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Community Treatment Orders: the evidence and the ethical implications

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Introduction

Community treatment orders (CTOs) are legal orders, provided for within mental health legislation, that are made by clinicians or tribunals. CTOs set out the terms under which a person with a mental illness must accept treatment or other services while living in the community (Light et al., 2012a).

The criteria for involuntary treatment differ from jurisdiction to jurisdiction, but most commonly include at least: that the person must suffer a serious mental illness; that he or she needs protections from some serious harm; that the person is refusing the treatment offered, and; that an order represents the least restrictive means of providing the person with protection. Only in some jurisdictions must it also be the case that people's mental illnesses rob them of the capacity to understand or weigh relevant information when they refused treatment (Ryan et al., 2015). CTOs go under different names,¹ and though the treatments they impose vary, in most instances they involve psychosocial interventions and medication (often delivered by long-acting injection) (Lepping and Malik, 2013, Burns and Molodynski, 2014). Non-compliance with a CTO generally results in the person being detained and, either involuntarily admitted to hospital, or being given the mandated treatment before being discharged back to the community. Since their introduction, CTOs have

gradually become a standard feature of contemporary mental health care internationally (Brophy and McDermott, 2003, Burns and Molodynski, 2014, Light, 2014).

CTO legislation emerged in tandem with the demise of large stand-alone psychiatric institutions and flourished in response to community concerns about suicide and violence (Muijen, 1996, Behnke, 1999). It was hoped that CTOs might prevent relapse, minimise repeated, ‘revolving door’ admissions (Dawson, 2008, Elbogen and Tomkins, 2000) and provide families and carers of persons with severe mental illness with much needed support (Power, 1999). Whether CTOs have actually achieved these outcomes is increasingly doubted, and there have been recent calls for them to be abandoned or dramatically scaled back (Newton-Howes and Ryan, 2017, Callaghan and Newton-Howes, 2017, United Nations 2017). Furthermore, CTOs are seen by some to be incompatible with human rights obligations and to hinder, rather than assist, the recovery of people with mental illness.

¹ In North America compulsory community treatment is often referred to as “assisted outpatient treatment” or “outpatient commitment”.

This chapter attempts to make sense of the controversy surrounding CTOs by considering three aspects of their use: their compatibility with human rights; their efficacy, and; their impact on individuals and healthcare systems. We conclude by briefly examining some alternatives to CTOs.

Background and the international context

CTOs have been adopted in the vast majority of US states, all jurisdictions in Australia, New Zealand, England, Wales, Scotland, Israel and nine provinces in Canada (Light et al., 2012b) . They exist in Norway, Sweden and Denmark, but are not a common feature of legislation in continental Europe (Churchill et al., 2007, Ramon, 2006, Rugkåsa, 2016).

In contrast to the United States and the United Kingdom where the implementation of CTOs has occurred in the context of considerable controversy, stakeholders in Australia, Canada and New Zealand generally reacted positively to their introduction (Gibbs et al., 2005, Gibbs et al., 2006, Dawson, 2005, O'Brien and Farrell, 2004, O'Reilly et al., 2006).

Are CTOs compatible with human rights?

The degree to which CTOS are compatible with human rights is hotly disputed. While, some commentators have argued that CTOs contravene human rights on the basis of their being compulsory treatment (Minkowitz, 2006), others claim CTOs provide a vehicle for the realisation of a patient's positive rights to care and treatment (Dawson, 2005). The advent of the *Convention on the Rights of Person with Disabilities (CRPD)* (United Nations 2007), the international human rights instrument governing the rights of people with disabilities, has changed the contours of the human rights debate, but not dampened the controversy (Maylea, 2016, Freeman et al., 2015).

While its implications for mental health law remain unresolved, it is clear is that the *CRPD* marks a significant turning point in the international human rights framework. It responds to the lived experience of people with disabilities by adopting a clear emphasis on equality, nondiscrimination and social inclusion and a new approach to the notion of equal access to goods and services, particularly the social, environmental and material determinants of health (Weller, 2010). Article 12, requires equal recognition before the law. Article 17 requires respect for physical and mental integrity. Article 25 protects the right to health by privileging the right to control one's health and body. The *CRPD* rejects the traditional position in the law that those who lack capacity should be

subject to best interests determinations. Rather, it requires a radical reinterpretation of participation in decision-making that asserts that people with disabilities be the heart of decision-making interactions which respect of the person's rights, will and preferences (United Nations 2014). The *CRPD* committee asserts that in cases where the wishes of the person are not known, decisions should be made on the basis of the 'best interpretation of will and preferences' (United Nations 2014, para 21). In short, the *CRPD* recognises that human rights principles do not insist on independent decision-making, but focus on the quality of the interaction between people with disability. In doing so the *CRPD* creates a new approach to decision-making in health. While the practices that will support that approach are yet to emerge, it is clear that CTOs in their standard form are inconsistent with international human rights principles (Newton-Howes and Ryan, 2017).

