

Family perspective on community treatment orders: a New Zealand study.

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Abstract

Background. People with serious mental disorders typically live with family members. Despite increasing interest in compulsory community treatment for such patients the experience and views of their family members have been little studied.

Material. Qualitative interviews with 27 family members, whose relatives have been subject to compulsory community treatment.

Discussion and conclusions. Family members are generally in favour of the use of compulsory community treatment orders. They perceive a positive influence on their relative, on themselves, on family relationships, and on relations with the clinical team. Family members are aware of the ethical and other dilemmas that attend the use of compulsory community care.

Introduction

In the wake of deinstitutionalisation a widespread trend has emerged to authorise the use of compulsory treatment for serious mental disorders outside the inpatient environment. Where available, this form of treatment delivery is authorised by mental health legislation, under what are usually known as community treatment orders (CTOs), or outpatient commitment regimes. Proposals for the introduction of CTOs have been attended by some concern about the potential implications for individual autonomy (McIvor 1998). Those in favour of CTOs argue that these orders improve treatment adherence, reduce risk and result in improvement in patients' wellbeing (Torrey and Zdanowicz 2001, Cornwall and Deane 2003, Hiday 2003). Others argue that CTOs will result in unnecessary coercion and intrusion on individual rights (Allen and Smith 2001, Pinfold and Bindman 2001). The clinical effectiveness of CTOs remains uncertain (Swartz et al 2001, Steadman et al 2001).

Families have a major role as stakeholders in outpatient commitment. Most individuals with severe mental disorders live with family members (McNeil et al 1992). Caring for a relative with a severe mental disorder may have a deleterious effect on the health of the family member (Falloon et al 1996). Family members may experience fear, stigma and suffer financial and other burdens (Solomon 1996). Close family members are disproportionately likely to be assaulted by their mentally ill relatives (Estroff et al 1994). Some family members may experience a positive

meaning in their caregiving role. Others have emphasised the sense of loss experienced by family members of individuals with severe mental disorders, likening it to bereavement (Jones 2004). A randomised controlled trial of outpatient commitment versus voluntary outpatient care revealed no significant difference in caregiver strain between the two groups (Groff et al 2004). However, when a non-randomised violent group was included in this study, sustained periods of outpatient commitment were associated with significantly less caregiver strain compared to brief periods of outpatient commitment.

The strategies used by family members to manage their role as carers may include informal methods of coercion, such as the overt or covert threat of formal measures and hospital readmission (Lovell 1996). Indeed, expressed emotion has been conceptualised as such a means of coercion (Greenley 1986). The case has been made that a CTO is just one form of leverage, with families often being involved in informal means of persuasion, such as making provision of finances or housing contingent on treatment adherence (Monahan et al 2005). However, a study of family perceptions of coercion in mental hospital admissions reported that family members see themselves not as coercive, but as frustrated in efforts to interact with psychiatric systems (Hoge et al 1993).

The concerns of family members have sometimes been portrayed as competing with the interests of patients and the freedom from coercion demanded by patients' rights organisations (Davis 2003). It would certainly be sentimental to suppose that the interests of individual patients and their families always coincide. Legal and clinical practice conventions inevitably emphasise the rights and needs of the individual patient over those of others close to them. However, it is pragmatic to recognise that mentally ill individuals cannot be considered in isolation. The value of family intervention in severe mental disorders is increasingly recognised as a mainstream clinical activity (Royal Australian and New Zealand College of Psychiatrists 2005).

In New Zealand compulsory community treatment is authorised by the Mental Health (Compulsory Assessment & Treatment) Act 1992. The principle criteria for a CTO are: serious mental disorder; serious danger to the patient or others, or seriously diminished capacity for self care; the order is "necessary"; and appropriate outpatient care and social support are available (sections 2, 27, 28). Where these criteria are met the Act requires that a community order be preferred to an inpatient order. The order is made by a judge and has an initial maximum duration of 6 months, although it may be extended. The application for a CTO requires consultation with family members, who commonly attend the family court hearings where applications for CTOs are heard. Many, but not all, CTOs follow periods of compulsory inpatient care. Such orders typically require the patient to accept treatment as directed by their responsible clinician. Additional conditions may include attendance at appointments, allowing others to visit, and residence at a certain address or supported accommodation. The responsible clinician may authorise return to hospital if the treatment conditions are not met. In practice the powers of the order give the clinical team considerable discretion. A recent national survey of New Zealand psychiatrists reported a high level of approval of the use of such orders (Romans et al 2004).

