Community Treatment Orders: The Service User Speaks

Exploring the Lived Experience of Community Treatment Orders

Karen Schwartz   PhD (corresponding author)

Assistant Professor Carleton University School of Social Work
1125 Colonel By Drive
Ottawa, ON, Canada K1S 5B6
Karen_schwartz@carleton.ca

Ann-Marie O'Brien MSW
Adjunct Professor Carleton University School of Social Work

Vanessa Morel

Meredith Armstrong

Courtney Fleming

Patricia Moore

Abstract

This study uses an exploratory qualitative design to examine the lived experience of one group of service users on community treatment orders (CTOs). The study was designed and completed by four graduate students at Carleton University School of Social Work.

Despite the unique features of CTO legislation in Ontario, many findings from this study are remarkably similar to findings of research conducted in other jurisdictions. What is unique in our findings is the lack of focus on the actual conditions and provision of the CTO. The issue for our participants was less about the CTO itself, and more about the labels, control and discrimination associated with severe mental illness.

Cette étude utilise un concept qualitatif et exploratoire pour examiner les expériences vécues d'un groupe qui utilise les ordonnances de traitement en milieu communautaire (OTMC). Cette étude a été designée et complétée par 4 étudiants de l'école de service social de l'université Carleton.

Malgré les nombreux aspects uniques de la loi gérant les OTMC de l'Ontario, plusieurs résultats de cette étude sont remarquablement similaires aux résultats découverts dans de différentes juridictions. L'élément unique de cette recherche est le manque de focus sur les conditions véritables et les provisions des OTMC. La problématique encourue par les participants n'était pas au sujet des OTMC en soi, mais plus tôt au sujet de l'étiquetage, du contrôle, et de la discrimination associé aux troubles de santé mentale sévères.

Introduction:

Prior to the introduction of Community Treatment Orders (CTOs) in the Canadian province of Ontario, service users were strongly opposed to this legislation arguing that it would contribute to the oppression of an already stigmatized and marginalized segment of society and violate a person's fundamental right to choose the kind of medical treatment in which they wish to participate. A review of submissions to the Ontario government's discussion paper on mental health reform found no consensus between the various stakeholder groups with the exception being advocacy groups for service users who were consistently opposed to this legislation (Boudreau & Lambert, 1993). More recently, the Ontario Ministry of Health and Long Term Care legislated review of CTOs found that : "If there was common ground among the consumers that we met, it was on the issue of respect for their dignity and autonomy, the necessity to provide proper services to them, the need for easy access to rights advice and advocacy, and most of all, the absolute imperative that their voices be heard and that they play a meaningful role in the events that affect their lives" (Dreezer & Dreezer, 2005). There have been no published studies that explore service users lived experience with respect to Community Treatment Orders in the Ontario context. This paper will begin to redress this gap.

What is a Community Treatment Order (CTO)?

Community Treatment Orders (CTOs) are one form of mandatory outpatient treatment that requires a person with serious mental illness to adhere to a plan of treatment or care and supervision while living in the community. CTOs exist in various forms in most parts of the developed world. Australia and New Zealand have well established CTO regimes (Brophy & Ring, 2004). Many American states have statutes for involuntary outpatient commitment, another form of mandatory outpatient treatment (Swartz & Swanson, 2004). CTO legislation has recently been introduced in Scotland (Campbell et al, 2006). Community Treatment Orders became part of the Ontario Mental Health Legislation in December 2000. The legislation was marketed as 'Brian's Law' in response to the murder of a popular sportscaster by a man suffering from untreated schizophrenia. Following this murder, the public demanded that criteria be established requiring some seriously mentally ill people released from institutional care to be compelled to receive treatment while they live in the community. The legislation targets those service users who have a history of noncompliance with recommended treatment that results in behaviour which leads to re-hospitalization. Opponents of the legislation

state that the new law violates an individual's right to choose whether or not they wished to participate in treatment. Proponents of this legislation argue that requiring a person to follow a prescribed form of treatment while living in the community is less restrictive than being detained in a hospital. However, "their coercive nature is seen as a threat to the community mental health sector's firmly held values of egalitarianism and partnership" (Everett, 2001, p6). Moreover, the association of this legislation with an act of violence further stigmatizes an already marginalized segment of our society (Schwartz & O'Brien, 2009).

