

Maori experience of community treatment orders in Otago, New Zealand

Anita Gibbs, John Dawson, Hine Forsyth, Richard Mullen, Te Oranga Tonu Tanga
(Maori Mental Health Team)

Objective: To consider the impact of community treatment orders (CommTOs) on Maori patients and their whanau (extended family) and the associated views of mental health professionals.

Method: As a distinct aspect of a larger study of CommTOs, eight Maori patients under compulsory community care were interviewed and, where possible, members of their whanau. Associated interviews were held with their psychiatrists, key workers and other carers: 39 interviews in total.

Results: Both benefits and drawbacks of CommTOs for Maori were identified by patients and whanau. CommTOs were considered helpful in increasing patient safety and whanau security and in promoting access to services. They were favoured over hospital care, forensic care and homelessness. The drawbacks included the sense of external control imposed on both Maori patients and staff, particularly concerning medication and restrictions on choices.

Conclusions: This was a small study of a limited number of Maori patients under CommTOs. Their views may not be fully representative. There was a general consensus among those interviewed that the timely use of CommTOs can enhance the mental wellbeing and social relationships of Maori patients. Continuing efforts are needed by health professionals to communicate effectively with whanau and to understand the conflicts experienced by Maori in reconciling their traditional beliefs with the medical model of mental illness.

Key words: community treatment orders, consumers, Maori, mental health legislation, whanau.

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Maori are the indigenous people of New Zealand (NZ) and constitute roughly 14% of the adult population.

Anita Gibbs, Senior Lecturer (Correspondence)

Department of Community and Family Studies, University of Otago,
PO Box 56, Dunedin, New Zealand.
Email: anita.gibbs@stonebow.otago.ac.nz

John Dawson, Professor

Faculty of Law, University of Otago, Dunedin, New Zealand

Hine Forsyth, Treaty of Waitangi Consultant

Ngai Tahu, New Zealand

Richard Mullen, Senior Lecturer

Department of Psychological Medicine, University of Otago, Dunedin,
New Zealand

Te Oranga Tonu Tanga (Maori Mental Health Team)

Healthcare Otago, Dunedin, New Zealand

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Although they have been subject disproportionately to institutionalization, as is well known, their experience of compulsory mental health care has rarely been investigated. Nor has much attention been directed to the contemporary position of Maori in Otago, in the South Island, where the Maori proportion of the population is considerably lower than in the North Island [1]. This study seeks to investigate, through qualitative methods, the experience of Maori patients in Otago treated under community treatment orders (CommTOs). It explores the views of patients' whanau (extended family) and of treating clinicians, including Maori health professionals. These views were collected as a distinct segment of a wider study of CommTOs in Otago, about which other reports have been published [2,3].

Community treatment orders are widely used in NZ, as throughout Australasia, where they are authorized in all jurisdictions. The *Mental Health (Compulsory Assessment and Treatment) Act 1992* of NZ authorizes compulsory outpatient treatment of those who are 'mentally disordered' within the meaning of the Act (section 2); compulsory treatment must be 'necessary' (e.g. because of a history of non-compliance with medication); it must be possible to treat the person adequately as an outpatient; and their social circumstances in the community must be adequate (sections 27–30).

A person on a CommTO must accept treatment (including medication) and supervision by designated health professionals who are granted a power-of-entry into the patient's residence at reasonable times and for proper purposes. Their care is co-ordinated and monitored by case managers or 'keyworkers', often experienced psychiatric nurses who visit patients where they live. The patients will also be expected to keep regular appointments with psychiatrists. If they do not comply, they may be taken to a clinic for treatment to be administered, or returned to hospital, even by force if considered necessary. The CommTO may therefore be considered an intrusive mental health intervention, authorizing treatment without consent of the patient over an extended period of time, albeit subject to regular, formal reviews. The order may nevertheless provide an important structure for patients' care. It may promote their community stability and help prevent readmission to hospital, through compliance with treatment and contact with services, particularly in patients with repeated compulsory hospital admissions [4,5].

There is a small but growing international literature on patients' perceptions of compulsory community care. Studies in the US [6–9] indicate that patients feel obliged to keep appointments with carers and to take medication as prescribed, but they experience greater liberty than in hospital. Patients also believe compulsory community treatment brings benefits, such as access to money for medication and transport. In Scotland, patients under compulsion are reported to experience difficulty in negotiating their preferred medication with their clinicians and feel compelled to accept it as prescribed [10]. In Australia, Carne [11] reported that a third of patients interviewed under CommTOs in New South Wales experienced no disadvantages, while another third perceived no benefits. The perceived advantages were the availability of community mental health staff and the opportunities for rehabilitation, recovery and discharge from hospital. The negative views concerned loss of freedom, infrequent contact with health professionals and medication side-effects. Other Australian studies [12,13] report patients' views that CommTOs reduce

their liberty, control their medication and last too long, with patients facing difficulties obtaining discharge.

