

What Families Have to Say about Community Treatment Orders (CTOs)

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ABSTRACT

Qualitative studies provide a different kind of understanding of the effectiveness of community treatment orders (CTOs) by exploring the perspectives of stakeholders. This article documents a systematic review of 12 qualitative studies that explored the views of families of individuals on a CTO. Relevant databases and grey literature were searched. Themes were identified: the benefits of CTOs outweigh the disadvantages, CTOs increased their involvement in care, and families were dissatisfied with aspects of the CTO process. Recommendations include how to maximize the benefits of CTOs, reduce administrative burdens and employ strategies to increase involvement of families in the care of their loved ones.

Keywords: community treatment order, family, qualitative, systematic review

RÉSUMÉ

Les études qualitatives proposent une lecture différente de l'efficacité des ordonnances de traitement communautaire (OTC) en examinant les points de vue des différents intervenants. Le présent article documente une revue systématique de 12 études qualitatives exposant le point de vue de familles d'individus faisant l'objet d'une OTC. Des bases de données pertinentes et des sources de documentation parallèle ont été consultées. Divers thèmes ont été dégagés : les avantages des OTC l'emportent sur les inconvénients; les OTC permettent d'accroître l'implication des familles dans les soins prodigués; les familles démontrent de l'insatisfaction vis-à-vis certains aspects des procédures des OTC. Les recommandations portent notamment

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sur la façon de maximiser les avantages des OTC, l'allègement du fardeau administratif et l'adoption de stratégies en vue d'accroître la participation des familles dans les soins apportés à leurs proches.

Mots clés : ordonnance de traitement communautaire (OTC), famille, qualitatif(ve), revue systématique

Community treatment orders (CTOs) are legal provisions that oblige a person, who suffers from a serious mental illness, to comply with a plan of treatment and supervision in community settings. In this article, we have used the term CTO to refer to a variety of legal statutes, including court-ordered outpatient committal (OPC) and renewable conditional leave provisions which take effect after discharge from an inpatient psychiatric unit. Compulsory supervision and treatment required by courts when a person with a mental illness has been charged with committing a criminal offence are not considered here. Quantitative studies of CTOs have produced inconsistent findings (Schwartz & Swanson 2004; Kisely & O'Reilly, 2015) and generated controversy about how these inconsistencies should be interpreted (Kisely & O'Reilly, 2015; Maughan, Molodynski, Rugkåsa, & Burns, 2014). Qualitative studies can often provide information and understanding of phenomena that quantitative studies cannot provide. We recently reviewed the qualitative literature that examined how individuals, who are on or have been on a CTO, view their use and found that these individuals report both positive and negative feelings about CTOs (Corring, O'Reilly, & Sommerdyk, 2017). A more unambiguously positive view of CTOs might be expected from their families (for brevity we are using the word family to include non-familial caretakers such as close friends) who represent an important stakeholder group in the design of services for serious mentally ill persons and who in some jurisdictions consent to the implementation of the CTO. In this study, we report the findings of a systematic review of qualitative studies that have examined the perspective and experiences of families of individuals who have been on CTOs. We discuss the implications of the research for jurisdictions that have or are considering introducing CTOs with a particular focus on Canadian jurisdictions.

METHODS

Qualitative systematic review/qualitative evidence synthesis is a method for integrating or comparing the findings from qualitative studies (Grant & Booth, 2009, p. 99). The accumulated knowledge resulting from this process may lead to the development of new theory, an overarching narrative, a wider generalization, or an interpretative translation. A qualitative systematic review looks for themes or constructs that lie in or across individual qualitative studies. The goal is not to combine studies, but to broaden understanding of a particular phenomenon (Grant & Booth, 2009, p. 99). The Cochrane Collaboration's Qualitative Research Methods Group promotes the use of "qualitative evidence syntheses" as the terminology of choice. In chapter 20 of the *Cochrane Collaboration's Handbook for Systematic Reviews of Interventions* (Noyes, Popay, Pearson, Hannes, & Booth, 2008, 2011), the authors note that a synthesis of the evidence from qualitative research can explore questions such as how people experience illness, why an intervention does or does not work, and for whom and in what circumstances an intervention is likely to be effective.

