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The lived experience of community treatment orders (CTOs) from three perspectives: A constant comparative analysis of the results of three systematic reviews of published qualitative research

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1. Introduction

Community treatment orders (CTOs) are laws that oblige a person, living with a serious mental illness, to follow a plan of treatment and supervision when they live in the community. Quantitative research on CTOs has predominantly focused on outcomes studies. These studies have produced inconsistent findings and their interpretation is contested (Kisely & O'Reilly, 2015; Little, 2017). Qualitative research is able to provide a more fulsome understanding of the feelings, values and perceptions of stakeholders as they experience CTOs.

The authors have previously published the results of a systematic review of qualitative research concerning the experience of CTOs from the three stakeholder perspectives (Corring, O'Reilly, & Sommerdyk, 2017; Corring, O'Reilly, Sommerdyk, & Russel, 2019; Corring, O'Reilly, Sommerdyk, & Russell, 2018). In this paper, each of the previously identified themes is compared and contrasted with the others in order to identify similarities and differences.

2. Methods

The constant comparative method is a structured analytic process. Each piece of data is compared and contrasted with other data to determine similarities and differences. The two primary authors each independently examined each theme identified as a result of the systematic reviews for each of the three perspectives, and compared and contrasted it with other identified themes from the three studies in order to determine whether there were any similarities and differences between the three stakeholder groups. The two primary authors then met on several occasions to discuss their findings and reached agreement regarding the four common themes that are presented below in the results section. Ethics approval was not required because there was no direct involvement of participants.

3. Results

In the systematic review, forty-three articles were identified that described the views about CTOs of one or more of the three stakeholder groups. In some studies the voices of different stakeholders were merged rendering it impossible to distinguish between the perspectives of stakeholders and these studies were therefore eliminated from the review (for example Brophy & McDermott, 2013). In addition, studies that were represented by more than one publication were combined for the purposes of the review (for example Gibbs, Dawson, Ansley, & Mullen, 2005Gibbs, Dawson, & Mullen, 2006). In the end, twenty-two articles that represented the views of people on CTOs, twelve studies the views of family members of individuals on CTOs, and fourteen studies the views of clinicians who worked with individuals on CTOs met the criteria (with some studies reporting more than one stakeholder perspective). These papers represented the views of 581 people on CTOs from seven jurisdictions, 215 family members from six jurisdictions and more than 700 clinicians from six jurisdictions. Details regarding each of the stakeholder perspectives can be found in the three previously published articles from this study noted above. Themes identified for the three stakeholder groups can be found below in Table 1.

Four themes were identified from the current constant comparative analysis of the themes noted above. The four themes were: 1. Benefits versus drawbacks of CTOs, 2. Medication adherence often the primary focus for CTOs, 3. Relationships that help and hinder and 4. Recommendations for improvement in the design, implementation and monitoring of CTOs. Themes 1 and 4 were present in all of the three groups. Theme 2 was present in the clinician and people on CTOs group and Theme 3 was more present in the studies with people on CTOs and families with some reference to relationships in the clinician group tied to issues of coercion and fit with a recovery orientation. Further description of the themes is provided below with quotes from the studies that were part of the original systematic reviews. It should be noted that

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Table 1
Themes for the three stakeholder groups.

People on a CTO	Family	Clinician
Feelings of being Coerced and Controlled		
Medication Adherence seen as the main reason for CTOs		Medication compliance is an important condition of CTOs
CTOs seen as providing a safety net		
Positive relationships with clinicians help	CTOs Enabled Families to Influence the Clinical Care	
Difficult relationships with clinicians		
Concerns that they lacked knowledge about CTO legislation and process	Dissatisfaction with aspects of the CTO process	There is still room for improvement
Feeling that a lack of respect and dignity is sometimes present		
CTOs were valued because of services provided		
Ambivalence regarding balancing acceptance of enforced treatment with feelings of increased wellness	Benefits of CTOs outweigh disadvantages	There are benefits for individuals on CTOs despite the tensions that exist within and between clinicians
Being on a CTO was viewed as being preferable to being in hospital		

not all studies illustrated their findings with direct quotes from participants.

3.1. Benefits versus drawbacks of CTOs

The most prominent finding of this constant comparative analysis of the themes of the three systematic reviews was that members of each stakeholder group view CTOs as providing specific benefits to those persons who are on CTOs that many times outweigh the coercive nature of CTOs. Benefits of CTOs figured most predominantly in the family studies, less so in those studies with people on CTOs, and clinicians emphasized the benefits for people that had histories of relapse and non-adherence.

