk missing important information that could be generated from the study. Viewing the participants as experts empowered them to share their experience of the phenomenon, in this case, CTOs.

Before commencing on the analysis of the data, the researcher made the effort to treat all the data generated equally through horizonalization. This meant none of the text was given priority over other texts. All information gathered was deemed important and necessary for the study and also ensured that there were no repetitive and overlapping statements.

While reading through the texts, notes were made in the margins reminding researcher of ideas, themes and sub-themes that may be identified. The statements, comments, thoughts and ideas expressed by the participants were grouped into 'meaning'

units" (Creswell, 1998). The textural description of the analysis was done by describing the participants experience with CTO process.

The structural description of the study sought possible meanings and different perspectives and creating a description of how the phenomenon was experienced by the participants. As a result, an overall description of the meaning and "essence" of the experience is done. The development of the themes enabled the researcher to present an account of the experience of the participants.

### Cultural Review / Reflexivity

Theorists have discussed, reflected and analysed reflexivity as a topic from different perspectives; nevertheless, for the purpose of this study, I will focus of the following definitions. Reflexivity is described as a researcher's experience or process of self-evaluation during the research process (Macbeth, 2001). Lamb and Huttlinger (1989) describe it as a "self-awareness of the relationship between the investigator and the research environment" (p. 766). Hutchinson and Wilson (1994) perceive reflexivity as a process of interaction whereby both parties, that is, the participants and the researcher are influenced in the encounter. Reflexivity focuses on the awareness of what we do not know and the consequences of not knowing (Raven, 2006). The application of reflexivity in a study ensures the minimization of the researcher's bias and thereby enhances rigor (Koch and Harrington, 1998). It is also the "acknowledgement of the role and influence of the researcher on the research project. The role of the researcher is subject to the same critical analysis and scrutiny as the research itself" (Coralan, 2009, p.8, as in Rice and Ezzy, 1999). Reflexivity calls for the exploration of feelings, thoughts

and experiences relating to the power dynamics between the researcher and the participants.

The above definitions of reflexivity are employed as the foundation for the cultural review of the researcher's experience in the current study to engage the ethnoracial minority participants in the interview process.

Prior to the commencement of the study, I followed a process of self-evaluation. As a person of colour, it was necessary to have a good understanding of the participants and ensure the most effective route of communication to solicit appropriate information regarding their experiences and to reflect an understanding of their situation.

As a CTO coordinator with about nine years experience working with this client population, I wanted to avoid taking the participants for granted or to assume I was more knowledgeable about their situation; rather, I wanted to put myself in a position where I was open to being educated by the participants by giving them the opportunity to share their experience as individuals of ethno-racial minority background on a CTO. It was important not to self disclose as a CTO coordinator as this would likely have impacted the interaction and created a power dynamic. However, my role and presence as an interviewer connoted power.

I realized the need to be cognizant of incidents and/or scenarios and maintained a journal during the course of the study that served as a reflection of my experience in engaging with the participants. This allowed me to learn a lot about myself: who I am as researcher, as a clinician with a number of years' experience as a CTO Coordinator and as an individual also of ethno-racial minority background.

The process made me realize the importance of listening and paying attention to my clients; rather than assuming I have the answers based on my education and experience. Though, clients of ethno-racial minority background may identify with me as a person of colour; it is important to know that I am willing to empower them to make decisions pertaining to their treatment. In this situation, I will not be the expert but the conduit or channel through which my clients are able to make significant progress with regard to their treatment.

Interacting with the participants was a learning experience, particularly with regard to their perspectives on CTOs as treatment. For instance, it dispelled the notion that individuals of ethno-racial minority background view CTOs as racist. The participants were thoughtful and insightful and a number of them expressed appreciation for this treatment. My understanding of the lived experience of the participants was greatly enhanced by their knowledge and understanding of CTOs.

On a number of occasions some of the participants responded to questions by saying, "as an immigrant I am sure you understand ...." One participant who was an engineer stated, "I am a professional as you are." On reflection, I realized that by identifying commonalities, participants were bringing to my attention the fact that though they may have diagnoses of mental illness, it did not define who they are as individuals.

#### **Section 3- Categories and Themes**

Through transcript analysis, the following major categories were identified, and themes were derived from within these categories based on participants' responses. The categories and themes that emerged include the following:

Table 6.14

Major Categories and Themes		
1.	Experiences with the mental health system	
	• Resources	
2.	CTO experiences	
	Appreciation	
	Ambivalence	
	Medication	
	Feelings about self on CTO	
	• Inhibition	
	• Stigma	
3.	Rapport with case management team	
	• Support	
4.	CTOs in cross-cultural context	
	• Racism	
	Culture: Canada vs. homeland	
5.	Power in the Treatment Process	
	• Coercion	
	Disempowerment	
	• Empowerment	

# Experience with the mental health system

Resources

To provide some context to the participants' views; the race, gender, age and length of illness for each participant is presented the first time the individual is quoted. This category explored the views of the participants with regard to the extent to which they were able to access support within the mental health system and the difference it has made in their lives compared to, prior to being on a CTO. Fifteen of the twenty-four participants discussed their interactions with the mental health system prior to being placed on a CTO. Most participants stated either they did not receive any services or that the services received were unsatisfactory. Only a few perceived the support received prior to the CTO as beneficial to their treatment.

Client AB001 (female, aged 40 years, diagnosed with schizophrenia 5 years ago) stated that prior to hospitalization, she did not receive any form of support or treatment in the community; though she periodically spent time in the hospital, however, did not have access to case management or community support upon discharge.

I wasn't receiving any services. The only thing was I went to the hospital, they monitored my illness and gave me medication and that's about it.

Client AB003 (female, aged 49 years, diagnosed with bipolar disorder 34 years ago) stated that she participated in a number of community-based programs prior to being put on a CTO, however, she did not find those services beneficial.

(Community mental health program), I deal with (community mental health centre) for quite awhile and I had a very good worker, more than one great worker, (name of worker), because (name of worker) dealt with me even before I came to move to (Participant's community) because even downtown I would be at the (Name of hospital).

(Name of worker) referred me over to...oh when I was home it was (Name of worker) that came to see me and she referred me to (community mental health centre) and she gave me a very good reference and I went to (community program) on my own because right through I've always tried

to be as independent as possible and when I went to (community health program) I went there for a long time. It must have been over five years but ...

Participant AB004 (male, aged 33 years, diagnosed with schizophrenia 10 years ago) was hospitalized at a large mental health institution a few times; however, he did not have access to a community-based mental health program until he was placed on a CTO.

First I was hospitalized at (mental health centre). I did one month hospitalization at a (large mental health institution). And that was very good treatment from the mental hospital at that time. They would buy me chocolates, give me medications, do good treatment for a month. So second treatment, that was a little bit harder; actually the first treatment I wasn't in the CTO was just for mental assessment. The second hospitalization was in....was a four month assessment at (Name of mental health centre), same hospital and so from then that was this doctor named (physician's name) and he put me through this CTO, Community Treatment Order.

Participant AB006 (female, aged 39 years, diagnosed with schizoaffective disorder 11 years ago) discussed how she was first diagnosed and her unawareness of resources in the community, as well as the role of family.

Uhm, I went to see my family, like I used to, I hear voices. Then when the voices told me to buy a rope and hang myself, I went to see my doctor and tell her. She said I was having a nervous breakdown. Then she suggested me to go see, to go to (name of hospital) right away, but I didn't go right away. But then when the voices were escalating, my sister took me there and I was admitted. I think I was admitted in 1999, I think. I don't remember the date, but (physician's name) have it down. And I spent, I think it was six weeks, then I came out and through the years I've seen my psychiatrist and I used to get the needle, so I didn't really know about, I didn't know about (community mental health program), I didn't know about, I only knew about (community mental health centre).

.....And I didn't care for that. I went there a few times, but I didn't care for it. But then 2006, the end of 2006, 2007, I think that's when (physicians name) put me on CTO.

Participant AB007 (male, aged 32 years, diagnosed with schizophrenia 8 years ago) reported seeing a psychiatrist while incarcerated. He continued psychiatric treatment on release but access to case management services was only facilitated after being put on a CTO.

Uhm, I mean I was seeing a psychiatrist when I was in prison and I had seen one after, I mean, I was saying things like that basically because, you know, it was a new experience, I was eating a lot more food and putting on weight and stuff like that and feeling different, you know, so that was pretty much it at the time.

According to participant AB008 (female, aged 36 years, diagnosed with schizophrenia 14 years ago), she was hospitalized numerous times but had no community support.

My mother bring me to the hospital for the first three years, I go to the hospital one or two times.

Later on, last year, I went to hospital 12 times

The experience of participant AB009 (female, aged 33 years, diagnosed with bipolar disorder 15 years ago), though similar to other participants, was also unique in that the hospital made provision for a community social worker upon her discharge from hospital and which she found beneficial.

Actually in 2007 I was sick and go to hospital and then before I leave the hospital, hospital doctor said I need a social worker. So they appoint a social worker and she always visit me in my home. That time I lived in Scarborough.

And so, I think it's good because sometimes it gives me some information, give me some support and so for example, sometimes I have some conflict with my husband. She can help me solve this problem and explain to me something. So I think it's good.

Participant AB010 (male, aged 34 years, diagnosed with bipolar affective disorder 8 years ago) had had previous hospitalizations at both a large psychiatric institution and a schedule-one facility in Toronto and discharged with community support.

I was rushed to the hospital back in 2002 by ambulance. I got there. I didn't know why I was there, but then I realized I was sick, diagnosed with bipolar disorder. Then I've been sick for eight years now, but I'm getting better because I'm on medication. This is how, since 2002. It's getting better than before.

Participant AB011 (female, aged 49 years, diagnosed with bipolar affective disorder 8 years ago) accessed case management when she was placed on a CTO on discharge from a hospital psychiatric unit.

It was when I had a nervous breakdown I think eight years ago. So I went to the hospital emergency. After the emergency treatment I was put on the tenth floor for a while. So when I was leaving, I was assigned to CTO

Participant AB012 (male, aged 22 years, diagnosed with schizophrenia 10 years ago) reported no particular case management support in the community despite threats of suicide, homicide, apprehension and admission to the mental health unit of a hospital.

I got kind of stressed out after my last year of graduation. I was about to graduate and I wanted to become a Manager at (a fast food restaurant) and they wouldn't give me the Manager position and I snapped. I snapped on the whole world. I started to see things. I started to want to kill people. They had to lock me up in the mental institution for two months. So basically I graduated from high school on time and I was supposed to be Manager and I never got my chance and I decided to, I decided to snap and flip out on people. So for the last ten years I've been in and out of mental institutions. I keep going in. The last couple of days ago, I ended up going to jail for the first time in my life. I've never been to jail in my life, but it was always mental institutions and now they're putting me in jail.

Participant AB013 (female, aged 56 years, diagnosed with depression 6 years ago) was hospitalized following a diagnosis of depression. She received no community mental health services prior to admission; the CTO was her first outpatient mental health support.

I became involved in the mental health system because I had been suffering from depression and I was unable to really care for myself. I had been a nurse, I am a nurse and I have been unable to function at work so I was just home lying down and not, just getting apathetic and vegetating and not doing anything to help myself and I wanted to die. I did not have the intention of actually actively killing myself, it was just some passive suicidal ideations so they took me to the hospital, (name of hospital) and I was admitted suffering from depression.

Though participant AB015 (female, aged 41 years, diagnosed with schizophrenia 18 years ago) had been diagnosed with schizophrenia for about 18 years, her only involvement with the mental health system was as an inpatient, and discharged after a couple of weeks or months with no community support.

Well, I was diagnosed with schizophrenia in 1991 and since then I've been in the hospital several times. And the latest, the latest time I was in the hospital was January of 2004 and that was my most severe episode.

Well to be kept in the hospital and to be kept on a ward without being even able to go down to the main floor, you know, to get a drink or anything like that, being on the same floor and the only place you can exercise is around the corridors and you couldn't really do anything unless you went to all the classes that they held. And I did do that but it would be confining for anyone to have to stay in the hospital on the same floor mostly in the same room for three to four months.

Participant AB016 (male, aged 29 years, diagnosed with schizophrenia 9 years ago) stated that his paranoia made him check himself into hospital. He went on to say that it was a good way dealing of with the stressors in his life. This approach ensured that the participant received appropriate mental health treatment.

I'd like to say I felt paranoid and I just started to hear voices and that's when I just felt uncomfortable all the time. I wasn't myself, right? So that's how I got there the first time, right and the second time I went for myself, my own self because I wasn't feeling all that great because I was starting to hear voices again too and I don't know, I started getting paranoid again as well and depressed. That's the second time and the third time I went was because I had to go because my work was getting stressful and then I was feeling the stress because everyday is a lot at the time and I thought I could handle it but I couldn't. So I had to go back to the hospital for the third time.

Participant AB023 (male, aged 25 years, diagnosed with schizophrenia 7 years ago) reported going to and from hospital for a long period of time and his involvement with the criminal justice system. He was not referred to any community-based support following these discharges.