CTO legislation in Ontario is defined in the Mental Health Act (Ontario, 1990). The legislation attempts to balance the collective need for safety and order, and the individual right to freedom and autonomy. The legislation is unique in that it is consent based, and physician directed, not court ordered, as it is in most American states. If the person being issued a CTO has capacity to make treatment decisions they must consent to the CTO, otherwise the person making treatment decisions on their behalf provides the consent. Prior to the CTO being issued a plan of treatment or care and supervision is developed by the physician issuing the CTO, the service user, and community based service providers. All parties must agree to the plan, and the service user and Substitute Decision Maker (SDM) (if applicable) must receive independent rights advice prior to the CTO being issued. All parties named in the CTO must receive written copies of all CTO documentation pertaining to them, and information on how to request a consent and capacity board hearing. The Consent and Capacity Board is the mental health tribunal in Ontario that reviews all matters in the civil mental health system.

Literature Review: Community Treatment Orders

CTOs in Ontario have been described as having 'admirable respect' for service user's autonomy (Dawson, Romans, Gibbs, & Ratter, 2003). However respectful, CTOs do limit service users' civil rights and, therefore, their value ought to be measured in terms of relative benefits to service users (O'Brien, Farrell, & Faulkner, 2009). Ten years after the introduction of CTO legislation there remains a paucity of research on its usefulness (O'Brien, & Farrell, 2005; Hunt et al 2007). The most significant limitation of all existing studies of CTOs in Ontario is that they fail to include service users' perceptions.

Most research aimed at exploring the opinions and beliefs of service users has been conducted in the United States. Swartz, Swanson, Wagner, Hannon, Burns, Shumway (2003) examined the preferences of four stakeholder groups: persons in treatment for schizophrenia (n=104), family members, clinicians, members of the public, concerning outpatient commitment for persons with schizophrenia. The study concluded that 'stakeholders were willing to accept the coerciveness of outpatient commitment to gain improved outcomes for certain persons with schizophrenia and related disorders'. (Swartz et al, 2003). Borum, Swartz, Riley, Swanson, Hiday, Wagner (1999) examined consumer perceptions of involuntary outpatient commitment. In this study 306 people with severe and persistent mental illness were interviewed to determine their perceptions of the requirements of the court order and its effects in improving treatment compliance

and community tenure. Eighty two percent of respondents believed that under PCT people are more likely to keep their appointments, take medication, stay out of hospital (Borum et al, 1999). Rain, Steadman, Robbins (2003) investigated whether mental health inpatients perceptions of coercion were associated with post discharge treatment adherence. One hundred and seventeen participants who were eligible for New York's OPC were interviewed and their perception of coercion was measured at 1, 5, and 11 months post discharge. These authors found no correlation between patients' perceived coercion and adherence as reported by service providers. (Rain et al, 2003). Van dorn , Elbogen, Redlich Swanson, Swartz, Mustillo (2006) explore the link between receipt of mandated treatment and reasons for avoiding or delaying treatment reported by persons with severe mental illness. These researchers found that "efforts to use leverage to improve treatment adherence may in some cases have the opposite effect by further alienating some individuals and strengthening the internal barriers that keep them from participating voluntarily in treatment." (Van Dorn et al, 2006). Scheid-Cook (1993) conducted an analysis of participant constructions of outpatient commitment. In general, he found that clinicians favoured the greater control over clients that an outpatient commitment provided. The clients in his study, on the other hand, were cognizant of the greater liberty it afforded them.

Brophy and Ring (2004) focus on both consumer and service provider perspectives of the efficacy of CTOs in Victoria, Australia. These researchers conducted three focus groups attended by 30 psychiatric consumers as well as conducting 18 interviews with service providers. Three themes emerged from the focus groups: understanding the purpose of CTOs; strengths and weaknesses of CTOs; knowledge about the discharge process. Most consumers expressed a general view that CTOs had a functional purpose, for example expedited access to inpatient services when required. However, the authors found that consumers are unsure about legal processes and their legally mandated rights (Brophy & Ring, 2004).

