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The lived experience of involuntary community treatment: a qualitative study of mental health consumers and carers

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Abstract

Objective: To describe the lived experiences of people subject to community treatment orders (CTOs) and their carers.

Method: We recruited 11 participants (five mental health consumers and six carers) through consumer and carer networks in NSW, Australia, to take part in interviews about their experiences. We analysed the interview data set using established qualitative methodologies.

Results: The lived experiences were characterised by 'access' concerns, 'isolation', 'loss and trauma', 'resistance and resignation' and 'vulnerability and distress'. The extent and impact of these experiences related to the severity of mental illness, the support available for people with mental illnesses and their carers, the social compromises associated with living with mental illness, and the challenges of managing the relationships necessitated by these processes.

Conclusions: 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 constrain autonomy, they may also be beneficial. These findings can inform improvements to the implementation of CTOs and the consequent experiences.

Keywords: carer, community treatment order, interview, involuntary treatment, mental health, patient experience, qualitative research

A community treatment order (CTO) is a legal tool that authorises and regulates the use of involuntary psychiatric treatment outside hospitals, in the community setting. CTO provisions in mental health legislation are increasingly widespread,^{1,2} corresponding to the shift from hospital to community settings for psychiatric treatment of people living with severe and enduring illness.

There are considerable regional and international differences in the use of CTOs.^{3,4} This is particularly so in Australia, where there are well-established CTO systems in all states and territories (a number of jurisdictions introduced CTOs more than 20 years ago). Rates of use are high (by world standards) but variable, ranging from 30.2 per 100,000 in the population, in the state of Tasmania, to 98.8 per 100,000 people in Victoria.⁵ In 2010–2011, about one in seven of the more than 7.1 million community mental health care service contacts across Australia were involuntary.⁶

CTOs are the subject of ongoing debate in all jurisdictions in which they operate, particularly in relation to the limited evidence of their efficacy and ethical issues surrounding their use. There is an ‘inconsistent’ and ‘patchy’ CTO evidence base.^{4,7} It has not provided robust evidence of positive or negative effects on patient outcomes⁸ and shows mixed views about their use among stakeholders.^{8,9} Recent research findings suggest that CTOs may fulfil some, but not all, of the objectives for which they may be designed: possibly reducing length of hospital stay,¹⁰ and/or reducing mortality associated with preventable physical illness,¹¹ and/or reducing the likelihood of being a victim of crime,¹ and/or reducing periods of homelessness. It is less clear that they reduce rates of hospital admission^{7,10,12} or whether this is an appropriate outcome measure of efficacy.⁷ It also remains unclear how CTOs have their effect on patient outcomes and, in particular, whether any benefit is due to their compulsory nature or to increased clinical contact.^{1,4,13}

The ambiguity of the research evidence highlights that there is no clear consensus on the instrumental value of CTOs: as they evolve at policy and practice levels, it can be argued that a number of objectives are sought by their use, from avoiding hospital admissions, to stabilising health, to prompting a health system response.¹⁴ The assessment of the effect, acceptability and implementation across different jurisdictions therefore needs to take account of a broad range of factors^{1,7,14}; and to utilise a range of quantitative and qualitative methodologies.^{4,12,14,15–17}

In the Australian state of New South Wales (NSW), 3377 people were placed on a CTO from 2010 – 2011, equal to a rate of 46.4 CTO per 100,000 persons in the population: this rate of use has increased in recent years (from 37.4 per 100,000 in 2003) and is high, compared to rates internationally.⁵ Introduced in NSW mental health legislation in 1990, involuntary treatment cannot be delivered unless, due to a mental illness, a person requires protection from serious harm to him or herself, or others.¹⁸ At the time of this writing, the Act was under review.

Despite more than 20 years in operation, there is very little research on the NSW CTO system. In 2005, Dawson⁹ noted the research to date had provided little more than a sketch of the role of CTOs in NSW. The findings of three quantitative studies conducted in the earlier years of the NSW CTO system’s operation^{19–21} reveal that CTOs facilitate increased contact with health services and medication compliance, and that stakeholders held both positive and negative views on their use. More recently, Kallapiran et al.⁷ found no significant difference between the number of hospital admissions or the length of hospital stays before and after a patient had been placed on a CTO. The authors also conclude that readmission rates, considered in isolation, are not a good outcome focus in CTO research.