Several qualitative studies of compulsory community treatment have been reported, with patients identifying a variety of advantages and disadvantages (Atkinson et al

2002, Brophy and Ring 2004, Gibbs et al 2004). However, the experience of family members has remained largely unstudied.

Method

The methods used in this study have previously been described (Gibbs et al 2004). All individuals in the New Zealand province of Otago who had been under a CTO, without hospital readmission, for more than 6 months during the preceding 2 years were identified for potential inclusion. They were invited to take part in a semi-structured interview regarding their experience of compulsory outpatient treatment. These participants were also asked to identify a family member who was then also interviewed, forming the material for this report. Interviews were recorded and transcribed, and analysed using a general inductive approach (Thomas 2004). Family interview transcripts were assessed for their overall attitudes independently by 2 members of the research team and consensus reached after subsequent discussion.

The study was funded by the Health Research Council of New Zealand. The study was approved by the local ethics committee. The consent of both the patient and their family member was required. Participants' names have been changed for purposes of this report.

Results

One hundred and three patients were identified. Nineteen were considered by their clinical team to lack the capacity to participate. Of the 84 that were subsequently approached, 34 declined to participate, and in 8 cases the research was incomplete due to patient withdrawal. The patients who completed the interviews had an average age of 38 years, and an average time since first contact with mental health services of 14 years.

Of the 42 patients who completed the research interviews 27 identified a family member who also agreed to participate. Two patient participants identified a close friend who had a caring role. The other 25 identified a spouse or first degree relative. Three of the 27 interviews were conducted in the presence of the patient. The following themes were identified.

Patient Rights

Several family members reported that their relative was unconcerned about rights and had felt no intrusion of the order on what they perceived as their rights. Several others commented that their relative had experienced the order as a negative intrusion on their rights in a minor way but were quick to add that this was outweighed by the order's benefits. One mother, who had been particularly alarmed at the behaviour of her unwell son, opined that too much emphasis was placed on what patients wanted for themselves.

Several family members reported that their relative resented the order, and felt coerced, but did not report any specific examples of how the CTO intruded on the persons life. Some family members were strongly of the view that the order had an adverse effect on their relative's rights. They spoke, for example, of "a sense of powerlessness", of "not being in control of his own life", of "being forced into something he doesn't want" and of a sense of being "held back" and restricted.

Overall, although views differed and many family members were able to see advantages and disadvantages of the order, none appeared to find the issue of rights a particular dilemma.

Risk

Thirteen of the 27 family members interviewed had no concerns that their relative might be a danger to themselves or to others. The others were of the opinion that the use of the order had been associated with a decrease in the risk posed by their relative.

Several family members were of the opinion that the use of CTO resulted in a substantial reduction in risk, and considered this a key justification for the use of the order. One parent asserted that the order kept her son alive. One family member was of the view that their relative felt safer because of the order. Reasons advanced as to why the CTO might have such an effect were improved treatment adherence and improved monitoring of the patient by the clinical team.

Impact on family

Several family members reported relief and an improved sense of security and safety for themselves from knowing the CTO was in place. Several reported that they had previously felt fear of their relative. Improved quality of life, lessened stress, and hope for recovery were all mentioned. One family member believed the order had “allowed the family to stay together”. Some family members indicated that their family had felt relief because of the order even though the CTO had appeared to have no influence on their relative’s mental health. One indicated that the CTO had given the family greater security but felt relations between their relative and family members would be better without it. More typical was the impression that the order had enabled family members relations with their relative to improve.

“I don’t have to mother Blair and check that he is taking his medication, or talk to him about it a lot. It just runs through the committal thing. The big pressure, that is off” (Blair’s wife).

Some family members recalled alarming instances prior to the use of the Act and considered continuation of the CTO as indispensable for their own peace of mind.