I've been in and out of hospital....I have been arrested before...I was in jail for a while...but maybe say 3 or 4 years of my life have been spent in hospital

Participant AB024 (female, aged 25 years, diagnosed with schizophrenia 8 years ago) had received some form of support from a community-based program. She found the support to be helpful however, upon reaching a certain age she stopped the treatment and had no further involvement with community-based program and support system.

Respondent: I was referred to a program at (community mental health program)

Interviewer: Okay

Respondent It was Cognitive Behavioral Therapy

Respondent It was really good. I felt really confident and really good at the

time. It was really helpful. It helped with my depression. It helped

me going out and being social and active. Even though I was

active before but I wasn't socially active. I wouldn't go out because of my depression.

Respondent: After a while when I reached a certain age limit, I stopped going

there and I was okay after that so I didn't need any treatment

Respondent: Um...right away.I went to the hospital, actually I went there

because I had overdosed on my medication in a way, like not...in a day but I wasn't in touch with my psychiatrist for like about a year and when I called her I told her that I have been fine but still I feel like my head is congested now so she said you have been overdosing on the medication, you didn't need it, so we were taking it. So I thought that before like when I had overdosed on the medication, they took me to the hospital and they took it out of my body by giving me something to eat. So I went there to the hospital to the emergency and I told them I want you to take it out from my system somehow but they admitted me. They thought that, they just admitted me for some and I declined to take any medicine and I refused it I mean. So they insisted that I should take the

medication but I refused it, that's why they put me on a CTO.

Most of the participants talked about the lack of mental health support in the community prior to placement on a CTO. Despite similarities in participants' responses, differences were also identified: one participant reported having received mental health treatment in jail; other participants commented on family members assisting them to obtain the needed support; another talked about support from a community program for adolescents. A number of the participants had no support at all, and those who did, found the support unhelpful. The issuance of CTOs may be viewed as necessary to provide the needed community support; a CTO was therefore utilized as a tool to ensure support, stability and treatment for this particular client population. In the midst of the analysis, the question that lingered was whether the lack of a well-structured and organized community based case management program impacted only ethno-racial minority participants or all CTO clients.

# **CTO Experiences**

The researcher explored participants' experiences regarding CTOs through their impressions and day-to-day lived experiences. The participants were candid and shared both positive and negative experiences, and their feelings from these experiences. A number of the participants agreed that the CTO provided them with a support system, including support compliance with medication. They felt clinicians / case managers reached out to them on a regular basis. The participants provided the following feedback on CTOs.

# Appreciation

Participant AB001 emphasized the significance of CTOs and supported the follow up by a worker in the community.

There are advantages and disadvantages of being on a CTO. One of the advantages is that you have a support system. They come in and they support you really well.

Some participants expressed appreciation for the treatment stating that it provided a form of protection, a support system that enabled them to stay grounded and responsive to treatment. Participant AB013 acknowledged the importance of being supported by a social worker that checked in with her periodically and looked forward to her visits.

I think it was a good idea mainly in that I realized that being in a CTO gave me some sort of support because it made me realize that they were really trying to help me. I had a nurse (name of worker) whom I liked very much and who was very helpful to me. She was very concerned about my condition and she would come once a week and I really kind of looked forward to her visits. And then I was seeing the psychiatrist more often...

According to the mandate of CTOs, physicians use the treatment as a treatment of last resort, when all other approaches have failed. A number of participants reported that CTOs helped them tremendously. It made them realize the importance of treatment compliance. CTOs also made them realize that they could interact with case managers and physicians in a respectful manner. The impact of the CTO on participant AB006 – was significant. She described it as a catalyst to improving her health, as the relationship with her psychiatrist was almost non-existent; she now had someone she could trust, depend on and look up to (referring to her CTO case manager).

It's good, it's good. You know, like, well, we answer questions, she asks me questions and we answer, I answer questions, but what I like about it is you have someone to talk to, because really, the doctor I find mostly push the medication, they push the medication. But when you have someone, my family they're good, but I don't really feel comfortable talking to them, because they don't really understand. I mean they're very kind to me. They help me out financially with my son and my sister's always there, but I find when I talk to (name of worker), the difference is I feel comfortable, I feel relaxed. It doesn't matter what I say, she doesn't judge me or think I'm crazy. So, it's been a blessing so far, yeah.

Like I said, it's a blessing. Not everyone knows what a blessing is, but it's like I have someone to talk to. She open up my eyes. She encourages me, she believes in me, she always tells me I'm a wise person, you know. She encourages me to get out of the house. Sometimes she suggests that we go out for a coffee or stuff like that. And so far I haven't, I've interacted with her and the employment specialist. I haven't interacted with anyone else from (community program). In the beginning, I remember when she came to the hospital, she had this gentleman with her, but then when she started coming to the house, she come by herself, so, I'm very thankful for it. And I prefer this over (community program), actually. Yeah. Because I feel like I'm getting somewhere with her. I'm not stuck in a rut, you know, she, like I said, she encourage me, she believes in me, you know.

Other participants reported positive experiences following compliance with medication as part of the CTO agreement.

#### **Ambivalence**

Most of the participants expressed ambivalence about CTOs. They disliked the thought of being on CTOs and felt it promoted the potential for police involvement.

Participant AB015 recommended CTOs for clients who may have had difficulty with treatment and recognized that though they may feel uncomfortable being on the treatment, it was for their own benefit.

I would say they should go through with it because for the most part people who are recommended for the CTO generally don't have the capacity to make decisions for themselves so in that way I think it's a good idea. But in terms of the way people feel while on it, they probably would describe it the way I have. But if it's needed then they should be under it.

I would say the treatment, if it's necessary then they should certainly go through with it because it's in the end for their own good. It's not because people want to restrict you or they want to keep you somewhere. It's because they want to make sure the treatment is the right one.

The experience articulated by participant AB016 initially reflected ambivalence for the treatment, and thus rejection of case management services, but eventually acknowledged that the CTO had indeed been helpful.

Oh I felt really uncomfortable. At first I didn't understand it, right, so I kept rejecting people that want to help me. And I just wasn't comfortable at the time, right at the beginning but then after awhile I sort of understood what they're supposed to be there for, right, so I knew myself right away, I'm going to need one in the end, right. So I said "okay sure" and that's how I met \_\_\_\_\_\_. That's when I started to say "okay you know what, you can help me out, this is my problem."

The perspective of participant AB017 was both positive and negative; while it was beneficial, ambivalence was expressed regarding the shift in the decision-making process.

I was put on a CTO to help, well I was explained to help bring things, to respect their help, get me help with housing and kids, court, get me back into perspective, work, home. In some aspects it did help and in some aspects, it hasn't. Mind you the CTO brought me back here. In other aspects if I wasn't on one, I wouldn't still be here. I'd probably be in my own, doing my own thing and it's not that bad because I don't find myself at a complete loss. I'm able to sleep and function so it's very disruptive and it means that people can make decisions for you.

Overall, ambivalence was expressed by a number of the participants on initial referral to the treatment, which may be explained by the uncertainty of what to expect from the process. The ambivalence of most of the participants, however, dissipated as they eventually appreciated the support and the opportunity to work with a physician and case management team.

#### Medication

Prior to being placed on a CTO, most participants had issues with medication compliance; for a number of the participants, treatment decisions had to be made on their behalf. Participant AB004's response echoed the issue of medication non-compliance. A CTO ensured that clients received support, and direction from their social workers in the community.

Well, definitely being on a CTO did help me a lot because I had a tendency to not take my medication properly and I was scared of medication. I totally needed a lot of support to take my medication and I was very scared of the doctors and it was very, sometimes it was scary for me to attend appointments with the doctors. I used to get very anxious and confused and nervous. It felt like some examination was coming over for me and I had to prepare for it. But being on a CTO, the doctors made sure that I regularly attended my appointments as well as took my medication, day and night and not only was it about medication and appointments, I also felt that it was about taking care of my diet and my personal activities as well.

Participant AB008 illustrated the impact of CTOs. She felt that CTOs provided support and in a way protected people from trouble, specifically from de-compensating and having to return to hospital; it compelled participants to comply with treatment. She acknowledged disliking the medication, however, felt persuaded to take it.

... I think it's more protective. Even though the doctors say you don't eat medicine, you have to go back to the hospital, ... Because if I sick, I need the medicine, right?

Sometimes I don't like, but sometimes I think it's necessary, because sometimes the CTO will, they have something, because CTO make me go to the hospital and I go to the hospital. I see another patient and I see myself just like them and then I wake up. And also, the CTO, but one thing I don't like is, I didn't think any mistakes, but the hospital give me the cuff. Cuff<sup>6</sup>? Cuff?

For participant AB010, the thought of being hospitalized motivated her compliance with medication.

Yes. Like I have to take my medication, because every day (name of worker) comes, every time she comes, the first thing she will ask me is "Where is the medication? Let me see. Did you take it today?' And she tells me that Dr. (Physician's name) says she should always checks on you. (laughter) Everyday she says that the Dr. (Physician's name) says she's to check on me, all the time. So I give her my medication to check and she checks and says 'Okay, you took it. You remember if you don't take your medication, you're going back to the hospital.' That's what she always tells me.

In addition to the support, participant AB010 believed the CTO made her medication compliant and without which she would have found herself back in the hospital and having to stay longer.

Yes, because I have to take it. If I don't take it, I won't be able to live. I'll be running in the streets. Police watch what happens is equal. It's not like, it's not a threat. It's like helping you. They're helping me, so I have to help myself. They don't do anything to harm me. I'm not going to,

<sup>&</sup>lt;sup>6</sup> Participant was making reference to handcuffs

they're not going to put me in jail. So they take me back to the hospital to get treatment right, then it's good for me, otherwise I won't be able to communicate with other people like right now, talking to you, right now, wouldn't be around.

Participant AB013 believed CTOs provided the option of exploring another form of treatment that eventually had a positive impact and credited it for motivating them to transform their lives.

Yeah, I think the CTO is a positive thing. I think it is perhaps after a lengthy mental illness, the doctor seem to think they have no other option but to put you on a CTO because you've been coming to the hospital so many times, the medication perhaps and the ECT hasn't been helping and I think they're just trying to go one step further to see if by doing this they can put you in a position where you have to take a little bit more responsibility for yourself and try to, you know try to get up and pull yourself out and become more responsible for the treatment that they're receiving and for the fact that you need this treatment. At least I think that's what they think.

Participant AB018 credited medication for helping her cope with her illness; it enabled her to take care of her children and she expressed appreciation for the support of all the case managers and nurses.

...And...they said I must continue to take my medication and things like that which I did. It's very important for me, which medication is helping me so I won't stop taking my medication and I'm looking after myself better and better each day which is good and I take care of my children, my children is one of my most important part and stay well. They are the ones that really keep me going, my children, they're very important. So I think CTO is very important. I could recommend it to anybody that it's a good, you know, it's a good team, yeah

I get, well the support from the nurses is wonderful, you know, and they remind me of you know, always telling me things, my medication which is important, you know. I feel like I'm not there alone. With the support I feel like I actually have a family, yeah

It was wonderful. It was wonderful to be on a CTO team because the support and the help, it was great, you know. The nurses were good and you know...

Medication is an integral part of the CTO process and participants are encouraged to take it. Despite some participants' opposition, CTOs compel them to comply to avoid hospitalization.

## Feelings about self on CTO

Participants expressed how they felt the CTO had benefited them. Participant AB005 discussed being "well in my routine." She described her ability to organize herself and take her medication regularly; she found herself in a better position to meet with her social worker, whose involvement kept her grounded and organized. She talked about assignments and other activities that required going to the library and attending support groups, something she never did when ill. Making the effort to integrate the demands of the treatment into her daily activity speaks to the effectiveness of the program in the life of this client.

When I get up in the morning it feels like I'm well on my routine with my medications, my appointments, my social worker visits, I'm active in my brain. I don't slug down, I don't want to sleep the whole day. There's definitely a lot to do; (name of worker)leaves me with a lot of homework to go to public libraries and to make charts and there are assignments of my health care and to get to know myself better and I have instructions from the doctors and the hospital to get to know my diabetes very well and attend an education program to know my diabetes at the hospital. And then I'm told to exercise and go to (Name of program) and I'm also told to take my medication properly and to work on my diet. So I'm really busy with CTO and everything because sometimes you can get lazy so CTO makes sure I'm not lazy.

Participant AB009 felt the CTO enabled her to interact with and get along with her family.

Support and help your family, help, they do not care too much about our medication, but they do care about what kind of mood do you have and what kind of real life difficulties you are facing, so I think CTO is better.

In addition to medication compliance and the ability to get along with family, participant AB010 discussed an important aspect of the treatment; the CTO stabilized his condition, and his relationship with the case management team enabled him to obtain a job and live a productive life.

Yeah, it's very, very, very good. Without them I wouldn't be able to do the things that I do. I can't get a job. They help me get a job. I work at (name of employer) for five years now. Then we slowed down, so I came home. They called me back to work, but I have a knee problem, so when I recovery, I go back to work. That's the information I have for you for now.