We wanted to better understand what families of people who were or had been on CTOs had to say about these legal tools. We were especially interested to know whether families approved of the use of

CTOs, and to understand which elements of CTOs families found positive or negative. To achieve this objective, we retrieved all relevant published and grey literature reporting on qualitative research on CTOs. We searched PsycINFO-OVID (1967 to June 2016), PubMed (1966 to June 2016), EMBASE-OVID (1980 to June 2016), and CINAHL-EBSCO (1981 to June 2016) databases using the terms in Table 2 adapted from Churchill, Owen, Singh, & M. Hotopf, 2007. In addition, the grey literature was also searched (see Table 2 for a complete list of search terms).

To be included in the current review, a study had to have used a qualitative methodology (for example, phenomenology, or ethnography), and had to have examined the perspectives or lived experience of CTOs of one of the stakeholder groups.

All abstracts resulting from our initial review were read by one of the authors (CS). If the abstract contained any indication that the paper used qualitative methods to examine any stakeholder perspectives about CTOs, the article was retrieved and read in full by three of the authors (DC, ROR, and CS). A decision on whether inclusion criteria were met was made by consensus. Articles that exclusively provided commentary, as opposed to newly generated qualitative data, were eliminated at this stage. Also eliminated were studies that merged stakeholder perspectives so that it was not possible to distinguish the perspectives of the various stakeholders (Brophy & McDermott, 2013; Owens & Brophy, 2013; LaForest & Lahey, 2013).

The number of study participants, methods, focus of the inquiry, country of origin and themes were recorded and then compared and contrasted to determine consistencies and inconsistencies.

RESULTS

We retrieved 152 abstracts of published papers from the databases and an additional 15 from the grey literature. Seventy-eight (78) articles were excluded after reading the abstract and an additional 46 after reading the full paper. This left 43 articles that described the views about CTOs of various stakeholders. A number of papers were duplicates or analysis of a subgroup of individuals from an original study. All of these reports were read and the findings subsumed under the original report.

Twelve of these studies—nine published articles and three formal reviews from two Canadian provinces—were determined to distinctly report the perspectives of families of individuals on CTOs and therefore were included in the current review. They are listed below in Table 1.

Together these studies incorporated the views of more than 215 participants from six countries around the world. The studies had two different focuses. They explored individuals' overall experience of being on a CTO, and in some cases the impact of their use.

The three reviewers independently recorded the themes and sub-themes reported in the 12 papers using the constant comparative method to compare and contrast themes, and identify themes and the relative prominence of the themes. The constant comparative method is a process in which any newly collected data is compared with previous data in a continuous ongoing procedure in order to confirm or discount themes. Several iterations of this comparative analysis were performed until there was consensus on the themes found in the literature and the prominence or strength of one theme relative to another. In this way, the important credibility strategies of triangulation and saturation were achieved. Triangulation was achieved given the

Table 1
Studies Included in the Review

Country	Authors	Focus	Number of participants	Methods
Australia	Light, Robertson, Boyce, Carney, Rosen et al., 2014	Lived experience of involuntary treatment in the community	6	Interviews
Canada	Dreezer & Dreezer Associates, 2005	Mandated legislative review	84	Interviews
	O'Reilly, Keegan, Corring, Shrikhande & Natarajan, 2006	Impact of legislation	14	Interviews
	Malatest & Associates, 2012	Mandated legislative review	11	Focus Groups
	LaForest & Lahey, 2013	Provincial review of use of CTOs	Not specified	Focus Groups
England	Canvin, Rugkasa, Sinclair, & Burns, 2014	Views on CTOs	24	Interviews
	Stroud, Banks, & Doughty, K., 2015	CTO user experiences	7	Interviews
	Gault, 2009	Views on CTOs	8	Interviews
	Lawton Smith, 2010	Review of CTOs	17	Survey
New Zealand	Gibbs et al., 2004, 2005, 2006; Mullen et al., 2006	Family views of CTOs in New Zealand	27	Interviews
Norway	Stensrud, Hoyer, Granerud, & Landheim, 2015	Experiences of relatives of patients on CTOs	11	Interviews
USA	Steadman, Gounis, Dennis, Hopper, Roche et al, 2001	NY City CTO pilot study	6	Focus groups

*Papers that were reporting on the same study were combined as follows: [Gibbs et al., 2004 & Gibbs et al., 2005, 2006 & Mullen et al., 2006; University of Sydney, 2013 & Light et al., 2014].