“For most of our family, when he was no longer under the close care in the hospital situation, it was reassuring to know that qualified people were able to monitor him still” (Bill’s brother).

One family member reported that the order had resulted in improved confidence within the family, permitting them to relocate to somewhere geographically apart from their relative. Several family members spoke of relief that they would be able to access clinical services more easily than would be the case without the CTO, referring to “having a back up”. The sister of one patient reported a dilemma, of wanting to help her brother exercise his right to challenge the order, whilst still wanting the order to continue for his sake.

Family involvement in treatment

In New Zealand the need for families to be adequately consulted and involved in the care of their relative has been a prominent issue in recent years. Family members were divided over whether or not they felt they had been adequately consulted over the use of the Act. Several reported that their relationship with the provider service had improved because of the CTO. Some who reported being well consulted about the initiation of the CTO were still disappointed about an apparent lack of information about their relative's subsequent care.

Several family members felt their concerns were taken more seriously because of the CTO, and that they would be able to access help more quickly as a result.

“It does give him easier access to the hospital and if they do get sick ... places are made a lot sooner. Health professionals are there as soon as you call” (Joe's sister).

Several family members had been involved in making an application for their relative to be treated compulsorily. Although this had usually occurred in the context of an acute admission to hospital, the subsequent continuation of compulsion in the form of a CTO was reported to have an adverse effect on the relationship with the patient for some. One father reported that his son had nothing to do with him as a result. Others who reported a deleterious effect on the relationship described feeling anguished at their role. One family member thought that avoiding such a dilemma again was a valid reason for continuing the order once it was in place.

Several family members reported that they often reminded their relative to take their medicine, or to attend appointments, but none of these reported feeling particularly obliged to do so because of the Act, or that the order presented them with additional problems or obligations. In contrast, one daughter, who saw no benefit from the CTO, complained that the order had put her in a parenting role.

Patient insight

Ten family members reported that the CTO had resulted in an improvement in their relative's understanding of their illness and needs. They were generally very sure about this effect, and saw it as a key positive outcome. Improved treatment adherence and longer periods of wellness for their relative were cited as the reasons. Several relatives spoke of improvements in insight occurring over the course of years, associated with a person's gradual rehabilitation. Several other family members reported that the CTO had no effect on insight, but they were still positive about its effect on their relative's mental health.

Treatment adherence

Improved treatment adherence was considered the key justification for the existence of the order by family members. Many reported that their relative's adherence with prescribed medication had improved. Several referred to their relative taking their treatment simply out of concern that they would otherwise be readmitted to hospital. Other family members reported that improved treatment adherence was a consequence of the improved monitoring and continuity of care associated with the order, rather than a result of the formal coercive powers of the Act. Although most family members considered medication adherence the key aspect of treatment, several

referred to the order's ability to ensure that their relative attended appointments, or to direct residence in specific accommodation.

“If he's not on this, he will wiggle his way out of it, but when the community treatment order is in place, he has just got to have it, he is quite compliant to this, and that is fine” (Blair's wife).

“He has more freedom but needs nursing into a routine of taking his medication... it's a very important responsibility and you can't sort of hand it over to someone and just cross your fingers” (Bill's brother).

Impact on patient

Twenty-five of the 27 family members interviewed judged the CTO to be beneficial overall in its effect on their relative. Most also had some negative comments to make about the order or their relative's treatment regime.

Family members reported that the order helped their relative's mental stability, by “imposing a structure”, “preventing a need for readmission”, and as “having a stabilizing effect”. The CTO was referred to as a “safety net”, as being “in the background”, stopping patients getting into crime, and as helping patients feel more secure. Several considered that the existence of the order gave the mental health service particular obligations to provide appropriate input. For several, the CTO was inseparable from all aspects of service delivery, including those that would not generally be considered an object of compulsion, such as learning how to cook. Several spoke of the value of having mental health staff involved with their relative over years, providing continuity, rather than interrupted clinical relationships.

Some family members spoke starkly about the alternative to a CTO being hospitalisation or jail. One relative indicated their relative was “only alive because of it”.

Several who were concerned about negative effects of the order, such as being stigmatised, being resentful of the order, having others in control, or a negative effect on relationships within the family, were still of the view that it was justified.