McSherry (2008) argues human rights protection of the right to physical and mental integrity in the *CRPD* is unlikely to completely overturn involuntary treatment, but will enable greater restriction on 'unbeneficial and overly intrusive treatment' (p.122). If CTOs are to be appropriately limited, rather than abolished, the question of whether they "work" remains pertinent.

Do CTOs work?

What we mean by "work" and how to judge this

Questions about the efficacy of a particular treatment (or element in treatment delivery) are common in medicine. One way to pose such questions is to consider whether people afforded an intervention will benefit from it, but this question raises two further issues.

The first issue arises from the fact that no treatment will benefit everyone who gets it, even if some people benefit from being subject to a CTO, others will derive no benefit. The second issue is a reflection on what we mean by "benefit" and how that can be measured. Ultimately, we are interested in whether the person's life is better on the treatment, but there are two serious problems with examining benefit in this sense. First, general well-being is essentially a subjective measure. Whether or how a person's life is "improved" will be interpreted differently by each person. Second, as so many factors influence well-being, it is hard to know to what extent the treatment of interest contributed to any improvement seen. The latter problem is particularly significant when the supposed benefits of treatment have taken months or even years to manifest.

For these reasons, quantitative researchers tend to avoid measures of general well-being, and focus

instead on outcomes that are more circumscribed, easier to measure, and directly related to the intervention.

Randomised controlled trials of CTO effectiveness

The studies that are usually regarded as most likely to yield meaningful results are randomised controlled trials (RCTs). RCTs are studies that randomly place some participants into one group that gets the intervention and others into a group that does not. The outcomes of the two groups are compared at the end of the study. The idea is that the randomisation will render the two groups roughly the same, with the only real difference between them being whether patients got the intervention. Any 'improvements' observed in one group are then attributed to the intervention.

Three RCTs that have tested the effectiveness of CTOs. Before discussing their results, it must be noted that all had significant limitations, both in terms of the way they were conducted and in terms of the extent to which their results can be generalised to other populations.

The first was conducted in New York State in the 1990s (Steadman et al., 2001). It was a state sanctioned pilot program to gauge the effectiveness of what would become known as Kendra's law

(New York Mental Hygiene Law § 9.60). The study had multiple problems. It was small, enrolling only 142 participants, which was fewer than half of those eligible for enrolment in the study. The study ran 12 months but, 45% of participants dropped out before the end. It was not clear to what extent the research protocol was adhered to and there was confusion among staff and patients about who was, and who was not, on a CTO. Finally, no non-compliant patient was ever made subject to the “pickup procedure” that the law enabled, that would have seen the patient brought forcibly back to hospital for treatment.

The second study, based in North Carolina, was conducted over the same period as the New York study and had a very similar design (Swartz et al., 1999). It was larger than the New York study, following 264 patients, and had a much smaller dropout rate. The North Carolina statute allowed an order to be made for a maximum of 90 days, but the orders were usually made for only 30 to 60 days (NC Gen Stat § 122C-271).

Both US studies excluded patients with a history of violence, and this, together with the unique characteristics of the US population and health system, mean that it is hard to translate their findings into day-to-day practice outside the US.

The OCTET study (Burns et al., 2013) was much larger than either of the US studies and randomised 366 patients to either a CTO or to a control group who were given leave under section 17 the UK *Mental Health Act*. Section 17 allowed patients to leave the hospital for days, or even months, while still subject to recall. The OCTET study also had problems. For example, although the length of initial compulsory outpatient treatment differed significantly between the two groups, with median lengths of 183 days in the CTO group compared with eight days in the control group, patients in the control group eventually averaged four months on some form of compulsory treatment.

Consequently, the intervention and control groups may not have been treated that differently.

Additionally, the study protocol allowed treating clinicians to later make treatment decisions independent of the initial randomisation and as a result around one fifth of patients in either arm swapped treatments.

There are, therefore, reasons to doubt the overall validity and generalisability of any of the three

RCTs. With that significant caveat in mind, what did they find?