This is the first reported study of patients' views of coerced community treatment in NZ, although there have been studies of compulsory inpatient admissions [1,14]. Wider studies of mental health services in NZ [15–17] have highlighted the need for culturally appropriate care for Maori, and other studies have noted ethnic differences in outcome of psychosis [18]. It has been argued that services should be designed and delivered on the basis of Maori health principles (through kaupapa [special] Maori services), and the relevance has been stressed of enhanced cultural identity, adherence to tikanga (customary practices and beliefs) and whanau support in the treatment and recovery of Maori patients.

The characteristics of a 5-year caseload of patients under CommTOs in Otago have been reported [2]. Fourteen per cent were found to be Maori, although the accuracy of such ascriptions of ethnicity can be doubted. On that basis, Maori would be over-represented in this patient group by a factor of more than 2 compared with their census numbers in the region. Many of these patients have moved to Otago from the North Island of New Zealand and therefore are not drawn from the local iwi (or tribal group), Ngai Tahu, and their connections with their whanau may be limited.

Method

This study was funded by the Health Research Council. Ethical approval was granted by the Otago Ethics Committee. Its general aim was to explore the functions and uses of CommTOs in NZ. The main method used was detailed semistructured interviews with patients under orders in Otago and with those most concerned with their care.

All patients in Otago who had been under a CommTO without readmission to hospital for more than 6 months in the previous 2 years were targeted for inclusion in the study; 103 patients met those criteria. Their key-workers were approached, with an initial request to assess the patient's fitness or competence to participate, consulting if necessary with their psychiatrist. Nineteen patients were considered to lack the capacity to take part at the outset. Of the remaining 84 who were approached, 42 agreed to take part and completed the process. Another 34 declined to participate, and in eight cases the research process was not fully completed, due to withdrawal by the patient, their relapse during its course, or a breakdown in communication. Only 42 of the 103 patients in the target group were therefore interviewed. This amounts to 41% of eligible subjects. It is unfortunate this proportion was not higher but as the group were all deemed to have a serious mental illness and had recently experienced compulsory care, it is not surprising that many did not wish to be interviewed or were too unwell. It is possible the patients who agreed to be interviewed had benefited more from the CommTO, or were more positive toward it, than those who did not take part. This is a limitation of our method that may affect the results.

Of the 42 patients recruited, 20 had been discharged from the CommTO and 22 remained on it when interviewed. Their key-workers and psychiatrists were also interviewed, plus at least one family member, if locatable and willing to participate. Permission to conduct interviews and to inspect files, was obtained from patients. Within this sample, eight patients identified themselves as Maori. The proportion of Maori was therefore 19% of those interviewed, 5% more than the proportion of Maori on CommTOs in Otago [2]. It cannot be assumed however, that the views of these eight patients and those associated with them represent the full range of opinion among Maori about CommTOs in Otago, or further afield, given the wide range of factors that may influence their views.

The semistructured interviews conducted concerned participants' understandings of the CommTO regime; their perceptions of why the order was required; the impact on patients' social and clinical relationships; its benefits and limitations; compliance with the order; indicators for discharge; and impacts on health and wellbeing. The interviews were taped, then transcribed and analysed under common themes using a general inductive approach and NUDIST software [19].

Regular consultation occurred, throughout the 3 years of the research, between the university-based researchers and local Maori mental health professionals, concerning the research process, the questions addressed and interpretation of results. This included six face-to-face meetings with Te Oranga Tonu Tanga, the Maori mental health team of Healthcare Otago, at their base. In addition, a member of the local iwi, an experienced patient advocate (HF), was contracted as a consultant and conducted the interviews with Maori patients and whanau who preferred that option. In all, HF interviewed five patients and three whanau members. The other three Maori patients and their whanau were interviewed by Pakeha (non-Maori) interviewers, as were the majority of mental health professionals. The fact that some patients and whanau were interviewed by a Maori interviewer and others by a Pakeha may have affected the responses given. We felt it was important that the choice of interviewer was offered. The different interviewers used the same semistructured protocol and study of the transcripts reveals that similar questions were asked. The overall process was consistent with that advocated by the Health Research Council [20] and by experienced researchers with Maori [21,22].

