

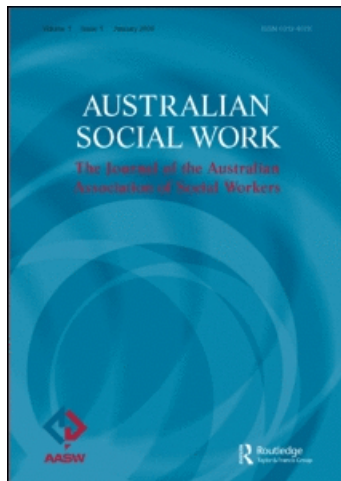
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### Coping with Compulsion: Women's Views of Being on a Community Treatment Order

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## Coping with Compulsion: Women's Views of Being on a Community Treatment Order

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### Abstract

*An interview-based study of 42 people with serious mental illness was undertaken in New Zealand during the early 2000s. Of the 42 people, 10 were women. The women were either currently on a Community Treatment Order or had been recently discharged from a long period of being on a Community Treatment Order. Analysis of the original interview data revealed how these women experienced both benefits and limitations under conditions of compulsory community treatment. The women's key workers, clinicians, and nominated family members were also interviewed. The findings indicate that women considered the overall advantages of Community Treatment Orders to outweigh the disadvantages. Advantages included: greater access to treatment and respite care in hospital; and an increased sense of safety and reassurance for women and their families. Disadvantages included: some restrictions, such as where women resided; feelings of stigma; and having to comply with treatment with the threat of being returned to hospital if they did not. Overall, Community Treatment Orders made a significant impact on the lives of the 10 women but they also allowed the women to remain out of hospital long enough to rebuild their lives and maintain their close relationships.*

*Keywords:* Community Treatment Orders; Compulsion; New Zealand; Mental Illness; Women

The New Zealand Mental Health (Compulsory Assessment and Treatment) Act 1992 allows for the compulsory community treatment of people deemed to have a serious mental illness. Compulsory community treatment is used mainly for people who have a history of previous hospitalisations when unwell, and who are noncompliant with medication (Gibbs, Dawson, & Mullen, 2006). For those placed on Community Treatment Orders (hereafter referred to as CTOs) the risk of harm to self or others is an important consideration; especially for clinicians in their decisions about whether to place someone on a CTO or not (Mullen, Gibbs, & Dawson, 2006; Romans, Dawson, Mullen, & Gibbs, 2004). More men than women are placed on CTOs, the

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average age is 40 years, and the main diagnoses are schizophrenia, and affective or schizo-affective psychosis (Churchill, Owen, Singh, & Hotopf, 2007; Dawson & Romans, 2001). A person may be placed on a CTO on transfer from an involuntary inpatient order, or a CTO can be made by a Judge during a hearing, after a person has been assessed by a clinician as being in need of a CTO (MH (CAT) Act, 1992, part 1 & 2). In New Zealand, data suggest that on average 44 people per 100,000 population are placed under a CTO, compared with Victoria, Australia (60 per 100,000 population) and Queensland, Australia (43 per 100,000 population) (Lawton-Smith, 2005). However, Otago, the region studied for this paper, has had a lower CTO rate per 100,000 population, about 22 (Dawson & Romans, 2001). Around 40% of those on CTOs in Otago are women. While it is a small population the impact of being on a CTO can be substantial. For example, the conditions of a CTO may include: attending appointments, accepting treatment, taking medications as prescribed, permitting visits by mental health professionals (social workers, nurses, occupational therapists, psychiatrists) to a residence, living at a specified residence, travelling restrictions, and avoiding substance misuse (Gibbs, Dawson, Ansley, & Mullen, 2005). Potentially, if a person on a CTO breaks the conditions they might be returned to inpatient care, although in practice return to hospital is more likely to occur if the person is deemed to have become so seriously unwell that they cannot be treated safely in the community. Safety, whether the risk of harm to self or others, is a critical consideration in the use of CTOs (Mullen et al., 2006; Romans et al., 2004).