Table 2
Search Terms

Databases
CTO" OR "community treatment order" OR "community treatment orders" OR "mandatory outpatient" OR mandatory outpatient treatment OR mandatory outpatient release OR mandatory outpatient commitment OR "involuntary outpatient" OR "IOT" OR involuntary outpatient treatment OR involuntary outpatient release OR involuntary outpatient commitment OR "outpatient commitment" OR "OPC" OR "involuntary commitment" OR "assisted outpatient treatment" OR "AOT" OR conjunction of civil commitment OR "OPC" OR "outpatient commitment" OR "conditional release"
AND
qualitative OR "lived experience" OR "lived experiences" OR "client perspective" OR "client perspectives" OR "stakeholder view" OR "stakeholder views" OR "qualitative review" OR "qualitative reviews" OR "qualitative study" OR "qualitative studies" OR "qualitative investigation" OR "qualitative research" OR ethnography OR ethnology OR "narrative therapy" OR "philosophical inquiry" OR "grounded theory" OR "participant action" OR "phenomenology" OR experience OR experiences OR perception OR perceptions OR interview OR interviews
Grey Literature
Google search using the terms: "Community Treatment Orders and qualitative research" which produced 25,300,000 hits. Given the large number of hits the research assistant then searched until 2 consecutive pages included links that were no longer relevant to the topic, for example if page 3 and 4 of the google search were all irrelevant, then any pages after that were not searched.

Source: Authors' compilation.

multiple researchers, and multiple data sources that were used to gather data. Saturation was achieved when it became clear that there were no new themes emerging from the results of the 12 studies.

In the end we identified three themes, which are discussed in the next three sections. A sample of quotes from the original research has been provided to illustrate the themes. It should be noted that not all papers included direct quotes.

Benefits of CTOs Outweigh Disadvantages

Families report a variety of benefits from CTOs including the provision of regular support to other family members as well as their loved ones who are ill; increased monitoring and continuity of care; rapid response to emergencies and the availability of quick recall to hospital if needed.

Other benefits noted were increased treatment adherence, hope for recovery, longer periods of wellness, decreased need for readmissions, and the increase in structure and predictability in the family situation.

I see CTOs as working to maintain compliance with treatment in the community, reduced hospitalizations, fewer episodes of deterioration, facilitating engagement with community resources, improved quality of life. (substitute decision maker [SDM]; Malatest & Associates, 2012)

I do feel OC as a relief, I must say. That's the right word, I think. There are more people to support us now. Because my sister is functioning so poorly. I mean, all the time you want—you hope it'll work.... (sister; Stensrud, Hoyer, Granerud, & Landheim, 2015)

Stroud, Banks, and Doughty (2015) noted that “an emergent theme across all groups in their study (service user, practitioner, and nearest relatives) was that the CTO was seen to provide a valuable “safety net” (p. 89). Quotes from several studies emphasized the feeling of security that the CTO provided for many families.

It does give him easier access to hospital and if they do get sick...places are made a lot sooner. Health professionals are there as soon as you call. (sister; Mullen, Gibbs, & Dawson, 2006)

Many families believed that as a result of these benefits the CTO brought stability to their loved one's illness, increased quality of life and reduced the risk of harm to the patient and the caregiver. Several studies noted that families felt that the infringement of autonomy was outweighed by these benefits. Canvin et al. (2014), noted that “most carers reported unprecedented or improved adherence (during and beyond the CTO period) and several said that their relative had not been back to hospital (either voluntary or via recall) under the CTO (p. 1880).” The following quotations illustrate this further:

The OC (outpatient committal) team has been there the whole time and kept this under control. So that's something we've benefitted from. We can't see everything either, as parents. We have our everyday lives, and our jobs, so it's time that people come from the outside and try to get things into perspective. What's been positive is that we've felt confident that there are at least some people dealing with this, behind it and steering it a bit. That's been good. (family member; Stensrud et al., 2015)

Because of the medication my son has been prescribed, he is more stable which has empowered him to be more self-reliant, which has led to less strain on me. (mother; Lawton Smith, 2010)

He wouldn't take his medication when he relapsed and that was the reason they could take him back into hospital. So we would have perhaps a fortnight of it instead of four months...it makes such a difference. It saves us all so much distress. (carer; Canvin, Rugkasa, Sinclair, & Burns, 2014)

It should be noted that despite the very positive feelings families have about CTOs many simultaneously reported some dissatisfaction expressed with the CTO process and we will expand on this under the third theme below.

CTOs Enabled Families to Influence the Clinical Care

Families believed that the CTOs gave them a voice in shaping the clinical care for their ill relatives. This in turn often resulted in increased services from clinicians who then more appropriately shared the burden of care with the families. Families said that a CTO often brought relief to chaotic family situations. A CTO was also seen as a “backup” that helped families manage emergency.

For most of the family, when he was no longer under the close care in the hospital situation, it was reassuring to know that qualified people were able to monitor him still. (Brother; Mullen, Gibbs, & Dawson, 2006)

I now have a voice which I didn't have before, it was ‘well you can let me know what you think about how your son is, but I can't listen to you....I can't do anything because of what you said...nor can we go to him and do anything until he becomes so ill that he's got to be sectioned’; and this system does away with all that. (mother; Stroud, Banks, & Doughty, 2015)

[I have someone] on the other end of the phone and I know they'll be around if I call. (carer; Gault, 2009)

Dissatisfaction with Aspects of the CTO Process

Although generally positive about the benefits of CTOs, families had suggestions for improvement of the CTO process. They noted that legislation is often structured in a way that makes the process of initiating and maintaining a person on a CTO too cumbersome, as the following quote illustrates:

We have been to a judge at least three times if not four, the CTO, the last one has run out again and she [her daughter] knows it, and we cannot get her back in. The three months business is way too short. Two psychiatrists or whatever should renew it automatically, so we don't have to go through all this emotional stress, over and over again. (parent; O'Reilly, Keegan, Corring, Shrikhande, & Natarajan, 2006)

They believed that CTOs were excessively concerned with ensuring that the patient was adhering to medication and neglected other important needs of the patient.

Basically after discharge, there should be something that improved his everyday life. And that part's missing. His life won't be improved by moving to the city now. With medication based on a compulsory paragraph. I think he should be at an activity center that could have helped. With a psychologist, physical exercise and the chance to socialize. The measures should be directed more towards letting the patient see possibilities. Our son sees no possibilities with antipsychotics. Then we need to find other things that might give a response to the real problems.... (parent; Stensrud, Hoyer, Granerud, & Landheim, 2015)

Other relatives and caregivers said that follow-up to ensure the patient adhered to the treatment plan was insufficiently rigorous. They also questioned whether the CTO should have been used earlier. Many felt that the process for contacting substitute decision makers (SDMs) could be improved. Legislation in some jurisdictions was viewed as "lacking teeth." Relatives speculated that some physicians avoid using CTOs as the process was too cumbersome. Families often talked about the need to promote awareness of the existence of CTOs and to educate families about how they can be initiated.

That's been the problem all along, whether he should have medication or not. And it's been a predicament as parents. [NN] might have been given a bit too much leeway by the doctor. The doctor's opinion was he should have medication, but he's renounced responsibility and let him look after himself. So this has been a difficult thing to deal with as relatives. (parent; Stensrud, Hoyer, Granerud, & Landheim, 2015)

Families also expressed a more general dissatisfaction with many aspects of the mental healthcare system that were not specifically related to the CTO process. Gault (2009) notes that "families too feel that the system is adversarial and describe carers' views being regularly discounted and family treated as the opposition" (p. 509).