Of the eight Maori patients interviewed, six were men and two women, aged 27–50 years. All had been in contact with mental health services on a compulsory basis for significant periods of time. Six had a diagnosis of schizophrenia, one schizo-affective disorder and one bipolar disorder. Four were discharged and four were still on the CommTO at interview. Five whanau members were interviewed, as were the key-worker and psychiatrist for each patient. A respected *kuia* (tribal elder) long involved with the health services, the staff of a supported accommodation service for Maori patients, and a local Maori doctor, were also spoken to. In total, 39 interviews were completed, in addition to extensive discussions with the Maori consultant and Te Oranga Tonu Tanga.

Results

The results are presented by reference to key themes discussed by participants. All patients have been allocated fictional names.

Theme 1: reasons for the CommTO and its significance

The health professionals interviewed consistently maintained that the main purpose of the CommTO was to ensure ongoing delivery of mental health services to patients who would otherwise refuse medication or assistance. The CommTO provided a way to manage their illness; helped patients face it; and ensured they took medication, attended appointments, remained in supported accommodation and received other services. Concerns about safety, involving danger to others or the patient, were prominent in seven cases. Whanau members generally supported use of the orders for similar reasons: to ensure the safety of their relative, to ensure treatment and to help the patient come to terms with their illness, though not all whanau members were enthusiastic about the use of medication. One considered the order took away her partner's rights.

The patients' comments focused more on the significance of the order as a whole. Heather felt that the CommTO had helped her recover from her mental illness, achieve independence and establish close friendships. She viewed the CommTO as a safety net: 'a community treatment order made me feel safe. If I have a breakdown or have trouble then I know that I have somewhere I can go'. Matthew considered it kept him in line and made him more aware of his illness. Andrew believed it got him out of hospital into supported accommodation. Most Maori patients acknowledged the order was needed to assist them or had stopped them getting severely ill.

Chi was a notable exception. He felt the order gave mental health professionals unnecessary power over him: 'They've always said you can't look after yourself, you are a danger to yourself. I don't think it helped me. It helped the system. I was very, very restricted, even leaving the city. I always had it in the back of my mind that the control wasn't mine.'

Theme 2: benefits and limitations of CommTOs

Seven patients articulated definite benefits of the CommTO. These included: access to mental health services and supported accommodation; guaranteed continuation of social welfare benefits; greater freedom and independence than in hospital; the sense of security that help was available if required; the relief and security for whanau members; the acknowledgement of illness with increased hope of recovery; improvements in relationships; small increases in mental wellbeing; reduced violence or self-harm; and reduced substance misuse. Hence, for Andrew the CommTO 'saved my life; it got me off the streets; it helped me communicate with people'. It also helped him reduce his violence and allowed him to explore Maori culture. For Helen, the order was a 'back-up', in case she had problems and needed help: 'it makes me feel safe'.

Nevertheless, even the most positive patients saw significant limitations in the order. Patients and whanau noted: the side-effects of enforced medication (e.g. weight gain or lethargy); an enduring sense of stigma; restrictions on place of residence or physical movement; limited social and work opportunities; the feeling that others made key decisions about their lives; and not getting better, merely existing. Helen, for example, complained the medication dragged her down: 'I don't like being numbed and it can make you feel really tired and dopey and hard to comprehend, you know, socially'. Heather felt the

order reinforced her dependence on mental health services. In many patients' minds, the order was inextricably linked with taking medication and continuing ill health. But all patients preferred life under it to being in hospital or prison.

For Chi, the whole order was a negative experience: it carried a stigma, made him dependent on the health system and significantly restricted his movements. Once he was discharged, 'life began again'.

Theme 3: compliance and discharge

Complying with the order was a major part of the experience. Most patients said they did comply, although at times they missed medication or appointments, or went AWOL for a few days. Some were returned to hospital for short periods to re-establish their medication regimens. Compliance was seen to be mainly about 'taking your meds' and 'doing what you're told'. For several patients, it was fear of a return to hospital and forced medication which kept them compliant. Matthew commented that if he had refused, 'the nurse would have forced it on you; they have got ways of doing it, you know'. Patients also said they complied with the CommTO for a variety of other reasons, such as the fear of relapse in their illness, family pressure, to enjoy a better life outside hospital and to gain stability.

