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University of Brighton

Social Factors, Care and Community Treatment Orders (CTOs). Service User and Practitioner Perspectives

About CTOs

There are 5,365 service users subject to a Community Treatment Order (CTO) in England (CQC 2015) and they are in a unique position, since they can have conditions about their care imposed upon them. Being on a CTO identifies these service users as being most 'in need' of services and of potential protection. This study investigated the discharge and renewal of CTOs and the associated social, environmental and care factors.

About the study

This study, funded by National Institute for Health Research, School for Social Care Research (*Ref. C088/T15-011/UBJS-P84*), was conducted between May 2016 and June 2018 at University of Brighton, in collaboration with Sussex Partnership NHS Foundation Trust.

The study aimed to:

- Identify and understand the factors, particularly the social care and social environmental factors, associated with the discharge or renewal of a CTO and with recall to hospital.
- Identify the social interventions and support provided and to explore whether these were experienced as helpful by service users, in order to inform good practice.
- Explore and understand whether relationships (personal and professional) or loneliness were influential in CTOs being renewed or discharged, or there being a recall to hospital.

Mixed research methods were used:

The quantitative analysis of:

- National and regional data on CTOs
- Data from a survey of 181 Responsible Clinicians and Care Co ordinators

The qualitative analysis of:

- Data from interviews with 41 mental health practitioners
- Data from interviews with 16 service users.

Recruitment of service users was difficult and a small scale longitudinal study did not recruit. Thus, it was not possible to investigate whether service users' attitudes to a CTO changed over time.

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Summary of key findings from the research

- Service users and practitioners both considered CTOs to be concerned with compliance, but social factors were taken into account as providing evidence for and against renewal, recall and discharge decisions.
- Service users were negative about medication because of side effects. Views were paradoxical, however, and some reported developing 'maturity' towards medication.

- Service users were generally pragmatic about CTOs, seeing them as a way out of hospital: for some they offered stability, supportive relationships and wide ranging social activities. Loneliness was minimally reported by those interviewed.
- Both care co ordinators and service users reported positive and supportive relationships which had developed in the context of CTOs. These can be seen as an important social intervention which may not have developed but for the CTO: they appear an essential component of making a CTO work well.
- In terms of resources, practitioners expressed concern about bed availability for recalls and reducing community resources generally. Some felt CTOs could be made to 'free up' beds.
- In terms of practice, service users felt that more time was needed talking about medication and they also reported that they were often not well engaged with the formalities surrounding CTOs (e.g. care planning, reviews, Tribunals).
- Recruitment of service users to the study was challenging and possibly only the more positive became participants

Aims and focus of the Research

This research study explored the social care and environmental factors associated with the discharge and renewal of a CTO and recall to hospital.

It aimed to:

- Identify and understand the factors, particularly the social care and social environmental factors, associated with the discharge or renewal of a CTO and with recall to hospital.
- Identify the social interventions and support provided and to explore whether these were experienced as helpful by service users, in order to inform good practice.
- Explore and understand whether relationships (personal and professional) or loneliness were influential in CTOs being renewed or discharged, or there being a recall to hospital.

Background

Recent concerns over mental health have focussed on trauma, depression, anxiety and the mental health of young people. However, earlier concerns were with the risk management of people with severe mental illness and CTOs, introduced in 2008 by the Mental Health Act 2007, were of central, strategic importance to address these issues. CTOs enable service users to be discharged and treated in the community, specifying conditions and include a power of recall to hospital. They have been used extensively. The OCTET randomised control study (Burns et al 2013) found no reduction in readmissions, although Awara et al (2013) did. CTOs are being considered by the Independent Review of the Mental Health Act.