Few studies have examined the lived experience of consumers and carers. The small existing scientific literature has found that consumers are generally dissatisfied with many aspects of the use of CTOs and view them as 'stigmatising' and 'disempowering'.²² Many consumers harbour concerns about the loss of autonomy that follows the use of a CTO.²³ In spite of this observation, many consumers and their carers are generally supportive of CTOs, in lieu of inpatient care. Indeed, many consumers attribute their clinical improvement to the improved quality of care they experienced under a CTO.²⁴ There is general acceptance of the use of CTOs for beneficial purposes, where there were psychiatric problems, lack of insight, or risk.²⁵ Many consumers prefer CTOs to hospital care, criminal justice settings or homelessness, although in contrast, they are aggrieved at the loss of control over their circumstances.²⁶ The literature also indicates that the experience of CTOs involves a tension between the undesirable sense of coercion and loss associated with such orders, and the benefits of improved clinical state, psychosocial function, and access and engagement with treatment services.^{8,9} Research on coercion emphasises that this tension is complex: coercion is a context-dependent process that requires rich and nuanced description to be better understood;^{27,28} and that any potential benefits, and therefore justification, may be eroded by how it is implemented in practice.^{4,29}

In the qualitative study presented here, we sought to derive an idiographic model of the lived experience of CTOs among consumers and carers in NSW. An idiographic approach aims to understand the meaning of specific and subjective phenomena, in this case the unique, dynamic and often multi-faceted experience of involuntary psychiatric treatment in the community setting.

Methods

These inquiries were part of a qualitative project examining CTO decision-making and experiences in NSW, which involved interviews with consumer, carer, clinician and Mental Health Review Tribunal member participants. A specific arm of the project sought to describe the lived experiences of involuntary psychiatric treatment in the community setting of people subject to CTOs and carers of people subject to CTOs, and to identify from those experiences potential improvements to CTO processes. The study design drew on grounded theory research methods, aiming to inductively build a model of lived experience based on the study data. The study was conducted by researchers from the Centre for Values, Ethics and the Law in Medicine (VELiM), the Discipline of Psychiatry, and Sydney Law School at the University of Sydney. The study was funded by NSW Health and approved by the University of Sydney Human Research Ethics Committee. The project also involved representatives from stakeholder groups: NSW Institute of Psychiatry; Mental Health Review Tribunal; Mental Health Coordinating Council; NSW Consumer Advisory Group - Mental Health Inc.; NSW Health Mental Health, Drug and Alcohol Office; InforMH; and Carers NSW. Investigators and stakeholder representatives participated in the study design, implementation and analysis.

Sample and data collection

Participants were recruited using a purposive model of sampling, recruiting people with a range of CTO experiences, including current or past CTOs, those ordered in different geographic locations, or those relating to people with different diagnoses of mental illness. The purposive model of sampling sought to build a sample of maximum variation, rather than a representative sample. Maximum variation sampling involves developing a sample in which many different subgroups of different participants are included. This did not allow justification of claims to generalisability of the findings of the study; but rather, it enabled the investigators to describe and understand a range of experience and build a comprehensive model of the lived experience of CTOs among consumers and carers in NSW. This involved an iterative process of data acquisition and analysis, in which the

analysis of one interview informed the conduct of the subsequent interviews. The value of this approach was that as new themes emerged from the existing analysis, subsequent interviews could be used to clarify or explore emergent themes. New themes, or expanded concepts of other themes, were compared with the existing data enabling detailed codes to be developed and be abstracted into categories of an emergent model of lived experience.

Initial contact between researchers and participants was at 'arm's length', with the circulation of an invitation to participate to the non-government organisations (NGOs) Carers NSW, the Mental Health Coordinating Council, and the NSW Consumer Advisory Group Mental Health Inc. This was further circulated through their relevant networks and by individual recommendations of the study. People interested in participating then contacted the researchers for more information and/or to arrange an interview. Participants received \$AUD40 at interview, to compensate the cost associated with attendance.