The three RCTs examined a variety of outcomes. All examined whether CTOs led to an avoidance of readmission to hospital. The New York and North Carolina studies examined compliance with medication, avoidance of arrest, avoidance of homelessness, and whether there was an improvement in subjective well-being or quality of life. The OCTET study also examined whether CTOs led to fewer days in hospital or improvement in symptoms and general function. The North Carolina study also examined if the patients on CTOs were less likely to be the victims of crime. Of all these potential outcomes across all three studies, the only outcome to reach statistical significance was the last – the avoidance of victimisation in the North Carolina study. This disappointing lack of positive effect remained even when the results of the individually small studies were combined via meta-analysis (Kisely and Campbell, 2014).

Other quantitative studies examining the effectiveness of CTOs

Although RCTs are generally regarded as the gold standard in determining whether an intervention is effective, they are not always the best method of approaching effectiveness questions. When researching CTOs, it is very difficult to recruit large numbers of participants to a randomised controlled trial. If the benefits of a CTO are relatively small, they may simply not become apparent if studies can only enrol a few hundred people. There may also be perceived ethical difficulties with

randomising some patients to CTOs and others not, which may explain why the US studies excluded patients with a history of violence.

These considerations have led some researchers to turn to epidemiological and case-control studies to try to determine the effectiveness of CTOs. These studies typically use large government databases to retrospectively compare the outcomes of larger numbers of patients, some of whom have been subject to CTOs and others not.

Studies of this sort cannot be randomised, so researchers must make some effort to try to match the patients that have been placed on CTOs with those that have not. The aim is to try and compare like with like: to make the argument that the only real difference between the patients who were placed on a CTO and those that were not, was the CTO.

There have been more than ninety of these types of studies and a number of detailed reviews (Churchill et al., 2007, Maughan et al., 2014, Rugkåsa et al., 2014). The studies have examined a range of possible benefits of CTOs including: a decreased rate of re-admission to hospital; a decrease in the number of re-admissions; fewer days in hospital; improved social function; community service

use, and; a reduction in all-cause mortality. Unfortunately, an overview of all these studies reveals inconsistent and conflicting results. In some studies, the changes in some of these potential indicators reach statistical significance, but in others they do not. In some studies, CTOs appear to improve these indicators, and in other studies, the indicators decline.

For example, one of the most reported indicators is the rate of readmission to hospital, which was examined in 22 studies. Thirteen studies suggested that CTOs decreased the rate of re-admission of people subject to them, but four studies suggested the rate of re-admission *increased* when CTOs were used. The remaining five studies mirrored the findings of the RCTs suggesting CTOs made no difference to the rate of re-admission (Rugkåsa et al., 2014). To further complicate matters, sometimes the decrease in re-admission only occurred after a person was on a CTO for six months, a finding that may be the result of a biased process, as CTOs are often renewed at around six months and it may be that some clinicians will only renew a CTO when it is felt that the person subject to it is benefiting from it. Even more confusingly, it is not clear that more re-admissions can properly be regarded as a bad outcome. Some authors argue that, on the contrary, early re-admission before the patient gets very sick, is a *good* thing and may lead to less time in hospital overall (Segal and Burgess, 2006). Though that line of thought is somewhat undermined by a similar examination of

studies that examine the effect that CTOs have on the number of days spent in hospital. These studies too are inconsistent (Rugkåsa et al., 2014).

One of the most robust findings came from a Western Australian cohort, where it was found that people placed on a CTO appeared to benefit from a significant reduction in all-cause mortality (Kisely et al., 2013). However, in this study, and in several of the other positive studies, the authors speculate that the benefit is not due to the coercive effect of CTOs *per se*, but rather due to the increased contact with health professionals associated with CTO use. The deaths in the West Australian study were primarily from physical illnesses such as cancer, cardiovascular disease or diseases of the central nervous system and the improvement associated with CTO use disappeared when adjusted for increased outpatient and community contacts with psychiatric services.

If, to the extent that CTOs *are* effective, they are *only* effective because they provide a key to gaining access to a service that people could, or *should*, have been able to access anyway - perhaps by influencing healthcare staff to provide a better service - then they are not being effective via their power to compel and, in a real sense, are not *really* effective at all.

The latest round of large cohort studies, which use new techniques to match those who were subject to CTOs with those who were not, appear to be finding more robust evidence of efficacy, at least with respect to decreased admissions. However, these studies suggest that the benefits of CTOs are modest at best. For example, one recent study, conducted in Australia, found that CTOs could decrease the number of re-admissions, but the number of people that needed to be subject to a CTO to prevent one person from any re-admission over a three year period was 48 (Harris et al., 2014). Even if one person will benefit from a CTO is hard ethically to justify forcing treatment upon 47 others who will not.