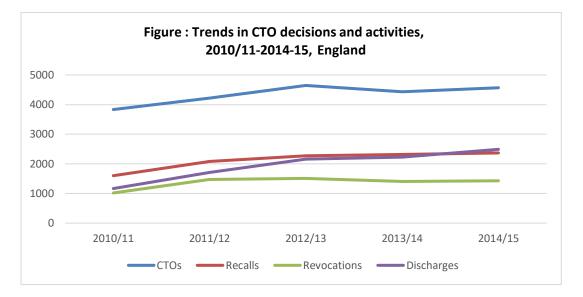
Involvement

Six peer researchers from the CAPITAL Project Trust (<u>http://www.capitalproject.org/?q=node/48</u>) and the Lived Experience Advisory Forum (LEAF) of Sussex Partnership Trust were involved in the study, developing the survey questionnaire, interview questions and reviewing data analysis. The peer researchers also led the development of a film about the project. The study benefitted from a Project Advisory Group who advised throughout and consisted of members of the Peer Researchers Group, the researchers and all relevant professional practitioners. Ethical and governance approvals were gained from the Health Research Authority, the University, the Trust and other relevant organisations.

Findings

National data on CTOs in England

- The national trend of activity is that approximately 4,500 CTOs are made each year, although 5,426 were made in 2015/6
- Recalls, revocations and discharges have followed a similar trend in the last five years to the making of CTOs, with only a marginal increase in discharge orders above trend in 2014-15 (see figure below)



Source: Derived from public information at the Health and Social Care Information Centre (HSCIC). 2015, Table 3, KP90. <u>http://www.hscic.gov.uk</u>. This data was used since the 2016/7 statistics are incomplete (NHS Digital 2017).

- The mean average number of CTOs made per Mental Health Trust in England in 2014-15 was 53.
- The maximum number of CTOs made by any one Mental Health Trust in in 2014-2015 was 210.
- Sussex has a relatively high ratio of CTOs to mental health detentions.

Data on CTOs in Sussex

340 CTOs were analysed (i.e. CTOs made in Sussex 2013 – 2015). Findings show that those on a CTO have particular characteristics –

- Two thirds were men (65% n = 221)
- Women subject to a CTO are more likely to be older (mean average age 51, compared to 43 for men)
- At admission, a high percentage (77% n=256) recorded their relationship status as single and their occupational status as unemployed (83% n=210). 9.5% (n= 24) were retired. Only 2% (n = 5) were working full time and 1% (n=3) working part time. Only one person was volunteering.
- While 73% (n=126) perceived they had a mental health disability, 17% felt that they had no disability. The number of people recording additional disabilities was small.
- A diverse range of accommodation circumstances was reported. 14% (n=34) were living in some form of hostel, care home, or supported accommodation, 13% (n=3) were living with family, and 7% (n=17) were homeless.

 Unlike national statistics, where Black or Black British service users were found to be nine times more likely to be given a CTO than a white person (NHS Digital 2017), this sample was predominantly white British (83% n =282), reflecting the local demography. 17 (5%) were from other white ethnic cultures. 5 (1.5%) orders were to those describing themselves as Black British.

Survey of Mental Health Practitioners

A total of 181 professionals (Responsible Clinicians (RCs) s and Care Co-ordinators (CCs)) completed an online questionnaire across Kent and Medway, Surrey and Sussex. The questionnaire explored views on discharge, renewal and revocation. 64 respondents were Responsible Clinicians and 119 were Care Co-ordinators (psychiatric nurses, social workers, occupational therapists). There was considerable similarity between the views of different professionals.

Discharge

Practitioners considered that the *very* or *extremely significant* factors influencing decisions about **discharge** were as follows:

- For 86% (155) taking medication
- For 90% (163(engagement with mental health professionals, and,
- For 63% (112) maintaining positive relationships

However, social/ environmental factors were also important in decision making about discharge:

- 54% (98) appropriate accommodation
- 51% (91) positive social activities
- 41% (73) meaningful occupation

Renewal

Practitioners stated that, in their view, the *very* or *extremely significant* factors in relation to decisions about **renewing** a CTO were:

- For over 80%: the service user is unwell or not always accepting need to take medication.
 Psychiatrists were marginally more likely to rate these factors as extremely significant
- 83% (147) the service user's lifestyle is chaotic
- 49% (88) recreational drug use
- 47% (82) social isolation

Recall

Practitioners thought that the very or extremely significant factors influencing decisions to recall a service user were -

- Over 99%: risk to self or others; psychiatrists were
- 87% (157) concerns expressed by carer/family/ friends

Thus, while compliance with medication and risk remained a dominant discourse, factors in the service users' social environment and their social functioning (e.g. quality of relationships) were also a key influence in decision making, providing evidence both for and against discharge, renewal and recall. In free text comments, the key themes that emerged were: service user insight; use of/ abstinence from alcohol and illicit substances; financial stability; views of significant others; stable personal and professional relationships and engagement in activities/ groups.