That's the gap [gap in the use of CTOs] that we see in any type of individual that has mental health addiction issues is that when they are housed in custody because of a criminal offence, they are not getting access to care they really need and when released, there really isn't much of a program for them to go to for that continued monitoring. (stakeholder; Malatest & Associates, 2012)

DISCUSSION

As we often say, there are really only eight kinds of people affected by mental disorder. It's a very small list, but we all know someone on it: someone's mother, daughter, sister or wife; someone's father, brother, husband or son. (Nunes & Simmie, 2002)

The above quotation highlights that mental illness is often a profound problem, not only for the individual, but also for their families. It has been estimated that eight million Canadians have a family member with a mental disorder of whom 560,000 are relatives of someone with a severe mental illness (MHCC, 2013).

With decreasing numbers of psychiatric beds and limited community-based services for individuals with severe mental illness who need long-term support, families have undertaken increasing responsibility in providing care for their mentally ill relatives (Flyckt, Löthman, Jørgensen, Rylander, & Koernig, 2013). Indeed, as Kirby and Keon noted "Families are often the principal resource and the sole support available to individuals with mental illness and addiction. Because of the limited resources available to the hospital sector and the community, it is [families] who house, care, supervise and provide financial assistance" (Kirby & Keon, 2004, p. 26). As families are expected to provide care to individuals with serious mental illnesses who are unable to care for themselves, the views of family members on policies, such as CTOs, must be given serious consideration.

We found that families are generally positive about CTOs. Support from families for CTOs is important as CTOs remain controversial (O'Reilly, 2004) and research suggests that support for CTOs from individuals who are subjected to them can best be described as neutral (Corring, O'Reilly, & Sommerdyk, 2017). The positive perspective of families appears to stem from their perception of a variety of benefits from CTOs.

These benefits include clinicians sharing the burden of care with families, the perception that CTOs act as a safety net providing a mechanism to intervene before deterioration or actual harm occurs, improvement in family relationships, and improvement in other aspects of the ill relative's quality of life. The findings from this review of qualitative studies align with those of Vine & Komiti (2015) who surveyed caregivers to ascertain their view on CTOs and found that most caregivers felt that CTOs had been beneficial.

It is perhaps not surprising that the families are more positive about CTOs than individuals who are subject to them. Many individuals are placed on a CTO because of a lack of appreciation that their experiences are pathological and require treatment. As the treatment is mandatory one might predict, a priori, that such individuals would have a negative view of CTOs. In contrast, relatives typically are supportive of treatment. Further, in some jurisdictions, a relative must actually consent to the CTO or consent to the treatment provided under a CTO.

While the dominant theme was that CTOs were helpful, some families have considerable dissatisfaction with CTOs. These families are frustrated by the legal and administrative process of initiating and maintaining a CTO, which they view as excessively cumbersome. Furthermore, many relatives feel that CTOs should have greater authority to ensure that their family member adheres to treatment and that clinicians should be more diligent in enforcing treatment requirements. While some relatives said the CTO increased their involvement in clinical decision making, others felt that they are only consulted on a "token" basis rather than being a genuine partner in the care of their relative. Some family members believed that the focus of CTOs is too narrow, with the sole emphasis on improving medication adherence rather than including

other requirements that would promote recovery.

What can be done to address the complaints of family members about CTOs? Excessive administrative burden associated with initiating and maintaining CTOs has also been identified by clinicians as a reason for not using CTOs (Dreezer & Dreezer Inc., 2005; Dawson, 2005) and was identified as an important reason for the lack of use of CTOs in some jurisdictions such as Florida (Pertrila & Christy, 2008). One contribution to the bureaucratic burden is the requirements of CTO renewal. The frequency of renewal has been identified as an important issue (Corring, O'Reilly, & Sommerdyk, 2017). In Saskatchewan, the original legislation required renewal every three months. In a study conducted in that province, family and other stakeholders, indicated that a renewal every three months was unnecessary and some reported that renewals caused the ill relative to become distressed (O'Reilly, Keegan, Corring, Shrikhande, & Natarajan, 2006). Partly as a result of these findings, the Saskatchewan government recently lengthened the duration of CTOs to six months (Mental Health Services Act, 2017). In the US the American Psychiatric Association (APA) recommends a duration of six months for an initial CTO (Swartz et al., 2016). Notably, other jurisdictions authorize the use of a CTO for a much longer time period. For example, in Quebec a court may renew a CTO for up to three years (Nakhost, Perry, & Frank, 2012). One possibility would be to have a first issuance of a CTO last six months, but subsequent renewals last 12 months.

