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Meaningful participation or tokenism for individuals on community based compulsory treatment orders? Views and experiences of the mental health tribunal in Scotland

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ABSTRACT

Background: The Mental Health (Care and Treatment) (Scotland) Act 2003 was considered as world leading when it was enacted due to its rights-based approach. Changes were made to encourage participation and enhance autonomy, including the Mental Health Tribunal for Scotland (the tribunal) replacing the Sheriff Court in making decisions about compulsory treatment.

Aims: To explore the views of individuals on community based compulsory treatment orders (CCTOs) and independent advocates to assess whether participation in the tribunal is perceived as meaningful in practice.

Method: A qualitative research design was adopted and semi-structured interviews were undertaken with 19 people with experience of being on a CCTO and eight mental health advocates in Scotland. The data were thematically analysed and explored using ethics of care principles.

Results: Individuals faced barriers to participation, including mental distress, medication, and inaccessible communication, and both the tribunal process and outcome were important in shaping perceptions of fairness. A perceived unsuccessful outcome was found to undermine an ostensibly participatory process, and unequal power dynamics resulted in feelings of powerlessness.

Conclusions: The findings suggest that participation is often experienced as tokenistic in practice and that cultural change is required if people are to be meaningfully involved in tribunal proceedings.

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Introduction



The participation of people experiencing mental distress in processes that affect their lives is a well-established policy requirement in various countries across the world (Bee et al., 2015; Beresford, 2013; Gee et al., 2016; Happell, 2008; Ocloo & Matthews, 2016). This reflects a shift from paternalistic practices towards more collaborative decision-making, including greater engagement in areas such as care planning, policy development, research, and service commissioning (Farrelly et al., 2016; Weinstein, 2010).

The impetus for change has been shaped by both a consumerist agenda, focused on patient choice and individualisation (Kemp, 2010), and more democratic models, valuing experiential knowledge (Bee et al., 2015; Sweeney, 2013). The latter includes the emergence of the survivor movement (2017, Sweeney, 2009; Beresford, 2002, 2009, 2013; Faulkner, 2009, 2017; Plumb, 1993; Rose, 2009) and “mad studies” (LeFrançois et al., 2013) which reflects a growing rejection of biomedical approaches that have been used to deny citizenship rights. Notably, survivor research has an emancipatory purpose and aims to disrupt power differentials so that

individuals have greater choice and control in their lives (Beresford & Rose, 2009).

Despite widespread support for participation, multiple barriers restrict genuine involvement, including tokenism, stigma, poor information, language, and culture (Beresford, 2013; Lewis, 2013; Weinstein, 2010). User involvement, embodied in the “informed patient”, has been condemned as an attempt to promote compliance rather than upholding autonomy, with individuals often having their views dismissed when these diverge from the professional viewpoint (Henwood et al., 2003). Furthermore, particular groups have experienced exclusion on the basis of perceptions about vulnerability (Beresford, 2013; Ocloo & Matthews, 2016; Raptopoulos, 2010). This includes people on community treatment orders¹ (CTOs) whose citizenship is conditional on meeting the terms of their order.

Community-based compulsory treatment² is a contentious, yet widely utilised, legal apparatus that has been implemented in over 75 jurisdictions globally (Rugkasa, 2016). CTOs aim to address the causes of repeated readmission to hospital by mandating adherence with a range of

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conditions, often centred on medication administration (Corring et al., 2019). Qualitative studies demonstrate that whilst CTOs are often viewed as providing a safety net and promoting engagement with services, they are also perceived as restrictive and disempowering (Gibbs, 2010; Light et al., 2014; Ridley & Hunter, 2013; Stroud et al., 2015). Furthermore, randomised control trials have found no evidence of improved outcomes in relation to readmission rates (Burns et al., 2013), service use, social functioning, or quality of life (Kisely et al., 2017). This is supported by a synthesis of non-randomised studies which concluded that “there is no evidence of patient benefit from current CTO outcome studies” (Rugkasa, 2016, p. 15). This weak evidence base raises significant issues regarding the efficacy and ethical basis of CTOs and brings into question their continued use.