In New Zealand, Gibbs, Dawson, Ansley, Mullen (2005) conducted semi structured interviews with 42 of a possible 84 eligible service users who, in the past two years, had been subject to a CTO and not readmitted to hospital. Similar to Brophy's findings the usefulness of CTOs was generally accepted by most service users. In contrast to Brophy's findings that a CTO might be useful in accessing inpatient services, the New Zealand findings suggest that CTOs are viewed as being useful in avoiding an inpatient admission. In the interviews, service users discussed the themes of "autonomy and dependence, freedom and control, power and powerlessness, medication and its side effects, and the desire of patients to achieve stability, meaningful relationships, and a better quality of life" (Gibbs et al, 2005). Gibbs, Dawson, Forsyth, Mullen, Tanga (2004) conducted a similar study focusing on Maori patients. In general, CTOs were seen to enhance the mental health, wellbeing, and social relationships of Maori patients.

Canvin, Bartlett, and Pinfold (2002) conducted a qualitative investigation into service users' perceptions and experiences of living with supervised discharge orders (SDO) in

London, England. They found that service users were able to communicate their understanding of why mental health professionals placed them on the order and how their lives have been affected. Interestingly, individual service users were found to be capable of seemingly contradictory responses, simultaneously accepting and resisting the orders (Canvin et al, 2002).

One study has been completed in the Canadian province of Saskatchewan. O'Reilly, Keegan, Corring, Shrikhane, Natarajan (2006) interviewed 11 patients on a CTO and three patients who had been on a CTO. Most participants reported experiencing some degree of coercion while on the CTO, but many believed that the CTO was necessary to provide structure to their lives. (O'Reilly et al, 2006). "Many of the themes that emerged from this study were similar to those from non-Canadian jurisdictions despite the use of different models of CTOs in those jurisdictions" (O'Reilly et al, 2006).

 In summary, studies of service users' perceptions of CTOs reveal, at best, ambivalence toward CTOs and their inherent coercion. Of concern is the somewhat hopeless resignation service users expressed. Given the unique features of CTO legislation in Ontario, and the dearth of information of service users' lived experience, the current study will redress this gap in knowledge. This exploratory study will discuss service users' perceptions of the impact CTOs are having on their lives, and offer suggestions for future studies.

Methodology

Service users living with a severe and persistent mental illness, subject to a community treatment order, and receiving services by the Royal Ottawa Mental Health Centre (ROMHC) including two ACT teams were eligible for inclusion (n=51). The availability of student researchers, as this project was not externally funded, was the primary factor that required a convenience sampling method to be used. Service users who presented at the mental health centre for their scheduled appointment with their treatment team were approached by the CTO coordinator and asked if they would be willing to discuss their experience with the students. Of the 51 service users subject to a CTO, 14 presented for their scheduled appointments during the students' availability. Of these 14 people, 6 agreed to be interviewed by the students. The students discussed the project with prospective participants and obtained written consent, prior to commencing with the interview. This research protocol was approved by the University of Ottawa Institute for Mental Health Research (IMHR), research ethics board.

Participants were involved in a semi-structured interview, with two student researchers, which lasted approximately thirty minutes. Interview questions were developed from a review of the literature, and included asking the service users' perceptions on the impact that the CTO was having on their lives (work, relationships, and housing); their ideas for improvements, as well as any areas of concern about CTO's.

An interview guide approach was used in the interviews, so that the order and wording of questions were flexible, allowed to emerge through conversation (Patton, 2003). A

semi-structured face-to-face interview was used to collect data on the opinions of service users regarding their experiences with CTOs. Tutty and colleagues (1996) explain that semi-structured interviews, which use "predetermined questions or key words" as a guide, "are particularly appropriate when you want to compare information between and among people while at the same time you wish to more fully understand each person's experience" (p.56).

Audio recordings of the interviews were transcribed and reviewed by pairs of student researchers. Thematic analysis (Braun & Clarke, 2006) was used in this exploratory study. Thematic analysis is useful in analyzing narrative material from in-depth interviews and focus groups (Dudley, 2009). We employed an etic perspective in identifying categories in our analysis; the categories were identified by the researchers (Rubin & Babbie, 2008). Researchers organized "the raw data into conceptual categories" in order to "create themes or concepts" to analyze the data (Neuman & Kreuger, 2003, p. 436). We looked for common patterns or themes presented in the transcribed notes of the interviews. We began with open coding to locate themes and assign "initial codes or labels in a first attempt to condense the mass of data into categories" (Neuman & Kreuger, 2003, p. 438). At least two independently evaluated the themes in order to insure inter-rater reliability, (Dudley, 2009).