The belief that CTOs provided a ‘safety net’ was mentioned by all parties. Stroud, Banks, and Doughty (2015) wrote that “*an emergent theme across all groups (service users, practitioners and nearest relatives) was that the CTO was seen to provide a valuable safety net*” (pp 89). Ridley and Hunter (2013) when reporting their findings noted that ‘coercion was generally unwelcome by participants (people on CTOs) but nonetheless over half of the 39 people interviewed reflected that compulsion had been ‘*the right thing for them at the time… a necessary evil’*. The loss of autonomy and respect is described as a very personal experience by people on CTOs but they are also able to note benefits in addition to the safety net such as improved quality of life, increased services provided, an increased sense of wellness as well as it being “*better than being in hospital*”. Gibbs (2010) reported that people on CTOs who had a history of treatment for schizophrenia and many suicide attempts told researchers that they saw the CTO as a safety net.

Families emphasized that CTOs brought stability to their lives and ended the chaos of previous experiences with their relatives. Families were very positive about the ability to share the burden of care for their family member with clinicians and noted the increased quality of life for themselves and their loved one. As one family member in Stensrud, Hoyer, Granerud, and Landheim (2015b) said “*I do feel the OC as a relief, I must say. That's the right word, I think. There are more people to support us now.”* The article goes on to note “*the possibility of readmission with a simplified procedure reassured them giving relief to the family and alleviating long periods of illness*” (pp. 585). Lastly, they are pleased with the additional services often provided.

Clinicians see clients with relapses and adherence issues as a group that most benefit from CTOs, and note an increased quality of life as well as a safety net for people on a CTO among the benefits they experience for their clients. In O'Reilly, Keegan, Corring, Shrikhande, and Natarajan (2006) a case worker noted *“Two people that I have on a CTO right now are on it because of clear non-compliance with treatments, and it's made quite a remarkable difference for both of them…it has made a remarkable difference in their stability and their functioning, so I think it has been of great value…to improve their quality of life and really get them on the road to better things.”*

In the Light et al. (2014) study of the lived experience of CTOs for people on CTOs and their carers the authors concluded that *“the lived experience of CTOs is complex: it is one of distress and profound ambivalence. The distress is an intrinsic aspect of the experience of severe mental illness, but it also emerges from communication gaps, difficulty obtaining optimal care and accessing mental health services. The ambivalence arises from an acknowledgement that while CTOs are coercive and restrain autonomy, they may also be beneficial. (pp 345).”*

3.2. Medication adherence often the primary focus for CTOs

Clinicians and people on CTOs noted that medication is often the primary focus of the CTO. People on CTOs frequently expressed concern about medication side effects and the lack of choice regarding taking medication. However, they were also able to associate being on a CTO and taking medications with feeling better, and being better able to maintain housing and relationships. One service user in Stroud et al. (2015) study said “*… It takes a long time, a very long time, to understand that* [that medication helps] *but I believe that everyone that wants to get on with their lives will see a CTO is a beneficial thing”*.Gibbs et al. (2006) reported that *“service users said that being on a CTO meant they had to do certain things, like ‘take your meds’ and ‘see the nurse’ …but still noted specific improvements in relations with their family, reduced substance misuse, reduced attempts at self-harm, increased understanding of themselves and their illness, and small improvements in feelings of well-being and self-respect”* (pp1092).

Clinicians viewed the non-adherence to medication as the key cause of recurrent illness and saw medication adherence as the solution. Many stated that the usual CTO conditions focused on medication adherence and contact with the clinical team to ensure enforcement. A nurse from the O'Reilly (2006) study noted that *“I have a lady who has lots of experience of stopping taking medication. She becomes manic. Then there's a long period of time before she comes for treatment, and that gives her a chance to let herself go in many arenas. Then she takes a long time to recover. So with the contact we now have (outpatient committal), we can avoid these unfortunate side effects, if one can call them that.”*

3.3. Relationships that help and hinder

This theme was most prominent with people on CTOs and families with some reference to relationships in the clinician group tied to issues of coercion and the use of practice philosophies such as a recovery orientation. Family members in many cases highly valued the relationship with clinicians. They were very focused on the benefits of sharing the burden of 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 emergencies. A brother in Mullen, Gibbs & Dawson (2006) noted that “*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.”* A carer in Gault (2009) said *“[I have someone] on the other end of the phone and I know they'll be around if I call.”* On the other hand relationships where family members are not listened to do not help. As one mother reported when contrasting clinicians who listened and those who did not said “*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.”* (Stroud et al., 2015).

Relationships with clinicians that were collaborative and recovery focused helped people on CTOs to accept the conditions of a CTO and feel that they could regain some control over treatment decisions. As one person on a CTO said *“It helps to have someone guide you and be your backup. I like being on a team.”* (Malatest & Associates, 2012) and another *“She's a good psychiatrist, she's changed my medication a few times. I've told her that my medication that I was on wasn't working for me and she's changed it about until she got the right combination.” (*Ridley & Hunter, 2013*).* In contrast, some people on CTOs noted that their interactions with some clinicians lacked understanding, were insensitive to their problems or clinicians had inflexible expectations of them. One person said *“What worries me a bit is that there can easily be misunderstandings if it's very rigid. What if I'm really trying hard to stick to their rules and something happens beyond my control?”* (Stensrud et al., 2015b), and another *“I think it was a case of banging your head against a brick wall, it's really like what's the point, you know in the end … you have to do it anyway.”* (Light et al., 2014).