CTOs, however, were introduced in Scotland as part of a wider rights’ based agenda and therefore have the potential to produce more positive outcomes. Community-based compulsory treatment orders (CCTOs) were enshrined within the Mental Health (Care and Treatment) (Scotland) Act 2003, which was regarded as progressive, distinctive, and world-leading when it was first enacted (Fischer, 2006; Ridley & Hunter, 2013). A suite of measures was implemented to modernise practice and aimed to bring it in line with human rights standards (Millan, 2001). This includes the provision of free independent advocacy and the ability to select a named person to be involved in decision-making³. There must also be regard to any care and treatment preferences set out in an advance statement (McKay & Stavert, 2017). One of the most distinctive changes was the introduction of the “Millan Principles”, which include participation, non-discrimination, benefit, reciprocity, respect for carers, and least restriction (Millan, 2001). These are designed to enhance voice and choice in decision-making and have been salient in building Scotland’s reputation as a leader in rights-based mental health care.

The use of compulsory treatment in Scotland is on an upward trajectory. There has been a 20.1% increase in all CTOs over the last ten years, with a 56.4% rise in CCTOs⁴ (Mental Welfare Commission for Scotland, 2019, p. 41). The Mental Health Tribunal for Scotland (the tribunal) replaced the Sheriff Court in making decisions about compulsory treatment with multi-member, multi-disciplinary⁵ panels being responsible for assessing whether the legislative criteria have been fulfilled (Lyons, 2008). Whilst this change was designed to make proceedings less formal and more participatory (Atkinson et al., 2005), there is a lack of empirical research examining the tribunal in Scotland. The limited evidence to date focuses on the early implementation period or is largely based on professional perspectives (Dobbie et al., 2009; McManus, 2009).

This paper uses Scotland as a case study to explore participation in the tribunal, addressing a gap in the research by (1) foregrounding the voices of people on CCTOs, and (2) examining the Scottish system ten years after it was implemented to evaluate it in the contemporary context.

This is particularly timely given that the current review into mental health legislation in Scotland aims to improve rights for people who fall within its provisions (Scottish Government, 2019). It is therefore pertinent to understand what it is like to attend the tribunal and whether individuals feel they are able to meaningfully participate.

Materials and methods

This article aims to explore the experiences of the tribunal to assess whether it facilitates meaningful participation in decision-making about compulsory care and treatment. This data was collected between October 2015 and May 2016 as part of a doctoral study that explored how CCTOs affect individuals and their families. This research utilised a qualitative research design influenced by a feminist ethics of care approach, which is based on a relational ontology and foregrounds issues of power, agency, and interdependency (Barnes, 2015; Brannelly, 2016; Lynch et al., 2009; Sevenhuijsen, 2003; Tronto, 1993, 2013).

This paper draws upon semi-structured interviews undertaken with 19 individuals who had been on a CCTO and eight mental health advocates⁶. All participants were over the age of 18, ranging from 24 to 57, and the majority of those on CCTOs identified as male (16 identified as male and 3 female)⁷. Participants’ diagnoses included bipolar disorder, schizophrenia, schizo-affective disorder, and depression⁸. Thirteen were on a CCTO at the time of the interview and all had to take medication, often antipsychotic medication administered by the depot, as a condition of the order. All participants lived in Scotland, with ten residing in supported accommodation.

A topic guide (see Table 1) was used to ensure the research questions were addressed, whilst allowing individuals to discuss their perspectives from their own standpoint. Participants were purposely recruited through third sector mental health, carer, and advocacy organisations, and a mental health officer (MHO) local authority team. These organisations assisted by advertising the project through their networks, including social media channels, and by providing a hard copy of the information sheet to participants. The interviews were conducted until data saturation was reached and quality was ensured by embedding an ethics of care (Tronto, 1993, 2013) within the data collection process and analysis. This enabled attentiveness to accessibility requirements, with some participants taking part in multiple shorter interviews, which were adapted to suit their specific needs. The interviews were transcribed verbatim and were uploaded to NVivo 10. Thematic analysis involved both inductive and deductive coding (Spencer et al., 2013) and Tronto’s (1993) integrity of care framework was used as part of a second-order analysis to develop the findings and recommendations. Table 2 provides an overview of how the ethics of care principles shaped the research analysis.