Participants' feeling about self was well articulated as they described their experiences prior to CTO and during the CTO process and the progress; the progress empowered the participants and enhanced their self-esteem.

### Inhibition

Though most participants appreciated CTOs, there were those who criticized CTO for its infringement on their rights, and its negative impact on them. Though Participant AB001 expressed a number of positive comments on the benefits of CTOs, she also felt CTOs were not necessary and considered them time consuming and inhibiting.

I still feel that sometimes it's not necessary although they provide the support; I just feel it's not necessary sometimes because they sometimes just come and they ask you questions and that can be done over the phone. It's time consuming. As I said, the medication factor, they don't really know whether or not, that's one of the most important things with the

CTO, they monitor your medication. They don't know whether or not you are taking your medication, you tell them but they don't know if it's true so, yeah.

Participant AB001 further expressed her discomfort with CTO in that she felt her movements were monitored and would interfere with her life.

My feeling is like "oh no, I'm going to be on a program and they're going to interfere with my life, my daily or my weekly living. I have to implement them into my schedule; it's going to be time consuming." And I still have those feelings, like sometimes it's not very useful because although they're very supportive, I have to take time out of my life to see them.

She again commented on the impact of the treatment; she felt controlled even though she was not in a hospital setting. Knowing the doctor could bring her back to the hospital made her feel helpless.

Just when I said I'm a part of the system, it's basically I'm a patient. That's what I'm talking about. I'm a patient, although I'm not in a hospital, I still consider myself as a patient and be monitored because if I don't adhere to the agreement of the CTO they would Form me and they would put me back into the hospital. So I'm still a patient, so I'm still, although I'm discharged out of hospital, I'm still a patient.

Participant AB001 also expressed her dislike of CTOs and described it as demanding and controlling.

I don't like it. I feel pressured that I need to be on my best behaviour. I can't speak about any certain things. I have to keep, if I'm thinking about it, I have to keep to myself because I'm being monitored so it's uncomfortable. Sometimes it's a little bit stressful because the case manager is always good, he comes and he asks you certain questions and you have to answer it perfect. You have to be careful what you say because if you say certain things, it's written down, it can be used against you and then he basically does a report and he speaks to your psychiatrist and then he can speak to the psychiatrist and state any concern that he has and then the psychiatrist can make a decision whether or not I'm able to function by myself or function in a community. So I have to be careful what I say to the case manager.

Well, first Community Treatment Order, you're being monitored, you're being assessed and you're being looked at as a patient still, however you're being supported as a person and as I said you're in the system still. You're not completely free. You're not completely discharged from the hospital although you are discharged from the hospital but you are being monitored very closely to make sure you stay in line.

According to participant AB002, being on a CTO limited the opportunity to do a lot of things, including the ability to express oneself and to make progress in society.

Well with a CTO, once they put you on the CTO, it limits your speech, it limits your freedom, it limits quite a bit of what you could do as an individual to prosper in life. That's basically what I would say.

Participant AB012 also shared this sentiment, believing that CTOs infringed on personal freedoms and the ability to make certain decisions.

Well, I feel good and in a way I feel bad because they did tell me what to do. So basically I'm not free. Basically they tell me I have to take my medication at night before I go to bed. Basically they tell me I can't smoke no weed. They say I can't drink no liquor. I can't drink alcohol anymore because when you're taking medication, on the bottle it says no alcohol. So I'm actually segregated from the whole world. I'm in a totally different world than everybody else, so a lot of people don't realize that my life is totally different than everybody else.

Participant AB013 feared that medication non-compliance could result in admission to a long-term facility.

Well I actually thought you know, I'm here right now and if I don't get better they're going to put me in Whitby type of thing and I had better try to get you know, to get to keep out of the hospital. That was one of my main fears that I could no longer go back in the hospital if I were really sick because then they would realize that, you know I was not improving and they would sort of seek more long-term institutional care for me. That was really my main fear.

This feeling was also shared by participant AB015, who viewed CTOs as very restrictive, as it was imposed on her against her will. Her CTO experience made her angry:

I think it's very restrictive and I didn't like being confined to the hospital because of the treatment order and at the time I didn't know why it was enacted because I was on medication anyway.

I still feel anger about it, that it took so many months and that my family sided on the side of the doctors as well. So I don't think if anything like that were to happen again, I don't think I would agree to it because it was basically forced on me. It wasn't really a mutual agreement.

Participant AB017 clearly felt his rights were infringed upon, by having to abide by someone else's rules and regulations.

I'm on a contract. I have to abide by what's going on. Abide to me means rules and regulations that may not be the same as my rules and regulations. Abide by somebody else's code of ethics. Abide by what somebody else says. Abide by what somebody else has chosen for me. Abide by what somebody else needs to sit out and deal with. Abide by what somebody else has chosen for me. Abide by their rules and going back to who, what and why my own existence is, is wrong. Nobody should have to abide by anybody else's rules and standards.

The initial reaction to CTOs by some participants was the fear that the treatment would hold them back from what they intend to achieve in life. Subsequent to treatment initiation, however, their perception tended to be more favourable.

#### Participant AB004

Initially that's how it feels, like it feels scary. It feels like somebody is going to hold you back and stop you from doing what you want to do and you're told what to do but as you go through it, they let you realize that you have absolutely all the freedom to let go and get out of it. And then you start to realize that they do help and support you so you kind of look forward to having CTO.

### Participant AB006

In the beginning I did not like it, yeah, because it was not my decision, it was not my choice. I didn't have anything against my worker. I didn't know them. I didn't know her, but then she start, when I go to hospital she come, you know, we would talk. I felt very comfortable. She's very friendly. I didn't feel like I was bothering her and she encouraged me to go and take my needle and then to see Dr. (name of Physician). Sometime she would come with me. She recommend me to Work On Track, which I did last year and that was good. I get out and I, Seneca College program. I don't know if you know what Work On Track is.

Despite the positive impact of CTOs in the lives of many of the participants, others clearly found the treatment inhibiting and an infringement on their rights. There were also those who despite initial ambivalence, the participants eventually viewed the support and treatment as helpful. A notable finding was that though participants expressed gratitude for CTOs, when asked whether they would like to be on a CTO again, the majority declined. They, however, considered it appropriate treatment for others. As expressed by participant AB013:

No, I'm just glad it's over, I'm just glad I've gotten better again and I would never want to be put on a CTO again so that's a very strong motivation for me to keep well.

Participant AB017 shared a similar sentiment:

It's an experience to be learned from and if I had to do it all again I probably wouldn't.

#### Stigma

Analysis of the interviews showed that the participants had a negative perception of CTOs because they felt it further stigmatized them and made them feel like second-class citizens. This view was also held by the participants who expressed optimism about the treatment and reported they were treated differently while in the hospital and in the community as well.

Participant AB006 described a situation in hospital where the psychiatrist had to reassure a nurse that she was not violent and talked about her as if she was not there. This tied in with the belief that the mentally ill lacked insight into their conditions. In this case, assuming the client did not understand what was going on around her. This participant's experience suggests that when others learn about individuals on CTOs, they make assumptions about their potential for violence, capacity to understand and the ability to integrate into society.

Maybe once at the hospital, a nurse, when I went, she was talking about me. I was in the room and the doctor was telling her to bring me to the tenth floor and she was talking negatively like I'm going to hurt her or, you know, I'm violent. And I heard the doctor say 'She's not going to hurt anyone. She's just hearing voices.' So maybe that was the only experience I had experienced, you know.

(Name of worker) brought up a good word the last time, mentalism, yeah, that, like mentalism is like racism, but I haven't experienced that really, except for that one incident when I went in the hospital to be admitted, the nurse was so scared of me. That's the only thing. And she was talking about me like I wasn't even there. But I didn't talk. I should have said something, but I didn't.

The negative assumptions about CTOs and persons referred to the program contribute to internalized stigma, where clients feel they are receiving the treatment because their condition is extreme or deviant. This is captured in the interviews with both participant AB003 and participant AB006.

### Participant AB003

Lots of thoughts came to my mind. As I said I felt like they figured that I was insane but on the other hand, someone who is insane isn't medicated, I wouldn't think, because they have to have a diagnosis but figured that was to put me on CTO that's the extreme, that was the extreme.

# Participant AB006

I think it was my condition, because the doctor had to reassure her that I am not dangerous. And I think, (name of worker) mentioned that when she tells people that she work with mental people, the first question they ask is 'Aren't you scared?' They have this image that we're this violent, outrageous person, people who never experience it, but no, no, I can't say it's because of my race. I don't think so. I think it's just because of the illness, you know, and they have this crazy, cookoo and all this stuff, but I find though that I had a friend who had cancer and she said she would choose the cancer, if she had to choose between my illness and her illness, she would choose the cancer. And I think maybe because a lot of people, you hear about cancer a lot, but you don't really hear about schizophrenia a lot, you know, and the stigma, there's a lot of stigma, like you know, you're going to be violent, you're a drug dealer, you're a drug addict...

The participants' responses clearly illustrate society's views toward two serious illnesses- cancer and mental illness. Cancer is considered life threatening and more acceptable than mental illness and its associated stigma. Other participants also experienced the stigma associated with mental illness.

## Participant AB012

...they want me to find a job where it's all mental health people working. I don't want to work with mental health people. I'm not really mental. I'm pretty much fine. The government say I'm mentally insane, you know what I mean. They label me as a mental person, so they're gonna have to pay for it, I mean, I just do what I do. If I have to cause trouble, I cause trouble.

## Participant AB023

... people put a name tag on me ... that sick guy....

Yay every one around me sees me different now because I've been in jail and in the hospitals ... like I'm a different guy ... everyone looks at me like I'm a poor character ...different guy ...look at me like I'm an invalid (sp?)... That I'm more of an invalid (sp?) than I used to be.

The treatment of mental illness in the hospital as well as the community promotes participants' sensitivity to their condition and the debilitating effects.

#### Participant AB015

Well, after I came out of the hospital there were activities that the CMHA were involved but I wouldn't go to them because I felt self conscious and because I don't think, like I wanted to be among normal people who were doing things that weren't related at all to their condition, you know? So I didn't want to feel as if I was doing the same thing that was connected to the hospital or the illness at all. So in that way I missed out on interacting with people that were with me in the hospital but in other ways I got reconnected to the friends I had before and that was better too.

## Participant AB017

Once you ask for medical records, most jobs ask for either medical records or criminal background; criminal background, if I come in here it's breaking a contract, which means it breaks a contract, it still puts a criminal flag on your record, on any record. That's how I know that it can be and most people, it works now is they're going to ask is there any disabilities and seeing as I'm covered by one, questions go deeper than most people like to know. I mean I can say it's my personal business but as long as they're not going to go deeper, they'll never know. It's how deep they want to go.

The participants articulated the effect of stigma associated with mental illness and the heightened stigma associated with CTOs. Their experience is a reflection of the fact that being placed on a CTO further marginalizes mentally ill individuals.

# Rapport with clinical support team

### Support

Another major theme on which the interviews were based was the participants' rapport with the clinical team (psychiatrists, nurses and the case management team). Participants acknowledged and described the importance of the role of the clinical team with regard to the CTO. Most of the participants had case management support and described impressions of their interaction with their case managers.

According to participant AB001, interaction with her case manager was very positive; they had good rapport and she felt comfortable and able to communicate freely with her worker. Her worker made her feel good about herself.

Oh well, my case manager is very good. He's very supportive, very understanding. He's a good communicator. I don't feel...he doesn't make me feel like a patient. He makes me feel good so by him doing that it reflects on the CTO that it's a good thing that they're doing in the community. However it's the time factor that I don't like, yeah.

...because I guess if my coordinator wasn't good, then I probably would have some feelings but my coordinator is a very good person, very skilled in what he does, so it's a positive feeling.

Participant AB001 further described her positive relationship with her case manager.

I develop friendships very easily so being a case manager, being that particular case manager, if it was a different case manager, maybe my personality would clash with that person but my personality with this case manager, we have developed a good relationship.

Participant AB002 expressed satisfaction regarding interactions with his worker and described it as a "positive experience." The supportive relationship has been beneficial and as a result, improved his condition.

Well it was very positive and very cooperative and they also feel, like my caseworker is (name of worker) and she feels very happy interacting with me.

It's a positive experience as I said. I always compare it with whatever she is saying, for example initially she was concerned about my taking medications so I brought and showed her my medications. Then she was concerned about my mental status, about how I approached life and that also I positively replied to it, then she, nowadays we are working on the recovery system, that what are the factors that show that I have recovered. And fortunately all the nine or ten points that she spelled out, I'm following all of them. So I'm in a way recovered from my problem and that's...

The participants went on to describe the positive interaction they had with the nurses at the hospital, which reinforced the positive support received at the hospital, and also the community with their case managers.

Participant AB004 described the relationship with his case manager as very beneficial, and spoke confidently about the impact of the relationship on his recovery.

Yeah actually I meet with him often and he's very interested by me. He said hopefully all of the patients, hopefully all of his clients or patients would be like me because he is very interested with me and he likes me and also he said I'm very polite and kind and something like that, that's what I have to do.. I try to be nice with anybody, and any person.