As noted above there was some mention by clinicians that they often had difficulty reconciling the compulsory nature of the treatment practice standards such as a recovery orientation and the subsequent effect on relationships with their clients. As one physician in the Stensrud, Hoyer, Beston, et al. (2016) study noted *“it does something to the relationship when you're operating with coercion”.* A case coordinator in Rawala and Gupta (2014) noted *“CTOs could lead to increase of mistrust especially if the patient does not have a good understanding of their illness, and is not willing to be involved with mental health services. Is it ethical to impose restrictions in the community? Still, it has helped some patients engage and take treatment.”* The recovery approach has been increasingly emphasized in mental health care (Anthony, 1993). Many clinicians wondered how compulsory treatment can be compatible with recovery and this sometimes results in tension both within and between team members. Other clinicians felt that it was possible to balance the principles of recovery with the need for treatment. In Courtney and Moulding (2014) a social worker noted that *“It's about being flexible, it's about being creative and it's about giving people a go. Just because you have a mental illness, doesn't mean that you're excluded or exempt from normal consequences. Applying recovery principles to concepts of CTOs is a good way to get someone off a CTO.”*

3.4. Recommendations for improvement in the design, implementation and monitoring of CTOs

People on CTOs note a need for better education regarding CTOs and many hold a negative view of the appeal process viewing it as biased toward the opinions of physicians (Malatest & Associates, 2012; Steadman et al., 2001). Families are very vocal regarding the failings of CTO processes, but also frequently expressed negative views about the mental health system in general. In a review of CTO legislation in Ontario, Canada (Dreezer & Dreezer, 2005) the authors noted *“one family member told us that lawyers, doctors and advocates debate philosophy while they and their ill family member suffered”* (pp86). Families want a system that works for them in a timely and effective manner. Both families and clinicians note the need for additional services and agreed that the CTO legislation and subsequent processes are too cumbersome often resulting in delays and bureaucratic burden of meetings and paperwork. Clinicians in O'Reilly et al. (2006), for example, noted that CTO procedures were incompatible with reality of practice and treatment. One said “*We have some ongoing issues with lack of clarity about the procedure to follow through. Even as much as two weeks ago I had to have a special meeting about people coming to the emergency department … it's like 10 years later and we are still stumbling through.”*

4. Discussion and conclusions

We found common themes shared by all of the three stakeholder groups and other themes shared by two of the three groups. All three groups saw benefits that outweigh the coercive nature of CTOs. However there is a need for some skepticism regarding the representativeness of the people on CTOs group as it is possible that the selection of more settled and cooperative people on CTOs may bias the results to be more favourable to CTOs. Clinicians are often tasked with identifying suitable participants for qualitative studies. Clients who are positive about their clinicians and treatment are more likely to be approached than dissatisfied and irascible clients. Further, when invited to join a study people with more positive relationships with clinicians may be more likely to consent to take part in a research study. We have examined this phenomenon in more detail elsewhere (O'Reilly, Corring, Richard, Plyley, & Pallaveshi, 2016). We note that some studies such as Gibbs (2006) and O'Reilly et al. (2006), tried to recruit all patients on CTOs from a region and that this may be better than convenience or snowball sampling for this type of enquiry. The utility of having peer researchers who may assist in recruiting a more representative sample both at the design and implementation stages of research may also be a strategy.

An important benefit that people on CTOs felt counterbalanced coercion was the ability to live outside hospital. This is consistent with the principle of reciprocity (whereby when the state takes away your autonomy it provides benefits). Other potential benefits include the provision of skills training, assistance with ADLs and assistance navigating the health and social service systems. The ultimate benefit, which unfortunately is not achieved by all, is improved health and real autonomy for those clients who regain insight. The authors argue that prioritizing people on CTOs who are generally the sickest for services such as Assertive Community Treatment teams, housing and other supports is in keeping with the principle of reciprocity. However, it would be necessary to offset concerns that people are being unnecessarily placed on a CTO, simply to secure services.

People on CTOs did not feel that the Review Board process was helpful (Corring, Plyley, & Skufca, 2013). This may reflect the low rate of CTOs rescinded by review boards. Some studies (Dreezer & Dreezer, 2005; Malatest & Associates, 2012) report that psychiatrists are not using CTOs for some of their patients who might benefit and only using them when there would be little chance of a challenge from a review board. This may represent the reluctance of physicians to use CTOs in cases that barely meet jurisdiction's legislative criteria. If this is the case, it would limit the number of cases rescinded by review boards.