Four of the eight patients had been discharged from the CommTO. The factors favouring discharge mentioned throughout the interviews with patients, whanau and mental health professionals were: the passage of time since last hospital admission (e.g. 1–2 years); sustained compliance with medication; establishing a degree of insight; taking responsibility for medication; keeping appointments; forming positive relationships; adequate self-care; living on their own or in adequate accommodation; getting a job; and reduction of risk. The four patients discharged had clearly met a number of these expectations. All were pleased to be discharged and felt they now had more freedom and independence, even if they continued the same treatment regimen.

The four patients still on orders also met several of these discharge criteria but their clinicians did not feel they were ready for discharge, mainly due to continued concerns about risk to others. The clinicians involved with Errol hinted that the order was mainly being continued for *their* peace of mind, and because they did not wish to 'rock the boat' when so much progress had been made. Errol was subsequently discharged after more than 5 years. Three patients on the order at interview wished to be discharged, one did not.

Theme 4: the role and concerns of whanau

Where whanau members were involved, they provided significant support and indirect supervision of their relative. This included help with taking medication, keeping appointments or with accommodation and generally 'going the distance' with the patient. Some whanau had personally initiated civil commitment proceedings. Patients almost always appreciated the help of whanau; only two had no ongoing contact at all. The whanau members interviewed wished to assist their relative but wanted more support from professionals. They did not always feel sufficiently consulted at key decision points, particularly about discharge. Chi's mother, for instance, while pleased she had key-workers to contact, felt she had to take the initiative: 'I have to get in touch with them most of the time. I would like them to keep me informed or updated.' Another concern was how strict adherence to

confidentiality frustrated discussion between professionals and whanau about the care of their relative.

Maori health professionals acknowledged there were practical barriers to achieving satisfactory contact between patients and whanau in some cases, especially after long periods spent in institutional care. Some whanau did not visit or communicate with patients and preferred them to remain in professional care. Contact with whanau was not always in the patient's best interests. There may have been a pattern of violence, victimization or substance abuse within the whanau, to which patients would be exposed. Some whanau lacked the resources and knowledge to take responsibility for their relative's care.

Theme 5: mental health professionals and cultural issues

Key-workers were generally viewed positively by patients: as advocates, friends and helpers. They were sometimes considered authoritarian, when they reminded the patient that if they refused medication they might be returned to hospital. But patients still felt able to maintain trusting relationships with their key-workers, whom they said had time for them and were willing to view them as a person not just a patient. Those who helped patients from a Maori perspective were especially praised for their help and understanding. Some key-workers saw themselves as substitute whanau for the patient, maintaining contact long after the order was discharged.

Psychiatrists, on the other hand, were nearly always viewed by patients as authority figures, the embodiment of 'the Act' and its negative aspects: control, loss of choice and limited freedom. They were seen as representatives of 'the system' and as highly focused on medication. The psychiatrists in turn lamented the lack of time they had to spend with patients (due to high caseloads) and bemoaned the inevitability of the law and medication as the defining features of their relationship with the patient.

For mental health professionals, the vital matter was seen to be achieving the right balance between the patient's need for assistance from the mental health service, on the one hand, and the need to foster the patient's independence with a view to discharge, on the other. Where that balance lay was much debated. The majority felt the CommTO was necessary in the cases discussed, with discharge at the right time in three of four cases. One nurse was vehemently opposed to CommTOs in all cases however, viewing them as a form of 'community institutional care' and a 'tool for punishment'. Another psychiatrist had strong reservations about their use. These were well-articulated positions but not the norm.

Maori key-workers, the kuia, and the workers at the Maori accommodation service all emphasized the importance of ensuring Maori patients could participate freely in cultural activities, learn Te Reo (the Maori language), and explore their identity and family histories. Three patients mentioned the benefits of help from Maori workers in this respect, with key-workers focused on such concerns making the most difference.

The Maori accommodation workers noted the lack of interaction between them and mainstream mental health services. They felt the dominant medical model of treatment prevented a holistic approach to Maori patients. While they and the Maori mental health team offered a kaupapa Maori approach, they felt the medical model still predominated in Maori patients' care, alienating Maori workers and patients

from the mainstream service. They were concerned that resources were not available to help more Maori patients leave hospital and enter supported accommodation.

On the other hand, Maori patients were also encountered in this study who chose to be treated through the mainstream service alone.