Data saturation was confirmed by triangulation of the data coded separately by two members of the team (MR and EL), and through discussion of the data and emerging analyses among the investigators and stakeholder reference group members at regular research meetings. Triangulation is an intrinsic aspect of qualitative research used to establish validity and completeness of an analysis, and can involve use of different investigators and stakeholders (as this study did), data sources, study theories and/or methods.^{30–32}

Interviews

We conducted in-depth semi-structured interviews in a variety of sites. Consumer and carer participants were not recruited nor interviewed in clinical settings, as the investigators sought to maintain a clear distinction between their voluntary participation in the study and their involuntary treatment status. Interviews were conducted at the offices of Carers NSW, Mental Health Coordinating Council and the NSW Consumer Advisory Group. In the conduct of the interviews, the investigators sought to prompt the participants to speak from their unique experience by providing narrative accounts of their experience of CTOs and related processes. This included asking participants how they, or someone they cared for, came to be placed on a CTO, what led up to the order being put in place, what was involved and what was the experience like. As detailed in 'sample and data collection' above, when participants raised experiences or ideas that might clarify or scrutinise an emerging theme in the ongoing data analysis, the interview explored those further. All interviews were recorded digitally, transcribed and de-identified, removing any details that might identify individual participants and compromise participant confidentiality.

Data analysis

The data was analysed using the NVIVO9 computer program,³³ which enables different coding strategies and cross-checking of different concepts across the sample. The analysis utilised grounded theory methods, as described by Charmaz,³⁴ Corbin and Strauss.^{35,36} As the data were coded, new themes were identified and a coding structure then developed. This involved a process of 'sorting' the different fragments of the coded data and 'memo writing', in which theoretical ideas about the nature of the codes and their relationship with other codes emerged. After this process of 'open' coding of the data, we collapsed the codes into different categories using the 'tree nodes' function of NVIVO9. This process included an intermediate step, generating visual models of the coded categories and their clustering around a central theme. This facilitated the emergence of 'concepts', which were then brought together to create 'categories'. As the model of lived experience emerged, we then linked the different categories, to theorise explanations of the model that emerged from the data.

Reflexive processes

Given the deep engagement with the data required by qualitative data analysis, researchers need to acknowledge the situation and identify sources of bias in the analysis of the data. In order to avoid the data being 'forced', the open-coding process was performed by a research officer who had no direct experience of the use of CTOs prior to the project (EL). The necessary reflexive process utilised a 2-phase triangulation strategy, where the chief investigator (MR) coded select transcripts, independent of the initial coding process. The two coding structures were compared for disparities and then, utilising a quasi-dialectic process, the divergent coding structures were synthesised into an integrated structure. The models were further triangulated through discussion at research meetings with the investigational team and stakeholder reference group. A preliminary analysis of the data was presented at several research seminars and scientific meetings, where audience responses were noted.

Results

Participant description

Eleven participants (five consumers and six carers) participated in our study interviews. Six were men and five women, from metropolitan or regional/rural areas. Among either the consumers or the relative of the carer were diagnoses of: schizophrenia, depression and bipolar disorder. All of the CTOs under discussion were initiated from a hospital, although renewals of CTOs in a community setting were also discussed at the interview. Six of the interviews related to CTOs currently in place, whereas the other CTOs had either lapsed or the status of the CTO was unknown.

One issue of note was the difficulty in recruiting consumers subject to CTOs through non-clinical pathways. In opting to not recruit through treating clinicians, the yield of suitable participants was lower than anticipated. In addition, several suitable participants agreed to participate, and either later withdrew or were unable to participate. Also noteworthy is that it is possible, as with other research about CTOs,^{24,37} that there may be systematic bias in the consumer participant sample, in that those whom agreed to take part were more likely to have some level of positive regard for CTOs and were more likely to have better insight into their illness. Regardless of the problems in achieving a maximum variation sample, we were confident in our claims of thematic saturation.

Results of qualitative analysis

Analysis of the lived experience of consumers and carers of CTOs in NSW revealed five themes: 'access', 'isolation', 'loss and trauma', 'resistance and resignation' and 'vulnerability and distress'. In Table 1, we detail descriptions of these emergent themes and exemplars of participant quotations.