Undertaking research on CCTOs raises important ethical considerations. Excluding people on the basis of perceptions about risk and vulnerability silences the voices of people

Table 1. Extract from topic guides.

Individuals	<ul style="list-style-type: none"> • Have you attended any mental health tribunals? Probe reasons for attendance/non-attendance. • Can you describe what happened? • Do you feel you were listened to? In what ways? • What was the outcome? How did you feel about this? • Did you have an advocate? How did you feel about this? • Do you have an advance statement? Probe around the reasons for uptake/lack of uptake. • What does your advance statement say? • Has it been taken into account? Probe around this.
Advocates	<ul style="list-style-type: none"> • What does the advocacy role involve? • How do advocates support individuals on CCTOs? • What information is given to individuals in advance of the tribunal? How is this provided? • Can you talk me through what happens at the tribunal? • Is there an order to proceedings? • What are your views about the level of formality? • How much do individuals participate in tribunals? In what ways? • Are people supported to participate? Are there any barriers to participation? • Are the views of individuals on CCTOs taken into account? In what ways? • Is this reflected in tribunal outcomes? • What evidence is given to fulfil the legislative criteria? • What are your views of advance statements? How are they used? How often are they overturned?

Table 2. The influence of the feminist ethics of care on the analysis.

This was conducted as part of a second order analysis to develop the thematic analysis	<p>Adapted from Tronto's (1993) Integrity of Care Framework</p> <ul style="list-style-type: none"> • Attentiveness: recognising and being attentive to the needs of others. This involves knowing a person, their likes, dislikes, wishes and preferences. This requires a holistic understanding of needs, not just medical needs, and recognition of those produced by both mental distress and the mental health system itself. • Responsibility: taking responsibility to meet identified needs. This must come from a genuine place of care rather than obligation (Sevenhuijsen, 2003). • Competence: focuses on the outcomes of caring practices. Good intentions are not enough; adequate resources and trusting relationships are important if good care outcomes are to be achieved (Brannelly, 2016). • Responsiveness: promotes voice and requires listening to care and treatment preferences. Having voice is significant for people whose agency has been eroded because of assumptions about mental illness (Tew, 2011). • Power and Trust: good care is grounded in trusting relationships, which is interwoven with issues of power (Lynch et al., 2009). An ethics of care requires moving "the interrelated factions of care, dependency, vulnerability and power from the background to the foreground" (Ward, 2011, p. 172).
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with lived experience, which can lead to professionals forming the dominant narrative (Thompson & Chambers, 2012). Individuals were given an information sheet prior to the research taking place and were provided with the opportunity to ask questions before signing a consent form. Pseudonyms⁹ and codes were assigned to provide confidentiality. Ethical approval was obtained from the

University of Glasgow College of Social Science Ethics Committee (400140238).

Results

Barriers: mental distress, medication & inaccessible information

An ethics of care requires attentiveness to needs (Tronto, 1993, 2013), including assistance to support participation. Individuals' on CCTOs, however, identified a range of barriers that restricted their involvement, including those arising from mental distress. Bill, for example, said: "I think that was because of my illness, not being able to take in the information. Like I think I would have been told [about his rights] but I don't really remember".

Others highlighted that the iatrogenic effects of medication had an adverse effect on their ability to process information. Carolyn said: "I had no preparation for the tribunal whatsoever. I didn't have a clue what a tribunal was... you're drugged up for that". Facilitating effective participation requires recognition of individual needs and how these are produced by both mental distress and responses by the mental health system. For Carolyn, it was the potent effects of medication that restricted her engagement.

Rather than encouraging meaningful participation, cultural practices were perceived to exacerbate this. Some participants reflected that a poor understanding was compounded by inaccessible methods of communication that were dominated by legalistic and clinical language. This was highlighted by one advocate who noted: "[The letters are] almost foreign languages. Too authoritarian, too distanced and cold. Why call someone an RMO¹⁰ when you can say 'your doctor' or an MHO¹¹ a social worker" [A06].

