



Doctoral Thesis

A qualitative study of the experiences of moving on from a non-residential Democratic

Therapeutic Community

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Abstract

This thesis explores experiences of stigma towards individuals with a diagnosis Borderline Personality Disorder and consider approaches to mitigate this. It examined the experiences of individuals with difficulties that can be understood as personality disorders who had attended a Democratic Therapeutic Community, focusing on what factors helped and or hindered the maintenance of the positive therapeutic changes achieved during DTC treatment.

A narrative literature review was conducted with the aim of exploring the existing literature relating to stigma and prejudice towards people with a diagnosis of BPD, focusing on how mental health professionals think about and behave towards individuals with this diagnosis and the clinical implications of these attitudes and behaviours. The Power Threat Meaning Framework (PTMF) was discussed as an alternative to psychiatric diagnosis.

A qualitative research study aimed to understand the medium-term factors that helped or hindered the maintenance and continuation of positive change after the end of day DTC treatment. It examined the experiences of individuals who had completed day DTC programmes and the subsequent follow-on group between six months to two years prior to taking part in the research, who felt they had an overall beneficial experience in the DTC. Interpretative phenomenological analysis (IPA) analysis was used. Six participants completed one-to-one semi-structured interviews. Four superordinate themes emerged: An Atmosphere of Belonging, Hope versus Struggle, Support, and Empowerment through Understanding. This study was the first to explore the experiences of individuals following discharge from non-residential day DTCs.

Declaration

This thesis presents work done in partial completion of a Doctorate in Clinical Psychology at Lancaster University. The work presented is my original work and has not been presented for any other academic or professional award.

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Word Count

Section	Main body	References, tables and appendices	Total
Thesis Abstract	241	-	
Narrative Literature Review	7,958	7,396	
Research Paper	7,992	4,045	
Critical Appraisal	3,989	252	
Ethics	6,419	4,164	
Total	26,599	15,857	42,456

Table of contents

Abstract	ii
Declaration	iii
Acknowledgement	iv
Word Count.....	v
Table of contents.....	vi
Chapter 1 Literature review	1-1
Abstract	1-2
References.....	1-30
Tables	1-44
Chapter 2 Research paper.....	2-1
Abstract	2-2
References.....	2-29
Figures and Tables	2-33
Appendices.....	2-36
Chapter 3 Critical appraisal	3-1
Chapter 4 Ethics.....	4-1
Chapter 5 Appendices.....	5-1

Chapter 1 Literature review



Stigma and the diagnosis of Borderline Personality Disorder: A narrative review

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LITERATURE REVIEW

Abstract

Despite decades of research confirming the significant stigma and prejudice towards people with a diagnosis of Borderline Personality Disorder (BPD), leading to changes in policy and treatment pathways, these issues still seem as relevant today. This narrative literature review sought to explore the existing literature relating to this issue, focusing on how mental health professionals think about and behave towards individuals with this diagnosis and the clinical implications of these attitudes and behaviours. The Power Threat Meaning Framework (PTMF) was discussed as an alternative to psychiatric diagnosis and implications of adopting this approach for service structure, interventions, and outcomes for those meeting the current criteria for a BPD diagnosis was considered. Clinical and future research recommendations were made.

Keywords: Borderline Personality Disorder, Stigma, Prejudice, Mental Health, Power Threat Meaning Framework, Psychiatric Diagnosis

The aim of this paper is to review the literature relating to stigma associated with the diagnosis of Borderline Personality Disorder (BPD), focusing particularly on how mental health professionals think about and behave towards individuals with this diagnosis and the clinical implications of these attitudes and behaviours. Relevant papers on BPD and stigma were identified by searching in a relatively systematic manner using several databases and search terms (see Appendix for further details). The Power Threat Meaning Framework (PTMF) will be discussed as an alternative to psychiatric diagnosis, considering the implications of adopting this approach for service structure, interventions, and outcomes for those meeting the current criteria for a BPD diagnosis. The paper will conclude with clinical and research recommendations.

LITERATURE REVIEW

In the Diagnostic and Statistical Manual of Mental Disorders: Fifth Edition (DSM-5) (American Psychiatric Association, 2013), the diagnosis of BPD is characterised as a pervasive pattern of instability in interpersonal relationships and self-image, with marked difficulties with emotional regulation and impulsivity. These difficulties must have been present since early adulthood and occur across a variety of contexts. A person must meet five or more of the criteria in Table 1 to receive a diagnosis. BPD is not found in the International Classification of Diseases: Tenth Edition (ICD-10) (World Health Organisation, 2010), however, the diagnosis of Emotionally Unstable Personality Disorder (EUPD) Borderline Type is comparable (Table 2). The term BPD will be used for the remainder of this paper, as it is more frequently used in the existing literature.

Insert Table 1 and Table 2 here

Stigma

Goffman (1963) described stigmatised people as being in possession of a “spoiled identity”: a product of social rejection resulting from having characteristics perceived negatively by society. Link and Phelan (2001) expanded on this, identifying four features of stigma: 1) a recognition of individual differences, 2) those differences being perceived negatively by society, 3) seeing the stigmatised group as the outgroup, and 4) a resulting loss of opportunity, power, or status for the stigmatised outgroup. From a social-cognitive perspective, stigma includes cognitive elements in stereotypes, affective elements in prejudice, and behavioural elements in discrimination (Corrigan & Kosyluk, 2014).

Evidence suggests stigma constitutes a stressor in its own right (Cruwys & Gunaseelan, 2016) and can compound existing mental health difficulties and reduce likelihood of recovery

LITERATURE REVIEW

(Rusch et al., 2014; Pascoe & Smart Richman, 2009; Yanos et al., 2010). The significant level of stigma towards people labelled as “mentally ill” has long been recognised (Goodyear & Parish, 1978) and BPD has been found to prompt a higher level of stigma than other psychiatric diagnoses (Knaak et al., 2015).

Stigma and BPD

For over 30 years, research has repeatedly demonstrated the negative attitudes held by mental health professionals at all levels towards people labelled with a BPD diagnosis. Furthermore, it appears stigma related to BPD may be higher inside mental health services than in general society (Bonnington & Rose, 2014).

There have been several reviews of the literature regarding stigma towards those diagnosed with BPD (e.g., Aviram et al, 2006; Sheehan et al, 2016; Nehls, 1998; Sansone & Sansone, 2013; Ocskova et al., 2017). Studies often find less empathy towards individuals with BPD from nurses (e.g., Fraser & Gallop, 1993; Black et al, 2011; Bodner et al, 2015) and psychiatrists (e.g., Bodner et al, 2015). However, research has found negative attitudes and feelings towards those with a BPD diagnosis across all professional groups in mental health services. For example, Brody and Farber (1996) found clinical psychologists self-reported higher levels of anger and irritation towards individuals with a BPD diagnosis, compared to those diagnosed with depression or schizophrenia. Deans and Meocevic (2006) found nurses had negative emotional reactions, also including anger, towards individuals with BPD and perceived them as “manipulative”.

Nurses in Woollaston and Hixenbaugh’s (2008) research also experienced people with BPD negatively; one describing them as “destructive whirlwind” (p.703). Nurses appeared to be

LITERATURE REVIEW

less helpful to individuals with a BPD diagnosis, compared with those diagnosed with major depressive disorder (Forsyth, 2007).

The experiences of people with a diagnosis of BPD seem to mirror these findings. An Australian study found participants with a BPD diagnosis had experienced significant discrimination and barriers when attempting to get needs met in public and private health services; with A&E departments posing a particular challenge, when individuals are attending in crisis (Lawn & McMahon, 2015). Similarly, Veysey (2014) found service users' perceptions of the stigmatising attitudes they were subject to were consistent with findings from numerous studies looking at clinicians' attitudes towards people with a diagnosis of BPD.

Day et al. (2018) conducted a 15-year longitudinal study in Australia examining the attitudes of mental health professionals over time, finding that attitudes had improved. Despite this, however, studies continue to find stigmatising attitudes amongst mental health professionals towards the diagnosis of BPD.

BPD and Self-stigma

Winter, Koplun and Liz (2015) found that individuals with a BPD diagnosis expect and perceive more social rejection than the general population. Indeed, although there has been little research regarding stigma from the public towards people with a BPD diagnosis, Bonnington and Rose (2014) point out that the general public having an unawareness of the BPD diagnosis does not mean that those with the diagnosis are invisible. For instance, self-harm can render "mental illness" visible in social interactions, which may increase the exposure of these individuals to stigma (Schulze et al., 2010).

LITERATURE REVIEW

Women with a BPD diagnosis showed higher levels of self-stigma than those with other diagnoses (Grambal et al., 2016). Self-stigma occurs when individuals accept negative societal attitudes and internalise these as part of their self-concepts (Corrigan & Calabrese, 2005; Livingston & Boyd, 2010). Corrigan et al (2011) expanded on this definition, regarding self-stigma as occurring in four stages: 1) a person is aware of societal labels; 2) they agree with those labels; 3) they apply those labels to themselves; and 4) they subsequently suffer a decrease in their self-esteem.

Aviram et al. (2006) observed that repeated hospitalisation of individuals with a BPD diagnosis increases their contact with stigmatising personnel, potentially contributing to the internalisation of stigma. This view was supported by Veysey (2014) who found experiences of discrimination from healthcare professionals contributed to participants' negative self-image and that levels of self-harm seemed related to increased numbers of discriminatory experiences.

Rusch et al. (2006) found self-stigma was inversely related to self-esteem, self-efficacy and quality of life, and that self-stigma predicted low self-esteem even when controlling for the effects of depression and shame-proneness. Grambal et al. (2016) also found self-stigma to negatively affect self-esteem in those diagnosed with BPD. In addition, they found negative effects on levels of hope, leading to poorer recovery rates. These negative effects of self-stigma, such as diminished self-esteem, can persist even after "psychiatric symptoms" have gone (Link et al., 1997).

What causes stigma towards BPD?

Having established the existence of these stigmatising attitudes about those with a BPD diagnosis an important question is: why? There appear to be two main stereotypes at play: the

LITERATURE REVIEW

perception that people with BPD have “self-control” (Lewis & Appleby, 1998) and the perception that those with this label are “difficult to treat” (e.g., James & Cowman, 2007; Cleary et al., 2002).

One of the earlier studies by Gallop et al. (1989) looked at the attitudes of nurses towards hypothetical patients with a diagnosis of BPD compared to those with a diagnosis of schizophrenia. They found nurses were more likely to remain sympathetic towards those diagnosed with schizophrenia and to make belittling responses towards patients with a diagnosis of BPD. The authors believed that nurses found it acceptable to derogate people with a BPD diagnosis and hypothesised it constituted a defensive response for nurses in reaction to their feelings of helplessness, anger, and frustration in relation to pessimism around treatment outcomes of individuals with this diagnosis. This explanation alone, however, does not account for the elevated levels of stigma when compared to schizophrenia; also considered a chronic condition, which could be expected to provoke feelings of pessimism. Consequently, the authors also hypothesised that the nurses’ reactions were due to a perception that people with a BPD diagnosis were deliberately manipulative in their behaviour, and therefore were “bad” not “mad”.

Markham and Trower (2003) found mental health nurses in the UK felt individuals with a diagnosis of BPD had more control over their challenging behaviour than those diagnosed with schizophrenia or depression. The authors linked this with the nurses’ more negative attitudes and reduced levels of sympathy towards those diagnosed with BPD in comparison with the other diagnoses.

Seeing individuals with this diagnosis as “in control” of their behaviour can lead to them being regarded as “manipulative” (Woollaston & Hixenbaugh, 2008), a common negative stereotype about people labelled with BPD. Kyratsous and Sanati (2017) argue that attributing

LITERATURE REVIEW

responsibility for actions to those diagnosed with BPD constitutes an act of epistemic injustice, which occurs when a person's credibility is questioned based on the hearer's prejudice (Fricker, 2009).

A consequence of questioning the credibility of those with a BPD diagnosis, believing them to be "manipulative", is that they become passively or actively denied treatment; an occurrence reported as common by Sulzer (2015). This attribution of control, Sulzer argues, is "de facto demedicalisation" of the BPD label; meaning individuals given this diagnosis, while still subject to the "mental illness" identity and associated stigma, are simultaneously denied treatment, due to the perception of them being "bad" not "mad" (King, 2014). This finding was echoed in Bonnington and Rose's (2014) study where participants reported feeling unjustly normalised by others.

Attributions of control are inversely related to sympathy (Weiner, 1985), which may account for the less sympathetic responses to those with the BPD diagnosis. Overall, this stereotype leads to the perception that the diagnosis of BPD does not represent an "illness" but is simply a label for someone who is "bad" (King, 2014). Davis (2009) argues that, typically, a psychiatric diagnosis reduces stigma by invoking the "sick role", however notes that those believed to be "difficult patients" do not receive this benefit. Indeed, Markham and Trower (2003) argue, the stereotype of being "bad" not "mad" gives the impression that these individuals are unsuitable for medical or therapeutic treatment.

Nehls (1998) observed that the terms often used to describe those with a BPD label reflect the lack of empathy towards them, signalling the potential for "misdirected" treatment. Research has found that service users labelled as "difficult" often have a personality disorder diagnosis (e.g., Colyson et al., 1986a; Colyson et al., 1986b). Other studies have found those

LITERATURE REVIEW

with a BPD diagnosis are perceived as more difficult than people with other diagnoses; to manage (Newton-Howes et al., 2008), to care for (James & Cowman, 2007), and to deal with (Cleary et al., 2002).

One explanation for the perception that those with a BPD diagnosis are difficult to treat and care for lies in a strongly perpetuated myth of untreatability, which still exists (Bateman & Fonagy, 2009) despite evidence to counter this myth. For example, Newton-Howes (2015) asserts that “over the course of six years, three-quarters of all patients with a diagnosis of BPD will attain remission with low recurrence, making it a diagnosis more prevalent prior to middle age” (p.36). Perceptions of “untreatability”, lead to those with the BPD diagnosis being “routed out” of care (Sulzer, 2015; p.82), with professionals often not acting in their best interests (Krawitz & Ratchelor, 2006).

Poor prognosis has been shown to increase levels of stigma towards mental health diagnoses (Goldin, 1990). King (2014) linked stigma towards BPD to the concept of “therapeutic pessimism”, which Jackson (2004) defines as the tendency of professionals to anticipate negative treatment outcomes, perceiving recovery as unlikely. The relationship between pessimism about recovery and negative stigmatising attitudes is supported by numerous studies. For example, Filer (2005) found nurses felt unable to help those with a BPD label, leading to feelings of frustration, resulting in poorer care. Similarly, Markham (2003) looked at attitudes of nurses and health care assistants towards people diagnosed with BPD, compared with the diagnoses of schizophrenia and depression. Both professions felt least optimistic about individuals with a diagnosis of BPD.

Lower levels of optimism for recovery have repeatedly been linked to increased desire for social distance from individuals diagnosed with BPD (e.g., Westwood & Baker, 2010;

LITERATURE REVIEW

Servais & Saunders, 2007), which is a typical behaviour towards stigmatised people (Goffman, 1963). Hinshelwood (1999) explained this pattern between clinicians and those with the BPD label as clinicians “retreating emotionally” under the guise of a “scientific attitude” (p.187). This is an understandable human reaction towards individuals that leave one feeling frustrated, inadequate, and challenged (Commons Treloar, 2009), however, as a reaction from a professional towards a service user, it creates a barrier to providing effective support. It also has a negative impact on clinicians’ sense of purpose (Chartonas et al., 2017), their satisfaction in their therapeutic role (Bourke & Grever, 2010), and increases their anxiety when working with clients diagnosed with BPD (Jobst et al., 2010).