It should be noted that the themes were relevant to the experiences described by both consumer and carer participant groups. Individual participants (consumer or carer) may have emphasised different aspects of these themes when discussing their own experiences and perceptions, but the themes described here emerged as common to participants. The theme of 'resistance and resignation' was one that was particularly relevant to consumers' direct experiences of coercive processes, but again, observations and opinions about acquiescence or disempowerment were made by carers as well.

Table 1: Themes for lived experiences of CTOs

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Theme	Descriptions	Examples from data
Access	<ul style="list-style-type: none"> • CTOs an access tool, a safety net for the health system. • CTOs an opportunity to foster agency and engagement within system. • Inadequate access, CTOs enforcing flawed care or disempowering. 	<ul style="list-style-type: none"> • 'It hasn't been until recent years that I've come to realise that with the dwindling resources in the mental health area, for people like my son, [a CTO] is the only way to access the service.' Carer • 'It's [a CTO] to make sure that you're given the best recovery, to make sure that you're taking medication, because obviously it keeps you well, and it helps you get on top of your life again...' Consumer • 'Okay, where [X] came into hospital and she did go to the mental health unit, the doctor pulled me inside and said, "[Y], I was wondering if you could tell me how [X] was when she was well, as there's nothing written in her notes"... So she's been maintained in a community mental health service, on a fortnightly depot injection, and the only thing that's recorded is the fact that she's been given an IMI injection.' Carer
Isolation	<ul style="list-style-type: none"> • Feeling alone, ignored or misunderstood because of illness. • Mental illness overshadowing identity. • Involuntary treatment being stigmatising/ marginalising. 	<ul style="list-style-type: none"> • 'It's nice just to be in touch with someone, a lot of people are lonely and live alone and what not, and sometimes we just need someone to talk to ...' Consumer • 'She's at high risk of exacerbating comorbid conditions. She's had open heart surgery and a mitral valve repair... The rest of the health system don't see anything else but schizophrenia.' Carer • 'No, I don't really know of too many people on CTOs, I know that they're probably on CTOs, people that I know, but they don't tell me about it. ... Because you don't want people to think that the government run your life, and it's embarrassing.' Consumer
Loss and trauma	<ul style="list-style-type: none"> • Shock and grief engendered by illness and experiences of health and police/judicial systems. • Losses of relationships, clinical progress and social roles. • Existential anguish. 	<ul style="list-style-type: none"> • 'Yeah, well it was a shock, it was definitely a shock being on a CTO, because I didn't understand what it all meant, and even when I did understand what it meant, it was still a shock, definitely. I thought I was put into a category of, you know I'd seen a lot of people on CTOs and they seemed, what I thought sicker than I was, but really I was sick, you know...' Consumer • 'Yeah, they can get scarred by [the loss of] relationships, relationships they've had since they've been very young, strong relationships can go down the drain.' Consumer • '...her core issue when she still talks to me, she'll talk to my brother and I and she'll say, "How come it worked out for you guys, how come you guys got married and had kids, why didn't it work out for me, why haven't I got someone for me", that basic core thing. That's the heartbreaking stuff, I know it sounds really simplistic, but when she is truly grieving and saying that stuff.' Carer
Vulnerability and distress	<ul style="list-style-type: none"> • Distress of CTO experience often intertwined with that of illness. • Distress of disabling consequences of illness: ability to care for self, work or study, maintain relationships, manage money or health conditions, or coming to attention of police/courts. • Vulnerability in community and interacting with health system, a potential source of injustice or indignity. 	<ul style="list-style-type: none"> • 'It's affected me, it's really made me a lot more scared of life.' Consumer • '...I feel I've lost her, she's not with me, she's somewhere else, she's in a different world and we can't communicate as well being husband and wife. And she doesn't have a quality of life, she loses her quality of life.' Carer • '... Like ask them what do they think of the injection process, having to go to hospital every second week and have the injection and have the student nurses watching over and all that process, it can be a bit humiliating I think.' Consumer • 'I think it's reasonable that people, if they've had their rights taken off them, if they have been an involuntary patient, if they're now going to be maintained in the community on a CTO, I think it's reasonable to expect that they're going to be provided safe, ethical, legal care. And they don't get it.' Carer
Resistance and resignation	<ul style="list-style-type: none"> • CTO brought about a process of submission: <ul style="list-style-type: none"> ○ implicit in submission was sense of disempowerment or feeling discredited. ○ process of acquiescence involved some acknowledgement of instrumental value of CTO. • Experience of CTO compulsion one of being monitored and intruded upon. 	<ul style="list-style-type: none"> • Well it felt like I was being watched closely and monitored, and sometimes I think back and remember my life when it was without as many constraints.' Consumer • 'I think it was sort of a case of banging your head against a brick wall, it's really like what's the point, you know in the end what he's [magistrate ordering a CTO] going to say, but you have to do it anyway.' Consumer • 'I think there's a positive in the dealings with the health profession, and any other injustices will have to be worked out later I suppose, because we can't solve the world's problems overnight.' Consumer