Advocates also highlighted issues resulting from attitudinal barriers:

MHOs make referrals for people when it's coming up to a review of their CTO and those referrals are often accompanied by "I'm obliged to make this referral. You're unlikely to get much sense out of this person. They don't appear to be resisting the fact that they're on a community order". But more often than not when you go out to see the person, because they've lost sight of, you know, what's actually happening because they've been on the order so long, they don't realise they've got the choice to, you know, to oppose it or to speak to a solicitor [A05].

This shows how beliefs about mental distress and competence can impact how information is provided and can restrict understanding about rights entitlements, which can impede participation.

Supported decision-making: advocacy and advance statements

Whilst inaccessible forms of communication reduce involvement, having the assistance of a mental health advocate or creating an advance statement can potentially help to promote participation and achieve responsiveness.

Advocates talked about the steps they took to encourage engagement. They described the workings of the tribunal: how the panel is constructed, the type of evidence that would be discussed, and legal rights and safeguards within the legislation. Craig valued their communication skills, noting: “they’re good at putting things into proper words. Like, you can say something to them and then they’ll put it into a presentable case, you know?”. Despite this, there was a low uptake amongst participants, a key issue adding to the barriers identified in the previous section.

Advance statements also have the potential to enhance choice by setting out views and preferences to be enacted when individuals have impaired decision-making abilities, a time when their voice is often most marginalised (Atkinson, 2007). However, advance statements were seldom used, with only four participants having created one. This was evident when Daniel said: “I’ve never seen wan ae them. What’s that?” and Jack who responded: “Advance statement, what’s that?”. Advance statements are rendered ineffective if individuals do not understand their purpose or how they function. This underpins the importance of the gatekeeping role of mental health professionals; for this to be effective, information must be provided in an accessible way and at the right time.

Those who had created an advance statement explained that they were used to outline treatment wishes, such as medication preferences, but also additional information to enable care to be attentive to their individual needs. Danielle used her advance statement to set out who could and could not be informed when she was in the hospital, and who could be involved in care and treatment decisions. She said:

My advance statement explains that if anybody phones the hospital looking for me, no information’s to be given. Em, the only person that can give treat-, decide on my treatment’s my sister, my named nurse, and my psychiatrist together. And what activities I like to do. And that’s about it [Danielle].

Danielle’s relationship with her mother had broken down. She did not want her to have any involvement in decision-making and creating an advance statement allowed her to formally exclude her from the process. This demonstrates how advance statements can be used as an effective form of participation, enabling individuals to communicate their views at a time where they may face challenges in doing so.

The importance of the process and the outcome

Both the process and outcome were important to participants and advocates highlighted the significance of the convenor¹² in shaping proceedings. Although the style of the convenor varies, those who adapted their approach and took the time to explain the process were perceived to encourage participation. This was reinforced by one advocate who explained: “people need to feel included and feel they can participate ... they [the convenor] say some things to put the patient at ease, trying to explain it’s meant to be an inclusive process” [A08].

Despite this, many participants were unable to separate the process and the outcome. Although individuals are encouraged to take part in the tribunal, the panel are required to make decisions based on the fulfilment of the legislative criteria, which includes risk and significantly impaired decision-making ability. This can result in an unsuccessful outcome from the individual’s perspective, which can reinforce a feeling of powerlessness. This was the case for Shoaib who explained:

I was listened to but they decide I should still be on it. They decide I should still be on it. My decision is I shouldn’t be on it because I think I can manage myself... No they [his views] wurny [were not] taken into account, no.

Being listened to was not enough in itself for Shoaib to feel that his participation was genuine. Although his preference was for the order to cease, the panel approved the renewal application for a further twelve months. Shoaib disagreed with the decision which left him feeling disempowered.

For Jack, his lack of influence on both the process and outcome caused him to withdraw. He explained that he no longer attended his tribunals due to his previous experience. Jack said: “[The tribunals are] a bit intense. Three acting authority figures sitting there, discussing what they’ll dae wae ye... I think they gave me a chance, but eh, they didnae really listen tae me. Just done what they want done”. Jack was not a partner involved in discussions about his care and treatment, but instead felt infantilised and that he lacked control.