Taking account of all the available quantitative studies conducted to date (RCTs, cohort and epidemiological studies), there is little or nothing to support a conclusion that CTOs are effective via their ability to compel individuals to accept treatment without consent. Such is the state of the evidence, the authors of the Maughan systematic review conclude, “There is now robust evidence in the literature that CTOs have *no* significant effects on hospitalisation and other service use outcomes” (Maughan et al., 2014). Though arguably this conclusion goes beyond the state of the

evidence to date, exactly when one should deem a lack of *evidence* of effectiveness as evidence of a *lack* of effectiveness is an issue upon which reasonable minds will differ.

Evaluating the wider impact of CTOs

Debates about the use and consequences of CTOs

While some of the literature surrounding CTOs contends that they are inherently coercive and therefore unacceptable, others assert that the experience of coercion, even though it may be distressing, needs to be weighed against the potential benefits of CTOs (Mfoafo-M'Carthy and Williams, 2010). Studies attempting to assess the degree of perceived coercion experienced by people on CTOs have produced mixed results (Kisely and Campbell, 2014). Some have argued that the coercive impact of CTOs has been exaggerated (O'Reilly et al., 2006), while others have argued that at least some people are 'totally humiliated' by all forms of coercion in psychiatric care, including forced medication (Nyttingnes et al., 2016).

There are now many studies suggesting that CTOs are perceived as important in assisting people with mental illness to gain access to services for continuity of care or when in crisis. In these studies, CTOs are understood as an expression of the commitment of the service to the person on a CTO

(Light et al., 2017). Swartz et al. (1999) , for example, conclude that a CTO “works when it represents a reciprocal commitment by community programmes to provide sustained and intensive treatment to patients under court orders” (p1974). In these studies CTOs are, rather pragmatically, considered positively because they enable continuity of care.

Nevertheless, the imperative to ensure adequate follow-up of people on CTOs creates significant problems for service providers and may generate unintended consequences (Brophy and McDermott, 2003, Light et al., 2017). For example, Power (1999) found that while there is considerable support from service providers for CTOs in well targeted situations, CTOs may act as a further deterrent to treatment compliance when poorly targeted. Whether or not that is true, CTOs are difficult to administer with homeless or itinerant people; those most at risk.

CTOs have also been associated with a net widening effect that occurs after their introduction (Geller et al., 2006), where the use of CTOs expands beyond those initially targeted to other groups, such as those experiencing only their first episode of illness (Morandi et al., 2016), or to women with less severe illness or less impoverished social circumstances (Brophy et al., 2006). A related concern is a potential 'lobster pot effect' (Morandi, 2016), where there is a low threshold for being placed on

a CTO, but a higher threshold for having it removed. Carney (2003) argues there is a growing, invisible, marginalised group in the community who experience significant curtailment to their human rights and are at risk of further stigma and discrimination.

Key stakeholder perspectives

Another way of examining the effect of CTOs is to consider the 'lived experience' of the people involved in their implementation, such as those who have been on a CTO, their families or carers, and service providers (mainly psychiatrists). There is a consistency in relation to qualitative findings across jurisdictions and over time, suggesting considerable similarities in the lived experience of people subject to CTOs (Churchill et al., 2007, Corring et al., 2017). In some studies, CTOs are described positively, offering 'comparative liberty'. People on them report that it is better to be on a CTO than to be in hospital, gaol or subject to other forms of coercion (Corring et al., 2017, McDonnell and Bartholomew, 1997). Some people have been observed to request a CTO in order to feel safe, have a boundary or avoid the potential of being overlooked or abandoned by service providers (McDonnell and Bartholomew, 1997, Corring et al., 2017, Dawson, 2005). Others appear to be simultaneously resisting and accepting orders (Canvin et al., 2002, Gibbs et al., 2005). Corring et

al (2017) found that people are sometimes ambivalent about 'balancing acceptance of enforced treatment with feelings of increased wellness' (pg. 4).

Lived experience research in New Zealand (Gibbs et al., 2005), Canada (O'Reilly et al., 2006), the US (Swartz et al., 2003, Wales and Hiday, 2006) and Australia (Brophy and Ring, 2004), highlights the issue of people 'not feeling heard' about medication preferences and side effects. Being heard, respected and receiving good quality treatment in the context of genuinely helpful relationships is commonly viewed as important, although deficiencies are often identified (Corring et al., 2017).