Results

1)   Demographics

This exploratory study included six interviews with six participants. Participants consisted of five males and one female, whose ages ranged from their early 20s to mid-50s. Five were interviewed at a mental health center. One was interview in their home. Length of time on a community treatment order for participants ranged from four months to over seven years. None of the participants had capacity to make treatment decisions and each had substitute decision makers (SDM) consent to the CTO.

2) Housing

All participants are currently living in independent housing that they find satisfactory. Three participants discussed the challenges that they faced in the past in obtaining and maintaining safe and stable housing in the past. Being on a CTO did not appear to have an impact on housing.

"My father kicked me out, my mother kicked me out, and so between them I was going back and forth. I found an apartment, and then I had a problem keeping the crack heads out of my house. Then the hospital, then the group home, then I found a place to stay"

"That's how I was in the hospital for like two months. They left me in there for a month and a half, they told me I had to go to a group home, I didn't like that idea. That was recently, like two years ago."

2)   Employment

Two participants are currently working part-time, and four participants discussed issues

relating to employment, in general. There were different opinions held by participants with regards to the impact of their CTO on employment and employability. Some of the participants experienced difficulty getting time away from work to keep appointments and others experience difficulty due to the mandate to comply with medications.
"You know, I can't drive a forklift, 'cause my job says I can't be medicated, you know what I mean?"

"I have had to modify my work schedule… yeah, you've got to juggle back and forth just have some days off, … keep up with your appointments and other things"

"I've had a couple of jobs that have tried to work out. Pretty hard to get up in the morning and go to work for me. So anyway, I have a job now, on the CTO, and I didn't have one before."

3) Personal Relationships

Participants were asked about the impact of their mental health and the CTO on their relationships with friends and family. This was not an area of questioning that participants seemed interesting in engaging in, and most responses were brief and provided minimal detail. From the responses given, the families of participants viewed their community treatment orders favorably, and felt that there had been positive changes in the lives of the participants.
"My mom, she mentioned that maybe they're just watching over you, my dad says, yeah, they're just watching over you."
"They said when I was 17, 16, I was really sick, and they say I'm doing great now, and sometimes they give a bit of input like you better be careful not to get sick again."
"They listen more, since the CTO."

4) Reason for CTO

The participants cited various reasons for their CTO being initiated. The two major reasons that were discussed were not taking medication, and not engaging in self-care.
"I was not taking my medication, and I was living by myself in a rooming house, and I guess that's about it, I just didn't get activities, didn't care for myself, do the groceries and stuff".
"I don't know why they put me on a CTO. But I think it might have been because I am so alone, so I have the contact".

5) Information Provided

Many participants were vague about the amount of information provided by their service providers, and their understanding of that information. The few participants who had strong opinions regarding information provided to them believed service providers did not ensure they had a clear understanding of the legal processes.
"My rights? I don't know about my rights…but I was given a folder with information and other changes"

"Yeah, I understand my rights. It's a CTO, there's no real lawyer that's gonna help you out, he just explains to you the CTO. The CTO is like law, its law and uh, you can't defeat unless you make like another act, or change the CTO, and then it's like for 6 months."

"Did she explain the reasons? Yeah, poorly, you know, with poor explanation, and poor, misinterpreted information."

6)   Understanding of Legal Processes

There was more variation amongst participants' responses concerning the legal aspects of CTOs, particularly the appeal process. Participants who had been on the CTO for longer periods of time (in excess of two years) expressed that they understood the appeal process, and had been involved with the appeal process, but did not have confidence in their ability to successfully change or end their order.

"Appeal? To go to the review board is kind of risky you know? They don't see you, they just see the CTO"

"Well in the beginning I did appeal, I started to appeal but I decided to go along with the program because the office threatened to take my driver's licence away, so I thought I better be cooperative. They took my driver's licence away anyways."

"Have you done an appeal before? Yeah, I've done several"

7)   Stigma

Participants discussed the different ways in which the label of mental illness creates experiences of stigma. These experiences were described as occurring in the community through labels, scrutiny and isolation, and in the stigmatizing behaviour and attitudes of their professional service providers.