Linehan (1993) stated that for positive change to occur, optimism for change is an important staff response towards those labelled with BPD. King (2014) discussed the idea that professionals can struggle to implement core conditions of empathy, congruence, and unconditional positive regard in therapeutic interactions with individuals with a BPD diagnosis. Often the blame for this is located with the clients (e.g., Deans & Meocevic, 2006) arguing that the challenging behaviour is to blame. Similarly, Bodner et al. (2011) found low empathy levels across professional groups towards individuals diagnosed with BPD; nurses scored lowest, which the authors hypothesised was attributable to their prolonged exposure to challenging service users’ behaviour, particularly in inpatient settings, as compared to other professional groups.

Aviram et al., (2006) point out that individuals diagnosed with personality disorders have difficulties that are often triggered by and experienced during interpersonal situations, which is why working with them can be experienced as hard. It has been observed that the negative reactions of professionals towards those whose behaviour challenges them can lead to further behaviour that challenges, in turn exacerbating the social rejection (Scheff, 1966).

LITERATURE REVIEW

Clinician and client expectations influence the actual outcomes of therapeutic interventions (Meyer et al., 2002). For individuals with a diagnosis of BPD this represents a serious concern, as the negative stereotypes prime clinicians to react to them negatively, and their own self-stigma leads them to anticipate those negative reactions; therefore, clinicians are primed to experience the client's behaviour as challenging and the client themselves may be primed to produce the kind of behaviour the stereotypes predict; resulting in clinicians retreating emotionally. Aviram et al. (2006) comment that this is especially unfortunate in this group of service users, given their sensitivity to and history of rejection, because in these cases, the stigmatisation related to the BPD diagnosis can independently contribute to negative outcomes.

Hinshelwood (1999) believed this process, which blinds clinicians to the subjective experiences of the service user, to be a deliberate but unconscious interference from the service user through the psychodynamic process of countertransference. Transference is an unconscious process where a person relocates their own experience and emotions onto another person. Countertransference is how a person responds in relation to transferred feelings and explains how one person has influence over another (Arundale & Bellman, 2010). Theories of transference and countertransference are important for understanding barriers to therapeutic optimism (Evans, 2007). Negative staff countertransference reactions are also associated with lower empathy (Liebman & Brunette, 2013). It is important, therefore, for clinicians to attend to the transference and countertransference as inattention can lead to blame for their negative reaction being attributed to the client (King, 2014).

Despite issues around transference and countertransference processes, which undoubtedly compound the stigma and prejudiced reactions experienced by individuals with a BPD diagnosis, it seems obvious, given the large research base, that the label of BPD itself brings stigma into the

LITERATURE REVIEW

dynamic before any “difficult” behaviour is displayed, or any emotional withdrawal by the clinician occurs. Link et al. (1987) argue that it is an interaction between the behaviour of individuals with a BPD diagnosis and the label itself that leads to prejudiced attitudes. Labelling can and does lead to stigmatisation and misunderstanding (Corrigan & Watson, 2002). With regards to the BPD label, there has been longstanding doubt cast on its validity as a psychiatric diagnosis (e.g., Bonnington & Rose, 2014) and issues raised about its unhelpfulness, particularly with regards to the level of stigma attached (Nehls, 1998). Some have called for it to be “abandoned altogether” (Herman, 1992, p.123).

Some relatively recent studies have demonstrated that the BPD label in and of itself, separate from the behaviour it represents, increases negative attitudes, including those of difficulty to treat (Lam & Poplavskaya, 2016; Lam et al., 2016). Lam and Poplavskaya (2016) found the act of labelling the client with BPD was associated with a negative impact on clinicians’ perceptions regarding optimism about the client’s treatment outcomes. This finding was not found in the ‘no label’ condition, where the background information contained descriptions of behaviours and characteristics consistent with the diagnostic criteria of BPD, but without the label itself. Lam et al. (2016), using the same data set, found more negative impressions of the client and more pessimistic views about the treatment of the presenting issues (panic disorder) in the ‘label’ condition. They also found the client was perceived as being significantly less likely to be curable, to comply with homework, to be motivated to change, or to have improved interpersonal relationships after having completed treatment. The client was also expected to respond less well to cognitive behavioural therapy (CBT) than in the ‘no label’ and control conditions. These findings strongly suggest that it is the label of BPD, rather than its associated characteristics, which led to the more negative views of the clinicians. For a

LITERATURE REVIEW

diagnostic label itself to create prejudiced views in mental health clinicians from a range of professional backgrounds, which may then bias their interaction from the start, must surely lead to serious concerns about the use of such a label.

Reducing stigma towards BPD

There have been many suggestions for ways to reduce or remove the stigma around the diagnosis of BPD. Warne and McAndrews (2005) recommended clinical supervision focused on addressing emotional reactions and negative attitudes to prevent “ethical distress” and burnout in staff. Numerous studies also recommended clinical supervision in combination with training for staff around BPD (e.g., Evans, 2007; Markham, 2003; Weight & Kendal, 2013; Eren & Sahin, 2016; Ocskova et al., 2017). In these studies, clinical supervision was suggested for managing the negative countertransference. Some studies explored using neurobiological explanations for the development of difficulties associated with the BPD diagnosis. However, although Clark et al. (2015) found this approach was associated with a change in knowledge and attitudes, they did not find a change in empathy in staff members towards those diagnosed with personality disorders. Lebowitz and Ahn (2012) found that combining neurobiological with recovery-oriented information was more effective for reducing stigma than either approach independently.

Hearing personal narratives of individuals diagnosed with BPD has also been found to help reduce stigma (Fielding, 2013). However, although Knaak et al. (2015) found stigma towards individuals with a BPD diagnosis reduced following a combination of education, skills training and social contact, levels of stigma towards the BPD diagnosis were still higher than the baseline scores for more general “mental health” conditions. It is also unclear in all these studies whether the detected attitude changes would translate to behaviour change.

LITERATURE REVIEW

Although all these suggestions appear to be beneficial for improving services offered to those receiving a BPD diagnosis and may have some effect in reducing stigma towards them, I believe something more radical is required to address the continued widespread stigma around this diagnosis. Ferguson (2016) commented that approaches such as reclassifying BPD as “complex trauma”, although they do allow for stigma resulting from trauma to be addressed in a way that creates opportunity for recovery and rebuilding a sense of self (Herman, 1997), despite best intentions, also collude with silencing forces that psychiatry exerts (Bracken & Thomas, 2001). For BPD, this means the diagnostic label and biomedical explanations obfuscate links to other social factors. A Division of Clinical Psychology (DCP) (2013) position paper called for a paradigm shift in how we conceptualise psychiatric diagnosis, following the publication of DSM-5 (APA, 2013). A key recommendation from that document was the development of a system that provides an alternative to the medical model, but also could perform the more utilitarian functions currently performed by psychiatric diagnosis. Psychiatric diagnoses profess to fulfil several functions including indicating aetiology, suggesting suitable interventions, predicting outcomes, aiding communication (particularly with other professionals) and providing a basis for research (DCP, 2013). They are also frequently used in medical record keeping, assessing eligibility for welfare benefits, in the justice system, and so on (Kinderman, 2019).

A new approach

An approach to address this issue might be found in the Power Threat Meaning Framework (Johnstone et al., 2018a), which developed out of the DCP position paper. This constitutes a first stage in providing a new overarching framework for conceptualising and identifying patterns in “emotional distress and troubled or troubling behaviour” (p.5) in a way

LITERATURE REVIEW

that seeks to understand people in their social and relational context; moving away from the “disease model”. The PTMF emphasises the different ways power operates in a person’s life, in both positive and negative ways; what threats these pose; what meaning a person makes of those threats; and how they respond to them.

One way power operates on people in mental health services, in relation to theories of causation and diagnosis, is that it obscures the meaning of their distress and how it links with their experiences of adversity (Read & Harper, 2020). The PTMF aims to create contexts where people have agency to develop their own meanings and personal narratives; whether it be using formulation in psychological therapy, or collectively with others in peer-led groups, or independently using the Guided Discussion produced by the PTMF authors (Cromby, 2020; Johnstone, 2020). Johnstone et al. (2018a) emphasise that people’s narratives can take whatever form feels valid for the individual, however, their “foundational pattern” is proposed as an evidence-based way of understanding how various factors have contributed to current mental health difficulties. There are also seven general patterns that describe common co-existing features within a narrative structure, which the authors claim are drawn from the existing evidence base. The pattern of “surviving rejection, entrapments, and invalidation” is seen as capturing the experiences of many of would be diagnosed with BPD. The narrative describes negative operations of power having often included prolonged interpersonal maltreatment within the context of a lack of control, dependence, and isolation, where the person felt powerless in the face of the threats, whilst often being dependent on the perpetrators for survival. The core threats are ones of rejection, invalidation, attachment loss, emotional overwhelm, powerlessness and bodily invasion amongst others. The meanings attached to these experiences often include, amongst others, ones of fear, shame, unworthiness, betrayal, and helplessness. The associated

LITERATURE REVIEW

threat responses are seen as largely reflexive attempts to protect oneself and constitute many of the “symptoms” associated with a BPD diagnosis. This pattern aims to emphasise the role of past adverse interpersonal experiences in the subsequent development of coping strategies in a protective response to the threats they were exposed to.

Read and Harper (2020) outline several key principles, which are also consistent with the ethos of the PTMF, used in effective community-based stigma reduction programs: co-production with those who are discriminated against; opportunities for increased contact where differences are valued; power differentials and negative stereotypes need to be openly addressed; and acknowledgement that educational campaigns alone are not sufficient and need to be combined with legislation which outlaws discrimination based on mental health.

In the published literature a key criticism of the PTMF is that the language in the PTMF documents makes the ideas inaccessible at times (Aherne et al., 2019). Griffiths (2019) concurred that the PTMF documents were “hard to read”, adding they were perceived by some as too clinically orientated for the lay person. Aherne et al. (2019) were also concerned that, if their organisation adapted how they communicate to be consistent with the PTMF principles, they may find it harder to publish research and to communicate with other mental health organisations who retain the more typical medicalised language when discussing mental health. They expressed their belief that to be able to fully embrace the PTMF in practice, even though it fit very well with their organisation’s approach to and perspective on mental health issues, a “major ideological change for mental health services” would be required and they had doubts whether psychiatric care and PTMF informed care would be able to integrate effectively.

Much of the criticism of the PTMF has not been published in academic journals but occurs online in blogs and on social media platforms. A blog post by Salkovskis and Edge

LITERATURE REVIEW

(2018) outlined several criticisms; chiefly they argue that, despite claiming to provide innovative and important perspectives, the core principles of the PTMF are a collection of existing ideas, with the novel aspect of the general patterns seeming to be a repackaged version of diagnostic categories. They conclude that the PTMF holds no new implications for practice. I would disagree with this conclusion. Although the individual concepts in the PTMF are not novel, attempting to assemble them into a coherent framework to offer an alternative way of understanding distress, as well as ideas about how to incorporate these ideas into service design and implementation, and wider systemic and social change can be considered novel.

The PTMF authors responded to some of the key criticisms of the framework in an article by Johnstone et al. (2019). They refute the suggestion that the general patterns are just diagnostic clusters by other names. They assert this criticism reveals a “failure to move beyond the diagnostic lens” (p.49) and claim they have discussed the fundamental differences between the general patterns and diagnostic cluster in detail in the Overview document (Johnstone et al., 2018b). Here they discuss that the general patterns cut across diagnostic categories and can be applied to those who would meet no diagnostic criteria at all. However, it must be noted that the PTMF authors do note that certain patterns do bear marked similarities to certain diagnostic clusters. They go on to explain that people are unlikely to fit neatly into a particular general pattern and most people will likely recognise aspects of their narrative in several patterns. They conclude by stating that the general patterns are expected to need amending and updating over time as more evidence emerges, but also as societal norms etc. change. It appears to me that most of the above points could also be said of psychiatric diagnoses, however, the authors do appear to hold a narrow view of how psychiatric diagnosis is perceived and used by many professionals and service users. I cannot see much to explain how the general patterns “fundamentally” differ

LITERATURE REVIEW

from diagnostic clusters, aside from the authors' perceived starting point that all psychiatric diagnosis roots mental health issues in biology first, versus the PTMF starting from the experiences that a person has had.

The authors' response to concerns that the PTMF seeks to completely replace psychiatric diagnosis (in many cases from service users who do value their diagnoses) is that the PTMF aims to further validate and support existing practices that espouse PTMF principles and ideally promote further development in this direction. They claim to advocate for service users to have the right to choose how to understand their difficulties, with the PTMF as an option running parallel, rather than only have the existing option of psychiatric diagnosis and the medicalised model of mental health care, which they regard as deeply flawed and untenable. Although they clearly hold the position that psychiatric diagnosis is an inadequate, inaccurate, and ultimately harmful way of understanding mental health difficulties, they remind readers that decisions about whether the current system requires "replacing" is not theirs to make, they are simply seeking to outline how an alternative could work in practice, which could act as a replacement in the future if the ideas within the PTMF are developed further.

Another criticism of the PTMF is that although many service users are against diagnosis, there are also those who prefer a clear and specific diagnosis that they perceive as giving them definite answers, rather than a more complex narrative. There are also those who have expressed an unwillingness to explore and or share their past experiences. These are valid concerns and are particularly relevant for people with difficulties associated with the BPD diagnosis. To force any approach would be to impose another professional model on service users; one of the very things the PTMF seeks to avoid. However, as discussed earlier, while diagnoses are portrayed as clear-cut and should, in principle, provide specific solutions to and explanations for difficulties, in

LITERATURE REVIEW

truth they are based on a system with validity and reliability issues (Johnstone et al., 2018a; Johnstone & Boyle, 2020; Kinderman, 2018), particularly with regards to diagnoses such as BPD, which have long been contested. Would people be as attached to the BPD diagnosis if they knew this to be the case? This question requires more thought and research as the PTMF continues to be developed.

The PTMF draws on several existing models that are used to different extents in mental health services, such as trauma-informed care, peer support, the recovery movement, the concept of wellbeing, person centred care, and co-production. The authors discuss numerous examples of existing services or projects that utilise combinations of these approaches in a manner consistent with many of the PTMF principles and point out that, although often still based on a medicalised understanding of mental health difficulties, many services in the UK operate without requiring psychiatric diagnoses to facilitate access (Kinderman, 2018).

In terms of recommended service design and delivery, the PTMF draws heavily on trauma-informed care (TIC), as its principles are consistent with the PTMF's conceptual framework (Johnstone et al., 2018; Read & Harper, 2020). The Blue Knot Foundation (2012) laid out comprehensive guidelines for trauma informed services. The PTMF authors argue for the application of these guidelines in all mental health services and discuss how these guidelines could work in practice. Some of the guidelines are particularly relevant to service organisation and clinical practice for those who would meet the current criteria for a BPD diagnosis. At service level, the guidelines describe “five foundational principles of TIC: safety, trustworthiness, choice, collaboration, and empowerment” (Fallot & Harris, 2009); emphasising the need to commit to systems being service user driven. They offer many suggestions for how these principles can be translated to practice, but two key suggestions are shifting from

LITERATURE REVIEW

“caretaking” to a “collaborative” way of working, and to shift from an illness or symptom-based model to a strengths-based model focused on skill acquisition. Echoed in the PTMF, they recommend asking “what has happened to you?”, rather than “what is wrong with you?”