The use of CTOs is controversial for many reasons, including ethical, moral, and legal concerns. Arguments against their use are that CTOs represent an infringement of people's liberty; they represent unnecessary coercion and restriction; they have a "lack of teeth" when it comes to enforcement, or when conditions are breached; and that the research results of their effectiveness are at best equivocal (Allen & Smith, 2001; Churchill et al., 2007; Lawton-Smith, Dawson, & Burns, 2008; Moncrieff, 2003; Pinfold & Bindman, 2001). Those in favour of CTOs argue that CTOs are not used in overtly coercive ways or misused by clinicians; that CTOs work well when targeted carefully to revolving door patients in order to facilitate engagement; that many patients themselves favour the use of CTOs over hospitalisation; and that by increasing compliance with treatment in the community patients have improved quality of life and stability (Cornwall & Deeney, 2003; Gibbs et al., 2006; Hiday, 2003; Lawton-Smith et al., 2008; Torrey & Zdanowicz, 2001).

Previous research of patient, family, social work, and other mental health professionals' perspectives on CTOs in New Zealand and Australia has been widely reported (Brophy & McDermott, 2003; Brophy & Ring, 2004; Brophy, Reece, & McDermott, 2006; Campbell, Brophy, Healy, & O'Brien, 2006; Churchill et al., 2007; McDonnell & Bartholomew, 1997; Gibbs et al., 2004, 2005, 2006). The advantages and disadvantages for people on CTOs have been noted, with both favourable and unfavourable conclusions—for some people, the gains have been greater freedom than that offered by the alternative of hospitalisation; for others there have been

significant limitations and restrictions of freedom. None of the studies in Australia or New Zealand have explicitly explored the views and needs of women patients; it is not known if there are particular experiences that stand out for them as women, or if there are needs that women have that are not being met. Khoury and Weisman (2002) note the need to develop gender sensitivity when it comes to research, as well as provision of health services, because it cannot be taken for granted that women experience their illness or help received the same as men. Indeed, general research on women and mental health reveals a picture of differences to men regarding mental illness type or diagnosis, treatment and medications, economic and social status, overall experiences of the mental health system, and how they are perceived by professionals working in the field of mental health (Busfield, 1996; Pilgrim & Rodgers, 1999; Romans, 1998; Romans & Seeman, 2006). Busfield (1996, p. 6) argued that “women need to be made visible and their experiences described and explored” as female users of the mental health system, and that it is not necessary to always compare women’s experiences to those of men. It could be assumed that women on CTOs share some of the same experiences as men on CTOs but it also could be anticipated that they will have unique experiences on the basis of gender difference (Romans, 1998; Romans & Seeman, 2006).

### **Aims of the Study**

This study presents the experiences of 10 women who were either currently on a CTO or had recent experience of being on a CTO. The aims of the study were to explore the benefits and limitations of being on a CTO; support and relationships; and discharge experiences.

### **Method**

In the original study previously reported elsewhere (Gibbs et al., 2004, 2005, 2006) 42 service users (patients) were interviewed about their experiences of CTOs. The service users volunteered for participation in the study. Eighty-four service users were approached after selection from their medical records and discussion with keyworkers and clinicians, and invited to be interviewed on the topic of CTOs. Forty-two of the 84 agreed to take part and they were interviewed during 2001 and 2002. The study had full ethics approval from the Otago Ethics Committee and participants signed consent forms. Twenty of the 42 were still on a CTO at the time of their interview and 22 had been recently discharged from their CTO. Of the 10 women in the study, 5 remained on a CTO at the time of interview, and 5 had been discharged from their CTO. The average age of the women was 42-years-old (range 21–62 years); 2 were Maori, and 8 were New Zealand European in ethnicity; half the women had a diagnosis of schizophrenia and half affective disorder; also, 7 of the women had more than one diagnosis. In the medical records of the women it was noted that most of them had self-harmed, attempted suicide, and suffered from severe depression. Several of the women had suffered sexual abuse and sex attacks in their

childhood, and violence against them in adulthood. A few women had been noted as being at risk of harming their family members. All the women had been in contact with mental health services for substantial periods, the average being 16 years of contact for the group. Between them they had had at least 75 previous hospitalisations for their mental health problems—2 women had 4 or less previous hospitalisations, 5 women had 5–9 previous hospitalisations; and 3 women had 10 or more previous hospitalisations.

For every participant an attempt was made to interview a nominated family member, keyworker (a mental health nurse or a social worker) and clinician. This was not possible for all the participants as sometimes they did not wish for a family member to be interviewed. For the 10 women all keyworkers and clinicians were interviewed but only 5 family member interviews were completed. All interviews were recorded, transcribed and analysed using a general inductive approach to ascertain the main themes (Thomas, 2006). The interview transcripts for the entire service user group were first analysed in 2003 through to 2007 and then re-analysed specifically for women service users by the current author during 2009. The medical record summaries of the 10 women were also reviewed. The overall study design was mixed method drawing upon quantitative and qualitative features. A large survey of mental health professionals was undertaken in 2002 (Romans et al., 2004) and complemented the interview-based study.