Community-based stigma was described by participants as a feeling that they were feared and isolated within their communities. Service users discussed the difficulty of feeling the constant gaze of the community judging their behaviour and deeming them something to be wary of.

"So it's like the community is judging you, you know? To see if you're safe to live in the community I guess"

"Police involvement, and then the neighbours are watching, then you're scared, and you're medicated. You wake up, and you don't know where the fuck you are, and there's dirty people around, and you're not in your clothes. Or you get up, and you just take another medication, you know?"

"I think the people across the hallway are getting suspicious of me. People coming in and leaving (ACT team workers), and we go out, you know? But I don't say anything."

Professional stigma was identified as a sense of de-personalization as a result of the use of diagnostic language, and paternalistic ideologies when working with consumers. Historically, the mental health system has been operating under a hierarchical "expert doctor"-patient relationship, commonly referred to as the medical model (Campbell, 2006). CTO service users discussed how this attitude still permeates many of their interactions with helping professionals. Mental health consumers, in general, often resist

the diagnostic labels placed on them, and resent losing their identity to the illness within the institutional (i.e. hospital) settings and when receiving treatment while living in the community.

"I went, they told me I was schizophrenic, and I said I wasn't, and there was a dispute, and from there on I've been taking medication."

"I don't want somebody calling me schizophrenic."

"I went to the doctor to get sleeping pills, and he tells me I'm schizophrenic, I was like listen mother-fucker, I don't have schizophrenia. And he goes, "you know what, I'm gonna pick my nose, and I'm going to spit on the floor, and I'm going to say you have schizophrenia "…and he told me I got to agree to disagree."

8)   Negative Feelings Regarding CTOs

Participants expressed some overall negative opinions about CTOs. Feelings of being controlled and labeled as mentally ill were dominant themes. Within our sample, there appears to be a connection between disagreeing with the diagnosis of mental illness (particularly schizophrenia) and negative statements regarding the conditions of their CTO, most frequently the condition of mandatory psychotropic medication.

"Well I think the psychiatrist who took my driver's licence away, I think he had too much power, he didn't even know me, because he was a new doctor at the hospital, when I had never been there before, and I had never talked to him for a long period of time. And he made an instant diagnosis that I might be a bad driver, and he took my driver's licence away by sending a letter to the ministry of transports, saying I was a threat to society or something, and actually I don't have any demerit points on my licence, I'm a good driver and I found that to be really bad."

"I think it's a hassle, I don't need a contract or law to tell me to take my medication and come for blood work. I think it's just; the big thing I think is coming in for programming every day. I just can't be bothered… Now that I'm on a community treatment order I have to follow and abide by it"

"What gives the CTO the power? It's the power of medication to our culture, crime, people, normal people, who are not alert to you, some guy. And after everything some crazy guy, some cop, some psychiatrist, some nurse, some shrink, some whatever you're on some medication you know, can you cook dinner for yourself, can you? Are you going to clean yourself, can you? Or you didn't do the laundry, and you're in public, and you stink, cause you don't have a washing machine or no car, or no job "

9)   Positive Feelings Regarding CTOs

The positive statements made by participants were usually associated with positive outcomes associated with the implementation of the CTO. These outcomes include increased supports, employment, self-perception of improved mental health, and positive interactions with professional, family and friends.

"Yeah, yeah. It changed my whole life around. I went from a paranoid freak, to a well groomed individual"

"All I know is, I come in and see my doctor, and he gives me medication, and it keeps me healthy. So that's good, he was doing his job, and I'm getting my help."
"Now I've got a doctor, I've got a social worker, I've got a nurse who gives me medication, I got peer support, a lot of people. Yeah"
"Well I like to have it (the CTO) it's kind of nice to have the attention at the end of the day"

Discussion

Service users frequently discussed concerns regarding a lack of control over various aspects of their lives. The impact of the CTO on the daily lives of service users is apparent. Issues such as having their drivers' license revoked, being mandated to take medication that has unpleasant side effects, and frequent appointments at the hospital were discussed by participants as negatively impacting the amount of control they hold over their own lives. This is consistent with the literature, as most studies found that community treatment orders were perceived as coercive by service users (Brophy, 2004; Gibbs et al, 2004; Gibbs et al, 2005; O'Reilly et al, 2006; Scheid-Cook, 1993; Cavin et al, 2002; Dreezer & Dreezer, 2005).