Repeatedly mentioned is the importance of service users’ voices being heard, with them and their views being in service design and implementation. Regarding clinical practice, the importance of recognising affect-regulation as foundational to all interventions and fostering this ability in service users; as well as understanding that, for some individuals, interventions will support acquisition rather than restoration of some modes of functioning (e.g., attachment difficulties related to childhood adversity). The guidelines also emphasise the need for professionals to be attuned to attachments issues, and to engage in regular professional supervision to support navigation of transference-countertransference dynamics, which can represent hazards for both service users and therapists if not attended to. Finally, the guidelines recognise the importance of boundaries and continuity of care, observing that these are particularly important for those with histories of adversity and trauma, which is in line with recent recommendations by the Royal College of Psychiatrists (RCPsych, 2020). Despite being largely consistent with the PTMF’s principles, the authors suggest it would be most helpful to broaden the range of adversities included in the trauma-informed model, as the term “trauma” can imply discrete events, which many service users do not identify as related to their mental health difficulties, whereas most would acknowledge having experienced adversities (Read & Harper, 2020).

Ferguson (2016) argued that a trauma-informed approach (TIA) to services could be seen as best practice for all who encounter human services and judicial and statutory organisations, viewing TIAs as a political stance highlighting problems in society, such as violence against women and children, rather than allowing it to be obscured under diagnostic labels such as BPD.

LITERATURE REVIEW

The NHS in the UK has stressed the need for trauma-informed services to make explicit links between trauma and mental health following its strategic direction for working with victims of sexual abuse (NHS England, 2018). In a similar vein, the authors of the PTMF consistently emphasise these ideas need to be applied in a non-pathologising way, with a continuous focus on the wider social factors that are impacting the individual and the community within which the service is located. However, Johnstone et al. (2018a) also note that trauma-informed approaches as they currently exist can often retain diagnostic categories, medicalised language, and associated ways of conceptualising distress, which they feel risks reducing the experience of adversities to “triggers”. They caution that the term “trauma” can be used as a concept in a similar way to which the BPD diagnosis operates: a label creating distance between cause and effect. The authors believe these issues can be minimised by viewing TIC from a PTMF perspective.

Sweeney et al. (2016) state the potential benefits for service users of TIC include hope, empowerment, and support that is not retraumatising. The authors conducted a review of the available evidence on the effectiveness of trauma-informed approaches, finding benefits including a reduction in use of seclusion (Azeem et al., 2011), reduced general mental health symptoms (Greenwald et al., 2012), reduced post-traumatic stress symptoms and increased coping skills (Gatz et al., 2007), and improved physical health (Weissbecker & Clark, 2007). Other studies have shown that interventions based on trauma-informed principles are effective in reducing low mood, self-harm, suicidality, and trauma reactions (Briere & Scott, 2013; Courtois & Ford, 2015). Lau and Kristensen (2007) also found that group therapy based on trauma-informed principles reduced low mood and suicidality. Furthermore, the group approach seemed to be especially effective in reducing shame, blame, and isolation. Araci and Clarke (2017) found

LITERATURE REVIEW

that embedding trauma-informed formulation in both inpatient and community services led to significant reductions in service user distress ratings and increases in self-management skills.

Sweeney and Taggart (2018) argue: “the rates of trauma and abuse experienced by people who go on to use mental health services are worthy of attention at a service development level”(p.383). They also discuss that an awareness of iatrogenic harm that exists in psychiatric systems is another driver behind the development of trauma-informed services. Bloom (2006) described “parallel processes” where the complex interaction between service users, practitioners and organisations can come to mirror one another; potentially causing traumatisation and preventing recovery. Bloom argues that parallel processes mean trauma un-informed organisations, as well as being toxic for service users, are also toxic for staff, many of whom also have trauma histories of their own. Bloom observes that when service users feel unsafe in trauma un-informed systems, they may become aggressive, which can make staff also feel unsafe, who then respond with authoritarian measures. The consequent lack of control can further increase service users’ feelings of unsafety, increasing their fear and associated defensive behaviours such as aggression, continuing the iatrogenic cycle. I think this echoes the transference, countertransference process discussed previously with regards to service users with BPD, suggesting that a trauma-informed environment would reduce the levels of defensive behaviour expressed by the service users, due to them feeling less threatened, which would result in less emotional withdrawal and social distancing by staff, allowing for a more effective therapeutic relationship and better outcomes.

The goal of this type of service design is to reduce stigma and prevent, as far as possible, retraumatising experiences within services by creating safe and validating environments for service users. All goals which would benefit individuals seeking support who may typically be

LITERATURE REVIEW

given a BPD diagnosis currently; meaning TIC as a model could significantly improve outcomes for these individuals. Particularly the idea of having more integrated services, preventing the exclusion from services based on a particular diagnosis, as often happens with BPD (Kinderman, 2019). Also, given the evidence that childhood adversity is a key factor in the development of difficulties that are diagnosed as BPD currently (Public Health Wales, 2016), understanding the impact of trauma at the heart of services and interventions may be extremely beneficial to those individuals in particular, whose histories of adversity are often obscured or dismissed because of the stigma associated with their diagnosis.

The PTMF stresses the need to place a greater emphasis on incorporating a social inequalities perspective within therapy (Smail, 2001). The authors note several existing therapeutic approaches which do this, such as narrative approaches (White & Epston, 1990), feminist therapy (Watson & Williams, 1992), and approaches informed by community psychology's core values of liberation, empowerment, and social justice (McClelland, 2013) such as Power-mapping (Hagan & Smail, 1997a; 1997b). There have also been efforts to embed these perspectives within therapeutic models such as, CBT (Hays & Gayle, 2006) and cognitive analytic therapy (Brown, 2010), which evidence suggests is a helpful approach for those diagnosed with BPD. If it is possible to incorporate this perspective within these approaches, it should also be feasible in other therapies shown to be effective in addressing difficulties associated with a BPD diagnosis (e.g., dialectical behaviour therapy and mentalisation-based therapy).

The PTMF authors recommend that everyone who comes into mental health services begins with developing a shared narrative or formulation based on PTMF principles, then interventions are offered broadly structured around the three-stage trauma model (e.g., Courtois

LITERATURE REVIEW

& Ford, 2015) (Safety/Stabilisation, Processing, and Integration). Psychological formulation is also heavily emphasised in the recent RCPsych position paper (2020), regarding best practice for treating individuals diagnosed with personality disorders. At stage one, the authors propose interventions regarding education and stabilisation are offered to all, alongside more practical support such as financial support and consideration to social circumstances. At stage two, “in-depth” interventions such as group or individual psychotherapy would be offered, including trauma specific work if appropriate. Stage three would focus on reconnecting with life and relationships, as in the Integration stage of the original model. The PTMF authors propose that all staff would be trained to use stage one and three interventions. They assert that they would like to see this service model as less of a pathway and more a “menu” of options, where each service user selects from a range of “starters”, with most going on to make a further choice of the more in-depth “main courses”, which they argue has already been implemented in a service (e.g., Clarke, 2015). In addition to this, the authors advocate for emphasis on individual therapy (“top-down”, expert-driven) as the preferred mode of intervention to be balanced with encouraging more “bottom-up” approaches such as self-help and peer-support groups.

For outcome measures, the PTMF authors call for a shift from measuring symptom reduction to a more holistic approach that considers overall wellbeing, recovery, personal goals, social functioning, and quality of life; focusing more on concepts of social functioning, general well-being, and quality of life; for example, the World Health Organization Quality of Life Instruments (Skevington et al., 2004) and the WHO Disability Assessment Schedule (WHO, 2016).

Several articles have described different applications of the PTMF in practice. Two of these relate to the experiences of peer support groups who had collectively discussed the ideas

LITERATURE REVIEW

and principles within the PTMF and used the Foundational Pattern to structure and share their own narratives. SHIFT Recovery Community (2020) expressed that they felt the PTMF “has the potential to instil hope within the mental health system and to reduce stigma and negative judgements by offering the opportunity to build healthier relationships between professionals and people seeking help, leading to a better experience for all” (p.9). Commenting on their use of the Foundation Pattern, they felt it had the potential to start the process of healing by “recognising, validating and legitimising a person’s experiences” (p.3), which combats feelings of isolation and instils hope for recovery. They attribute this to the PTMF’s perspective on mental health difficulties as “normal human responses to abnormal situations” (p.3), which they felt was different to messages they have received in the past, which had led them to believe that something was wrong with them: that they were “disordered”. Significantly, they found it validating that this new perspective was coming from a “professional group”. Griffiths (2019) wrote about the experiences of the York Mental Health Peer Support Group in considering the PTMF and using the Foundation Pattern to create personal narratives. Griffiths commented that the group found the framework to be applicable to many forms of adversity, such as stigma and unemployment, even when there was no history of overt trauma. She notes that group members were able to use the supportive peer-led environment to develop their narratives, guided by the PTMF’s Foundational Pattern, without requiring clinical intervention from mental health professionals. Like SHIFT Recovery Community, Griffiths reports the group welcomed the description of behaviours and strategies, traditionally referred to as symptoms, as normal human responses to challenging events or circumstances. She reflects that this shift in perspective highlighted to group members the way statutory services can currently disempower service users by failing to validate and understand the impact of damaging life experiences, seeing the PTMF

LITERATURE REVIEW

perspective as a remedy to this. Griffiths described that the sharing of narratives within the group, utilising the PTMF, provided a powerful way of connecting to others who have similar experiences and having an opportunity to be heard and validated. She argued this led to a sense of connection to a community as opposed to isolation and stigma and that the focus on adversity seemed to offer group members hope that the negative legacies of adversity can be overcome.

These examples highlight the destigmatising effect of developing personal narratives which validate people's responses to adversity as normal and understandable, rather than a symptom of an "illness". They also demonstrate the value of sharing narratives with others and the sense of validation and connection that comes from feeling understood and heard. These experiences appear to have introduced a sense of hope to the peer support groups, linked to them feeling less alone and stigmatised with their current difficulties.

Although the PTMF offers a radical alternative, which certainly cannot be implemented wholesale without major changes to service structures and how mental health services and other systems conceptualise mental health difficulties, there are ways that it is possible to begin to implement the ideas and values of the PTMF right now. For example, ICD-11 (currently in draft form) contains several phenomenological and contextual codes. The DSM-5, which generally mirrors the ICD system also has some descriptive and contextual codes. Phenomenological codes are descriptive, representing discrete presenting issues (e.g., MB24.5 Depressed mood, MB23.E Non-suicidal self-injury, or MB26.9 Suspiciousness), while contextual codes can offer additional information about the contextual circumstances within which the presenting issues occur (e.g., PJ21 Sexual Maltreatment, QD50 Poverty or QD82 Problem associated with threat of job loss). Kinderman (2019) argues that these codes, if utilised more routinely, could be used within the current classification systems, to offer information about people's mental health difficulties in a

LITERATURE REVIEW

manner consistent with the PTMF values, without using psychiatric diagnoses. Kinderman (2019) goes further, arguing that routinely recording the additional contextual information would help, not only provide a more holistic understanding of people's difficulties, but also provide valuable epidemiological data, demonstrating links between social circumstances and mental health issues, increasing the pressure that can be brought to bear on governments to address these issues, driving social change.

Conclusion and Future Directions

It is evident from years of research that there are significant levels of stigma attached to psychiatric diagnoses, and that this is especially pronounced in the case of BPD. For people with a diagnosis of BPD, this stigma has a significant effect on how their behaviours are framed and, consequently, how they are perceived by others, particularly clinicians. In turn, this affects access to services, effectiveness of interventions and therefore recovery rates. In fact, the treatment they receive from services may cause added harm because of negative attitudes.

To fully address the stigma associated with the BPD label, a shift away from psychiatric diagnosis and the medical model of understanding 'mental illness' altogether is required. The PTMF offers a framework to an alternative understanding of mental health difficulties that achieves this. Although there is a long way to go before this approach could constitute a mainstream alternative to the medical model in mental health, if this is indeed desired, there are still many existing approaches that can be promoted and enhanced using the PTMF perspective, which would help provide non-stigmatising, inclusive, and effective treatment for those currently attracting the diagnosis of BPD.

LITERATURE REVIEW

Clinical recommendations

I suggest the trauma-informed care approach with the added PTMF emphasis on social context is an excellent and evidence based starting point for creating services that will reduce stigmatising attitudes of staff and experiences of service users. The incorporation of codes from ICD as a method of record keeping that fits with a non-pathologising PTMF perspective, whilst also using the existing diagnostic structures, appears to be an elegant solution to keeping social causes central to our understanding and helping collect important data which can fuel both future research and efforts to promote significant social change which will ultimately have a greater benefit than individual interventions. It also opens up possibilities for created collaborative ways forward with those who still value the current mainstream approach.

I also recommend that the PTMF or the underpinning ideas and theories it is based on be more significantly addressed in professional training in the various mental health professions, with more joint training of different professional groups. Clinical psychologists are well placed to support with this process, given the emphasis on psychological formulations that include social and contextual factors and can integrate multiple perspectives. It is also important, however, to ensure training for clinical psychologists has an enhanced focus critical analysis in order to consider theories, approaches, and practices in the context of wider issues (e.g., societal and political) with an understanding of the operations of power, including those within our own profession and how these affect people's mental health and the support they receive.

Future research

LITERATURE REVIEW

Several recommendations for future research follow from the discussions in this paper. Firstly, it would also be useful to conduct large scale surveys of mental health professionals and service users regarding their views on redesigning services and other systems to provide alternatives to psychiatric diagnosis and a medicalised understanding of difficulties currently labelled as BPD as part of mainstream choices available to service users. This would help to establish whether the kinds of approaches discussed above are desired by those who use and deliver these services and may help provide further impetus to implement the system wide changes that would be necessary for a real impact to be felt in mental health services and society more broadly.

Secondly, I would suggest further research into the specific relationship between trauma-informed approaches and levels of stigma towards individuals who meet the criteria for the diagnosis of BPD. Finally, I would also recommend further research into the experiences of different services who have attempted to integrate PTMF ideas into their practice, including quantitative studies on how this has affected key outcomes.

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Tables

Table I DSM-5 Diagnostic Criteria for BPD (APA, 2013)

Borderline Personality Disorder
DSM-5 Diagnostic Criteria 301.83 (F60.3)
<p>A pervasive pattern of instability of interpersonal relationships, self-image, and affects, and marked impulsivity, beginning by early adulthood and present in a variety of contexts, as indicated by five (or more) of the following:</p> <ol style="list-style-type: none"> 1. Frantic efforts to avoid real or imagined abandonment. (Note: Do not include suicidal or self-mutilating behaviour covered in Criterion 5.) 2. A pattern of unstable and intense interpersonal relationships characterised by alternating between extremes of idealisation and devaluation. 3. Identity disturbance: markedly and persistently unstable self-image or sense of self. 4. Impulsivity in at least two areas that are potentially self-damaging (e.g., spending, sex, substance abuse, reckless driving, binge eating). (Note: Do not include suicidal or self-mutilating behaviour covered in Criterion 5.) 5. Recurrent suicidal behaviour, gestures, or threats, or self-mutilating behaviour. 6. Affective instability due to a marked reactivity of mood (e.g., intense episodic dysphoria, irritability, or anxiety usually lasting a few hours and only rarely more than a few days). 7. Chronic feelings of emptiness. 8. Inappropriate, intense anger or difficulty controlling anger (e.g., frequent displays of temper, constant anger, recurrent physical fights). 9. Transient, stress-related paranoid ideation or severe dissociative symptoms.