Yeah it does help me a lot, you know. Actually I used to live in this place with bad shape housing, like there were bed bugs and cockroaches and mice and he helped me out, he got me a very nice place especially for people with mental illness to live. He got this place that was very nice and I lived there, that was a very comfortable bed and...but finally I have now my own place so that was very good help for me to find me a nice place and to help me out for any reason.

This participant AB004 also commended the nurses and psychiatrists in the hospital acknowledged, they have the welfare of their clients at heart, and do all they can to ensure that the best of care is provided to the clients.

No, they are good people. They try to do all the best to give good treatment and to help the patients. They try to do all the best to give good treatment and to help the patients; in-patients or outpatients.

Other participants also described positive interactions they have had with the nurses at the hospital, making the hospital a source of positive support.

Participant AB010 expressed appreciation for the support he received regarding his compliance with medication. Knowing his worker checked his medication ensured that he followed through with the expectations of the treatment and also provides the opportunity to discuss issues of concern.

Yes. I have rights. I tell the CTO what I want to. I can tell (name of worker) anything I want. If I'm not happy, I will tell her I'm not happy. 'Why,' she will say 'Why?' This and this and this and this. She will ask me 'Have you heard from your brother yet?' I will say yes. We sit down and talk, we discuss. 'Have you heard from your family in Nigeria?' I say 'Yes'. 'How is everything?' I will tell her.

# Participant AB012

She's nice. She buys me food. Like whenever I'm hungry and I have no food, she gives me a dollar or tooney of her own money. I've seen her take her own money from her own pocket, not what the company give her and buy me food because I say I'm hungry in the morning time at breakfast. I can tell her every time I go there and she has the heart to say she buy me food. Because I'm paying her. If she doesn't have me as a client, she does not get paid. You understand? So, she's happy that she has a guy named (worker's name) that she gets to see every week and the other clients that she gets to see every week, because if she don't see us, she ain't getting paid. Her house mortgage ain't getting paid.

Participant AB013 discussed being treated with respect by her psychiatrist.

I think my psychiatrist has treated me personably. I think he has treated me as a human being. I would like to think we have some kind of a client relationship but I think now and then he has shown a bit of a human side where I think he sees me not only as a person who had a mental illness but just as a human being and I think he has tried as best as he knows how to treat me with dignity and respect and my nurse (name of practitioner) has always treated me as a human being, like she has always treated me very pleasantly and in a very caring manner.

The positive nature of the relationship with the case manager and psychiatrist was also expressed by participant AB015 and reiterated by others.

It was generally good. My social worker (name of worker) was very good. She answered most of my questions and she was there for me after I left the hospital.

Oh, well we would go to the mall or we would go to the coffee shop or you know, we were very friendly because she was more like a friend than a social worker and she genuinely cared about what had happened to me and what I was doing.

Very good. (Dr's name) is excellent and he never really pushes his opinions or therapies. He lets you...he let's you work it out for yourself.

# Participant AB016

No, nothing really. She does her job, I think. Well my mom is not happy with her sometimes though, but I'm happy with her, like what she does for me. Like she organizes, she makes sure, she checks everything is there so that's good. It's good to have her.

Negative feedback was also reported by some of the participants, in the case of participant AB017, it was from expectations not being met.

Like sometimes she leaves early, like she leaves too early and sometimes like, she wouldn't tell me everything, right and that's what my mom doesn't like, like my mom thinks she's lazy, right and she doesn't want to get off her feet and do something about the situation, right, because she knows there is a situation but she can't do anything about it, right? I just don't like the part where I can't get a ride. Let's say we were supposed to meet at a bank, where like Markham and Sheppard, at that bank, we were supposed to meet there one time and she couldn't give me a ride, right, she just gave me a bus ticket. But that's okay right, just giving me bus tickets is fine, I guess. But my brother, he has something like what I have and he can get into her ride too.

That makes you feel pretty mad because I can't get in her car, right? I can't get a drive home, you know? So it's pretty lousy.

# Participant AB018

After I left the hospital and go, when I was in the hospital they...get the program, signed me up and get the program for me and then the nurse started to visit me at home and then she continued, you know, sending nurse to visit me, like I'm always living downtown at Annette Street, and then the nurse came to visit me, actually every day she came in to visit me. She drove a car, sometimes she took me to High Park, I go to the park with her and things like those. She, you know, she watches what I'm doing, cooking, she was you know, like that.

Participant AB005 felt compelled by her worker to participate in activities she was uncomfortable with.

Well, yes it does. Every time she comes in I get intimidated and scared and shocked because I know that she's going to bring some tickets for me and we're going to have to take the subway and go all the way down downtown. And going downtown, it's scary for a girl, you know sometimes. So it has an effect, yes. You go through some of the feelings like intimidation, my pulse rate when she comes in and says "let's go to downtown today on the subway."

Most of the participants appreciated the services and resources provided by their case managers, however, a few were critical of their case managers and felt they were not doing enough to support them.

### **CTOs in Cross-Cultural Context**

#### Racism

This section discusses participants' experience of CTOs from the perspective of their background as ethno-racial minority clients from different cultures and explores their experience with racism and culture. This study explored the lived experience of participants from the perspective of their culture to determine if CTOs discriminated against them or had any racist undertones. Most of the participants did not think the treatment had any racist implications, nor did they perceive the assignment or delivery of CTOs to be race based.

Both participants AB001 and AB004 believed who they were had nothing to do with the treatment they received. They believed CTO was the best treatment for them at that particular time.

### Participant AB001

Well I don't really think about ethnicity of being on a CTO. It's just when I was placed on a CTO, this was not taken into account. I was just placed on it because I was not taking my medication; I was a patient so my ethnicity was not taken into account.

## Participant AB004

No, no I don't think it has anything to do with Arab or race or stuff like that. It does have to do with people that have a lot of problems and mostly the Toronto or Canada people; they don't have a lot of problems, like in the head. Sometimes they could be nice with people and not nice with people, they have family problems or God knows what problems but not with race or stuff like that. I couldn't say there is race with blacks, or Arabs or other nations or whites or something, maybe somewhere else in a different country.

Participants' experiences during hospitalizations also did not reveal any racial undertones. Participant AB006 pointed out that treatment is provided by nurses and doctors of all races and did not feel treated differently.

# Participant AB006

I don't feel, I never really do feel since I got sick. I didn't really feel like it's affected me in a negative way. If anything, it's been positive. I mean, I go to the hospital, there's black nurses, white nurses. I don't see they treat you any differently. I have not experienced any racism or anything like that from anyone that I've come in contact with since I've been sick, you know.

### Participant AB007

I think it might have had something to do with me going to the hospital to begin with, but once I was there, I didn't feel that way, because I was brought to the hospital by the police and I know the police and black people in this country haven't always gotten along (laughter) and me in general dealing with the first few officers that came, you know, it's not something that I exactly wanted to do or, but I had to and that's, you know, yeah.

Most participants agreed that CTOs were not based on race, but what was believed to be in the best interest of the client.

# Participant AB012

So that's how I see the CTO. It's not a racial thing. CTO is not a racial thing, because it's all different minorities helping you. You have black case workers in CTO. They have white case workers in CTO. So you

can't say it's a black thing only. It's an all multi-cultural thing.

# Participant AB013

I think from what I saw in the hospital and other people who were being put on CTOs, I also saw that there were some Canadian girls there that were telling me that they were being put on a CTO and they would try to get rights advice and they wanted to try that. So it seemed to me that the treatment, or the choosing of people to go on CTOs, to some extent from my limited perspective because I only saw about three or four people there and that's not a lot of people, to me I would say it was colourless. I don't think it was racially motivated.

Participant AB021 was of the opinion that CTO treatment is the same for everyone, regardless of race or class.

No, I think they treat everybody the same, who is on the same treatment. I don't think because of my colour or racism is different because you know, look at the world, I'm not the only coloured person. There's millions upon millions of blacks and Indian and Chinese and White. There's not just one or two, there's so many. So you know, it's only stupid that they treat people so bad as if it's one or two persons like that.

However, two participants associated the CTO treatment with racism. They believe that had they been of the dominant race, they would not have been placed on a CTO.

One further believed that he was provided with inadequate treatment because he is a minority and that had he been of the dominant race, his physician would have requested a different treatment (the cognitive behavioral model) for him.

### Participant AB012

It is. CTO is a racist thing. Do you want to know why CTO is a racist thing? Because the majority of the minorities that are on CTO, they are either African-Americans or they are Hispanic and they're from some third world country...

## Participant AB015

I think so because I wasn't offered any other therapy like cognitive therapy or anything else like that because I'm not sure whether it was because of my race or because they were limited on finances. But I would have preferred talk therapy or something more in depth than just going in to see the psychiatrist and not really doing anything except telling him you know, giving him an update of what was happening in my daily life, you know, without any kind of response. So I would have liked more interaction with the therapist and also maybe if other activities were included like, I don't know initially I didn't get a chance to go to the classes or whatever was offered in the daytime activities because I wasn't aware of them and then as other people were involved that's how I became involved so if they could just start with those kind of activities early on then that would be beneficial.

Although most of the participants acknowledged they encountered racism in their day-to-day lives, they did not believe CTO to be race-based, nor have any racist undertones. Only two participants believed that CTOs are racially motivated.

### Canada vs. homeland

As part of the lived experience of ethno-racial minority participants, the study also explored the cultural differences in mental health treatment of how care in Canada differed from their homeland / country of origin.

During the course of the interviews, five of the participants inadvertently made a comparison of the mental health treatment between Canada and their country of origin. Most of them felt the services provided in Canada were superior to those provided in their country of origin. One participant went to the extent of grading the Canadian mental health system. One participant, on the other hand, preferred the mental health services in Pakistan, his homeland, to Canada. This was primarily due to the wait times rather than the service itself.

Participant AB002 described the Canadian mental health system as being well organized and providing the best treatment to individuals in the mental health system. He believed he is entitled to good care, unlike in India, where as he put it, one is treated like 'a dog' by the health care system.

Beautiful, wonderful! The issues that came up in all my treatments, see my friend, I have very positive feelings about what has happened with me. It has introduced me to a system, the system is very systematic, very well organized and it is for the benefit of the patient. Whereas back home the system is in a mess, oh especially of mental patients.

In India. So the mental health system, the mental health care that the patients are treated like dogs, you know, like worse than animals and not only by the doctors and by the staff but by the family members also.

Participant AB008 stated that due to the size of the population in China and the attitude of health care providers, appropriate care is not provided to those in need and referred to the system as 'a mess'.

China is more, is more close, it's shut down in the culture. Many, many people, if they don't, you cannot bother, you cannot complain, because too many people. If they don't use that way, it's not culture, because too many people. But here is not many people and he can treat one by one to cure, to, you know what I mean. In China, maybe they just (chopping sound) 'Shut up. Go to the room. Don't come back.' It's totally different. You see Taiwan is freedom. It's not a real freedom. It's like a mess. Because Taiwan people, Taiwan too small, so you cannot say, you cannot say it's like freedom. It's like a mess. It's like a mess.

Participant AB009 referred to the Chinese mental health care system as 'inhuman.'

Respondent: In China the treatment is really inhuman.

Interviewer: Inhuman?

Respondent: Yeah. They treat us just like animals. They have string to tied you and maybe some needle to make you faint and a lot of things that were inhuman and sometimes the nurse and the needle fall to the floor, they also pick up and inject me

and make me fever the whole night. So I feel, compared with

Canada, that place is really awful.

Participant AB011 had high marks for the Canadian mental health system and said she would give it an A+ in comparison to her homeland, Nigeria.

Respondent: This one is A+.

Interviewer: Why?

Respondent: It's so advanced.

Interviewer: When you say advanced, what do you mean?

Respondent: Advanced medical doctors, there's more specialized than the ones in my country and the medications here, most of them are not in my country. People travel all the way from the third world to this place to look

for medication when they are sick, to look for treatment.

The majority of participants favoured the Canadian mental health system over that of

their homeland, despite the experience of CTOs.

Power in the treatment process

Analysis of the interviews revealed that power, as a theme was dominant in the

discussions with the participants. Power was often defined in the way the participants

discussed feelings of coercion, empowerment and feelings of disempowerment by the

system. Some of the participants felt the treatment put them under the control of the

system and their physicians, taking away their right to either think for themselves or

decide what was in their best interests. Some, on the other hand, felt empowered by the

treatment and voiced how much it had helped them.

Coercion

A number of the participants expressed feeling coerced to participate in the treatment.

Even though they were fundamentally opposed to CTOs, they agreed to the treatment out

of fear of lengthy inpatient hospital stays, fear of police involvement and in other

situations, the child welfare system. Participants felt their input was not solicited in the

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CTO process, but rather felt pressured into it.

Participant AB005's description of her experience with the CTO process speaks to the coercive nature of the treatment and how they felt crippled with fear.

Yes that happens all the time and like I said before they make it seem like they're going to hold you back and they look like they're going to control your life and they're going to take your freedom and they're going to take you back to the hospital if you don't take your medication. They're going to get you arrested. There's a lot of that in there and it is very scary but if you talk to them about it, you have all the support of the lawyers and all the papers and cards given to you if you want to make a law case against them and you're free to do whatever you want to do.