The involvement of families in the initiation and maintenance of CTOs and in determining the treatment provided under a CTO varies greatly between jurisdictions. The schemes in most international jurisdictions allow a physician or judge to initiate a CTO without consent from an SDM, whereas in some Canadian jurisdictions such as Nova Scotia, a SDM, who will often be a relative, must consent to the CTO and to treatment administered under the powers of the CTO. This requirement for consent can help ensure that relatives are involved in these key decisions for their loved ones. In contrast, in jurisdictions in which CTOs are issued by a court, or by a physician without the need for consent, relatives often have limited or no statutory power.

A large body of literature attests to the benefit of family involvement in the care of patients with serious mental illness (Glick, Stekoll, & Hays, 2011; Hartmann, Bänzner, Wild, Eisler, & Herzog, 2010; Martire, Lustig, Schulz, Miller, & Helgeson, 2004). Despite this evidence of benefit, families often complain that they are excluded from decisions about the care of their relatives. (Flyckt, Löthman, Jørgensen, Rylander, & Koernig, 2013). Our review indicates that many relatives felt that a CTO helped to make them partners in care but that some relatives still felt excluded—including being excluded from decision-making in the CTO itself. The requirement for consent from a SDM for initiation of a CTO or for the treatment provided under a CTO would improve family involvement. A downside of this type of scheme is the potential for inappropriate refusal of consent.

Codes of practice can also influence the actions of clinicians. Some jurisdictions stipulate that, unless the patient objects, families should be informed about decisions to initiate and discharge a patient from a CTO (Department of Health, Mental Health Act, 1983: Code of Practice, 2008). In the US the APA recommends that clinicians should involve families, ensuring that families understand the requirements and powers of the CTO and conversely that clinicians understand the treatment preferences of families (Swartz, Hoge, Pinals, Lee E., Lee L. ...Johnson, 2015).

Many families see CTOs as having too narrow a focus that only requires attendance at clinical appointments and adherence to psychotropic medication. In contrast, psychiatrists favour limiting the mandatory elements of treatment orders to those essential to maintain the stability of the individual (O'Reilly, Dawson, & Burns, 2012). Limitation of the mandatory elements is consistent with the principle of using the least restrictive alternative (Munetz & Geller, 1993). However, the principle of reciprocity suggests that patients who are required to take psychiatric treatment, should also be offered a comprehensive package of services and have priority when these services are in short supply (Eastman, 1994). The APA recommends the CTOs should be accompanied by high intensity services such as assertive community treatment (Stein & Test, 1980) or intensive case management. Indeed, in the US some states have set aside funding to support additional services to individuals who are placed on CTOs (Swartz & Swanson, 2013). It is important that families understand the limits of a CTO and the likely ineffectiveness of coercing treatments such as attendance at day programs or psychotherapy. But this is an area where, if included as part of the treatment team, families could encourage their relative to accept these additional services.

CONCLUSIONS

Families provide most of the caregiving for people with serious mental illnesses, for whom CTOs are typically used and they report that CTOs give them a voice in the clinical care of their ill relatives which often results in increased clinical services and a reduction in the burden of care. Families seemed to be particularly appreciative that CTOs provided a safety net when things went wrong. In contrast to these positive views, families reported many difficulties with the structure of some CTO schemes and how they are implemented. Given the major contribution of families to the care of these individuals, and research indicating the value of family involvement, it would be wise for system planners and clinicians to listen carefully to family members' views on CTOs.

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