Table II ICD-10 Diagnostic Criteria for EUPD Borderline Type (WHO, 2010)

Emotionally Unstable Personality Disorder, Borderline Type
ICD-10 Diagnostic Criteria
<p>A personality disorder in which there is a marked tendency to act impulsively without consideration of the consequences, together with affective instability. The ability to plan ahead may be minimal, and outburst of intense anger may often lead to violence or “behavioural explosions”; these are easily precipitated when impulsive acts are criticised or thwarted by others.</p> <p style="text-align: center;">Borderline type:</p> <p>Several of the characteristics of emotional instability are present; in addition, the patient’s own self-image, aims, and internal preferences (including sexual) are often unclear or disturbed. There are usually chronic feelings of emptiness. A liability to become involved in intense and unstable relationships may cause repeated emotional crises and may be associated with excessive efforts to avoid abandonment and a series of suicidal threats or acts of self-harm (although these may occur without obvious precipitants).</p>

Appendix A

Search Strategy for Narrative Literature Review

Databases searched:

PsycINFO

PsycArticles

Web of Science

Examples of search terms used:

BORDERLINE PERSONALITY DISORDER

EMOTIONALLY UNSTABLE PERSONALITY DISORDER

STIGMA

PREJUDICE

DISCRIMINATION

1. Results from the searches from the different databases were pooled.
2. Duplicates were removed.
3. Remaining search results' abstracts scanned to identify relevant articles.
4. Key articles' and relevant literature reviews' reference sections searched for further relevant articles.

Related topics such as PTMF or TIC were searched for separately, with more targeted searches.

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Appendix B Social Science and Medicine notes to authors

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Chapter 2 Research paper



A qualitative study of the experiences of moving on from a non-residential Democratic
Therapeutic Community

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Abstract

Purpose: The aim of this study was to understand the medium-term factors that helped or hindered the maintenance and continuation of positive change after the end of day Democratic Therapeutic Community (DTC) treatment. It examined the experiences of individuals who had completed day DTC programmes and the subsequent follow-on group between six months to two years prior to taking part in the research, who felt they had an overall beneficial experience in the DTC.

Design: A qualitative design using interpretative phenomenological analysis (IPA) analysis was used. Six participants completed one-to-one semi-structured interviews. Following analysis, a final set of superordinate themes emerged, with relevant illustrative quotes selected.

Findings: Four themes were developed representing the factors that helped and or hindered participants' efforts to maintain positive changes made during the DTCs: An Atmosphere of Belonging, Hope versus Struggle, Support, and Empowerment though Understanding.

Originality: This study is the first to explore the experiences of individuals following discharge from non-residential day DTCs.

Keywords: *Democratic Therapeutic Community, Belonging, Hope, Support, Mental Health*

RESEARCH PAPER

Democratic therapeutic communities (DTCs) place service user empowerment as central. This becomes a radically different approach when involvement extends beyond the increasingly common practice of involving service users in processes like staff recruitment, to managing the processes of the therapeutic group and having direct input in one another's therapy (Pearce & Haigh, 2017). DTC treatment aims to help people with emotional and interpersonal problems; structured around a set of values and beliefs about how people should treat each other. These include self-awareness, interdependence, mutual respect, and an assumption of personal responsibility (Oxford Health NHS Foundation Trust, 2020).

In the National Health Service (NHS) DTCs most commonly provide support for individuals with severe and enduring complex interpersonal, emotional, and behavioural problems; often referred to as personality disorders (PDs). DTCs have been developed for other populations, including individuals with acute and long-term psychoses (Kennard, 2004), learning disabilities (Taylor et al., 2015), and in prison settings (e.g., Cullen et al., 1997).

Therapeutic communities fall into two broad categories: concept and democratic (Lees et al., 1999). Concept TCs were developed to treat addictions and differ from DTCs in having a hierarchy within the community, with staff and more experienced members having more authority (Vandeveldt et al., 2004), as opposed to the flattened hierarchy in DTCs (Campling, 2001).

A long-standing body of research suggests that TCs are an effective treatment for individuals with difficulties associated with a PD diagnosis (e.g., Lees et al., 1999; Veale et al., 2014). For example, Capone et al. (2016) found improved interpersonal outcomes following DTC treatment for individuals diagnosed with a PD in forensic and residential settings, but mixed results in non-residential DTC settings. As in other systematic reviews,

RESEARCH PAPER

however, conclusions were tentative due to continued issues regarding methodological quality of the studies included.

Pearce et al. (2017) conducted a randomised controlled trial (RCT) finding significant improvements in levels of self-harm, aggression, and satisfaction with the care team in the DTC condition. However, they concluded a longer follow-up period was necessary to robustly demonstrate effectiveness of day DTC treatment, therefore, are currently conducting a five-year follow-up RCT, which may build on current findings.

One of few studies of non-forensic DTC settings with follow-up measures was a mixed methods study by McFetridge and Coakes (2010) exploring longer-term outcomes of a DBT-informed residential TC. Finding significant reductions on the CORE-OM. Qualitative findings indicated three major themes relating to change for the participants: changes in sense of identity, life, and thinking.

Chiesa et al. (2004) included follow-up measures comparing three TC-based treatment programmes for individuals diagnosed with a PD: inpatient, inpatient plus step-down, and community. By 24 months, participants in the step-down condition (closest to day DTCs) demonstrated significant improvements on all measures; superior to other conditions.

In 2003, TCs were recommended in the policy guidance: *Personality Disorder: No Longer a Diagnosis of Exclusion* (National Institute for Mental Health in England). Despite not being included in the National Institute for Health and Care Excellence (NICE) guidelines for the treatment of individuals with a PD diagnosis this led to the setup of several non-residential DTCs meeting between one to five days a week (Pearce & Haigh, 2008), which will be referred to for the remainder of this paper as “day DTCs”.

DTCs follow four key principles developed from the anthropological study of Henderson Hospital by Rapoport (1960), which describes core elements that create the TC environment: democratisation, communalism, permissiveness, and reality confrontation.

RESEARCH PAPER

More recently, Haigh (1999, 2013) identified five qualities that create a DTC: attachment (describing a culture of belonging), containment, open communication, involvement and inclusion (referring to a culture of participation and citizenship), and agency (describing a culture of empowerment). Haigh argues 'good enough' experiences of these principles is required for healthy emotional development and sense of self in relation to others, therefore TCs provide a 'secondary emotional development' to alter profound and deeply held thoughts, feelings, behaviours, attitudes, and expectations that contribute to the group members' pre-existing difficulties.

Pearce and Pickard (2012) highlighted the promotion of a sense of belongingness and the capacity for responsible agency as being two specific factors that contribute to the effectiveness of TC treatment and argue that their "combination, extent and emphasis are unique to TCs"(p.636). Subsequently, Pearce and Haigh (2017) describe belongingness, social learning, promotion of responsible agency and narrative development as the main therapeutic factors identified as drivers of change within a DTC. Debaere et al. (2014) developed a process for change model for DTCs, which supported Pearce and Pickard's (2012) conclusions, asserting the atmosphere of belonging provides necessary safety and containment as the foundation for the process of change.

Collins's (2004) work on interaction ritual chain theory posits everyday social interactions, occurring outside formal therapy, can facilitate change by promoting a sense of belonging; suggesting a mechanism by which belonging develops in DTCs. Clarke and Waring (2018) built on this, finding even negative emotions could result in shared motivation and belonging amongst group members. Arguing the shared nature of the negative emotions creates "high emotional energy"(p.1278), they suggest this explains why individuals tolerate high levels of negative emotions over long periods: because the community holds a sense of hope and belonging for them, allowing the transformation of negative emotions into a sense

RESEARCH PAPER

of solidarity with other group members. Meaning emotional energy from DTC interactions can prompt feelings of confidence and hopefulness, whilst providing a steady basis for building feelings of trust and belonging. This motivates group members to repeatedly engage in difficult interactions over long periods of time: crucial for achieving meaningful change in DTCs.

Evidence suggests DTCs are effective treatment for individuals diagnosed with a PD, therefore it is important to build upon existing research examining how DTCs produce positive change and establishing how it is maintained after treatment. To my knowledge, there is no existing research, exploring the experiences of individuals following discharge from day DTC treatment. This study examined the experiences of individuals who completed day DTC programmes and subsequent follow-on group between six months to two years prior to taking part, who felt they had an overall beneficial experience in the DTC. The aim was to understand medium-term factors that helped or hindered the maintenance and continuation of positive change after the end of DTC treatment.

Method

Design

The design of the study was qualitative, employing interpretative phenomenological analysis (IPA) (Smith & Eatough, 2016) to analyse the data collected via semi-structured interviews. This approach was appropriate as IPA aims to explore how participants make sense of their experiences of their personal and social worlds by examining in detail the meanings they attach to experiences and events. This study is concerned with participants' experiences and understanding of what has helped or hindered the maintenance and continuation of positive change following day DTC treatment. Experts by experience and professionals working in DTCs in the north-west of England were consulted in the design of this study. Draft documents relating to the study such as participant information sheets and

RESEARCH PAPER

interview topic guide were sent to a DTC for review; these were approved by the group and subsequently reviewed by an NHS Research Ethics Committee (REC), where an expert by experience requested that the information regarding the study's purpose be simplified to aid participant understanding.

Participants

To be included in the study individuals had to have completed (defined as having a planned discharge from the DTC after completing the expected duration of treatment) non-residential DTC treatment between six months to two years prior to time of interview, be over 18 years old, and to have felt that they made positive changes during DTC. This time frame was chosen in consultation with staff from DTCs in north-west England, as well as an expert by experience; it was felt participants would require some time to process their experiences in the TC before articulating their experience, but not so long that it would be difficult for participants to recall a sufficient level of detail. An upper age limit was not felt to be appropriate as the DTCs themselves did not appear to have an upper age limit.

Participants were recruited through follow-on groups attached to the DTCs that agreed to take part. One of these was a moving-on group, occurring monthly for a year after completion of the DTC; the other a peer support group that people could attend indefinitely after completing DTC treatment. I will refer to these collectively as follow-on groups throughout. Information packs (see Chapter 4 Ethics) were sent to these groups and presented to the attendees; inviting them to opt-in to discuss taking part in the study.

A total of six people opted in and were interviewed. This was within the recruitment goal for study, appropriate for IPA analysis.

Data Collection

All materials used can be found in Chapter 4 Ethics. Data was collected using one-to-one semi-structured interviews. Prior to each interview, consent was gained and demographic

RESEARCH PAPER

information (see Table I for participant characteristics) collected. The topic areas followed the interview schedule; however lines of questioning were also guided by what participants considered to be relevant and important. The interviews were between 53 and 96 minutes long. All were audio recorded, then transcribed verbatim and anonymised.

Insert Table I here

Data Analysis

Analysis was performed by the first author using IPA (Smith & Eatough, 2016). Initially, transcripts were each analysed individually. Each transcript was read through several times, alongside the audio recording, to allow familiarity with the contents. Each transcript was then annotated with descriptive statements, notes of linguistic features and initial interpretations. For each participant, emergent themes were developed from these annotations. At this stage, the emerging themes from all participants were pooled; some were then removed due to lack of relevance to the research question; some were merged with other similar themes. The remaining themes were then collected and organised into a final set of superordinate themes across all participants, with relevant quotes selected from the transcripts to illustrate.

Validity/quality

Themes were analysed in consultation with the research supervisor who is experienced in IPA, providing an additional perspective improving rigour and coherence, supplementing understanding. Demographic information for participants and the recruitment methods used have been provided to provide contextual information (Yardley, 2008).

To enhance reflexivity, a research journal was kept by the first author throughout the study to note personal thoughts and reflections in relation to interviews and the process of analysis. This was done to support the identification of personal beliefs in order to try and 'bracket' these off during analysis, to reduce biases when analysing and interpreting the

RESEARCH PAPER

results of this study. For example, I have close friends and family who struggle with difficulties meeting criteria for BPD and am aware of their personal experiences regarding mental health treatment they have received and factors that help or hinder their ability to cope. Therefore, it was important to recognise when I was reminded of my personal relationships, to separate my understanding of their experiences from those being expressed by the study participants.

To aid transparency (Yardley, 2015), an annotated transcript extract can be found in Appendix C and a breakdown of the superordinate themes can be found in Table II.

Insert Table II here

Ethical approval

Ethical approval was granted by the Health Research Authority and Liverpool East Research Ethics Committee (approval letter in Ethics section).

Results

Four superordinate themes were developed from the analysis, representing the factors that both helped and hindered participants' efforts to maintain positive changes made during the DTCs: An Atmosphere of Belonging, Hope versus Struggle, Support, and Empowerment though Understanding. As the processes they represent interrelate, the four themes, although distinct, frequently interconnect.

An Atmosphere of Belonging

This theme captures participants' experiences of being in an atmosphere, created by the DTC, which fostered a sense of belonging in group members. Those experiences had a lasting effect on participants' sense of self, and connection with others in the group, facilitating other factors (discussed in the remaining themes) which fostered the maintenance of positive changes. Continued access to an atmosphere of belonging was also a factor that maintained and continued positive change for participants after leaving the DTCs.

RESEARCH PAPER

Participants described being “amazed” (Sam) and “shocked” (Linda) by the sense of belonging they encountered in the DTCs. The language illustrates how unexpected this experience was; many participants also described it as a novel experience: “once in my life” (Emma); “the first time” (Linda); “not had that before” (Rachel).

Feeling a valued and cared for part of the group was common to most of the participants. Sam and Emma both commented that it became like a “family”. All but one participant made repeated references to feeling understood and having shared experiences with other members of the DTC: “we were with like-minded people, people who understood me” (Emma); “I could relate to people” (Linda).

Participants felt validated knowing they were not alone in thinking and feeling a certain way: “I was like ‘wow’, I didn’t realise anyone else felt like that...I didn’t feel that I was on my own” (Mary). This feeling of validation was internalised, having a transformative effect on their self-perception: “I have always felt the odd one out, the black sheep...you suddenly got people who think like you do...I can’t tell you how much of a difference that makes, because... it gives you opportunity to go: ‘well, I can work with that now’” (Rachel). Rachel linked her new understanding of not being alone in her thinking about the world to a change in perspective about her ability to “work” with her thoughts and feelings.

Rachel’s choice of language to describe how she felt before the DTC is echoed in other participants’ descriptions “I was this odd person out” (Mary); “I felt like an alien...I just stuck out like a sore thumb” (Emma). These echoed Rachel’s descriptions and shared a sense of disconnection and isolation from others, tapping into the experiences of stigma. This was not often directly referred to by participants but present in the subtext of their comments about the sense of belonging in the DTCs. Comments about what the DTC *was* highlighted what was absent in the outside world; “People pick on people with mental health. I’ve noticed that” Sam commented; noticing the negative way people treated those with mental health

RESEARCH PAPER

difficulties. These kind of comments indicated they were accustomed to experiencing the antithesis of belonging: being misunderstood, negatively judged and isolated. Sam continued: “People understand [in follow-on group] but then you come out of there...it’s like ‘wow, here’s the real world again’...and it’s not a nice place.” “It was nice just to...be around...like-minded people who didn’t pre-judge you because of like mental health...because everyone’s kind of in the same boat.”, Linda described, commenting on the contrast between follow-on group and general life, implying she has felt judged and misunderstood by others outside the DTC. These experiences of stigma in the “real world” were significant barriers to maintaining positive changes and continued growth after the DTC. Mary demonstrated this point: “I love Zumba, but I won’t go...because I just feel different because I’ve got mental health, so I don’t feel I fit in there...Whereas the likes of groups here [at the personality disorder service] it’s different because you know everyone’s in the same boat.” Although she experienced increased confidence and self-esteem, this did not always transfer to life outside services due to her fear of stigma.