This argument is supported by participant AB006, the threat of her son being apprehended by child welfare services compelled her to cooperate with the treatment recommendations. Though she expressed feeling peaceful as a result of the treatment, she considered the treatment coercive.

Sometimes I do with my son, because they told me, Children's Aid, if I don't take the medication, my son, you know, I might lose my son. So I used to think like that, because I said, in the beginning I did, and I don't know if I'm just getting a rest from the devil or it's the medication, because I've never had a medication that didn't let me hear voices. All the medication through the years, you know, it's just that now, it's not so evil, it's not foiling, it's not telling me to hurt anyone or hurt myself. So, I have a peace of mind for the first time in a long time.

Participant AB007 made reference to the coercive nature of the treatment, feeling that following through with the expectations of the treatment was viewed as a way of leaving the hospital.

Well, I could refuse it. They let me know that, but that would have lengthened my hospitalization, which would have been totally contradictory to what could be a good outcome, you know. I wanted it to be something like even if I felt like I shouldn't be on a community treatment order, I felt like I should deal with it head on, you know, and answer all questions and deal with it and when it was dealt with it would

be all over, so.

Participant AB009 also felt coerced into agreeing to the treatment.

## Respondent:

First I don't know what this, but they said if I don't join the CTO, I cannot go outside to the hospital, but I don't want to stay in the hospital, so I say okay.

#### Interviewer:

So, you agreed, not because you wanted to be on a treatment, but because ...

# Respondent:

I don't know what CTO. At that time I don't know anything. I even don't know \_\_\_\_\_, who's this, so I don't know.

In the hospital I feel we have no freedom. By the way, I really wanted to get out of the hospital as soon as possible. And every time I go to hospital I must adhere to or something and I can go also to the hospital

# Respondent:

First time I, when I was in hospital, actually they give me the paper, let me sign, actually I cannot, I cannot say no, because I, contract say if you say no, and maybe you need stay in the hospital a long time or, let me think about, or you need to sign it and if you don't sign it, maybe police come and catch you to the hospital, something else, all of these, make me feel I have no choice. I feel the give me the contract, make me feel I have no choice at that time.

The coercive nature of the treatment was emphasized by AB011, where discharge was contingent upon consent to the treatment.

#### Respondent:

They say they do it for my own good, right, and I appreciate that. But I would have liked to do it myself, right. I like doing things myself.

#### Respondent

Because he said to me 'if you don't go on the CTO, I won't discharge you. You'll stay in hospital longer.'

### Interviewer:

And how did that make you feel?

### Respondent:

Sad

Interviewer:

Yeah.

## Respondent:

So I said if I won't be on a CTO, then I won't be discharged and I want to be discharged, I want to go home, I want to be discharged, so I decided to be on CTO.

The feeling of being controlled was discussed by participants AB013 and AB024.

## Participant AB013

### Respondent:

Oh I thought that was mean. I thought there was someone trying to say "look we're going to have to force you to have this type of thing but I really was scared of that and I thought it was kind of taking it a little bit too far. I thought it was taking all my rights away from me.

#### Interviewer:

Yeah and how did that make you feel?

### Respondent:

Well it made me feel very vulnerable. And I also built quite a bit of anger at them as well. I thought they were interfering too much in my life and not leaving anything up to me, I mean at that point I never thought I would get my life back anyway. But still I thought that as a human being, I should have some rights or I should be able to tell when I had to go to the hospital and that the hospital should be there for me not them sending police to drag me off to the hospital.

# Participant AB024

It's like I get up in the morning and I'm a bit concerned that I should take my medication on a continuous basis, that we should go and see my doctor and I should go for injections and I should see my personal support worker. So it puts a bit of stress, not a stress but it concerns me sometimes because I have to be very efficient and I have to remember and I have to keep appointments and I jot it down that I have to go there and I have to do this, I have to do this. So it's a bit pressurizing and it's scary too that if they would take me to the hospital and they would hospitalize me again if I don't comply with their demands. So it's scary in that sense that it would make my condition worse if they take me to the hospital and they hospitalize me again against my wishes, so even if you are talking to me and I seem very clear and logical, right, but the doctors there, I think

they're inefficient. They don't understand this, they say that I'm not capable of making my own decisions and I'm not this, I'm not that, I need medication. Even though you can talk to my doctor there, the one who knows me for eight years that I'm very capable of looking after myself and stuff, doing my own thing.

The participants shared their experiences of feeling coerced and lacking the opportunity to make their own treatment decisions. They believed the treatment infringed on their rights as individuals and compelled them to make decisions based on the fact that they wanted to be discharged from the hospital.

### Disempowerment

Participant AB001 described how helpless she felt on the CTO. She saw herself as part of a system, one that forced her to abide by rules and regulations that she found dominating which prevented her from being her own self.

Well I believe that I'm a part of the system.....I'm a part of basically...I'm a patient of a CTO...I need to follow certain guidelines that I was committed to, the contract that was signed with me and the CTO and the psychiatrist so I need to follow certain guidelines

Just when I said I'm a part of the system, it's basically I'm a patient. That's what I'm talking about. I'm a patient, although I'm not in a hospital, I still consider myself as a patient and be monitored because if I don't adhere to the agreement of the CTO they would Form me and they would put me back into the hospital. So I'm still a patient, so I'm still, although I'm discharged out of hospital, I'm still a patient.

I don't like it. I feel pressured that I need to be on my best behaviour. I can't speak about any certain things. I have to keep, if I'm thinking about it, I have to keep to myself because I'm being monitored so it's uncomfortable. Sometimes it's a little bit stressful because the case manager is always good, he comes and he asks you certain questions and you have to answer it perfect. You have to be careful what you say because if you say certain things, it's written down, it can be used against you and then he basically does a report and he speaks to your psychiatrist and then he can speak to the psychiatrist and state any concern that he has

and then the psychiatrist can make a decision whether or not I'm able to function by myself or function in a community. So I have to be careful what I say to the case manager.

This sentiment was echoed by AB003 who stated that being part of the CTO process meant one's freedom and the ability to express one's self is curtailed. This participant also felt being monitored by family members to ensure compliance with the rules and regulations of the treatment.

Well with a CTO, once they put you on the CTO, it limits your speech, it limits your freedom, it limits quite a bit of what you could do as an individual to prosper in life. That's basically what I would say.

They get your family to watch that too, you feel like a prisoner you know, like you're a prisoner in your own household, you know like even your younger child is being set up to hide mom's things to see if she's going to go bonkers, you know?

Participant AB004 articulated that though there is the perception CTO participants have rights; physicians and members of the Ontario review board were able to make decisions that override the rights of clients on a CTO.

I do have rights but I kind of feel, but sometimes it's up to the doctor or like I say sometimes doctor asks strange questions; like you talk to the doctor if he can cancel the CTO or something but the review board and the doctor have a lot of power in the CTO. So sometimes the review team they listen to him a lot more than they listen to the patient; especially when the lawyer is not strong. Last time I had my review board the lawyer was not strong and the CTO team, it depends what people work there, they were not listening to her, to my lawyer, they were listening to my doctor to put me back on the CTO and the same treatment. They put me back on the CTO again. So now he says he's going to cancel it but it doesn't make any difference if I'm...if I didn't continue just to take my medication, he's going to put me back.

Another reference to power was when participants felt they were excluded from deciding what was in their best interest. Participant AB008 made reference to the use of "cuff, cuff" referring to hand cuffs and the power of the police to apprehend.

Sometimes I don't like, but sometimes I think it's necessary, because

sometimes the CTO will, they have something, because CTO make me go to the hospital and I go to the hospital. I see another patient and I see myself just like them and then I wake up. And also, the CTO, but one thing I don't like is, I didn't think any mistakes, but the hospital give me the cuff. Cuff? Cuff?

Participant AB011 discussed how she had to be at her best behavior for appointments with her case manager and the need to assure her worker that she is complying with every aspect of the treatment. She had to go to every length to portray herself as doing well, which offered a form of control as she believed it was a way of keeping her out of hospital and avoiding contact with the police.

## Respondent:

At least I know we have plans on the days she will come, right, because I know those days she will come. I have to be at my best.

### Interviewer

Why would you have to be at your best on a day the worker is coming?

### Respondent:

So that she will know I'm doing well. (laughter)

#### Interviewer:

So the worker will know you are doing well. But other times, do you feel you are not doing well?

#### Respondent:

No, I'm doing well too. I do my best the days she is coming.

Interviewer:

So do you feel like, there is added pressure on you or something?

#### Respondent:

It's like that it's like an added pressure.

#### Interviewer:

Like always, do you want to explain that, describe that a little bit?

# Respondent:

Like I always have to be my best, I always have to do things that to make me happy, that they have to be happy, right.

Participant AB012 believed that the treatment imposed controlled every aspect of his

life and segregated him from the rest of the world.

Well, I feel good and in a way I feel bad because they did tell me what to do. So basically I'm not free. Basically they tell me I have to take my medication at night before I go to bed. Basically they tell me I can't smoke no weed. They say I can't drink no liquor. I can't drink alcohol anymore because when you're taking medication, on the bottle it says no alcohol. So I'm actually segregated from the whole world. I'm in a totally different world than everybody else, so a lot of people don't realize that my life is totally different than everybody else. When I walk the streets, I walk the streets to my ability and do what I do to my ability. I always look to see if it's justified for me to take a person's life. Is it justified for me to punch a bus driver in the face if he try to tell me my mental capacity \_\_\_\_\_? Is it justified for me to rob Tim Horton's if I'm hungry? You know, is it justified for me to do what I do, you know? Is it justified for me to walk around the streets and thinking I was supposed to be a cop and now the cops are arresting me because they think I'm crazy. Is it justified? That's a powerful word, 'is it justified.'

Participant AB019 made reference to the contractual nature of the CTO and the belief is that participants under this treatment did not have any rights.

Um...no, I cannot refuse it but, because if I refuse it I'll be back to the hospital again. That's not something I want. So I don't have the right to refuse it ...

## Participant AB020 reiterates this sentiment:

No I didn't feel like I had any rights, whatsoever; I even mentioned that to the, I think one of the nurses or to the doctors, saying "you know I have a right to not take this medication, you know. I'm a human being just like everyone else and I feel like I deserve to be treated with respect and having an illness doesn't make me any less of a person.

Well the name suggests that it's a Community Treatment Order, community treatment order meaning it's an order that's been ordered by the courts to have somebody placed under surveillance to make sure that they are taking their medication. I don't know why the CTO came in to be, to place, maybe some people...who are a menace to society or I don't know what the whole reasoning was behind setting up a CTO but if I did know that, it would probably help me understand better why the CTO was put in place.

Participant AB020 also expressed feelings of powerlessness; not being able fight or appeal the treatment created more anger and frustration.

My overall experience is...I just felt powerless in a sense. My rights were, I don't know if I had any rights. I mean I did have a rights counselor but I didn't hear the sign that I had a choice to say no to it. I didn't hear that from the rights activist or I don't know what to call her. But there should be someone that can say "you know what, even though they're putting you on the CTO, you have the right to say no to it because what you do with your illness is up to you whether you go for the medication or not" and in the sense I think if people decide not to take the medication, it'll be less of a strain on the system. But if they do decide to take it, which I've been taking it then it's also their right to do so. Overall I think it's...I don't know as much about it as I should but I don't even know how long it took them to put the paperwork, all the paperwork together for just me, for the individual but...yeah I think, I think it's a lot of work for just one person to be put on a CTO.

The participants believed that the treatment made them feel as if they had been court ordered to undergo treatment, which limited their ability to make decisions on what is in their best interests. They stated that the thought of "order" made them feel they had no rights regardless of the case managers who worked with them. Reference to "order" reminded the participants of probationary order in the criminal justice system.

## **Empowerment**

Despite the number of participants expressing powerlessness under CTO, there were those who believed the treatment enhanced their situation. The treatment made them realize the importance of following through with the CTO and how it has improved their condition. Though most initially expressed disdain for CTOs, they eventually realized its importance.

Participant AB005 described the CTO process as a proactive treatment and despite

her initial apprehension, she felt supported throughout the process by the case management team. She believed that the treatment was not against one's freedom rather to provide support.

Like I said, it's definitely one step at a time; you feel very nervous, very disturbed and confused and uncomfortable and there's not a lot you can say or do and they definitely do care about you the CTO, and you're free to do whatever you want to do from the CTO perspective. They're not forcing anything. So it feels like they're forcing something on you. It feels like they're trying to tease you or bother you or waste your time, take your money and just completely abuse you or something. That's exactly how it feels like. But they make sure that they're not forcing anything on you and they make you sure that you have all the freedom in the world. You can even talk to the lawyers if you want them to back off.

She believed the CTO offered the freedom to make any decisions she wanted, including termination of the treatment.

I have all the freedom to back off from her and CTO and CMHA if that's how I like it.

According to participant AB006, being on a CTO empowered her. Her relationship with her CTO case manager enabled her to take control of her life.