These accounts illustrate that whilst individuals have the right to participate, to have their views heard, the failure of this to deliver outcomes in line with their preferences can undermine meaningful involvement. This highlights that the approach adopted can prevent rather than promote inclusion, and not being listened to and not having one’s views acted upon can result in disengagement.

Hierarchies of power

Existing international research on tribunals demonstrates hierarchies of power operating at various levels of the tribunal, including the structure of the panel and the weight given to clinical expertise (Macgregor et al., 2019; Murphy et al., 2017; Thom & Nakarada-Kordic, 2014). An ethics of care requires examining relations of power (Lynch et al., 2009; Tronto, 1993) and a patient/professional binary was prevalent within the thematic analysis, with participants on CCTOs talking about the difficulties they faced when their views diverged from their psychiatrist’s perspective. As Craig said:

The psychiatrist has firmly decided I’ve to be on the treatment I’m on. He’s not really shifting at the moment... the tribunal by default will go with the professionals because they’re qualified. So, if you do try and go up against professionals you’ve got no chance because the CTO tribunal prefers their evidence.

Craig’s psychiatrist focused upon the necessity of medication, arguing that his self-care deteriorated post withdrawal.

There is a clear paradox here: professionals are able to talk about medication, often in relation to non-adherence and risk, whilst individuals face challenges in discussing their subjective experiences. This reflects wider literature demonstrating that participation is undermined by a narrow focus on the legislative criteria (Beupert & Vernon, 2011; Carney, 2012).

Power was further eroded by the marginal position resulting from having a diagnosis. Disagreement with treatment is often associated with lacking insight (Dawson & Mullen, 2008), which falls within the significantly impaired decision-making ability criteria¹³ (Shek et al., 2010). This was reinforced by Mathew who said:

[I told] them I wasn't happy about it... I don't know what else I could have done... there aren't a lot of options, eh, because the more vigorous you are in challenging the more it gives the people who you're challenging excuses to say that you've got a mental illness.

Matthew was not opposed to all forms of compulsory treatment and agreed that he required short-term hospital-based care during periods of psychosis. He was, however, against being on a CCTO that compelled him to take medication on a longer-term basis. Matthew explained that the akathisia and tardive dyskinesia¹⁴ he experienced negatively impacted his mental health, saying: "I felt suicidal with it". Matthew experienced negative outcomes from medication but also from having his agency denied. Whilst over-riding autonomy is often justified on the basis of "best-interests", this negates the harms experienced through treatment, which has implications for the bioethical principle of non-maleficence (Beauchamp & Childress, 2001).

Advocates also provided examples where the presence of a diagnosis resulted in discrimination, with views being erroneously perceived as "delusional":

The fact that he co-run a business was completely dismissed out of hand. It turned out his named person was his business partner. But this had all been put down to delusional thinking, the fact that he was, the fact that this guy was capable of running a business [A04].

Whilst diminishing the capabilities of people who experience mental distress is oppressive and undermines personhood, an ethics of care requires that experiences must be located within the wider social, cultural and structural context (Barnes, 2012). The dominance of the medical domain contributes to feelings of powerlessness, however, psychiatrists are trained to diagnose "mental illness" and excessive workloads and burnout impact upon how adequately professionals are able to perform their role (O'Connor et al., 2018).

Discussion

Scotland's principled approach to mental health law has been widely celebrated for its focus on voice and inclusion (Griesbach & Gordon, 2013; Mackay, 2012). The findings demonstrate some positive examples of convenors taking a person-centred approach as well as advocacy and advance statements helping some participants to have a voice.

Nevertheless, the analysis illustrates that participation is often experienced as tokenistic and is restricted by poor understandings of rights entitlements arising from mental distress, medication, inaccessible language, and attitudinal barriers.

Foregrounding the views of people with lived experience of compulsory treatment, and their advocates, has highlighted the subordination that individuals experience when their autonomy is denied. Individuals on CCTOs talked about their power being diminished because of their diagnosis and the difficulties they faced in effectively challenging their clinician's viewpoint. This adds to the existing body of international evidence that demonstrates the dominance of the medical domain on tribunal decision-making (Livingston et al., 2016; Murphy et al., 2017; Ridley et al., 2010; Swain, 2000).