This atmosphere represents a collective version of an individual sense of belonging, characterised by an implicit recognition of the group consisting of others like yourself, providing important sources of hope and facilitating motivation to make positive changes. The combination of belonging and hope underpinned the practical support they received in the DTCs and follow-on groups (such as coping strategies and ways of understanding themselves). Therefore, belonging functioned as a facilitator for the other key factors captured in the remaining themes.

For this reason, most participants expressed a wish to have access to environments where they could regain something like the atmosphere of belonging they discovered in the DTCs. For example, Emma, who had finished both the DTC and two-year transition group, expressed: “It was amazing to be around people who understood you and it still is...and

RESEARCH PAPER

that's why I volunteer there." For many, the follow-on groups provided this but, in most cases, only for a limited time.

Further support that a sense of belonging is important for the maintenance and continuation of positive changes can be found in Karen's interview. Karen was the only participant who described experiencing a distinct lack of belonging in the DTC: "I don't feel that they're like me" (Karen). Consequently, Karen described only feeling "safe" with staff members of the group. As a result, she felt: "It's only as long as the support's there that I feel sort of better about things" describing that the positive effects of attending the DTC began to disappear as soon as she lost contact with the staff members. She had not experienced an internal transformation to her sense of self, nor had she found a useful resource in her peers to draw upon for support, ideas and hope for change. She explained having a "struggle with being around happy people, because I'm not" describing how she found it difficult to benefit from the follow-on group when other members described their successes whilst she is still struggling. This was unlike other participants interviewed who derived hope for the future possibility of positive change when hearing about the success of others in the group. This suggests that belonging to a group creates an investment in the achievement of other group members as well as oneself, which links to an increase in positive outcomes, when compared to situations where a sense of belonging appears absent.

Hope versus Struggle

This theme reflects the tension between factors that gave participants hope that change was possible and the struggles that made maintaining changes difficult. Hope helped preserve motivation to continue striving to maintain positive changes in the face of difficulties, as well as increasing self-esteem and confidence levels. Broadly these fell into sources of hope provided by others in the group and sources from within the individuals.

RESEARCH PAPER

Conversely, sources of “struggle” presented barriers to maintaining hope, and threatened motivation to continue striving to maintain positive changes.

Hope that positive change was possible was a factor that participants spoke about: “I felt there was hope and that things could be done” (Mary). The starting point for this came from being in an atmosphere of belonging and seeing positive change being modelled by other group members; usually those further along in their journey: “It was like more of an understanding from another mental health patient to another...they get it...the group for *that* is *massive*...you can take things away...you go back and say: ‘I’ve been doing that, and it does work, and try this.’” (Sam). For Sam, the ability to receive feedback from similar others gave him hope that the suggestions would be worth trying. This increased motivation to attempt them, because he felt they were coming from people who understood what he experienced.

As participants began to make progress, recognition of their own achievements helped maintain hope and motivation. For Mary, this began with others noticing how she had changed: “it was only when people pointing out to me thinking, ‘oh yeah’, you didn’t automatically think of that change”. Then she was supported at other times to recognise changes: “they ask you a lot of questions about that and it’s only at times like that you’re thinking, ‘oh god, yeah’.” prompting self-reflection. Gradually, she began to self-reflect independently. Other participants reported similar development of self-reflection. Emma deliberately used self-reflection to retain hope and motivation when she was struggling to manage her anger: “I say to myself: ‘right, I’ve come so far and you’re not going to take that away from me’.” At other times: “it’s like a light bulb moment...there was no like major shift in anything but its little things that you suddenly go: ‘that’s a [DTC] moment’” (Rachel), recognition seemed to happen spontaneously.

RESEARCH PAPER

The jobs participants held as DTC members provided opportunities to recognise change. These were times when participants were pushed out of comfort zones, providing concrete examples of changes in, for instance, skills, which they could later reflect on as signs of progress: “building...confidence” (Mary). Emma said: “they don’t realise how much that’s put them in the right mind for the big world...them little things that we’re getting put into place were all for the good”, meaning the jobs subtly built transferable skills preparing group members for leaving the DTC.

Noticing a change in their roles within the group from only receiving support, to also offering valued support to others was another way of recognising positive change. This reciprocal support was important to participants, as it helped them feel “part of something good” (Linda). The concept of reciprocal support was distinct from an atmosphere of belonging, however, arguably, could not have occurred without it. This role change had a significant, positive impact on participants’ self-worth. Linda described a gradual change that occurred; from the group supporting her to develop her communication skills, to her finding “the ability to find words for other people”. She explained: “being able to help other people through their journeys...I was able to, like, contribute, when usually I didn’t feel that way.” This was a key reason Linda found the DTC experience “empowering”. Linda qualified as a peer support worker but was searching for a job in that role. She expressed needing to find “a purpose...to keep you feel[ing] like you’re contributing”.

Sam and Emma had moved into peer support roles: “it helps you because you’re sort of being given responsibility, where other people...are looking up to you [saying] ‘it’s remarkable’ and like, ‘it’s an achievement to get to where you are’” (Sam); “most of the service users in there come to me like I’m staff...because of, [I] don’t want to blow my own horn, but I’ve...changed so much and I’m quite confident.” (Emma) seeming to value this shift in their identities: External acknowledgement and validation of this shift in role was also

RESEARCH PAPER

an important way they recognised their progress. Having others seeking advice and inspiration from them due to witnessing evidence of their progress was a strong validator for Sam and Emma.

It seemed that having frequent opportunities to recharge this sense of hope was important in helping counter the negative impact of the constant “struggle” (Linda) that participants spoke of. Sam expressed that: “in life, everything’s difficult. DTC is, for me, making it easier”. Most participants spoke about the ongoing challenge of experiencing strong emotions: “I think it’s ultimately like the biggest difficulty is just the feelings that you get that, and I know that’s just part of who I am...but I think the main struggle is getting through those feelings.” (Linda). Talking about struggling to cope, Emma commented: “it’s always there, it hasn’t gone away”. Rachel spoke about having a better awareness of her emotions and the impact of unhelpful coping strategies but reflected that: “I’m kind of more conscious now...and trying to develop and deal with stuff but that also makes it harder because then you don’t know what the hell to do with all the feelings that you couldn’t identify before”.

Karen explained: “I’m very negative thinking, I don’t always see the positives in things”. It seemed, for her, the struggle outweighed her hope when she did not have direct support from mental health professionals. Karen’s lack of a sense of belonging in both the DTC and, subsequently, the follow-on group meant she struggled to find hope and inspiration to bolster her motivation to maintain and continue making positive changes without the support of the DTC. This tension between the reality of the difficult thoughts, emotions and experiences and the need to keep levels of hope for the future high enough to create motivation to maintain and continue positive change was evident in all the interviews.

Support

RESEARCH PAPER

This theme captures the participants' appropriate need for ongoing support after leaving the DTC and the difficulties that arose trying to access it. It highlights the importance of the follow-on group, with all participants finding some form of continued support from services important for the maintenance of positive changes after DTC; and conversely, that losses in support were barriers to this.

All participants could identify sources of support external to their DTC. Some mentioned family: "I've got like a partner...who is still really supportive" (Linda); "as much as we argue, everyone's still there for me" (Emma). Karen received input from an addiction service: "I really like the guy that I'm seeing...it's helpful as it's a source of emotional support".

Despite these external sources of support, there was a consensus among participants that an abrupt end to support from the DTC would have been damaging to their ability to maintain positive changes and that attending the follow-on group was also essential. Sam said he felt he "would've ended up back exactly where I started...in fact it could've been worse...if my mental health starts talking to me and starts saying: 'well you've been away for two years now, so you've been naughty'". Similarly, Linda liked the idea of attending the follow-on group, rather than "just being thrown into the world from therapy, from heavy like weekly therapy, to like nothing." She went on to say: "I knew that...if I was going to have any kind of like control over my life that I shouldn't just pull the rip cord and say: 'see you later'. I needed to like stick to it". For Linda, attending the follow-on group was both a way of reducing her level of support more gradually, and about consolidating the learning from DTC. For some participants it was important they still had somewhere, away from home, where they could go to "vent" (Emma) or get support if needed.

There appeared to be a difference in how participants from the two services viewed support after the DTC. Emma and Linda had recently completed the follow-on group at the

RESEARCH PAPER

time of interview, while Mary and Rachel were still in their first year. Both Emma and Linda felt that they were ready to reduce their level of support further. Emma acknowledged that, although she would have liked to remain in the DTC environment, she thought: “if it had of gone on longer than it did there could have been some kind of reliance on it. I could’ve ended up feeling that I couldn’t live without it”. Linda similarly said that “no-one feels ready to leave”, but that as the membership of the group changed with old members leaving and new ones arriving, there seemed a natural, gradual process of separating from the group. By the time she left, she reflected: “I was ready to go. Well, I was *scared* about going; I was *nervous* about going but I was *ready* to go because... ‘this isn’t my group anymore, it’s for, like, other people to take over’”, which helped her let go of the group.

There was also an acknowledgement that being an experienced member of a time-limited group led to a helpful change in role (as already discussed) and this evolution happened in part, because older group members left and newer members stepped up into higher levels of responsibility: “I was consciously kind of stepping back...saying: ‘it’s time for them to kind of pick up this now...I’m going to be less vocal today because I know that [these] guys’ll benefit from it’” (Linda).

Emma reflected that being forced, by the time limit, to relinquish contact with the DTC, then subsequently the follow-on group, allowed her to realise she could cope without the support:

I thought that that was the only thing that helped me be slightly normal...and helped me to deal with things; what was I going to do without it? But little did I know that...[things I] had already put into place and been living with in there, was there for life...so it’s proven that I don’t need it in that way.

However, despite this, she still felt the need to maintain her connection with the service, and thus access to the atmosphere of belonging that she had not yet experienced

RESEARCH PAPER

outside the wider personality disorder service: “I made sure I volunteer to make sure that I don’t [get thrown] out...I need it. Without that...I don’t know.”

In contrast, Sam believed: “there’s nowhere else we can go apart from these groups that can give you that support...I need this, because if I don’t have this, I’m going to end up back the way I was”. He felt he needed the non-time-limited follow-on group to maintain his wellbeing and had no plans for working towards a reduction in support. Karen, as already mentioned, felt as soon as the DTC support was withdrawn the benefits began to reverse and was searching for other sources of professional support to replace it, finding the peer support insufficient. Mary and Rachel, still in the early months of their transition to follow-on group, both acknowledged their need for a continuing, if reduced, level of support from the service: “transition’s a very good idea because to...go from having weekly... I’m struggling anyway but I can’t imagine how difficult it’d be if you didn’t have access to the transition group” (Rachel).

Opportunities to continue pushing out of their comfort zones and to grow in confidence and skills after the DTC appeared to be important in continuing to sustain the positive changes made during the DTC. The follow-on groups provided opportunities for this, whilst continuing to provide a supportive environment. Mary reflected: “there was no way I’d ever consider that [before]” describing how her increased confidence allowed her to use the day services at the PD service. For her, they provided an intermediate space, away from the “hustle and bustle” of the general public; “somewhere where it’s safe and you’re keeping your self, mind occupied and you are socialising with others”. Having developed the confidence to attend day services provided her with continuing opportunities to develop; perhaps, in time, to the point where she would feel confident enough to get involved in activities in the wider community.

RESEARCH PAPER

Emma reflected: “I have a place in the middle between service users and staff. I find it more hard to speak to the staff because I have a different relationship than most of the other service users...because I work alongside them. So, I find that very, very hard.” Often finding it difficult to know when and where to seek support since taking on a voluntary peer support role within the service: She spoke about feeling “embarrassed” and not knowing what to say to staff, perhaps believing, now she was working alongside them, she could not approach staff for support.

Empowerment through Understanding

This theme represents the learning and practical skills participants gained during the DTCs and follow-on groups. In general, gains in understanding empowered participants to discern why and when to employ coping strategies and other skills they had learned to maintain and continue the positive change, which occurred during the DTCs. A factor that hindered maintenance of positive changes was the continued use of negative coping strategies.

A key factor that contributed to participants maintaining and continuing to make positive changes was developing an understanding of where their difficulties came from and the related patterns of thinking, feeling and behaviour. As Karen said: “it’s always good to understand yourself”. For many participants, an understanding of how difficulties developed led to a more compassionate understanding of themselves, allowing them to take a different perspective when thinking about their thoughts, feelings, behaviour etc. Rachel, for example, experienced a significant shift in how she regarded her overdoses: “it took me months to identify that my overdosing was actually a bad thing”. For her, understanding developed due to input from other group members expressing their concern: “letting the group actually realise that they cared for me and that I did matter; and it’s still a really hard concept for me to have...: people actually cared, people didn’t want me to go home and take 24 pills”. This

RESEARCH PAPER

demonstrates the importance of the atmosphere of belonging in facilitating other factors; as without it, Rachel would not have given the same weight to their reactions. Hearing from people she regarded as similar to her, who understood how she thought and felt, meant their care and concern had a more profound effect on her own assessment of the seriousness of these incidents.

For Sam, understanding led to realising what kind of support was and was not helpful in the long-term. In the past, services offered him practical support, such as helping with household chores, but the DTC pushed him “to live a normal life”; meaning he was equipped and encouraged to take responsibility for his own self-care, rather than relying on external support for this.

Most participants spoke about the importance of learning their triggers: “to know what *does* trigger me...what to avoid, having that kind of control is really important” (Linda). Participants also discussed learning the patterns of emotional reactions and behaviour that follow those triggers: “the biggest thing I’ve found out, through all this journey, is that my biggest problem is abandonment issues...I push people away before I love them” (Emma). Understanding the triggers and subsequent patterns helped participants anticipate when they needed to use strategies or skills to cope in a more helpful way. It also allowed them to avoid unhelpful situations in the first place, and helped them recognise when those patterns had been triggered: “it may take a day...for me to realise, ‘oh, this is me’; but I know when it’s me” (Emma). This offered more opportunities to respond differently: “being able to identify things makes it easier to cope a bit more” (Rachel).

Having recently completed the follow-on group, Emma discussed examples of applying new skills and strategies to manage difficult situations more positively, based on understanding her triggers and previous, unhelpful, reactions. For example: “[DTC] made me able to take deep breaths and walk away from situations...even though on my hardest of day,

RESEARCH PAPER

when I am walking away, I feel like I've let someone else win; the next day, I realise what I did was the *best* thing". She used self-reflection to validate her use of new skills, feeding into the process of creating a new perspective and maintaining hope and motivation, as discussed in the theme Hope versus Struggle: "when I've calmed down, I understand and realise that if I'd have stayed, maybe I could've kicked off...and because I'm not in the same mind-set as I used to be, I actually don't want that."

Several participants continued using unhelpful coping strategies; such as self-harm, overdoses and using drugs or alcohol: "I smoke weed and that's...one of the ways that I cope" (Karen); "I did self-harm...that's one thing I don't feel it's changed...to me, it's a way of releasing what I'm feeling" (Mary). These were barriers to maintaining positive change. Emma commented that it could be hard creating new patterns of behaviour when others are holding onto old dynamics: "I find myself stepping up, shutting the door, going out...and you'll find them all running after me." Here she used the strategy of leaving the situation to calm her anger but was followed by others wanting to continue the confrontation. This was a significant barrier to her efforts to maintain and continue making positive changes. She reflected that sometimes a "fresh start" seemed the best solution; but like most of us, had relationships and responsibilities that could not be dropped, even if they were unhelpful.