CTO: community treatment order; IMI: intramuscular injection

Discussion

The picture that emerges from this study is that the experience of living under a CTO in NSW is a mixture of distress and of acknowledgement of the perceived value of the process.

Some of the distress, isolation, grief and loss experienced by those subjected to CTOs was primarily a result of the experience of living with a severe mental illness, in addition to that of involuntary community treatment (see descriptions of isolation, loss and trauma, and vulnerability in Table 1, above). Putting aside instances where CTOs were implemented poorly by clinical services, the kind of illness and level of disability experienced by those whom needed such treatment interventions was an intrinsic source of distress. The perceived need for a CTO emerged from that illness and, by extension, that distress. In essence, the experience of distress around a CTO was frequently indistinguishable from the distress of the severe illness that caused it to be invoked.

The actual process of implementing CTOs contributed to and shaped the experiences and perceptions of those subject to them and their carers. It was integral to their accounts of vulnerability, trauma, isolation and agency (Table 1). All of the consumer participants and many of the carer participants described the experience of being treated under a CTO as characterised by problems with communication and understanding. Both consumers and carers described experiences of suboptimal care, usually the result of excessive demands on particular health services. CTOs were frequently regarded as a mechanism to ensure access to services in an environment of limited resources. Many of the narratives depicted the kind of deprivation or social injustice faced by many suffering from severe mental illness.³⁸

From our analysis of this data, we have distilled the lived experience of CTOs, for consumer and carer, as one of distress and profound ambivalence. The distress emerges from mental illness itself, and from the sense of isolation and disempowerment that arises with it, but also from communication gaps and difficulty obtaining optimal care and accessing mental health services. The ambivalence arose from an acknowledgement that while CTOs are coercive and constrain autonomy and agency, they may also be beneficial – a perception of CTOs that has been described in other contexts.^{16,22↓–24,37,39} This ambivalence does not describe a simple dichotomy between paternalism and autonomy⁴⁰; but an experience characterised by intense practical, moral, existential and legal complexity and uncertainty.

The results of this research are important, not simply because they describe the experience of CTOs, but because they suggest that the distress arising from being subject to a CTO can be assuaged by those tasked with their implementation. This can be achieved by focusing upon clearer communication about the order (including strategies to ensure consumers and their carers are aware of the specifics of that order), strategies to improve access to mental and physical health services and other social institutions, and acknowledging that the CTO is a part of the overall distress of a severe mental illness. Our research results also highlighted an obligation owed to people made vulnerable by both illness and by the use of coercive powers to improve the implementation of CTOs. This reciprocity (the right to adequately resourced and appropriate care in exchange for intrusion on civil rights)^{41,42} is a significant responsibility for a health system, if it is trying to achieve positive outcomes and to justify CTOs.^{41,43}

The fact that CTOs may be beneficial but may also have limited or specific efficacy, and may cause psycho-social harm and distress, demands consideration of both the ethical and social aspects of the care of patients with severe mental illness. It requires that we continually ask ourselves: what purpose are CTOs fulfilling and how can we maximise the benefit and minimise the harms that result

from their application? These questions should be the focus of deliberation of public policy, community debate and discourses within the various mental health disciplines.

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Notes

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