Research shows that disagreeing with treatment is frequently associated with lacking insight (Dawson & Mullen, 2008), a factor that has been found to influence tribunal decision-making (Jobling, 2019). This, however, undermines subjective experiences of care and treatment, including the iatrogenic effects of medication and the impact of this on quality of life. Not everyone benefits from antipsychotic medications and adverse effects are commonly experienced (Bentall, 2004; Moncrieff, 2013), yet individuals on CCTOs have limited agency over their treatment plans. These unequal power differentials also raise questions about the ethical basis of CCTOs more broadly, especially when situated within the wider context of existing evidence which demonstrates a lack of efficacy in relation to a range of outcomes (Kisely et al., 2017; Rugkasa, 2016).

If the tribunal system in Scotland is to be genuinely participative, then fundamental power differentials must be addressed, with experiential knowledge being fully recognised and valued. A range of practical recommendations is therefore proposed to instigate cultural change. These should be grounded in an ethics of care which prioritises both people's needs and their preferences in relation to care and treatment (Tronto, 1993, 2013). There should be attentiveness to the support needs required to facilitate meaningful involvement, including a flexible, person-centred approach that is free from clinical and legal jargon. Responsibility should not only be based on professional obligation but should come from a place of care (Sevenhuijsen, 2003). Given that the wider structural context impacts upon practice (Carney & Tait, 2011), greater investment of resources is also recommended to help to ensure professionals have a manageable workload and time to provide adequate support. Further measures are also needed to promote autonomy and embed the value of situated experience. This could be facilitated by including people with lived experience of compulsory treatment in the creation and delivery of training and support. Advance statements also have the potential to promote autonomy (Atkinson, 2007), ensuring responsiveness to care and treatment preferences, however, there is a need for greater promotion, including being routinely discussed and revisited in advance of the crisis.

Conclusion

This paper examined the extent to which participation in the tribunal is perceived as meaningful for individuals on CCTOs. Although Scotland's principled approach is world-renowned (Fischer, 2006), this did not translate into participants' accounts of the tribunal. This analysis will be of interest to other jurisdictions attempting to work towards compliance with competing human rights standards and trying to navigate tensions between care and control. Whilst these findings have important implications for policy and practice, this article is limited in that it is based on a small self-selecting sample. Furthermore, it does not address the complexities of decision-making surrounding compulsory treatment or consider the perspectives of tribunal panel members or health and social care practitioners. Further research should therefore focus on the decision-making practices of the tribunal and how meaningful participation can be supported within this process.

Disclosure statement

No potential conflict of interest was reported by the author(s).

Notes

1. In Scotland, CTOs can be either hospital based or community-based orders and these are termed compulsory treatment orders rather than community treatment orders. CCTOs refers to community based compulsory treatment orders.
2. This takes multiple forms and includes community treatment orders, community based compulsory treatment orders, and involuntary treatment orders.
3. The named person replaced the nearest relative, who had powers in relation to detention and discharge. It is important to note that the named person's views are independent of the individuals and therefore can diverge.
4. This is based on point prevalence in January 2010 and January 2019.
5. Tribunal panels consist of a medical, general (individuals with relevant lived experience of mental distress and the mental health system or professional experience), and legal member.
6. The wider study also included family members, however the data is not presented here.
7. Whilst there were significantly more male participants, men are more likely to be placed on CCTOs in Scotland.
8. Not all participants agreed with their diagnosis.
9. Individuals from the CCTO group were assigned a pseudonym whilst advocates were provided with an identifier based on the format A (for advocate) followed by a number.
10. RMOs are Responsible Medical Officers.
11. MHOs are mental health officers who are specially trained social workers responsible for supporting people who are subject to the 2003 Act.
12. The convenor is the legal member.
13. This is one of the legislative criteria that must be fulfilled for compulsory treatment to be authorised in Scotland.
14. Akathisia and tardive dyskinesia are movement disorders that are caused by medication.

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