...the more I talk to her, the more empowered I feel, like I'm taking my life back in control, you know. I can survive. I can take care of my son, you know.

Participant AB011 realized that taking her medication improved her condition, and an improved condition meant an improvement in her quality of life.

Obligation that I promised myself I would be taking my medication everyday. I didn't promise anybody. I promised myself.

I feel it's my own obligation to take my medication. It is up to me whether to take it or not, but I decided to take it.

Participant AB017 articulated the sentiments expressed by other participants

regarding initial reaction to the treatment and eventually realizing it was for their wellbeing. The participant expressed appreciation for the rapport and good working relationship established with the case management team.

Being on a CTO right now means I'm still under orders and that's what bothers me the most, being under orders. It's a contract. Contracts are not that bad if your best interests are at heart. As I said once before, it can help you and it can harm you. It took awhile for me to see which is which right now and if it's not done right, it can harm me and if I'm not right, it can help. But how it chooses to help me is all up on me and someone to the CTO worker and that varies. I have a very good worker but there is some fine links that need to be worked out.

This chapter presented the findings of the interviews with the participants and described the meanings participants associated with their experiences within the mental health system. The chapter explored the major categories and themes which included experiences with the mental health system, rapport with case management team, CTOs in cross cultural context and power in the treatment process. The next chapter is devoted to the interpretation of these findings.

# **Chapter 7**

## **Discussions**

This study explored the lived experience of twenty-four participants of ethnoracial minority backgrounds who either were or had been recipients of community treatment orders (CTOs) in Toronto, Canada. The study sought to narrow the gap in literature on the lived experiences of mandated outpatient mental health treatment among ethno-racial minority clients and also to fulfill the researcher's curiosity of the impact of CTOs on this marginalized population.

The investigation utilized a phenomenological approach to gain insight into the experience of the participants while being on a CTO. It explored the extent to which CTOs met the needs of ethno-racial minority clients compared to other experiences they encountered within the mental health system, as well as their perspective of the treatment and its impact. An analysis of findings is categorized in Table 7:1.

Table 7:1 Lived experience of CTOs among ethno-racial minority clients

Dimension	Description
Experiences with the	Experience of participants within the mental health system
mental health system	prior to being on a CTO. Experiences refer to the relationship
<ul> <li>Resources</li> </ul>	with outpatient mental health or community based support
	programs.
CTO Experiences	Participants lived experiences with CTOs, the impression of
<ul> <li>Appreciation</li> </ul>	CTOs and impact on their day-to-day activities.
<ul> <li>Ambivalence</li> </ul>	
<ul> <li>Medication</li> </ul>	
<ul> <li>Feelings about</li> </ul>	
self	
<ul> <li>Inhibition</li> </ul>	
• stigma	

Rapport with clinical	The participants' interaction and communication with case
team	management team and physicians/psychiatrists in terms of
<ul> <li>Support</li> </ul>	support.
CTOs in Cross-cultural	Issues relating to treatment from the perspectives of ethno-
context	racial minority clients and its impact on race and culture.
<ul> <li>Racism</li> </ul>	
<ul> <li>Canada vs.</li> </ul>	
Homeland	
Power in the treatment	Encompasses multiple forms of power within the mental
process	health system; power that dominates an individual and also
<ul> <li>Coercion</li> </ul>	that which empowers and enhances one's self esteem.
<ul> <li>Disempowerment</li> </ul>	
• Empowerment	
-	

The themes generated from the analysis of the study provide perspectives on the lived experiences of the participants on CTOs. Interpretation of the participants' feedback is divided into three main parts: the first part consists of three major topics: experiences with the mental health system; CTO experiences; and rapport with the clinical team, all of which are described as the *Interface between Clients and the System* and focuses on participants' interaction with either the mental health system or representatives of the system. The second part consists of racism and culture (Canada versus homeland), described as *Intersecting Diversity*. The third part explores power and focuses on the following themes: coercion, empowerment and disempowerment, and is described as *Forms of Power*.

### Interface between Clients and the System

The interface between the participants and the mental health system is multifaceted, as it involves multiple players in the process of ensuring efficient treatment for the marginalized. The term "treatment" is described as resources or services that are provided clients to improve their condition. The findings in the study revealed that most

of the participants acknowledged benefiting from CTOs, the absence of which, a number of them would not have had access to outpatient mental health support and fallen through "the cracks" of the mental health system.

The study suggests that the structure of the mental health system contributed to the inability of individuals of ethno-racial minority backgrounds to access effective treatment. The participants' response highlighted the importance of resources in the treatment of the mentally ill; particularly those deemed seriously and persistently mentally ill, and that case management support played a significant role in their lives. The majority of the participants reported lack of resources in the community upon discharge from hospital. As Participant AB001 stated, "I wasn't receiving any services. The only thing is I went to the hospital, they monitored my illness and gave medication and that's about it." Even those who received support did not feel they benefited much from it.

Studies have shown that mental disorders are on average more prevalent among minority communities than the dominant group, and this is fuelled by race, socioeconomic disparity and other factors (McKenzie, Semele, van Horn, et al, 2001; US Department of Health and Human Services – Mental Health, 2001). Also, ethno-racial minority clients have less access to treatment and are more likely to reject treatment due to its inadequacy and the lack of trust of the system (Nelson, 2004; Shavers and Shavers, 2006). Based on the study, most of the participants tended not to benefit from the resources available in the mental health system prior to being on CTO. This was due to the lack of support and information regarding the mental health system. Thus, they held on to their fear and distrust of the system and refrained from seeking help.

The study showed that ethno-racial minority participants benefited from being on a CTO. The treatment facilitated access to a system that provided support and guidance, and also ensured continued support and stability in the lives of these clients. Studies show that CTOs play an integral role in improving the lives of those who participate in the treatment, as it provides continual support (Currier, 1997; Dawson and Romans, 2001; Romans, Dawson, Mullen and Gibbs, 2004).

For participants of ethno-racial minority background, CTOs ensured they would not fall through the "cracks" of the mental health system (Hiday and Scheid, 1991).

Reference to "hard to treat," or "falling through the cracks of the system" refers to individuals diagnosed as seriously and persistently mentally ill. These are individuals who typically receive treatment in hospitals but do not follow through with outpatient treatment and thus decompensate, which often necessitate readmission to hospital.

Frequent admissions to and discharge from hospital is often referred to as the "revolving door syndrome." The participants' narratives suggested that having a more effective outpatient support could have prevented the revolving door syndrome. Could there be the probability that the participants needed effective outpatient treatment rather than mandated outpatient treatment? In the study, CTOs provided the participants with the needed community resources, which would neither have been available nor utilized had they been given the choice to make their own treatment decisions.

With regard to participants' experience with the CTO, majority of the participants expressed appreciation and supported the benefits of the treatment. According to the participants, CTOs enabled them to follow through with the expectations of the treatment and gave them the opportunity to get on with their lives. Nonetheless, when questioned

whether they would participate in the treatment again, all the participants said no, however, they all agreed they would recommended it for others. This may be interpreted as an acknowledgement on the part of the participants of the benefit of the treatment and their intention to build on the progress made.

In studies by Gibbs, et al, (2004) and Mullen, Gibbs and Dawson (2006), participants expressed some benefit of the treatment and found it helpful and safe, while others felt it prevented them from making their own decisions. Studies that have explored the effectiveness of mandated treatment have primarily been through the lenses of clinicians, family members or other stakeholders. This study therefore lends to the epistemological breadth of the literature because it utilizes an interpretive methodology to complement all the post-positivist work.

Despite the participants' appreciation with regard to CTOs, it should be noted that most of them did not initially embrace the treatment. The participants' ambivalence was reflected in the opposing feelings or emotions toward the treatment. These emotions may be attributed the lack of understanding or familiarity with this treatment option. The participants likened the treatment to being on probation and associated it with the criminal justice system.

The finding of ambivalence in this study is significant, as it has not been previously explored in the literature. While the impressions of participants have been addressed in previous studies (Gibbs, et al, (2004); Mullen, Gibbs and Dawson, 2006), none have specifically explored participants' feelings of ambivalence.

Participants' compliance with medication is an integral part of the CTO process, and this is clearly articulated in the treatment plan. The participants reported on the

impact of medication on their wellbeing. According to the participants, medication compliance enhanced their treatment. The finding confirms what the literature has looked at on how mandated outpatient mental health treatment improve medication adherence (Murhead, Harvey and Ingram, 2006; Swartz, et al, 2001; Vaughn, et al, 2000). The participants valued medication as an outcome in the study.

Participant AB004 succinctly articulated the impact of medication in the following statement; which sums up the feelings and lived experience of the participants in the study.

Well, definitely being on a CTO did help me a lot because I had a tendency to not take my medication properly and I was scared of medication. I totally needed a lot of support to take my medication and I was very scared of the doctors and it was very, sometimes it was scary for me to attend appointments with the doctors. I used to get very anxious and confused and nervous. It felt like some examination was coming over for me and I had to prepare for it. But being on a CTO, the doctors made sure that I regularly attended my appointments as well as took my medication, day and night and not only was it about medication and appointments, I also felt that it was about taking care of my diet and my personal activities as well.

The emphasis on medication in the implementation of CTOs in Ontario brings to the fore importance of the recovery model. The recovery approach to mental health treatment emphasizes the wellbeing of the client and the client's involvement in his/her own treatment. Recovery focuses on the empowering of the participant / client rather than focusing solely on medication in the treatment process. For example, participants AB015, felt he needed cognitive therapy as part of his treatment, and was not getting it. It is therefore important to empower clients to explore the treatment regimen that is deemed most appropriate for them.

A literature search did not reveal any study that explored participants' perception or feelings about mandated outpatient treatment or CTOs. The phenomenological approach to this study facilitated examination of the participants' feelings about CTOs, and for the most part was reported as positive. Most of the participants found the treatment beneficial; for instance, one client reported that the treatment enabled her to be in her "routine", that is, it gave her the ability to be organized and lead a "normal life" without necessarily frequenting the hospital, as in the past. The feelings expressed by participants reflected their motivation to make the best of the treatment opportunities available to them.

The finding in this study adds to the body of literature on CTOs that participants of ethno-racial minority background appreciate CTOs as it keeps them organised and well grounded. The benefit of the treatment enabled them to establish rapport with loved ones, thus enhancing their self-esteem.

An observation regarding benefits of the treatment was that participants of ethnoracial minority background benefited from the care provided by and interaction with the CTO treatment team, and the close resultant relationship enabled the participants to open up and positively respond to the treatment.

Participants' interaction with the mental health system with regard to CTOs was generally reported as positive. However, concerns were also expressed about CTOs, where a minority of the participants found the treatment inhibiting and time consuming, and believed that it infringed on their rights and had a negative impact on their treatment. This assertion by the participants is consistent with the literature (Ajzenstadt, Aviram, Kalian and Kanter, 2001; Currier, 1997; Dawson and Romans, 2001; Gibb, et al, 2004;

O'Reilly, Keegan and Elias, 2000; Ozgul and Brunero, 1997; Rolfe, 2001; Szigeti, 2004). However, those were based on the observations of the researchers rather than the feelings of the participants. The uniqueness of this study is that, it gave the participants an opportunity to express their feelings regarding the treatment. It not only confirms the findings of other researchers, but also sheds light on the views of ethno-racial minority clients whose voice has not previously been heard regarding CTOs.

Studies have explored the impact of the support provided by clinicians and case management teams, many of which addressed the perspective of clinicians and stakeholders (Gibb, et al, 2004; Mullen, Gibbs, and Dawson, 2006; O'Reilly, Keegan and Elias 2000; Rolfe, 2001). The uniqueness of this study was the feedback from the participants. The support and close relationship with the caseworkers and clinicians provided participants with some form of security.

There is a paucity of literature on participants' perception of CTOs; most of the studies elicit perspectives on CTOs from clinicians and family members and not the participants themselves (Ajzenstadt, Aviram, Kalian and Kanter, 2001; Currier, 1997; Dawson and Romans, 2001; O'Reilly, Keegan and Elias, 2000; Ozgul and Brunero, 1997; Rolfe, 2001). Feedback from these sources were both positive and negative; CTOs were found to have positive outcomes and reduced family conflict and client distress, as well as negative effects on clients which prevented effective treatment (Ajzenstadt, Aviram, Kalian and Kanter, 2001).

The study showed that the rapport between the ethno-racial minority clients and the clinical team was enhanced during the CTO period. Most of the participants felt they were heard and treated with respect and dignity. Existing literature does not discuss the

rapport between the clinical team and participants of the treatment from the perspective of the clients. However, studies among clinicians reported the perception of most practitioners with regard to CTOs as enhancing clients' priority for care and the therapeutic alliance between the client and practitioner (Dawson and Romans, 2001; O'Reilly, Keegan and Elias, 2000; Romans, Dawson, Mullen and Gibbs, 2004; Rolfe, 2001). Others described it as enhancing support for continued contact and stability. In this study, the participants clearly articulated the benefits of the treatment and appreciated the rapport they developed with their clinicians; they felt validated and respected by their clinicians.