It is possible that reducing the adversarial nature of Review Boards might help to reduce this behaviour (O'Reilly, 2003). But would an inquisitorial approach help the patient? One study Diesfeld and McKenna (2006) found evidence that review boards were willing to actively challenge some professional participants' decisions regarding treatment. Many tribunals have adopted an inquisitorial approach and one helpful focus of future research would be to determine if this was a more acceptable approach for people on CTOs.

Clinicians can increase or reduce the level of perceived coercion by their actions and language. However, clinicians, even those working with clients on CTOs often receive little detailed training on specific techniques to improve relationships with these involuntary patients. The authors are aware that there is some discussion in medical, nursing and social work training regarding coercion but not a great deal about how to apply theory to practice. Incorporating such a topic into training that encompasses the recovery model might be considered incompatible by some. But as noted above, clinicians in the studies that were reviewed are suggesting strategies to accomplish the objective. Such training would also be important in other sectors of the mental health care field more generally, for in reality leaving CTOs aside, a large percentage of inpatients in both acute and tertiary care hospitals are also involuntary, thereby making such training very applicable and important for inpatient clinicians as well.

Concerning other relationship matters, could/should professionals be better trained regarding building relationships with people on CTOs and families? The general difficulties of clinicians working with families and the tensions that arise were reflected in our findings. 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, Bäzner, 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, Jörgensen, Rylander, & Koernig, 2013). Emphasizing family involvement in care decisions when appropriate and respecting their knowledge and expertise regarding their relative's illness would be a starting point and easily achieved. Building relationships with patients is central to client centered care, psychosocial rehabilitation and a recovery orientation. Many care centres are supporting one or more of these approaches to care and perhaps need to take a closer look at how their clinicians are incorporating these principles into every day work with their patients (Corring, Speziale, Desjardins, & Rudnick, 2016).

Many people on CTOs complained that CTOs are *"all about medications and compliance"*. There is likely truth to this perception. In many jurisdictions a very high proportion of people on CTOs suffer from psychotic illness (for example, Malatest & Associates, 2012) and nonadherence to antipsychotic medication is often identified as the critical factor in past relapses (Morken, Widen, & Grawe, 2008). Clinicians will often consider a CTO for a person who has a history of responding to antipsychotic medication when in hospital but subsequently deteriorating after stopping medication when discharged.

We wonder if this is primarily an education issue of the purpose of a CTO and requirements placed on the people on a CTO. Education would start with clearly defining the purpose of CTOs which may differ among jurisdictions but perhaps could be brought into some alignment with input from those with lived experience. CTOs should not be oversold as the solution to the systems problems – they are not. There should be a well-defined limited target group. Ongoing education about what a CTO can and can't do is critical – this in addition to the ongoing education about the law and interpretation of its implementation. A key piece here is that only the essential treatments should be compulsory (O'Reilly, Dawson, & Burns, 2012). CTOs are different in different jurisdictions and convey different powers to the clinicians in those jurisdictions, thus in addition to medication adherence CTOs may require attendance at clinical appointments (including medical), blood work, living at a group home, or attendance at addiction services. The sanction for refusal is hospitalization which is the same for medical nonadherence. A voluntary component should also be offered but not written into a mandatory treatment plan. The importance of the relationship between clinician and people on a CTO in the implementation of the CTO cannot be overemphasized as the Nyttingnes, Roud, and Rugkåsa (2016) study demonstrated that the effects of compulsory medication and poor therapeutic relationships often result in people on CTOs feeling *'unbelievably humiliated and oppressed'*. The authors attributed these feelings to involuntary medication, and the dismissal of the patient perspective.

Finally, to the issue of improving CTOs both specifics of processes tied to legislation. Dawson (2006) has noted that physicians are reluctant to use CTOs if they are excessively complex or lack effective enforcement. Cumbersome processes just do not work. The trick is not to have them so easy that they become overused. Education as a key component, and requiring the components of the system to work together have to be in place. For example, CTOs will not work if one component of the system does not play its role. This was the case in the pilot project in New York in the 1990s when the New York Police Department refused to apprehend a person on a CTO who had defaulted from their treatment (Steadman et al., 2001). Other studies have noted when police and caregivers work in tandem, results in saving police time and contact with individuals with mental illnesses can be reduced (Corring et al., 2010). The authors have also noted other suggestions for improvement in their previous publications from the systematic review (Corring et al., 2017; Corring et al., 2018; Corring et al., 2019).

What are the next steps? Perhaps a carefully designed participatory action or mixed methods study that would examine these four themes further would quantify and document the quality of life and other benefits that these previous studies have noted and help us further define what makes CTOs effective and alternatively what stands in the way of their effectiveness.

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