Many people on CTOs see medication adherence as their main rationale. People in these studies appear to be engaged in active evaluation of their care and express concerns about the poor standard of care they are receiving (Canvin et al., 2002, Corrigan and Liberman, 1990). For some this might be described as concerns about a lack of reciprocity. Reciprocity would require people on CTOs to receive a level of service, treatment and care commensurate with the loss of liberty they experience (Bartlett and Sandland, 2007). Hence deficiencies in service delivery are potentially re-framed as a human rights issue (Light et al., 2017).

Lived experience research also reveals an emphasis on safety and security (Churchill et al., 2007).

CTOs have been compared to having an insurance policy or safety net, particularly in relation to ensuring that services are accessible and could not be withdrawn (Light et al., 2017). People who view CTOs in this light appreciate that services are obliged to provide them with care, and family and carers are relieved that they are receiving assistance in helping their loved ones (Mullen et al., 2006, Corring et al., 2017).

Corring et al (2017) identify CTOs as being associated with difficult relationships with clinicians even though some studies have found fewer negative effects. In New Zealand, it was suggested that CTOs offered, at least in the long term, the possibility of enhancing the relationship - through enabling engagement and providing a structure or framework for difficult conversations to occur (Gibbs et al., 2006). Service providers did express concerns about the difficulties in balancing the care and control dimensions of their practice when implementing CTOs (Churchill et al., 2007). Key stakeholders also appear to often have poor awareness about their rights and responsibilities and the powers contained in CTO legislation (Rolfe et al., 2008, Atkinson et al., 2002).

Alternatives to CTOs

In response to doubts about the clinical efficacy of CTOs and the wide impacts of a mental health system based on coercion, it is important to consider whether there are alternatives to CTOs (Nagra et al., 2016). Szmukler (2015) argues that, in the context of increased use of involuntary care without adequate evidence of its effectiveness, and international human rights obligations, all efforts should be made to reduce the use of coercion, including CTOs.

A wide range of alternative approaches and interventions have been proposed. Some have called for far greater emphasis on whether a person's ability to competently refuse treatment has been effected by their illness. Dawson and Szmukler (2006), have long advocated a the abandonment of specific mental health legislation, favouring the adoption of legislation that covers all people with impaired decision-making capacity, whether this is due to mental or physical illness. Others have insisted that CTO legislation should not allow the forced treatment of people whose refusal of psychiatric treatment is competent (Newton-Howes and Ryan, 2017). Still others suggest that people with lived experience of mental illness should be an integral part of legislated panels that review a person's decision-making capacity (Munetz and Frese, 2001).

While CTOs offer one way of increasing a person's acceptance of treatment in the community, there is a paucity of research on other, less coercive methods of achieving the same end. For example, simply increasing the intensity of therapeutic contact with a person in the community improves outcomes without the need for coercion, but this is yet to be compared to CTOs in efficacy studies (Kisely and Campbell, 2014). The availability of housing is also a form of leverage into treatment has rarely been the subject of research (Monahan et al., 2005).

Advance directives and advance statements are additional mechanisms by which people with mental illness can set out their treatment preferences when well, so that they may inform treatment decisions if they later lose decision-making capacity. These, and other ways of supporting a person's decision-making are favoured by many service users (Henderson et al., 2008). While the efficacy of these tools is only now beginning examined, de Jong et al (2016) conclude that there is greater evidence for advance directives in reducing compulsory admission than there is for CTOs.

Conclusion

The *Convention on the Rights of Persons with Disabilities* has raised the stakes on the human rights credentials of CTOs. Moreover, an analysis of the efficacy of CTOs reveals mixed evidence at best and a likelihood that any positive effects are probably small. The utilisation of CTOs seems influenced by more than just the needs of the people subject to them. Social and structural issues are also being played out in their existence and implementation. Nonetheless, CTOs are now embedded in the mental health care systems of many jurisdictions and impact on how those systems operate. They may be encouraging an increased reliance on coercion to achieve compliance with treatment and sometimes appear to do naught but facilitate access to necessary care and treatment. The evidence from both qualitative and quantitative research is consistently mixed and does not appear to be the main driver of practice or policy change.

The high and increasing use of CTOs is a problem. Calls for a moratorium or at least a dramatic reduction of their use ought to be heeded (Burns and Molodynski, 2014, Newton-Howes and Ryan, 2017, Callaghan and Newton-Howes, 2017). Urgent efforts are needed to explore non-coercive alternatives such as decision-making supports and improvements in treatment and service provision.

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