“It seems to be an appropriate stepping stone from being under full time care to being fully able and responsible Without that I think Bill would have had to stay in the hospital environment for a much longer time” (Bill's brother).

“It's not a perfect world but you know it's about maximising the best possible scenario for him” (Jeff's sister).

Family members did not generally refer to the order having direct coercive effects. Instead, they referred to it as influencing their relative's care and health in an indirect fashion, or as providing a safety net, or imposing a structure. When asked about the impact of the order on the care of their relatives, several family members referred to the various follow-up arrangements with the service, and to accommodation and other

rehabilitative efforts. The quality of life of their relative was seen as having benefited as a result.

Discussion

A limitation of this study is the low participation rate. However, the 42 patients who completed interviews had a similar demographic profile to those of a larger cohort of patients under CTO reported previously (Dawson and Romans 2001). The need to obtain agreement for interview from both the patient and their relative contributes to a small sample size. The requirements of consent may also mean that family members who were more favourable in their view of the CTO were over-represented in the sample interviewed.

The acceptability to family members of having relatives treated under a CTO is similar to that reported elsewhere, with the coercion implicit in the order being seen as acceptable in the achievement of a better outcome (Swartz et al 2003). The findings here complement those of Swartz and colleagues who presented family members with clinical vignettes. The findings here support the opinion that outpatient compulsion operates through a variety of mechanisms, and that coercion (or its threat) may not be especially prominent (Swanson et al 1997). Family members have been identified as a source of coercion in involuntary psychiatric admissions, and it appears that in the community family members may sometimes see themselves in a coercive role, and experience understandable worry about this (Lidz et al 2000).

In this study, family members did not experience themselves as particularly stigmatised. Östman and Kjellin have reported that a majority of relatives experience stigma by association when their relative is admitted acutely to hospital, but that this did not differ between voluntary and compulsory admissions (Östman and Kjellin, 2002).

Family members appear to feel more involved in the care of their relative as a result of the order, reflecting what is increasingly recognised as optimal practice in the management of psychosis. The CTO appears give them a sense of purchase and influence on a mental health system that can too readily be experienced as insensitive and inadequately responsive. We have previously reported that one of the concerns experienced by Maori extended family (whanau) was a perceived lack of consultation over clinical decisions (Gibbs et al 2004).

The changes in insight reported by family members, sometimes occurring over several years, is interesting in suggesting that insight in psychosis may have important social determinants that go beyond the presence or absence of particular mental state phenomena associated with severe mental disorders that may fluctuate more rapidly.

The dilemmas faced by family members as part of compulsory treatment are numerous (Lefley 1997). The overall positive impact on family relationships reported by relatives here is consistent with the improvements in relationships reported by the patients, who also referred to the family's improved sense of safety, lessened stress, and a reduced burden of monitoring (Gibbs et al 2004).

Family members, like the patients under compulsion, appear less concerned about CTOs than about the need to avoid hospital admission and to maintain good

interpersonal relationships (Swartz et al 2003; Gibbs et al 2004). The dilemmas posed by the CTO for relatives, who may feel the order places them in a potentially adversarial situation with their relative, appear similar to, but less than, those experienced by family members involved in compulsory inpatient care (Lefley, 1997). The improved quality of life reported by family members for their relative when under the CTO, despite the sense of coercion, is a similar finding to that reported by Swanson and colleagues (2003). This improved quality of life was mainly seen by family members to be due to improved treatment adherence.

Our findings are similar to that of a survey in Oregon, that reported 57% of family members were in favour of CTOs, although they did not see it as an appropriate alternative to hospitalisation. Family members wanted greater education about mental disorder, and more information about civil commitment (McFarland et al, 1990).

At times, debate about coercion in community mental health has been phrased in a crude dichotomy, between the paternalistic approach of families and family organisations and an approach that emphasises the autonomy of the patient (Davis 2002). This study suggests that describing the situation in such polar terms fails to do justice to the complexity of the situation faced by both those under CTOs and their families. Family members' views were not found to be wholly paternalistic. On the contrary, family members appear to be aware of the ethical and other practical dilemmas implicit in the use of CTOs, and of the potential for conflicts of interest between them and their relative to arise.

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