All participants had specific skills and strategies which they learnt during DTC and continued to use to maintain and continue making positive changes; some of which have already been touched upon. One skill, mentioned several times, was the ability to recognise and communicate about emotions. Rachel developed the ability to recognise and label her emotions: "Just *having* feelings and being able to understand that that's actually upsetness...and *feeling* them; much as they suck, is different because...it's bringing you as a whole person, it's not you permanently separating everything." Despite describing this as a positive change, which helped her cope more positively, she felt being able to communicate

RESEARCH PAPER

more easily about her emotional experiences led to a reduction in the support offered to her: “because it gives people the impression that you are better than you are because you can verbalise it.” This contrasted strongly with Linda’s experience. Linda also developed her ability to communicate about emotions and experiences during the DTC: “you could basically see the progression of people on how they could explain themselves and how much they understood themselves...it helped to understand *myself* a little bit.” She explained: “it really did help me identify stuff and really did help me to learn how to communicate better; because my communication has gone from zero to...like I’m able to communicate with you so that you understand what I’m saying, whereas before, people didn’t...or didn’t understand my reactions to stuff.” She found her increased ability to communicate was “empowering”, allowing her to “be like the expert in your own illness to advise the doctors about what was right and what is wrong for you...to be educated enough to be able to explain this stuff to your doctor I think it’s important.” For her this was a strong factor in maintaining the positive changes and helping her continue to make further changes, in contrast to Rachel, who seemed to find it personally helpful to understand and cope better, but less helpful when transferred to communicating with others.

An important aspect of understanding often was acceptance that aspects of themselves and their experiences may be impossible to change: “I’ve accepted through the journey that I’m never going to be...normal but I’ve accepted that this is my life and I have to just...ride the rollercoaster...We have to accept the good and the bad and...live with it the best we can and manage it” (Emma). Linda reflected:

you’re going to have these moments and, because your emotions are a bit stronger than the average person’s, you’re going to have really bad times...I think that’s the hardest thing to get through; it’s enduring these things like the feelings and coming out the other side.

RESEARCH PAPER

Here, her use of the word “enduring” suggested an acceptance that this part of her experience would continue, but an acknowledgement, in the phrases “get through” and “out the other side” that the difficult times pass. Acceptance of this struggle made experiencing it easier to bear and, therefore, was an important factor for participants in the maintenance and continuation of positive change. They subsequently experienced some sense of freedom to look at the situation and consider what skills and strategies could be used to improve coping and increase wellbeing: “you can train yourself to deal with stuff and you’d got the chance to because you’ve recognised that actually that’s not necessarily...a ‘normal’ way of thinking, but it is *my* way of thinking so let’s deal with it that way” (Rachel).

Discussion

The results illustrate the importance for the participants of belonging to a group, which offered hope and support and fostered a new way of understanding themselves and their place in the world. Within the DTC these experiences were internalised and continued to have a lasting effect afterwards. The results also demonstrate the importance of finding continuing sources of these factors outside the DTC setting to maintain and continue positive change.

In summary, factors that help maintain and continue positive change from DTC treatment in the medium-term are: access to an atmosphere of belonging; sources of hope that change is possible; continued access to some form of structured support but at a reduced intensity; and understanding one’s difficulties and skills to make more helpful choices. Factors hindering maintenance and continuation of positive change are: experiences of stigma and prejudice; experiencing difficult thoughts, emotions, and events; a lack of access to appropriate support; and use of unhelpful coping strategies.

Findings from this study suggest belonging is both a factor in and of itself helping maintain positive changes and a facilitator of other important factors. A sense of belonging

RESEARCH PAPER

within the DTCs transformed participants' self-image; increasing their self-esteem; an effect that became internalised and, therefore, continued after leaving the DTCs. These findings correspond to Peace and Pickard's (2012) assertion that positive change associated with belonging should persist beyond end of treatment because change was promoted by increased self-efficacy and modifications of core cognitions, such as "I am not acceptable" as well as improving self-esteem, which they posited was an essential precondition of behavioural change and one of the features unique to TCs. Research has linked self-efficacy and self-esteem; suggesting a person must believe in and care enough about themselves to begin the arduous task of behaviour change (Judge et al., 2002). Overall, these findings are in line with the qualitative findings of McFetridge and Coakes' (2010) five-year follow up study, where participants reported long-term changes in sense of identity and thinking.

Findings from this study suggest belonging acts as a catalyst; kick-starting a process beginning with an increase in self-esteem and a change in self-image. The atmosphere of belonging then promotes hope and motivation for change by similar others modelling how change is possible. Once initial change has occurred, noticing these changes increases self-confidence and self-efficacy, and refreshes people's sense of hope. Over time the ability to self-reflect and notice examples of change for themselves develops, which becomes a positive and self-sustaining feedback loop, maintaining a sense of hope and motivation, supporting the maintenance and continuation of positive change (see Figure 1).

Insert Figure 1 here

An atmosphere of belonging was also important in how it related to other factors such as hope. For example, the experience of engaging in reciprocal support with other group members was made possible for participants due to the impact of the atmosphere of belonging, which enabled them to feel safe and cared for enough to allow themselves to be vulnerable in the group, offering up personal experiences and opinions and taking on board

RESEARCH PAPER

those of others. Clearly this factor was an important driver for change within the DTCs, in accord with Pearce and Haigh (2017), however, continued access to this kind of atmosphere appeared important to the maintenance of hope, which promoted motivation to continuing striving to maintain and continue making positive change, particularly in the face of “struggle”. The follow-on support participants all accessed seemed to provide this, and for some participants, access to the day services attached to the PD service that the DTC was part of.

There was a consensus amongst participants that further support was essential after the DTCs to maintain the positive changes that occurred. Continued access to the atmosphere of belonging was a significant factor in this, several participants commenting that they felt going from the intensity of the DTC to no support would feel extremely hard. The time in follow-on groups appeared to provide both a chance to consolidate skills learned, but also a chance to test the idea that it was possible to maintain positive change, without still being part of the DTC. Two participants attended a peer support group as their follow-on group, which had no time limit. For those participants, this seemed to result in a feeling of dependence on the support group, as if the positive changes would reverse without it, as opposed to the two participants who had finished their time-limited follow-on group and experienced it as a demonstration that they could now cope, and the time limit forced them to test this. This fits with existing research by Chiesa et al. (2004), which found that specialist step-down support after six-month residential TC treatment was found to result in superior outcomes compared with long-term residential TC and community-based treatment. The follow-on groups appeared to bridge the gap between psychotherapy and rehabilitation, which historically has been a conflict in many TCs (Campling, 2001). Similarly, participants in this study noted the importance of continued, but reduced support after DTC treatment, helping them transition

RESEARCH PAPER

out of the intense environment of the DTC and consolidating their practical skills to “rehabilitate” into everyday life.

Current findings suggest being able to reciprocate the support they received had a positive effect on participants’ self-esteem and their sense of hope for the future, which, as previously discussed, may be a mechanism for motivating behaviour change. Existing research has demonstrated positive effects on self-worth and wellbeing because of someone feeling they can make a useful and valued contribution to others (Heard & Lake, 1986) and reciprocate support (Yalom, 1995).

Having something to contribute gave participants a sense of purpose, which was also a positive outcome in and of itself for some, becoming part of their new self-image. Bates (2005) observed that the experience of having something to offer to others in the group countered the sense participants had that they were of no value to others.

For some participants, a continuation of this experience was found in working as a peer support worker. This fits with the existing evidence base, for example, a systematic review and meta-analysis found evidence that peer support was associated with positive effects on measures of hope, recovery, and empowerment for individuals with “severe mental illness” (Lloyd-Evans et al., 2014). These findings fit with those of the current study, which link hope and empowerment to the experience of being with and supported by similar others whilst reciprocating that support. Salzer and Shear (2002) suggested peer support works through promoting self-efficacy and hope by modelling recovery and coping strategies, consistent with participants’ experiences receiving peer support in the current study. Supporting the idea that continued access to spaces where peer support is available is important to the maintenance of positive change in the medium-term, by promoting hope for the future and mediating experiences of struggle, which can negatively impact maintenance of change.

RESEARCH PAPER

Limitations

All participants had or were attending some form of optional follow-on group following completion of the DTC; therefore, it is unclear if tapered, continued support is an important factor to the maintenance and continuation of positive change for all who access DTC treatment, or just those who chose to attend the follow-on groups. As only two participants had completed and left their follow-on groups, it is also unclear if different factors are involved in maintenance of change once all support is withdrawn. While these differences were reflected in the theme of Support, I feel the core of the overall experiences were similar enough in the other themes to maintain the homogeneity of the sample.

Further research and clinical implications

It would be useful to explore experiences of individuals who completed DTC treatment but chose not to attend any follow-on support, and how their experiences compare to those of participants in the current study. This would be helpful in establishing whether follow-on groups should be a consistent feature of all DTCs, as currently some do not, while others do, with the existing follow-on groups varying in frequency, duration and content.

It would also be useful to conduct in-depth interviews longitudinally at different points of the participants' journeys; continuing for a period of time after all support is withdrawn. This would shed light on how factors that help or hinder the maintenance and continuation of positive change alter throughout the treatment journey and what this may be able to suggest in terms of what provisions are most likely to elicit long-term, positive outcomes. For example, what form and for what length of time should follow-on support be and do they significantly improve the chance of maintaining positive change?

Conclusion

In conclusion, participants described how positive changes made during the DTCs were maintained in the medium-term following completion of DTC treatment. Factors which

RESEARCH PAPER

were reported to help or hinder the maintenance of these changes are discussed above. Of particular note was the importance of belongingness for all participants as a discrete factor, but also as an important facilitator for other factors; seemingly both during and after DTC treatment.

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Figures and Tables

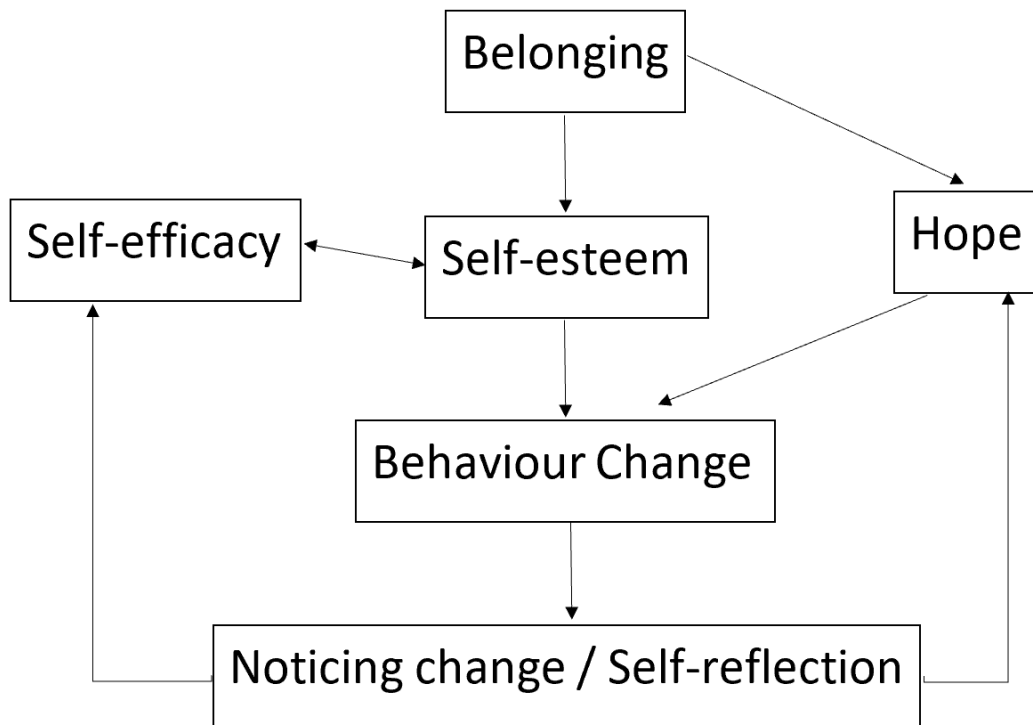
Table 1 – Demographic details for participants

Name of participant (pseudonym)	Gender	Age	Length of time in DTC	Length of time in follow-on group	DTC attended	Format of interview	Length of interview in minutes
Sam	Male	46	2 years	1 year, 2 months (still attending)	Service A (i)	Face to face – in community	96.26
Emma	Female	39	1 year	2 years (finished recently)	Service B	Face to face – in community	81.45
Linda	Female	30	1 year	2 years (finished recently)	Service B	Telephone	70.59
Karen	Female	50	1 year	1 year (still attending)	Service A (ii)	Face to face – at service location	64.44
Mary	Female	49	1 year	9 months (still attending)	Service B	Face to face – at service location	53.19
Rachel	Female	39	1 year	9 months (still attending)	Service B	Face to face – at service location	95.32

Table II - Breakdown of superordinate themes

<p>An Atmosphere of Belonging</p> <p><i>Feeling part of a group</i></p> <p><i>Feeling understood</i></p> <p><i>Shared experience</i></p> <p><i>Validation</i></p> <p><i>Stigma</i></p>
<p>Hope versus Struggle</p> <p><i>Shifting roles</i></p> <p><i>Self-esteem/confidence</i></p> <p><i>Hope through other members of the group</i></p> <p><i>Pushing out of comfort zone</i></p> <p><i>Noticing changes</i></p> <p><i>Struggle</i></p>
<p>Support</p> <p><i>Continued tapered support after DTC</i></p> <p><i>Protective factors outside services</i></p> <p><i>Loss of support</i></p> <p><i>Uncertainty/difficulty seeking support</i></p>
<p>Empowerment through Understanding</p> <p><i>Understanding self (i.e., learning triggers)</i></p> <p><i>Acceptance</i></p> <p><i>Change in perspective</i></p> <p><i>Positive coping strategies</i></p> <p><i>Negative coping strategies</i></p> <p><i>Communication skills</i></p> <p><i>Processing/tolerating emotions</i></p>

Figure 1 – How belonging facilitates behaviour change



Appendices

Appendix B Notes for authors for *Therapeutic Communities*

Author Guidelines

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Research funding	<p>Your article must reference all sources of external research funding in the acknowledgements section. You should describe the role of the funder or financial sponsor in the entire research process, from study design to submission.</p>
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<i>For journals</i>	<p>Surname, initials (year), "title of article", <i>journal name</i>, volume issue, page numbers.</p> <p>e.g. Capizzi, M.T. and Ferguson, R. (2005), "Loyalty trends for the twenty-first century", <i>Journal of Consumer Marketing</i>, Vol. 22 No. 2, pp.72-80.</p>
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	<p>A., & Ternel, M. (Ed.s), <i>CAUTHE 2008: Where the 'bloody hell' are we?</i>, Griffith University, Gold Coast, Qld, pp.115-118.</p>
<p><i>For unpublished conference proceedings</i></p>	<p>Surname, initials (year), "title of paper", paper presented at [name of conference], [date of conference], [place of conference], available at: URL if freely available on the internet (accessed date).</p> <p>e.g. Aumueller, D. (2005), "Semantic authoring and retrieval within a wiki", paper presented at the European Semantic Web Conference (ESWC), 29 May-1 June, Heraklion, Crete, available at: http://dbs.uni-leipzig.de/file/aumueller05wiksar.pdf (accessed 20 February 2007).</p>
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<p><i>For encyclopaedia entries (with no author or editor)</i></p>	<p><i>Title of encyclopaedia</i> (year), "title of entry", volume, edition, title of encyclopaedia, publisher, place of publication, page numbers.</p> <p>e.g. <i>Encyclopaedia Britannica</i> (1926), "Psychology of culture contact", Vol. 1, 13th ed., Encyclopaedia Britannica, London and New York, NY, pp.765-771.</p> <p>(for authored entries, please refer to book chapter guidelines above)</p>
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e.g. Campbell, A. and Kahn, R.L. (2015), *American National Election Study, 1948*, ICPSR07218-v4, Inter-university Consortium for Political and Social Research (distributor), Ann Arbor, MI, available at: <https://doi.org/10.3886/ICPSR07218.v4> (accessed 20 June 2018)