Service users with negative feelings about their CTOs spoke more often about the labels placed on them, and the ways in which they felt they were perceived by the community and their service providers, than about the actual conditions of the CTO. The stigma associated with having a severe mental illness is of obvious concern to all participants interviewed. The term "schizophrenic" was particularly disliked by service users. This speaks to the need for professionals to provide space for self-definition. As stated by Campbell in his article about psychiatric survivors' perceptions of the mental health system,
"self-definition is an essential part of changing the lives of people with a mental illness diagnosis and choosing a self-description is an element in this. All service user action is concerned directly or indirectly, with changing the ways we think about ourselves and others think about us." (Campbell, 2006, p. 578)

The stigma experienced by service users from the community was articulated as a feeling of being under surveillance. The "othering" of individuals with severe mental illness is well documented in the literature, and it is implied in the results of this research which suggest that the CTO further builds on this feeling of being identified as having a mental illness, in that it legally defines an individual as mentally ill (Scheyett, 2006). The feelings of stigma felt by service users from community members were further compounded by the stigmatizing attitudes that participants perceived in their interactions with their service providers.

Professionally based stigma manifested itself in the participant's narratives through the acts of diagnosis, coercion, and authority. Service users discussed the inability of professionals to empower them to participate in the decision making process, or move away from an 'expert-patient' model of care. Participants, when talking about feelings of

being controlled, most often discussed medical professionals such as family doctors and psychiatrists. This is probably reflective of the fact the CTOs in Ontario are issued by physicians, not courts. If a service user is noncompliant with the order, it is the physician who has the responsibility to issue at form for psychiatric assessment that authorizes the police to apprehend the person to bring them to the physician for assessment. Moreover, if the person appeals their CTO to the consent and capacity board it is the physician who has the burden of proof to demonstrate that the requirements for a CTO have been met. Service users only occasionally mentioned the role of social work, and this was generally more positive, noting that ACT teams were often adaptable to the service users' needs and schedules.

Service users, when asked about their understanding of their legal options and the process of CTOs were unclear about the amount of information that had been given to them by service providers. All service users stated that the processes had been explained to them, but several stated that they did not understand their order, the appeal process, or how the CTO would end. This limited understanding of the CTO suggests that service providers should review the information, policies and rights of the service user with them on a regular basis. This is necessary due to the varying levels of wellness that service users may experience, along with documented side effects of medication such as reduced attention span (Dreezer & Dreezer, 2005).

Limitations

This pilot study was limited due to time constraints and difficulty accessing participants. All of the participants were deemed incapable with respect to treatment decisions regarding their mental health. This group of service users may experience a CTO as more coercive than service users who are deemed capable of making decision for themselves. It would have been beneficial to conduct several interviews over time with each applicant, as this would increase rapport with the interviewer. It would also provide the opportunity to revisit certain questions with the participants in order to clarify or elaborate on their previous answers. The challenges of interviewing individuals living with severe and persistent mental illness, such as side effects of medication, or difficulty-focusing attention, occasionally caused researchers to ask questions that may have influenced participant's answers. Due to the difficulty of interviewing a population living with varying levels of wellness over time, multiple interviews may better reflect the overall perceptions of participants.

Conclusion

The findings of this study have been consistent with the published literature regarding the perceptions of service users of community treatment orders. Similar themes emerged across the literature in which participants report feelings of coercion and powerlessness, but also recognize some positive aspects of CTOs (Brophy, 2004; Gibbs et al, 2004; Gibbs et al, 2005; O'Reilly et al, 2006; Scheid-Cook, 1993; Cavin et al, 2002; Dreezer & Dreezer, 2005). What is unique in our findings is the lack of focus on the actual

conditions and provision of the CTO. Our research suggests that the CTO adds to already problematic feelings of stigma and powerlessness that are associated with living with a mental illness. The issue for our participants was less about the CTO itself, and more about the labels, control and discrimination associated with severe mental illness. There is limited research in Ontario on the topic of service users' experience of CTOs, and no study to date that has been completed in collaboration with service users. A participatory action research (PAR) project would be ideal in conducting anti-oppressive research, and supporting the goal of empowerment of individuals on community treatment orders (Tew, 2008).

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