Theme 6: overall outcomes

While this study did not explicitly seek to measure the effectiveness of CommTOs, the overall outcomes for the eight patients provide some indicators. Risk of harm to self or others, for example, was noted as an issue for seven patients and for five this was considered to have reduced over time, including during the period the patients were on the CommTO. Three patients had remained stable in the community while on long stays at Maori-supported accommodation, whose availability was in turn facilitated by the CommTO. Without these supports, they would probably have continued to pass through the 'revolving door'. Other outcomes identified for the eight patients include increased insight, continued medication and treatment compliance, and reduced hospital admissions. For three patients reduced substance misuse was a factor in their rehabilitation. Full recovery from illness was not viewed as a vital outcome by mental health professionals. Rather, the manner in which the CommTO assisted patients to come to terms with and to manage their illness was viewed as most significant. The fact that four very long-term patients, who between them had a total of 77 years' contact with mental health services, including long stays in hospital, had eventually been discharged from the CommTO, was also viewed as a good outcome. Whether these outcomes indicate that CommTOs are a 'good thing' in general is more difficult to establish, as it cannot be shown that the CommTO itself produced these changes. Further research would be needed to reveal the multiple influences on rehabilitation for long-term users of mental health services.

Discussion

This was a small study of the experience of Maori patients under CommTOs and of those most involved in their care. The experience of these patients was not substantially different from others interviewed in the larger study. Their views as a whole are consistent with patient perspectives previously reported in the literature, including perspectives on coercion [6–14]. The Maori patients felt CommTOs *both* helped them in their recovery and imposed significant constraints on their choices, particularly about medication, travel and residence. Most were able to articulate both sides of this experience and to reach a judgement on its benefits overall. In most cases, while patients expressed a certain ambivalence about the CommTO [3], they valued its total impact on their lives, especially in comparison with their previous inpatient and forensic experience. They accepted such orders would infringe their liberties, but they still wanted to increase their range of choices about treatment and to have a greater degree of participation in their care.

Discharge from the order was a particular area in which Maori patients and whanau sought increased choice and consultation. All four patients discharged felt a greater sense of control and independence. Of the four still on the order, three wanted discharge. Their psychiatrists and key-workers identified stability, insight and taking medication and responsibility as key discharge factors. The main factors counting against discharge were the perceived degree of risk posed by the patient and the desire not to subvert and progress made.

Australian studies [12,13] have reported patient views that it is very difficult to obtain discharge from a CommTO. Elsewhere we have talked of the 'dilemma of discharge' and the 'paradox of success' [3], to describe how hard it is to determine the right moment for discharge, when continuing use of the CommTO without the patient's relapse can be viewed both as a successful, and as an unnecessary, use of the order, depending on the criteria of success employed. If extended use of a CommTO appears to promote the patient's stability and recovery, there may be great reluctance to change the status quo. There may also be an element of defensive practice involved, which is understandable when clinicians face serious personal consequences, including complaints to professional bodies and intense media scrutiny, when discharge decisions appear to go wrong.

The whanau of some Maori patients in this study provided critical support for their relatives. Other studies have shown professionals often fail to recognize the vital contribution of family to mental health care, effectively disempowering them [23,24]. Whanau want more communication and support. This could be achieved through greater sharing of information, initiating more family meetings and increased commitment to the principles of collaborative care [25].

Maori patients especially valued the work of key-workers and other Maori professionals in assisting them to explore Maori tikanga (customs), Te Reo and their whanau connections. The supported accommodation service for Maori was seen by many as a critical step from hospital to independent living. Durie has also argued persuasively that meaningful participation of Maori in their culture will enhance wellbeing [16,17]. Through support and understanding of kaupapa Maori services, and better resourcing of community houses run by Maori, mainstream services can support greater participation by Maori in mental health care. If Maori patients are enabled to participate in appropriate and beneficial cultural activities, their overall satisfaction with CommTOs and mainstream mental health services may increase. The majority of patients in this study valued this support. This view was not universal, however. At least one patient was strongly opposed to participation in

Maori cultural activities and any insistence on this course for him may have only increased his resentment of contact with mental health services.

Conclusion

This small study has shown that compulsory psychiatric treatment in the community for Maori is experienced as having both advantages and limitations. Appropriate, individualized care can, it seems, achieve substantial success in some cases. Some patients will ultimately come to value the care received under the CommTO, as other research has shown [26]. Nevertheless, in what seems to be a minority of cases, there is continued resentment at the use of compulsory powers and strong feelings of coercion and loss of freedom. Here use of compulsion may be counter-productive. It is important therefore that CommTOs orders are used with great discretion, for the most suitable people, and for the shortest possible time. Other options, such as voluntary treatment, or supported whanau care, should be tried at appropriate times. In turn, health professionals should not be unjustly criticised for taking some calculated risks in discharging patients from a compulsory community care.

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