Appendix C – Extract of annotated transcript from analysis

<p>Therapy as catharsis not helpful</p>	<p>295 296 297 298</p>	<p>P: it didn't really, I know that people can find that cathartic, that experience cathartic, you know, letting things out of the cupboard, you know like secrets out and that kind of thing</p>	
<p>Wanted therapy to be helpful rather than sympathetic?</p>	<p>299 300 301</p>	<p>M: yeah P: but, to be honest, I've got like a partner who was really, who is still really erm, supportive, so I do talk</p>	<p><i>Corrects self – was and is really supportive. Partner is important to her, wants to make this clear?</i> Has partner to speak to as a method of catharsis – didn't need services for this. <u>Wasn't looking for sympathy, but for help?</u></p>
<p>Supportive relationship</p>	<p>302 303</p>	<p>M: ok P: all the time M: yeah</p>	
<p>Uses personal relationships for catharsis</p>	<p>304 305 306</p>	<p>P: to somebody about all the rubbish stuff that's happened to me in <u>me</u> life M: yeah</p>	<p><i>Rubbish – referring to difficult experiences in the past. Something to be thrown away? Defective?</i></p>
<p>Process of moving through 'levels' of therapy</p>	<p>307 308 309 310 311</p>	<p>P: all the time. M: so that isn't what you need is it? Yeah P: So, it was kind of like, yeah, and that's, at the end of the counselling erm, and I had like it extended for quite a while.</p>	<p>Counselling was extended for a longer <u>period of time</u> than expected.</p>
<p>Wanted tools to help self</p>	<p>312 313 314</p>	<p>M: ok P: At the end of it, the counsellor said, 'I think you'd benefit from CBT', because what I was really looking for was things to help me. Knowing, with the fact that I'd had a bad</p>	<p>Counsellor suggested CBT. Participant wanted tools to help. <u>Not just to talk about things that have happened/are happening?</u></p>
<p>Using childhood experiences to inform rather than to dwell upon</p>	<p>315 316 317 318</p>	<p>childhood in mind M: Mm P: kind of like, move on. And like things, tools that had helped me to kind of cope with the stresses of day to day life</p>	<p>Holding childhood experiences in mind, but not dwelling on them, using that information to move on. <u>Make positive changes, do things differently?</u></p>
<p>Wanted tools to cope better</p>	<p>319 320 321</p>	<p>M: yeah P: and knowing that I have these feelings, how can I cope with these feelings a bit better? How can I be a bit more prepared <u>and</u></p>	<p>Wanted tools to help cope with the stresses of day to day life.</p>
<p>Desire to address difficulties</p>	<p>322 323</p>	<p>prepared <u>and</u> M: yeah</p>	<p>Wanted to know how to cope with feelings better. Wanted to be more prepared. <u>Prepared for what? For a crisis? For when things become overwhelming again? Or stressful?</u> <u>Language very focused on 'I' – things she wants to do. Sees the responsibility for change as being located within herself?</u></p>
<p>Seeing self as responsible for change</p>	<p>324 325 326 327</p>	<p>P: react to things a bit better. How can I be less impulsive etcetera, you know? M: yeah</p>	<p>Wanted to react less impulsively.</p>

Chapter 3 Critical appraisal



Belonging and hope: antidotes for stigma?

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Word Count: 3,989

CRITICAL APPRAISAL

The narrative literature review aimed to explore the stigma towards individuals with a diagnosis of Borderline Personality Disorder (BPD). Research literature going back decades demonstrates that stigma is a real issue in relation to this diagnosis and how mental health professionals feel about and react to service users with this label, inevitably having a negative effect on the treatment they receive.

Although different strategies have been suggested to mitigate these issues, the issue still persists, suggesting a more radical approach is required to make significant change in this area. I explored the Power Threat Meaning Framework (Johnstone et al., 2018) as an alternative to psychiatric diagnosis. I then discussed how this may apply to services and interventions in practice, thinking specifically about what that might mean for individuals diagnosed with BPD. As many of the principles of the PTMF aim to normalise and destigmatise, it would appear to be an approach to mental health that would benefit all those who hold stigmatising psychiatric labels, but particularly those diagnosed with BPD.

The research paper aimed to understand the medium-term factors that helped or hindered the maintenance and continuation of positive change after the end of day Democratic Therapeutic Community (DTC) treatment. It examined the experiences of individuals who had completed day DTC programmes and the subsequent follow-on groups between six months and two years prior to taking part in the research, who felt they had an overall beneficial experience in the DTC.

Four superordinate themes were developed representing the factors that helped and/or hindered participants' efforts to maintain positive changes made during the DTCs: An Atmosphere of Belonging, Hope versus Struggle, Support, and Empowerment through Understanding. Participants described their experiences within the DTC and in the follow-on

CRITICAL APPRAISAL

groups afterwards, explaining their understandings of the positive changes that occurred as a result and what factors helped or hindered the maintenance of these changes.

There are several common themes between the research and narrative review papers. Two in particular appear to be important for reducing stigmatising experiences and improving positive therapeutic outcomes for individuals who meet the criteria for a diagnosis of Borderline Personality Disorder (BPD): hope and belonging. These themes have often emerged from contexts of mutual sharing of experiences and understanding in group settings, such as therapeutic communities (TCs) and peer support groups, where the power hierarchies are flattened.

The themes of belonging and hope also fit well with the model of trauma-informed care (TIC), which emphasises creating safe environments where people feel understood and validated and can form healthy attachments, whilst empowering service users to co-produce the services they receive and encouraging the involvement of people with lived experience of mental health issues in delivering services to others. Trauma-informed approaches (TIAs) can trace their origins back to the era of moral treatment, social psychiatry, and the concept of the TC (Bloom, 2013), so it makes sense that these approaches fit well together.

Haigh's "quintessence" (1999, 2013) highlights the importance of paying attention to therapeutic and counter-therapeutic factors in any therapeutic environments, not just TCs. The quintessence is offered as a developmental sequence of emotional development. It describes, based on existing psychological theories, what is necessary for "normal" emotional development, leading to relatively resilient adults.

CRITICAL APPRAISAL

Crucially, the quintessence describes universal principles that apply to us all, rather than only specific groups of people labelled with certain diagnoses or seen as particularly disturbed. It consists of five “necessary experiences”: attachment, containment, communication, inclusion, and agency. Haigh suggests that “good enough” experiences of each of these is required for healthy primary emotional development in all humans. It seeks to describe how environments can be created deliberately, using those necessary conditions, to provide a “secondary emotional development” for those who experienced disruptions to their original emotional development as is usually the case in individuals diagnosed with personality disorders. The ethos and intentions behind these five principles closely match many of those presented within the Power Threat Meaning Framework (PTMF) (Johnstone et al., 2018), which also aims to place mental health difficulties on a spectrum of “normal” and understandable human reactions to adverse experiences and seeks to promote and further expand the use of approaches such as trauma-informed care (TIC), which mandate, amongst other things, creating a safe environment that fosters personal agency and belonging.

The quintessence is used in teaching and training and has been utilised in the development of standards for areas such as the criminal justice sector and the Enabling Environments (Royal College of Psychiatrists (2019) standards. The Enabling Environments standards were produced from a thematic analysis of the findings from the Community of Communities audit cycles across several years. It is based on the idea of extending TC principles to settings outside TCs, and, therefore, shares many similarities with Haigh’s quintessence, which seeks to describe a universal human experience, not just limited to those who benefit from attending TCs.

CRITICAL APPRAISAL

The aim of the Enabling Environment project is to bridge the gap between clinical and non-clinical settings to develop a shared set of standards. These core standards describe values that are present in all TCs, but that do not depend on the TC setting. Like the quintessence, they deal with essential human values and needs, which can be flexibly applied to a wide range of environments; aiming to embed factors thought to be involved in promoting health and improve relationships and wellbeing for everyone in that environment; both providers and recipients of care in a service, for example. The standards are: belonging, boundaries, communication, development, involvement, safety, structure, empowerment, leadership, and openness. All of which seem consistent with the principles of TIC and the PTMF. Environments that meet these standards should foster experiences of belonging and hope, which appear so important in positive outcomes, particularly for those diagnosed with BPD.

Hope for the possibility of positive change or ‘recovery’ in the future emerged as an important factor for participants in the research paper. Hope, from the perspective of mental health professionals, also seems important in the design and delivery of mental health services. Referred to in the literature as ‘therapeutic optimism’, a lack of this in clinicians working with individuals diagnosed with BPD appears to have a significant relationship to clinicians’ negative attitudes towards those individuals (Jackson, 2009 and therefore on treatment outcomes in BPD.

For service users, hope often seems intertwined with a sense of belonging. This was the case in the research paper but was also articulated by individuals from other peer-led groups discussed in the narrative review (e.g., SHIFT Recovery Community, 2020; Griffiths, 2019). The experience of being with others with shared experiences, being able to share your personal

CRITICAL APPRAISAL

narrative, and having this validated and empathised with produced a sense of belonging and feelings of hope for positive change.

By developing an overarching Foundational Pattern, using the perspective of normalising rather than pathologising people's behaviour and responses, the PTMF appears to allow for everyone to find commonalities in experience and understanding that can allow them to connect with the narratives of others in a validating and compassionate way. PTMF authors posit that if this way of understanding mental health difficulties was a ubiquitous alternative, or even replacement, to the current, predominantly medicalised model, there would be a significant reduction in the stigmatisation of mental health difficulties. I would suggest that, perhaps, this would be due to the widening of opportunities for a sense of shared experiences between people: increasing opportunities for a sense of belonging between those with more severe difficulties and those with less severe difficulties: as the PTMF would see us all as qualitatively similar, with differences only in amount of adversity and distress and/or difficulty experienced. Similarly, the Enabling Environments standards, being applicable to many settings, both clinical and non-clinical, could also be a key strategy for creating safe and therapeutic spaces that bring together all those who seek to utilise them, irrespective of current categories such as that of "mental illness".

Belonging is an important factor in general wellbeing for everyone, not just those with difficulties that have been diagnosed as 'personality disorders'. Pearce and Haigh (2017) argue that the long-term effectiveness of interventions that do not address the need for belonging are likely to be limited in people with interpersonal problems, given the deleterious effects of low levels of belongingness; such as suicidality and lack of hope (Joiner, 2007). This is particularly important for those who meet the criteria for a personality disorder diagnosis, as this applies to a

CRITICAL APPRAISAL

substantial portion of them. Belongingness is also likely to be an important factor in the success of interpersonal therapy for a range of mental health difficulties, including personality disorders (Cuijpers et al., 2016).

I chose interpretative phenomenological analysis (IPA) as the method of analysis for the research paper over approaches such as grounded theory or narrative because it seemed the most suitable given the research focussed on a significant shared experience (what maintains change following completing DTC treatment) upon which participants were likely to have reflected repeatedly; producing rich data for analysis. Although my analysis resulted in a suggested model (see Figure 1 in the research paper), this was a by-product of the analysis rather than being the main goal of it. My aim was to give primacy to the way participants made sense of their experiences.

Originally the aim was to recruit between six and 12 participants. Practically, it would have been difficult to recruit more in a reasonable timeframe. Therefore, given the richness of the interview data, with all but one being over an hour in length, I felt that the sample of six was sufficient to gain useful insight into the topic under investigation and an acceptable number for IPA analysis. I was also aware that similar themes were emerging with all participants, even in Karen's case where her experience seemed the reverse of the others'. Therefore, it also appeared the sample was sufficiently homogenous.

My own interest in both DTCs and personality disorders began in 2012 with my first NHS job as a support worker in a day service for individuals with eating disorders, run loosely on DTC principles. Since that time, I have worked in different services and settings but often

CRITICAL APPRAISAL

come across the narrative of individuals with a BPD diagnosis as being difficult to treat. I also have close friends and family who have received this diagnosis and struggled with the treatment options offered to them in mainstream mental health services. I became interested in more ‘radical’ approaches to mental health treatment, such as DTCs, as different ways to approach the whole subject of mental health and illness. I was very drawn to ideas around destigmatising mental health and rethinking the use of diagnostic labels. However, many of my family and friends with psychiatric diagnoses have found them to be very useful and reassuring: hence my interest, albeit critical at times, in the PTMF (Johnstone et al., 2018) when it was first published around the time I was beginning to write this thesis.

I felt privileged that the participants agreed to take part in this research and spoke so openly to me about their experiences. I was conscious conducting the interviews, that we may discuss sensitive, and potentially, distressing topics. This, necessarily, led to some interviews being conducted slightly differently to others.

In my interview with Rachel, for example, she discussed her overdosing behaviours. She also discussed having a difficult period emotionally at the time of the interview. As a result, the interview was the longest of the six, because it was necessary to ensure she was able to keep herself safe after the interview, and was feeling stable enough to discuss potentially triggering topics during it. This meant diverging from the interview schedule to conducting an ad hoc risk assessment and at times meant that I paced the interview slower, in order to manage the anxiety that she was presenting with.

In my interview with Sam, I was unable to explore certain topics in as much depth as I would have liked, as he seemed to avoid reflecting about his own individual experiences, preferring to speak more generally about what he felt was the collective experience of those

CRITICAL APPRAISAL

attending the follow-on group. This likely still provided good insight into Sam's own views, however, he also avoided expressing criticism of the DTC or, subsequently, follow-on support, as he was actively trying to promote the value of DTC treatment to me. I believe this was his main motivation for engaging in the research. He wanted to help demonstrate the value of DTCs to ensure future funding, perhaps for fear that the peer support group, which he valued so highly, would be at risk of being cut.

More generally, from my personal perspective, it was difficult to hear participants describe ongoing distress and struggles, particularly as I was there to interview them as a researcher, not as a clinician. I often felt a pull to offer therapeutic input. On the other hand, it was inspiring to hear about the significant and meaningful changes that most participants had made, and hear their sense of hope for the future, which had developed as a result of attending the DTCs and follow-on groups. I was also particularly struck with how isolated the participants had felt before joining the DTCs and my conversations with participants increased my belief, as a clinician, in the potential power of group-based approaches, particularly those based on DTC principles.

There seemed a considerable difference between the follow-on groups offered by the different DTCs included in this research. The follow-on group for Service B, which Emma, Linda, Mary, and Rachel attended appeared, to me, to offer a better chance of maintaining and continuing positive change. This follow-on group was facilitated by professionals associated with the DTC and focussed on consolidation of learning from the DTC and supported problem solving. Also, crucially, it was time limited; meaning from the start, group members, as in the DTC, were aware they would eventually leave, moving to the next phase in their treatment

CRITICAL APPRAISAL

journey with a further reduced level of support. There was a sense of continuing progression from the participants that attended this kind of follow-on group. For Sam and Karen, their follow-on group was a peer support group that occurred more frequently and members could attend indefinitely following completion of the DTC. Sam found this follow-on group essential to the maintenance of the positive changes made in the DTC, but this seemed precarious. Reports from the participants suggested the peer support group began due to the original follow-on group, seemingly more similar to that of Service B, being suddenly discontinued; likely due to issues of funding. The change in the nature of the follow-on group for those participants, although it did seem to have benefits, appeared to stall further progress. The peer support group for Sam and, from his perspective, for many others who used the group, seemed to have become their secure base and source of a sense of belonging. However, because there was no time limit on attending, it also seemed to reduce the impetus for further growth, which may have led group members to require less support from statutory services in the future, due to finding sources of belonging and support in the community as a result of the skills and experiences taken from their time in the DTC and follow-on group.