Interviews with practitioners

41 practitioners were interviewed: 17 Responsible Clinicians and 24 Care Co ordinators (community mental health nurses; occupational therapists and social workers; of the latter, the majority were Approved Mental Health Professionals).

The service user – care co ordinator relationship was seen as being important. Practitioners described working in a 'relational model' ('*I think we value our relationship with people more than anything'*) and efforts were described at building collaborative relationships. It was felt that engagement with the co ordinator/ care team could be understood as an important social intervention, which militated against isolation.

Social interventions/ support were not routinely conditions of a CTO, but were rather part of associated care plans, about which service users had choice, in contrast to the conditions of the CTO. Accounts were given of the considerable attempts to engage service users with support and social interventions, with the extent and nature of these being dependent on how well the service user was engaged with the care team. Compliance with medication, risk and the development of insight were again major themes and it was felt that CTOs could provide a platform from which service users could access support/ engage in social activities.

Engagement or not in support or activities was discussed as providing evidence for potential discharge, renewal or recall ('looking at social factors helps create a picture, a holistic picture of really where the service user's at'). Negative social factors which might be influential included, living in an environment where alcohol and drugs were easily available, withdrawal from personal and professional relationships, insecure/ changing accommodation. Nearly half of practitioners felt that the views of relatives/ carers were a significant factor in making decisions about CTOs.

Practitioners considered being on a CTO could affect the service user's sense of self or identity, although it was difficult to separate this from the stigma of their mental health diagnosis. There was also a feeling that being on a CTO could affect the service user's agency and sense of control (*'she felt it was really restrictive; s/he was like 'I can't believe I've got to do this'*). Practitioners considered that service users preferred living in the community on a CTO to being in hospital on a section.

In terms of working practices and resources, while practitioners felt they worked well together, over half mentioned challenges when a user's care transferred from an in-patient to out-patient psychiatrist, who may not know the service user. CTOs were seen as making a lot of bureaucratic work and the process of recall was considered difficult and unclear, with the availability of beds being an issue. Some participants felt CTOs were being made so users could be discharged from hospital early to 'free up' beds and over half of practitioners discussed the shortage of the of beds generally.

Interviews with Service Users

Recruitment of service users was difficult and different strategies were attempted. 16 participants were recruited, against a target of 20-25. Information from care co-ordinators was that 50 service users declined to be involved, mostly stating they did not want to be part of research. It is possible that those interviewed were more positive about CTOs, although they still reported strong views. The data gathered, however, indicates positive experiences can arise from being on a CTO. 12 men and 4 women were interviewed. Most reported having some kind of psychosis.

Service users, too, considered that CTOs were mainly concerned with compliance. The CTO was viewed as a way of getting out of hospital ('I *left hospital on a CTO, just cos that's what they do ... they put you on a CTO to...make sure you take your meds, it's sort of like an understanding ... if you want to be out of hospital you just take your meds'*), but also as ensuring the service user could get back into hospital quickly if necessary.

Service users all had negative views about medication because of the side effects ('*Take me off it ...I* always think no more medication, please'). However, views were paradoxical and some gradual

acceptance and benefit was reported ('*I have got to a place where I am happier about my medication. And how I am doing and my life and everything like that*'). The CTO could assist with having to take medication (*'it (the CTO) made it harder to refuse, so I stay well'*). Service users reported insight into the need for medication, mostly linked to difficult behaviour (*'I used to have outbursts'*). There were references to increasing maturity, which enabled service users to manage their illness and taking medication. It is as though service users were describing a journey (*'I don't know whether it is a case of medication or my maturity through the illness*). All described a belief that they would be recalled to hospital if they did not take their medication.