## Results

### Overall Views of Community Treatment Orders and Their Benefits

Seven of the women interviewed expressed clear opinions that the overall advantages of being on a CTO outweighed the disadvantages. The other three women expressed neutral to ambivalent views on the usefulness of the CTO in their case. None of the women were wholly negative about the CTOs. Positive features of being on a CTO mentioned were “safety and security”, being “protected”, gaining quicker access to hospital or other services, and treatment—“it gets you treatment faster” as one participant put it. Three women talked of the CTO as having literally “saved my life”. Four of the women mentioned the benefits of a CTO as keeping them out of hospital while allowing them back in quickly for respite care or a rest if they became unwell again.

Anna was 17 when she first came into contact with mental health services (21 at the time of her interview for this research). She had been diagnosed with schizophrenia, depression, and an eating disorder. Her self-harming behaviour had led to many suicide attempts and long stays in hospital. She had spent 2 years on a CTO but was now discharged. Anna was strongly in favour of her CTO even though at times she “hated it”. For her the CTO “kept me alive” and without it she was not sure she “would still be here”. While Anna mentioned that the CTO had restricted her freedom she also was clear that the order and the help she received through it got her “to the point of being well enough to sort of make my own decisions”. For Anna,

the CTO meant that she had to “take her medications” and was “not allowed to self-harm”. She felt the CTO was used as a safety measure and as a means to gain respite to hospital when she needed it. She felt she had to comply with the order but she felt the order had help her “get her life back” so she accepted it. Anna’s parents, keyworker and clinician were all of the opinion that the CTO had been essential for reducing Anna’s self-harm and suicidal attempts. Anna’s discharge reflected that she had improved in her mental health sufficiently to be able to live safely in the community without the need for a CTO.

Loretta, a 50-year-old divorced women, with three grown children, had a bi-polar disorder and had been in contact with mental health services for 9 years. For her, the CTO, which she was still on, signalled that “I am unwell” and that “I have to comply with treatment”. This meant she had to “take my medication”. Loretta felt, at times, she was being controlled by doctors and she had felt angry about this. But over time she realised the CTO had brought her some gains. It had protected her and other people: “I accept now that it is best for me and best for my family . . . it protects me and it protects other people”. Loretta was “relieved to be under it” and did not wish to be discharged, especially as she felt the CTO enabled her to access a disability benefit, which meant she would not be forced to work if she felt unwell. Loretta was worried that by continuing on a CTO she may be “locked in the role psychiatric patient for ever”, yet at the same time she needed to stay on the order to “keep me compliant, which is the only way I would stay compliant”!

Heather, a 26-year-old Maori woman with a history of schizophrenia and many suicide attempts felt the CTO had helped her get better and gain some positive relationships. She saw the CTO as a “safety net”. She felt it was a “back-up” in case she became unwell again and she was grateful to still be on the order: “I am quite thankful I am on the Order because I know I am not quite strong enough to look after myself”. Heather also talked of the CTO bringing her some stability and that while on the CTO she had grown up a bit with more understanding about herself. She was making good use of supports and friends outside of the mental health system to help her get well.

### **Disadvantages of CTOs**

The disadvantages of CTOs mentioned by the women included having to comply with treatment, especially taking medications, restrictions over accommodation, limits to freedom and choices, feelings of stigma and an over reliance on medication to deal with problems. All of the women viewed aspects of the CTO as controlling, even if the CTO did not interfere with their overall quality of life. Typical comments were that the CTO: “imposes rules”, “it took a lot of power off me”, “it caused me stress” and “it is not my choice to be on the CTO”. Two women, Edith and Libby, noted how the order was used to ensure they lived in supported accommodation, away from their first choice of accommodation. Libby, who was 40-years-old with a diagnosis of schizophrenia and substance abuse disorder, talked of the conditions of her CTO as having to: “take my medications, stay off the alcohol, live here”. She did

not want to live in a shared living arrangement with daily support from mental health workers. She felt the CTO meant that she could not be trusted and that others had power over her. She also felt that the threat of being returned to hospital was always there if she refused to take her medications. For her this was a genuine fear because of previous “bad” hospitalisation experiences. Libby was the most negative of the 10 women and was extremely pleased to have been recently discharged from the order. Nevertheless, Libby commented at the end of her interview that she was half in favour of the order and half against it: “half and half, because the negative was that I didn’t want to come here, and the positive was that I did come and it hasn’t turned out all that bad”.