Also, the information provided by the participants showed the participants did not find the treatment "culturally responsive" (Chow and Austin, 2008). They attributed their wellbeing to the support and care of their clinicians. It could therefore be argued that CTO as treatment does not put emphasis on the cultural responsiveness of the treatment.

Another theme generated from the findings was stigma. Most of the participants reported feeling stigmatized as a result of the treatment. The literature cites numerous studies on stigma and mental health; however, there are only a few on CTO clients and stigma. According to Brophy and Ring (2004), CTO participants often feel stigmatized by the treatment due to the involvement of the police and the threat of hospitalization for non-compliance with treatment. This study confirmed those findings and also suggested that CTO clients could feel stigmatized based solely on the fact that they have been on a CTO and therefore subjected to the stereotypes and assumptions about CTO clients. The participants indicated that the experience of being on a CTO made them feel like second-class citizens.

#### **Cross-Cultural Context**

There is a dearth of literature on CTOs within the context of race and culture. The review of CTOs in Ontario identified concerns around the lack of consideration for diversity in the establishment CTOs and the provision of services to clients of ethnoracial minority backgrounds (Dreezer, Bay and Hoff, 2005). This study makes a significant contribution to the body of literature as it reveals the participants' perception in relation to race and its impact on their treatment. The researcher further explored the experience of immigrant participants within the mental health system in comparison to their countries of origin.

Research shows that clients of ethno-racial minority backgrounds experience racism in the mental health system, in part due to the socio-economic status of the clients and their distrust of the system (McKenzie, Semele, van Horn et al, 2001; Nelson, 2004; Shavers and Shavers, 2006; US Department of Health and Human Services – Mental Health, 2001). In this study, the findings were contrary; participants believed that CTOs were neither racist nor had any racist implications or ramifications on the participants. Twenty-two participants of the study believed that outpatient mandated treatment, that is, CTO was fair, worthwhile and respectful of all races.

The views of two participants dissented from the majority; they felt the treatment was racist and that it was not necessary for clients of ethno-racial minority backgrounds to experience fair treatment. One participant argued that the racist nature of the treatment is evident in how clients of ethno-racial minority backgrounds are discouraged from, or not referred to psychotherapy, unlike their counterparts of the dominant race. They believed CTOs were discriminatory, infringed on their rights and did not provide adequate

opportunity to explore other forms of treatment. They felt they were not offered the services made available to individuals of the dominant culture. This argument supports the findings by researchers that individuals from minority backgrounds diagnosed with mental illness are less likely to receive adequate treatment, thus making compliance with mental health treatment difficult (Nelson, 2004; Shavers and Shavers, 2006).

This line of argument, however, lacks applicability to CTOs where referred individuals are provided available treatment options, irrespective of their race, socioeconomic status or diagnosis. Treatment plans are developed by the coordinators in conjunction with the client as stipulated in the Ontario Mental Health Act; it mandates CTO participants be provided with case management and other supports that enhance their welfare in the community (Appendix F – sample treatment plan).

Feedback from the participants presented a measure of dichotomy often experienced by immigrants (Bhabha, 1998). Racism as expressed by the majority of clients is sometimes counter-intuitive. According to Bhabha (1998), the perception of one's current environment in comparison to the country of origin often presents difficulty accepting whether what is being experienced has a negative impact. Racism may be contextualized in different forms. In this study, the participants acknowledged knowing what racism is and acknowledged experiencing it. However, the finding that the majority of the participants did not associate CTOs with racism may be attributed to a number of factors. Firstly, the fact that they believed treatment is meted out fairly, secondly, that the participants viewed the treatment as being better than the resources or the support prior to the CTOs or that offered in their homeland.

The second important factor addressed cultural differences, or the interaction of

different cultures. The ethno-racial minority participants, the majority of whom were immigrants, felt comfortable discussing and comparing the mental health system and services in Canada, a western country, to those in their native and developing countries. These discussions raised the issue of identity and citizenship, and the struggles immigrants experience as part of the process of acculturation (Ho, 2002). Despite how long one has lived in a host country, there is often the tendency of either comparing or looking at issues through the lenses of their countries of origin. Most of the participants, however, appreciated the opportunities and support received in the host country, Canada.

The participants' perception of the CTO process could be explored from the perspective of the post-colonial framework, where treatment is generally graded higher than that of the home country of the participant. These views of the participants may be juxtaposed with the idea propagated by the colonial powers that anything Western is superior. So the superiority of the oppressor or whether the treatment is inferior or infringes on the rights of the participants is either not recognized or ignored (Fanon, 1967).

On the other hand, the issue of racism comes into play where individuals of ethnoracial minority background are made to feel inferior about who they are and the type of resources / services provided to them. In this regard, service deemed appropriate for the dominant race is appreciated whether it has their welfare or interest at heart (Williams, 2003). It is acknowledged, however, that CTOs provided participants with treatment that they lacked in their home countries where mental health services are under resourced and associated with colonial rule.

### **Forms of Power**

Power, as observed by the participants can be both empowering and disempowering, with regard to the CTO. Power in the interviews was often defined by the way the participants felt disempowered by the system. Existing literature does not explicitly discuss issues of disempowerment among mandated outpatient treatment participants; rather, most of the studies explored the subject from the perspective of service providers (Mullen, Gibbs, Dawson, 2006).

The insight provided by the participants is unique because it sheds light on the their feelings and impressions about the disempowering nature of the treatment, and in particular, their perspective as ethno-racial minority participants. Some of the participants reported feeling helpless and powerless, and that CTOs made them a "part of a system," taking away their right to make meaningful decisions. Comments like, "I need to follow certain guidelines that I was committed to…" speaks to the feelings of powerless and the need to abide by the strict rules of the treatment. Others described the fact that they had to be on their best behaviour and believed the treatment limited their speech and freedom.

Participants reported the treatment made them feel powerless and thus prevented them from seeking help; they felt controlled in every way by the system. Their lived experience was based on fear that they might inadvertently violate the conditions of their treatment and be apprehended. Others questioned the worth of CTOs as a result of this.

Linhorst (2006) postulates that the mentally ill experience hopelessness as a result of powerlessness, which exposes them to inhumane, emotional, physical and psychological treatment. For individuals of ethno-racial minority backgrounds,

hopelessness and being persons of colour creates multiple levels of oppression. Thus, being of a minority race entails its own problems and is further compounded when coupled with mental illness. The anti-oppressive and anti-racist frameworks support the notion that oppressions can increase due to the intersecting identities presented by the participants. Therefore, empowering individuals of ethno-racial background provides the knowledge and skills to address conditions of oppression. Knowledge and support equip the participants to be capable of questioning issues that seek to oppress them.

Despite arguments that CTOs are considered disempowering, the participants, based on their lived experience revealed that they found CTOs to be empowering. They reported that the treatment "enhanced their situations," alluding to the fact that the treatment played an important role in improving their condition. They appreciated what the CTO had done for them and acknowledged the benefits of the treatment.

Furthermore, their improved condition made them realize the importance of following through with the treatment. One participant described the CTO as a "proactive approach" to their wellbeing in that it impacted and transformed their lives. Despite the negative impression or connotation attached to mandated treatment as reported in the literature, a number of the participants in the study believed the treatment enhanced their condition.

The empowerment framework speaks to the enhancement of clients' condition based on the support and resources provided by workers. The view of the participants regarding empowerment is particularly important as it adds to the body of literature that presents contrary points of view. A number of research investigations report that the treatment affects CTO clients in a negative way. Among the ethno-racial CTO participants in this study, however, the impression was positive and that it offers another

viewpoint to the existing literature regarding the perspective of this minority population where they felt supported, and encouraged and also appreciated.

Coercion emerged as an important theme in the study; this confirmed previous studies on CTOs in the past (Chodoff, 1984; Diamond, 1995; Elbogen, Swanson and Swartz, 2003; Geller, 1986; Mfoafo-M'Carthy and Williams, 2010). Participants described that the treatment made them feel coerced, powerless and thus prevented them from seeking help from the mental health system. They entertained the thought that seeking help might result in long hospitalizations. The participants talked about their experiences with the implementation of CTOs where they felt compelled to agree to the treatment or endure prolonged hospitalization. Others shared experiences where they felt threatened to follow through with CTOs or risk child welfare involvement in their situation. They stated that they felt controlled in every way by the system. Their lived experience was based on fear - the fear that they might inadvertently abrogate the conditions of their treatment, and be apprehended. The thought of being on a CTO made a number of the participants wonder its worth. Although the implementation of CTOs could be ethically questioned, the eventual benefit of the treatment to the participants should not be overlooked.

Despite the positive feedback regarding CTOs, some participants criticized the treatment as a program that monitored and inhibited their progress and likened it to a parole or penal system that imposed conditions and limited people's freedom. The participants found it inhibiting because it did not respect their rights in the decision-making process and wondered why a physician could make a treatment decision on their behalf without their input. The post-colonial, anti-oppressive / anti-racist and

empowerment frameworks converge in the participants opposition to processes involved in the use of power or control over people under the guise of benevolence.

The findings of the study identified a number of themes from the CTO participants of ethno-racial minority backgrounds. Some themes confirmed the findings of earlier research while others added to the existing body of literature on CTOs. Of significance, participants in this study believed CTOs enabled them to access treatment resources which otherwise would not have been available to them. Previous studies have neglected this aspect of CTOs, focusing instead on how the inclusion of case management and medication makes a difference in the lives of outpatient mental health clients.

Participants' appreciation of the treatment and feelings about being on a CTO added to the literature. These topics within the context of CTOs have not previously been explored even within the dominant race.

Participants' perspectives on racism, empowerment, disempowerment and the cultural context of CTOs also added to the literature as it explored the viewpoint of ethno-racial minority participants. The ambivalence expressed by participants, the role of medication, inhibition of the treatment and stigma reported in this study has been addressed in the literature. This study presented the perspective of ethno-racial minority participants and their impressions and lived experience of CTOs.

The utilization of a phenomenological study enabled the participants to articulate their lived experience in a way that would not have expressed if any other qualitative method had been used. The participants discussed the impact of the experience of CTOs on their lived experience as individuals of ethno-racial minority background. The experience of the participants with regard to the mental health system was clearly stated.

The participants talked about their experience as immigrants in Canada and their perception of CTOs as treatment. Overall, majority of the participants believed that CTOs in Toronto did not have any racist implications; rather it ensured that they received adequate treatment. The participants also discussed the importance of power and its impact in the treatment process.

# **Study's Limitations**

The purpose of this study was to explore the lived experience of ethno-racial minority clients who have experienced CTOs in the City of Toronto. Though it may reflect the experiences other minority CTO clients, it cannot be generalized to all ethnoracial minority clients in Ontario. Another limitation is that participants interviewed for this study do not reflect actual representation of the ethno-racial minority communities in Toronto; the recruiting process and purposive sampling utilized in this study resulted in more participants from one ethno-racial minority community (Blacks) than any other minority group. Furthermore, there was little representation from other communities, even though they are reflected in CTO data. It is worth noting that there was a sampling bias in the recruitment of participants for the study. The majority of the participants were Blacks (14) which was about 58.3% of those who responded to the study.

The researcher's position as a CTO coordinator may be considered a limitation based on the exposure to and experience with this client population. To mitigate any preconceptions about the treatment, the researcher paid particular attention to bracketing. The researcher's role in this study could be viewed as an "insider looking in", rather than an uninvolved and independent outsider.

Another limitation is that, due to financial constraints the study was conducted solely in English despite the sample population being from diverse ethno-racial minority groups. As a result, the research may not have heard from participants who were not native speakers and would not have fully captured all the experience of participants who did not speak English.

A number of the participants at the outset of and during the interview were a bit hesitant to provide information and engage with the researcher even though they had agreed to participate in the study and had signed the confidentiality agreement. This feeling could have been the participants' perception of the interviewer as a person wielding power and may be considered him as part of the system. To mitigate the demands of the interview and remove any fear, the researcher did not identify himself as a CTO Coordinator, and in doing so, may have allayed any suspicion or fear of being punished for any negative feedback to interview questions.

The final limitation is one that is common to studies involving virtually any person or groups of people, and this includes individuals with serious mental illness, and that is recall bias. As was expected, not all the participants were able to provide vivid accounts of their experience. A number of participants were unable to clearly articulate their lived experience on the CTO. It could be described as part of human nature where there is the tendency for individuals to either forget part or details of an experience in life.

### **Implications for Research / Future Research**

The finding of this study adds to the broader mental health literature and provides a deeper understanding of mandated outpatient treatment of seriously mentally ill individuals of ethno-racial minority backgrounds. The study provides the opening for further investigations, particularly those that focus on ethno-racial minority communities less represented in this study. The outcomes shed light on an area of research that has been neglected in the literature, and lends importance to further explore the perspective of ethno-racial minority clients in the treatment process. It is hoped that this study, and similar research based on ethno-racial minority communities, will bring awareness to the importance of the immigrant population as they continue to grow in Canada.