Service users reported knowing their CTO had a condition to take medication, but most did not know the other conditions. They did not report great understanding of, or involvement in, the management of their CTO or care plan; ('There probably is a care plan, but I probably didn't even take notice of it, do you know, I'm just not interested'). Doctors were seen as important because of making decisions on medication. Feedback on review tribunals was not generally positive, with service users feeling they were 'talked about' and that their opinion was not asked for, nor heard; this was reported more widely also for other meetings/ reviews.

For service users, social activities provided a structure to their time and chance to meet other people. Activities (e.g. meditation, participation in faith groups, volunteering; bingo, fishing, sport) were not always organised as part of the CTO/ associated care plan, but by the service user themselves. Limited engagement in part time employment/ college courses was reported, but transition to paid employment was difficult because of needing to earn enough to live on. Relationships with family and friends were significant and had been re kindled since being on the CTO: contacts in supported housing/ residential care were important to people who were on their own. Only one person reported they did *'not find much to do'*. There were only limited accounts of being isolated or lonely and those few also described a lot of social activities. It seems that these individuals were reporting being emotionally lonely and would like to have a partner.

Attitudes to the CTO were pragmatic ('*it's now a matter of course....it's just a lifestyle'*). More positive views about the CTO were expressed than negative ('*I think it has helped me to be quite honest'*). Again, views could be paradoxical and it could be hard to separate views about the CTO from an intense dislike of medication. Some service users felt pressured by being threatened with a return to hospital ('*I'm always worried I might be put back in hospital'*). For some, the CTO had no effect upon their sense of self and autonomy ('*it didn't make me feel any different'*), but others felt that they did not want people to know about it. These feelings were not easily differentiated from those about having a mental health diagnosis.

A major theme from service users, as from practitioners, was the positive relationship with the Care Co ordinator (*it's good I have so much support'*) and often the wider mental health team too, (*'any kind of dire situation I can contact the AOT, they would be there for me'*). The support from, and good relationship with, the Care Co ordinator was reported even by those who felt negatively about medication and the CTO. Service users did not report positive relationships with the Responsible Clinician, perhaps because of their power of recall. While service users sometimes reported feeling not heard in formal settings, they felt the Care Co ordinator listened to them. Service users felt there needed to be much fuller, ongoing discussions about medication with doctors and also about the CTOs when it was made.

Conclusions

CTOs

Service users on CTOs form a discrete group with defined characteristics and have great need of supportive services. Data from this study supports the suggestion that CTOs can offer an important

care option between detention and treatment in hospital and voluntary treatment in the community. Use of CTOs is high, and renewals and revocations correspondingly so. Greater understanding of the reasons for these is important. It is also important to debate whether recall to hospital should define whether a CTO is successful or not. Notwithstanding this, intensive community resources and support are needed. Processes and responsibilities for recall and the availability of psychiatric beds require review.

The importance of the working relationship between the service user and care co ordinator

Data from service users and practitioners provide strong evidence that the working relationship between the Care Co ordinator (and mental health team) and a service user is of key importance. This engagement can be understood as an important social intervention, providing support and militating against isolation. The stability which emerges for the service user provides a platform from which to access social activities and recovery. In an environment where the forms and processes in social care often predominate, this relationship can be understood as a key message for mental health care.

Social Environment and Activities

Practitioners described considerable efforts to support service users and engage them in social activities; service users also described wide ranging activities, many of which they had organised themselves. While compliance with medication and risk remained a dominant discourse for both practitioners and service users in relation to CTOs, social factors were found to be influences in decision making, providing evidence for and against discharge, renewal and recall.

Attitudes to medication

Service users were pragmatic about CTOs but were negative about medication; however, paradoxical views were expressed, with attitudes toward medication changing. It is as though service users were describing a journey ('*I don't know whether it is a case of medication or my maturity through the illness'*). Service users wanted more opportunities to discuss medication, the CTO and also more attention needs to be paid in practice to their involvement in the formal processes associated with the CTO (care planning, reviews and tribunals).

Service user led video about the research study *Community Treatment Orders: Complex Journeys:* <u>https://mediastream.brighton.ac.uk/Play/15432</u>

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Dr Julia Stroud and Professor Phil Haynes, August 2018

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