Three of the women mentioned feeling stigmatised, and of feelings of being viewed as an “outsider”, by being on the CTO. Heather, Sasha (a 36-year-old with bipolar disorder), and Emily (a 62-year-old with schizophrenia and bipolar disorder) talked of people “backing off” them, not offering them jobs, and not being trusted to look after children. Emily said “I felt as if I was in prison but outside”. She felt she could not speak to anyone about her illness in case her comments were viewed in a negative light: “there is such a stigma attached to mental illness and it’s still there in the community” she commented. Emily was always fearful of a return to hospital, which she wanted to avoid at all cost.

Three women Karen, Edith and Heather mentioned the side effects of having to take medications that they did not want to, the medications gave two of them the “shakes” and for two of them significantly increased their weight. Two women felt that mental health professionals relied on medications to help people with mental illness, instead of providing other supports like counselling. Heather commented: “I was given drugs instead of support . . . I needed support!” Heather felt that her underlying loneliness and depression had not been addressed while on a CTO. Heather said there could have been more of a focus on “holistic healing”.

### **Role of and Impact on Family Members**

Where family members had been involved in the care of their unwell relative they provided significant support and supplementary supervision to their relative. The help provided included looking after their unwell relative at home, monitoring their use of medications, taking the patient to appointments, contacting mental health professionals for feedback, and initiating a return to hospital. The five women who agreed to a family member or close friend being interviewed for this study were positive about the help they received from family and friends. The other five had estranged relations with their families or were not in contact with them. The help from relatives and close friends was also considered to have had a considerable impact on their lives by the patients, especially where children were involved.

Loretta, Sasha, Helen, Karen and Ellie all mentioned the impact of their illness on their relationships with their children. Loretta’s notes stated that in the past her children had been afraid of her aggressive behaviour. Loretta was mindful of the effect

of her illness on her children over the years and had made every effort to stay well out of hospital so that she would not upset them further. Complying with the CTO was part of this effort. She now had one grown-up daughter with whom there was a strong supportive relationship. Sasha's mental illness and being on a CTO had, in her opinion, led to her "losing" a child to adoption. Sasha had two other children who were also intermittently cared for by Sasha and Sasha's parents with the involvement of Child, Youth and Family (New Zealand social work agency). Sasha's wider family were very supportive and she felt for them that the CTO provided them "relief". For her it was about "security and control". She was in no doubt that she had to remain well on the CTO to stand any chance of regaining care of her children. She remained deeply saddened at the effect of her mental health experiences on her children and parents.

Helen, a 43-year-old mother of two, with a diagnosis of schizophrenia and schizoaffective disorder, discussed how she involved her family including her children as much as possible. The CTO acted as a "safety-net" for the whole family and she felt that the CTO also helped her family to get help speedily when she needed it.

### **Volunteers for Compulsion?**

As mentioned previously five women who were interviewed were still on their CTO and five had been discharged. Of the five women still on a CTO four of them were content to remain on the order and one was neutral about being discharged. Of the five who had been discharged they were all pleased but at the same time they acknowledged the CTO had been useful. For some of the women on CTOs, gaining discharge was seen to be unlikely, and for others they would have to demonstrate a long period of reasonable mental wellbeing, insight and compliance, before they would be discharged. The women also highlighted the dilemmas of remaining on orders for a long time—in that they felt they had become dependent on the "mental health system", or institutionalised, making independence from the system a difficult goal to achieve.

Edith, a 61-year-old woman with a history of depression and bipolar disorder, had had more than 30 years of contact with mental health services. She had been discharged for about 12 months but had become totally dependent on the continued input of mental health professionals. She said the CTO had "stopped me taking my own life" but she had also not wanted to be on it. She was never sure if the CTO had been a "good option" for her, yet at the same time she said several times how it had "helped". She was pleased to have been discharged but she was still accessing help from a variety of social and mental health services on a daily basis.

Ellie, a 37-year-old with a history of depression, had also been discharged from her CTO. She felt the CTO had taken "power" and "responsibility" off her but had also provided her with the means of reducing the chances she would harm herself. She felt the CTO neither harmed nor helped: "I don't think it made it any worse or any better". She felt she had been discharged when it was obvious she was able to take responsibility. She was now a "voluntary patient" and "taking her meds," because



she had decided (and not the mental health professionals) that was what would keep her well.