Also, studying individuals of ethno-racial minority background is very helpful as they are in a position to provide insight to conditions that affect individuals of different cultural or racial background. Their feedback and expertise will enhance the services and resources needed in the community and other aspects of the system.

A critical finding of the study was that the participants found CTOs provided them with the needed resources when they were not getting them. Further research is therefore needed to explore whether individuals in the mental health system will be well supported with resources without necessarily participating in a mandated outpatient treatment. This study will require a comparison to regular mental health case management services. It will be also be important to do a study of clients who are not of ethno-racial minority background but of other ethnic groups. A study exploring the lived experience of the dominant race / culture will be worth looking at.

A final recommendation is the replication of this study in other provinces of Canada with CTOs, such as Saskatchewan, Nova Scotia and Newfoundland to confirm the findings of this study.

### **Implications for social work practice**

According to Williams (2008), it is imperative for social workers to explore research from the perspective of ethno-racial minority clients, as this is an area far too long neglected. As the profession of social work continues to explore avenues and devise the means to effectively engage marginalized clients and those from ethno-racial minority backgrounds, this study adds to the literature on the skills of engagement. It also provides an avenue for practitioners to utilize their skills to balance out coercive and potentially coercive experience like a CTO.

Cultural competence merits exploration in social work, as well as further investigation on the appropriate ways to provide effective treatment for clients in the community. The study showed that with adequate support and knowledge of cultural sensitivity, professionals are able to provide effective treatment for individuals in the mental health system.

Also, there are many community-based mental health treatment options that are available and should be explored, as not all mental health clients would benefit from a CTO. Knowledge of treatment options would enable clinicians to make better treatment decisions on behalf of their clients. Knowledge of CTOs would enable social workers to better advocate on behalf of their clients and better identify treatment options most appropriate and beneficial for the clients they serve. The study sheds light on the

importance of community-based supports for individuals with mental illness. It brings to the fore the importance of the mental health act (MHA) and the health care consent act (HCCA) without which individuals in the mental system in Ontario may find themselves underserved or unable to utilize the treatment and the resources available.

The study also highlights the importance of support of clinical support in enhancing practice rapport with clients. Providing adequate case management support for clients in the community contributes to their well being as it plays an effective role in enhancing their condition.

# **Implications for Policy**

The study raises questions and concerns about the status quo, and encourages the development of policies to more effectively address the provision of treatment for individuals of ethno-racial minority background. The research brings to the fore an important issue that affect the mentally ill, the fact that the lack of services and resources could result in the implementation of services like the mandated outpatient treatment. The study poses questions about mental health service provision to clients of ethno-racial minority background that have not been asked before. The findings of the study provide insight for policy makers and practitioners in the treatment of the mentally ill.

In the wake of the government of Ontario ensuring that effective system is utilized to ensure that adequate treatment is provided to the mentally ill, this study will add to the call as it speaks to the importance cultural competence and the importance of treatment.

The importance of this study cannot be over emphasized as it brings to the fore important treatment issues in the Canadian context. That is, mental health treatment among ethno-racial minority clients. The thesis presents the perception of ethno-racial minority clients by giving voice to this client population. The study will contribute to the discourse on treatment as it relates to individuals from ethno-racial minority communities and explore effective ways of engagement.

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## Appendix 1

## **Table: Summary of participants**

Ethno-racial	Gender (Female)	Gender (Male)
minority community		
Black	3	3
South Asian	3	3
East Asian	3	3
Other	3	3



#### **Appendix A:**

**Client Copy** 

"Experience is the best teacher": Community Treatment Orders (CTO) among Ethno-racial communities in Toronto: A Phenomenological study

#### **CONSENT TO PARTICIPATE IN RESEARCH**

#### • Purpose of Study

You are invited to take part in a study that is looking at the experiences of people from ethno-racial minority background that have either been or are on CTOs.

#### Procedure

You will be required to meet with a researcher for a period of about 60 to 90 minutes to answer questions on your experience of being on a CTO. For the purposes of accurate data collection, the interview will be audio taped and eventually transcribed. You will be assured of your confidentiality, as any information like your last name that links you to this interview will be deleted.

#### Potential Benefits and Risks

Though the outcome of the study may not benefit you directly, it will enhance professional understanding of how clients from ethno-racial minority backgrounds experience CTOs. At present there are no studies that provide that perspective and your participation will help add that perspective to the research literature. There will be no significant risks or negative consequences as a result of your participation. However,

there is the possibility that describing your experience may generate unsettled felling or stress. In the event of feeling unwell or exhibiting signs of stress the interviewer may pause or stop the interview and may seek medical attention on your behalf. Your involvement or refusal to participate will not negatively or positively affect the services you receive as a result of being on a CTO.

#### Compensation

There will be no costs to your participation in the interview. You will however be compensated \$20.00 for participating in this interview.

#### • Confidentiality

Every effort will be made to maintain your confidentiality during the interview. All information identifying you that is provided during the course of the interview will be properly secured. The information you provide in this study is confidential with the following exceptions: 1). If you disclose a plan or desire to harm yourself; 2) if you disclose a plan or desire to harm someone else, or; 3) if you disclose a situation in which a child is being abused or neglected. In any of these situations, the interviewer is professionally obligated to share this information with appropriate authorities. As a participant, you have the right to make a request to review, erase or edit any part of the transcript of the interview. Upon request, a copy of the transcript could be sent to you. All information gathered, will be stored in a secure, locked cabinet and the information will be destroyed after seven years. All electronic information will be stored in password-protected files on a secure computer and will also be destroyed after seven years. On the publication of the information or its publication, no information identifying you or other participants will be included.

• Participation and withdrawal

You have the right to agree to participate in this interview or not. On agreeing to be a

part of this study, you have the right to withdraw at any time without consequences.

Also, as a participant, you have the right to either answer or decline to answer any

questions.

**Dissemination of Findings** 

The research findings of this study will be published in professional journals and

presented at conferences and forums in the community. None of the information

presented will identify you. As a participant of the study, you have the right to request a

copy of the study report.

If you have any further questions about this study please contact:

Magnus Mfoafo-M'Carthy, MSW, RSW, Investigator

(416) 988-7469

Email: magnus.mfoafo.mcarthy@utoronto.ca

Or

Professor Charmaine Williams, PhD, Supervisor

(416) 946-8225

Email: Charmaine.williams@utoronto.ca

I have been given a copy of this form to keep.

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## Appendix B

### **Informed Consent**

I agree to participate in this study. I understand that I w	vill be asked questions about			
CTOs as treatment and its impact. I can do this by face	e-to-face interview. All my			
questions about the study have been answered. I have been made aware that I may choose				
to stop participating in the interview at any time and thi	is will not affect the services that I			
am receiving and would need in future.				
Signature of Client – Participant	Date			
Printed Name of Client – Participant	Date			
Signature of Witness	Date			
Signature of Researcher	Date			
If you have any questions or concerns about the rese	earch study, please do not			
hesitate to contact Magnus Mfoafo-M'Carthy at (41	6) 988-7469 or via email:			
magnus.mfoafo.mcarthy@utoronto.ca or				
Professor Charmaine Williams, PhD, Supervisor, (4	16) 946-8225			
Email charmaina williams Qutaranta an				

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#### **Appendix C: Participant Interview Guide**

**Introduction:** As you know, I am conducting interviews with individuals of ethno-racial minority background who have been or currently on Community treatment Orders (CTOs). The interviews are being conducted as part of my dissertation research at the Faculty of Social Work, University of Toronto. The purpose of the interview is to learn more about your experiences as an ethno-racial minority individual on a CTO in the mental health system.

- 1. First, I would like to start by asking how you became involved with the mental health system.
  - How you were initially referred?
  - Tell me about other services you have received prior to the CTO
  - What is your impression of those services in comparison with CTOs?
- 2. I am interested in exploring what it is like to be a person of ethno-racial minority background on a CTO
  - How do you feel being on a CTO?
  - How is your interaction with the case management system?
  - How is your involvement with your psychiatrist?
- 3. Some people have difficulty deciding to participate in the treatment program. What decision process did you go through as a person of ethno-racial minority background on whether to participate or not?
  - What particular things were you concerned about?
  - What is happening in your life now that you have been on a CTO?
- 4. Now that you have been on a CTO, how do you feel about it?
  - When you think of CTOs, what stands out for you?
  - How would you describe your feelings right now?
  - What doubts or lingering feelings do you have?
  - Tell me a story about a CTO experience that stands out in your mind
- 5. One of the things I am interested in finding is your experience as a client of ethno-racial minority background on a CTO. Some of the things I am interested in are:
  - How does your background affect the services you participate in or receive?
  - Are there activities that you wish you would engage in but unable to due to the treatment or who you are?
  - How does it affect your interaction with your worker? How about your psychiatrist? Other clients?
  - Are you comfortable discussing or talking about issues relating to race?

- 6. Would you share with me your experience with CTOs and how it has affected you as a person of ethno-racial minority background?
  - As you think of your participation in CTOs, what particular feelings do you have being part of it?
  - In what ways do you find the treatment of people like you client, immigrant, man / woman of ethno-racial minority background different from others?
- 7. Is there anything else you think is important for me to know, as a person of ethnoracial minority background, with regard to your experiences with CTOs?



## Appendix D: Participant Demographic Questionnaire

1.	Age:
2.	Ethnicity:
3.	Relationship status:
4.	Level of education:
5.	Employment:
6.	Source of income: <ul> <li>Employment</li> <li>Ontario works</li> <li>ODSP</li> <li>CPP</li> <li>Paid disability</li> </ul>
7.	How long have you been diagnosed with mental illness?
8.	How many years having been receiving mental health treatment?

9.	Involv	rement with any community-based mental health programs?
	0	Name of Program
10	. How l	ong have you been / were you on a CTO?
10.	How o	often do you go for appointments (meeting with psychiatrist, case worker)?
	0	Never
	0	Twice a week
	0	Once a week
	0	Once a month
11.	. How	often do you attend mental health program / activities?
	0	Never
	0	Twice a week
	0	Once a week
	0	Once a month



#### APPENDIX E: FLYER

## RESEARCH STUDY: Community Treatment Orders (CTOs) among Ethno-racial Minority Clients

ARE YOU OR HAVE YOU BEEN ON A **COMMUNITY TREATMENT ORDER (CTO)?** 

ARE YOU OF ETHNO-RACIAL MINORITY BACKGROUND?

IF YOU ANSWERED 'YES' TO THESE QUESTIONS ...

# I AM INTERESTED IN HEARING ABOUT YOUR EXPERIENCES WITH CTOs and MENTAL HEALTH SERVICES

I am a doctoral student in social work at the University of Toronto. If you are interested in talking to find out more about the study please contact

Magnus at (416) 988-7469.

# YOUR PARTICIPATION IN THIS RESEARCH WILL BE KEPT ANONYMOUS

If you have any questions, you may contact my supervisor, Prof. Charmaine Williams, PhD at (416) 946-8225 or charmaine.williams@utoronto.ca



# **Draft Community Treatment Plan**

Name of DOB: MR #: Date:	Client:		
1.	Dr (or his delegate) will issue and monitor's Community Treatment Order (CTO).		
2.	. Mr will meet with his physician, Dr (or his delegate), at scheduled appointment times for psychiatric follow up and medication evaluation. The appointment will be held in the office of Dr located at RVHS- Centenary Site or in the office of his delegate.		
3.	will take all oral and/or injectable antipsychotic medications prescribed by Dr (or his delegate). Side effect medications may be prescribed depending on 's physical and mental condition.		
4.	The CTO Case management team from CMHA –East Metro will meet with, a maximum of twice a week to provide case management including community support. The meeting will either be in the home of or at a mutually agreed location.		
5.	maker		
6.	Should refuse to follow through with the expectations of the order, (or his delegate) will issue an order for examination (Form 47).		
7.	All information relating to's treatment will be shared with all parties listed on his treatment plan.		



# **Community Treatment Plan (Contd.)**

Name of Client: DOB:	
MR #:	
Date:	
1	
Client or SDM	Date
2.	
Psychiatrist	Date
1 by omacriot	Zuic
3	
Case Mgt Team	 Date
Case wigt Team	Date
4.	
Coordinator's signature	Date

#### Appendix G

#### **Coding Structure**

- 1. All the participants' interviews were read to derive a feeling for the text.
- 2. Important statements from the interview phrases, descriptions and sentences that pertained to CTOs as treatment were noted.
- 3. Meanings were created from the contexts of the phenomenon present in the descriptions.
- 4. The emergence of clusters of themes derived from the meanings generated
- 5. The descriptions of the themes were analyzed.

For the purpose of the study, the researcher created and organized files for the data

After the interviews, all the texts were read and notes were made in the margins of the paper, also, attempt was made to start forming initial codes.

The researcher explored meanings of the participants experience as it relates to CTOs Began looking for and listing statements of meanings for the participants.

A textural description of participants' feedback was done. The researcher made the effort to explore "the what" from the perspective of the participants experience of community treatment orders.

A structural description of the process which looked at "the how" of the process was also done.

The researcher then embarked on an overall description of the experience.

The themes were presented in the form of a narrative with the participants sharing their experience of the treatment process.