Sasha, while wanting to be discharged, noted how she “might panic” if she was, because she felt very dependent on the system. The CTO was keeping her safe but at the same time, in her opinion, others were making “key choices” for her and she did not know if “I will ever get out of the system”. She both wished for greater freedom yet also wanted to feel safe through the clear framework of a CTO.

Finally, Karen, who was also still on a CTO, said she wanted “to stay on it” to remain out of hospital. For her this was the *only* means of staying out of hospital because she knew that if she was not on a CTO she would not take her medications and then she would get ill again and end up in hospital. She was clear that the CTO meant that she was taking some responsibility to take her medications “to show that I am in control of myself”, and that discharge was not an option. She was not actually too concerned about this; she was happy with the status quo and had only thought about discharge because she had been asked about in the research interview. Otherwise it was a non-issue.

### Discussion

It would be presumptuous to infer too much from the experiences of just 10 women on CTOs. Their experiences are similar in many ways to those of all male and female populations on CTOs with both positive and negative experiences (Churchill et al., 2007; Gibbs et al., 2005; Scheid-Cook, 1993). The 10 women highlight the ambivalences faced by patients on CTOs and the way in which they become “volunteers for compulsion” (Dawson et al., 2003). The women wanted to be discharged but then they didn’t. They “hated” their CTO but then it had “helped” them. They wanted to be “independent” from the mental health system but they couldn’t get by without the regular input of social work and mental health professionals. They felt “controlled” but they also said they had “more freedom” than they would have had by being hospitalised (Scheid-Cook, 1993). The women were reflective enough to try and make sense of their CTO experiences, and to try and make the best of the limited choices and options they faced. They were acutely aware of the impact of their illness on their immediate families and held a deep sense of responsibility to reduce the worries and trauma of their close family members.

Was there anything special about being a woman on a CTO? Again, this is difficult to infer given the limited qualitative study. Of probable significance is that this group of women had experienced high levels of abuse whether as children or as partners. They were also noted to be at risk of suicide, self-harming and aggression. They had had many years of being users of the mental health system both as inpatients and outpatients. They were a “troubled” group with more than one diagnosis and multiple health, emotional and social problems. Use of a CTO in their case may well have been the only option, given that most other options and services had been tried before. For a few women the CTO may have even re-traumatised them if they felt they

were overly controlled. Yet, this same group of women also “accepted their lot” when faced with the uphill struggle of trying to stay well out of hospital. They agreed to be “under compulsion” because they felt they had few other choices left for them. Some of them wanted more help than “just the drugs”, and some of them knew that taking the drugs had made all the difference in a positive direction. The ten women were mostly in favour of a CTO in their case but it was still important for them that mental health professionals including social workers, and others working with them encouraged them back into responsibility, self-determination and mental wellbeing in the long-term.

New Zealand’s CTO scheme is now well-embedded having operated for over 15 years. It would seem that CTOs are mostly used for the right people at the right time. The numbers on CTOs are low but the people gaining the orders are a classic revolving door, multiple-problem and high-risk group. The women in this study fitted the group and while they were negative in parts about their experiences they were still mostly in favour of the order in their case. The one area of practice where improvements could be made in the light of women’s comments would be for professionals to acknowledge the negatives of the CTO and allow the patient space to complain about such things as restricted liberty, lack of choices and fears of re-hospitalisation. This may already occur in some cases, especially where social workers are keyworkers, but the women found that the experience of being interviewed for this research was a great opportunity to get things “off their chest”, in a way in which they did not always get the chance with their keyworkers or clinicians. Mental health professionals should not be too complacent about the more harmful impacts of the CTO for service users just because the service users are not complaining—there still may be issues for the service user around the order that could be alleviated or regarded more sympathetically. Where a woman has experienced negative impacts of being on a CTO their mental health professionals might wish to offer additional counselling, or referral to agencies outside of the mental health system who might help women deal with past and present trauma.

### **Limitations of the Study**

The service users who participated may have had more favourable views of CTOs than those who declined. There were only 10 women and they may not be typical of all women service users on CTOs. The other limitation is that the original study was not designed to be gender sensitive (Khoury & Weisman, 2002), and therefore specific questions were not asked of women service users about the impact or influence of gender on their experiences of CTOs.

### **Conclusion**

Community Treatment Orders made a significant impact on the lives of the ten women in both positive and negative terms. In spite of the constraints CTOs allowed

the women to remain out of hospital long enough to rebuild their lives, maintain their close relationships, and regain some levels of control.

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