Service B also had a day centre with a wide range of social and psychoeducational groups, which individuals could access for two years following the end of formal therapy with the service. This seemed to provide another step-down version of support, that, again, was time limited, but that continued to equip people with skills and confidence to continue to build up their lives outside of the support of mental health services. It would be useful for further research to compare the different types of follow-on groups offered by different DTCs to find the optimum model, which could then be incorporated into the gold standard model for DTC treatment. Currently there appears to be great variability to this aspect of DTC treatment, but my

CRITICAL APPRAISAL

findings would suggest that it can have a significant impact on the longer-term maintenance and even continuation of positive change following DTC treatment.

In terms of having a homogeneous sample, Karen presents an interesting case. Although she opted-in on the basis of having achieved positive change via DTC treatment, and stating in the interview that overall she regarded it as a positive experience; based on her interview she clearly gained less from it than the other participants and struggled more to maintain the positive changes in the absence of regular support from mental health professionals.

As discussed in the research paper, a key issue for Karen seemed to be that she never developed a sense of belonging amongst her peers in the DTC. She even felt bullied at times, retriggering past experiences of bullying from childhood. This experience seemed in line with Clarke and Waring's (2018) ideas concerning the importance of social rituals outside of formal therapy in building a sense of hope and belonging. They discuss that when social rituals in DTCs fail, or when group members are left out of these rituals, they can be left feeling excluded and hurt. They suggest this is important, as it is the sense of belonging that motivates group members to continue to engage in a treatment which requires them to tolerate periods of negative emotion and uncomfortable interactions in order for change to occur.

For most of the key themes, Karen's experience seemed contrary to the rest of the participants', which, for the purposes of this research, acted as a foil; seemingly demonstrating how the DTC experience differed in the absence of the key factors identified by the other participants as useful for maintaining changes. The findings from Karen's interview reinforced the idea that belonging is a crucial factor in the effectiveness of DTC treatment, but it also demonstrates that it does not happen for everyone. Could Karen's experience have been

CRITICAL APPRAISAL

different? Could group facilitators have managed the dynamics of the DTC group differently? Or are there individuals, like Karen, who seem to benefit more from individual professional support than peer support? This may also be a useful avenue for further research.

Originally, I planned to include participants who both did and did not attend the follow-on groups after completing DTC treatment. As I have discussed in the research paper, as all the participants were attending or had just finished follow-on groups, it is unclear whether the factors maintaining positive changes remain the same once support is removed and group members truly leave the DTC environment. My results suggest that the factors that cause change initially within DTCs are also important in maintaining change long-term. However, the limitations of this study would need to be addressed to determine this more clearly.

It was clear from participants' descriptions that many DTC group members decide not to attend the follow-on groups. It would be helpful to understand what influences this decision, and how it affects the maintenance of change. This could provide clinically useful information to inform decisions to use follow-on groups and determine best practice for the format of follow-on groups. For the participants in this research the follow-on groups seemed an essential part of maintaining change as they allowed for a more gradual transition out of the DTC; providing time for consolidation of skills, as well as time to accept the necessity of moving onto a new phase (for those who attended Service B). For those who do not choose to attend follow-on groups: does this negatively affect their long-term outcomes, or were they better able to cope with a more abrupt ending to treatment (perhaps due to having better existing support structures outside of services)? For this research, unfortunately, it was practically too difficult to contact individuals who had left the DTC and were not attending follow-on groups, in order to invite them to take

CRITICAL APPRAISAL

part in the study. In hindsight, however, not including them was useful for the IPA analysis, in terms of having a sample that was sufficiently homogeneous in their experiences.

It may also have been useful to have more than one participant who identified as male. Although there likely is a larger proportion of female group members in DTCs in the community setting, it is unclear how and if gender/gender identity plays a role in how DTC treatment is experienced.

Similarly, it would have been useful to include a wider selection of DTCs in the study. Several other DTCs were invited to take part in the study, and one other NHS Trust did originally agree to take part, however, in the end, they did not respond to efforts to arrange contact with the DTCs, so could not be included.

All these limitations provide interesting avenues for future research on this topic.

In light of the research findings in relation to DTCs, it would appear necessary to establish a best practice model for the nature of the follow-on groups after DTC treatment. My findings suggest, for example, that some form of professional facilitation may be useful, and that this should be time limited; as opposed to open-ended peer support. However, the findings also clearly illustrate the invaluable role of peer support as both a mechanism for initial change and a key factor in maintaining positive change longer-term. There is also an interesting question of the pros and cons of online versus face-to-face support. While there are clear practical benefits to delivering interventions online (i.e. lower cost and space requirements; can be offered to wider geographical areas, improving accessibility for service users with transport/travel issues etc.; not to mention being able to continue running a service during situations like the recent COVID-19 lockdowns) I feel my findings suggest face-to-face is likely to be the most effective option for

CRITICAL APPRAISAL

creating and maintaining significant positive change, because of key elements like the weekly jobs and tolerating being in the room with other who may be disagreeing with you or providing positive feedback: those uncomfortable interactions, which are important but can be more easily avoided online. Also online delivery does not allow for as many interactions outside of the more formal group settings, which as Clarke and Waring (2018) discuss, are also important in facilitating change within DTCs.

There are numerous roles for clinical psychologists in light of these findings. There is the obvious therapeutic role, but also as scientist practitioners clinical psychologists are ideally placed to conduct research with populations such as this where it is crucial to be mindful of participants' wellbeing as part of the interview process. Further research will be essential to the future of DTC treatment as the ability to justify the cost effectiveness of services becomes ever more important.

Clinical psychologists can also play an important role in the design and implementation of services; drawing on the evidence base to inform how service are set up, in a way that will optimise positive outcomes, which can be maintained long-term. For example, in Service B, the DTC was embedded within a wider service that provided an extensive range of day services, including both therapeutic and social groups, as well as a crisis drop-in service. In this context, group members, once they had finished the DTC, and then also the less intensive support of the follow-on group, still had access to all the day services for the next two years. This added another, further reduced level of support; providing rich opportunities for further expanding their skills learnt in the DTC; scaffolding their future growth and supporting the possibility of feeling able to integrate more effectively in community life outside statutory services in the future. One of the skills of clinical psychologists is the ability to synthesise information from different

CRITICAL APPRAISAL

sources and determine where useful changes can be made. This works at the service level, as well as at the individual formulation level.

CRITICAL APPRAISAL

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CRITICAL APPRAISAL

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Chapter 4 Ethics



Nina Hewitson

Doctorate in Clinical Psychology

Lancaster University

Word Count: 6,419 (NHS REC application and protocol)

IRAS Form

Full Set of Project Data

IRAS Version 5.19

Welcome to the Integrated Research Application System

IRAS Project Filter

The integrated dataset required for your project will be created from the answers you give to the following questions. The system will generate only those questions and sections which (a) apply to your study type and (b) are required by the bodies reviewing your study. Please ensure you answer all the questions before proceeding with your applications.

Please complete the questions in order. If you change the response to a question, please select 'Save' and review all the questions as your change may have affected subsequent questions.

Please enter a short title for this project (maximum 70 characters)
The experience of moving on from a democratic therapeutic community

1. Is your project research?

Yes No

2. Select one category from the list below:

- Clinical trial of an investigational medicinal product
- Clinical investigation or other study of a medical device
- Combined trial of an investigational medicinal product and an investigational medical device
- Other clinical trial to study a novel intervention or randomised clinical trial to compare interventions in clinical practice
- Basic science study involving procedures with human participants
- Study administering questionnaires/interviews for quantitative analysis, or using mixed quantitative/qualitative methodology
- Study involving qualitative methods only
- Study limited to working with human tissue samples (or other human biological samples) and data (specific project only)
- Study limited to working with data (specific project only)
- Research tissue bank
- Research database

If your work does not fit any of these categories, select the option below:

Other study

2a. Please answer the following question(s):

- a) Does the study involve the use of any ionising radiation? Yes No
- b) Will you be taking new human tissue samples (or other human biological samples)? Yes No
- c) Will you be using existing human tissue samples (or other human biological samples)? Yes No

3. In which countries of the UK will the research sites be located?(Tick all that apply)

England

Full Set of Project Data

IRAS Version 5.19

- Scotland
 Wales
 Northern Ireland

3a. In which country of the UK will the lead NHS R&D office be located:

- England
 Scotland
 Wales
 Northern Ireland
 This study does not involve the NHS

4. Which applications do you require?

- IRAS Form
 Confidentiality Advisory Group (CAG)
 Her Majesty's Prison and Probation Service (HMPPS)

Most research projects require review by a REC within the UK Health Departments' Research Ethics Service. Is your study exempt from REC review?

- Yes No

5. Will any research sites in this study be NHS organisations?

- Yes No

5a. Are all the research costs and infrastructure costs (funding for the support and facilities needed to carry out the research e.g. NHS support costs) for this study provided by a NIHR Biomedical Research Centre (BRC), NIHR Applied Research Collaboration (ARC), NIHR Patient Safety Translational Research Centre (PSTRC), or an NIHR Medtech and In Vitro Diagnostic Co-operative (MIC) in all study sites?

Please see information button for further details.

- Yes No

Please see information button for further details.

5b. Do you wish to make an application for the study to be considered for NIHR Clinical Research Network (CRN) Support and inclusion in the NIHR Clinical Research Network Portfolio?

Please see information button for further details.

- Yes No

The NIHR Clinical Research Network (CRN) provides researchers with the practical support they need to make clinical studies happen in the NHS in England e.g. by providing access to the people and facilities needed to carry out research "on the ground".

If you select yes to this question, information from your IRAS submission will automatically be shared with the NIHR CRN. Submission of a Portfolio Application Form (PAF) is no longer required.

6. Do you plan to include any participants who are children?

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IRAS Version 5.19

 Yes No

7. Do you plan at any stage of the project to undertake intrusive research involving adults lacking capacity to consent for themselves?

 Yes No

Answer Yes if you plan to recruit living participants aged 16 or over who lack capacity, or to retain them in the study following loss of capacity. Intrusive research means any research with the living requiring consent in law. This includes use of identifiable tissue samples or personal information, except where application is being made to the Confidentiality Advisory Group to set aside the common law duty of confidentiality in England and Wales. Please consult the guidance notes for further information on the legal frameworks for research involving adults lacking capacity in the UK.

8. Do you plan to include any participants who are prisoners or young offenders in the custody of HM Prison Service or who are offenders supervised by the probation service in England or Wales?

 Yes No

9. Is the study or any part of it being undertaken as an educational project?

 Yes No

Please describe briefly the involvement of the student(s):
This is a study for a Clinical Psychology Doctoral thesis.

9a. Is the project being undertaken in part fulfilment of a PhD or other doctorate?

 Yes No

10. Will this research be financially supported by the United States Department of Health and Human Services or any of its divisions, agencies or programs?

 Yes No

11. Will identifiable patient data be accessed outside the care team without prior consent at any stage of the project (including identification of potential participants)?

 Yes No

Integrated Research Application System
Application Form for Research involving qualitative methods only

The Chief Investigator should complete this form. Guidance on the questions is available wherever you see this symbol displayed. We recommend reading the guidance first. The complete guidance and a glossary are available by selecting [Help](#).

Please define any terms or acronyms that might not be familiar to lay reviewers of the application.

Short title and version number: (maximum 70 characters - this will be inserted as header on all forms)
 The experience of moving on from a democratic therapeutic community

PART A: Core study information
1. ADMINISTRATIVE DETAILS
A1. Full title of the research:

A qualitative study of the experience of moving on from a non-residential Democratic Therapeutic Community

A2-1. Educational projects

Name and contact details of student(s):

Student 1

	Title	Forename/Initials	Surname
	Miss	Nina	Hewitson
Address	[REDACTED]		
	[REDACTED]		
	[REDACTED]		
Post Code	[REDACTED]		
E-mail	n.hewitson@lancaster.ac.uk		
Telephone	[REDACTED]		
Fax			

Give details of the educational course or degree for which this research is being undertaken:

Name and level of course/ degree:
 DClinPsy - Doctorate in Clinical Psychology

Name of educational establishment:
 Lancaster University

Name and contact details of academic supervisor(s):

Academic supervisor 1

	Title	Forename/Initials	Surname
	Dr	Suzanne	Hodge
Address			

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IRAS Version 5.19

Furnes Building, Lancaster University, Lancaster	
Post Code	LA1 4YG
E-mail	s.hodge@lancaster.ac.uk
Telephone	01524592712
Fax	

Please state which academic supervisor(s) has responsibility for which student(s):
Please click "Save now" before completing this table. This will ensure that all of the student and academic supervisor details are shown correctly.

Student(s)	Academic supervisor(s)
Student 1 Miss Nina Hewitson	<input checked="" type="checkbox"/> Dr Suzanne Hodge

A copy of a current CV for the student and the academic supervisor (maximum 2 pages of A4) must be submitted with the application.

A2-2. Who will act as Chief Investigator for this study?

Student
 Academic supervisor
 Other

A3-1. Chief Investigator:

	Title	Forename/Initials	Surname
		Miss Nina	Hewitson
Post	Trainee Clinical Psychologist		
Qualifications			
ORCID ID			
Employer			
Work Address			
Post Code			
Work E-mail			
* Personal E-mail	n.hewitson@lancaster.ac.uk		
Work Telephone			
* Personal Telephone/Mobile	[REDACTED]		
Fax			

* This information is optional. It will not be placed in the public domain or disclosed to any other third party without prior consent.
A copy of a current CV (maximum 2 pages of A4) for the Chief Investigator must be submitted with the application.

A4. Who is the contact on behalf of the sponsor for all correspondence relating to applications for this project?
This contact will receive copies of all correspondence from REC and HRA/R&D reviewers that is sent to the CI.

Full Set of Project Data

IRAS Version 5.19

	Title Forename/Initials Surname Becky Gordon
Address	Research Support and Systems Manager Research Services Lancaster University
Post Code	
E-mail	ethics@lancaster.ac.uk
Telephone	01524592981
Fax	

A5-1. Research reference numbers. Please give any relevant references for your study:

Applicant's/organisation's own reference number, e.g. R & D (if available):

Sponsor's/protocol number:

Protocol Version: 0.1

Protocol Date: 05/12/2017

Funder's reference number (enter the reference number or state not applicable):

Project website:

Additional reference number(s):

Ref.Number	Description	Reference Number
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Registration of research studies is encouraged wherever possible. You may be able to register your study through your NHS organisation or a register run by a medical research charity, or publish your protocol through an open access publisher. If you have registered your study please give details in the "Additional reference number(s)" section.

A5-2. Is this application linked to a previous study or another current application?
 Yes No

Please give brief details and reference numbers.

2. OVERVIEW OF THE RESEARCH

To provide all the information required by review bodies and research information systems, we ask a number of specific questions. This section invites you to give an overview using language comprehensible to lay reviewers and members of the public. Please read the guidance notes for advice on this section.

A6-1. Summary of the study. Please provide a brief summary of the research (maximum 300 words) using language easily understood by lay reviewers and members of the public. Where the research is reviewed by a REC within the UK Health Departments' Research Ethics Service, this summary will be published on the Health Research Authority (HRA) website following the ethical review. Please refer to the question specific guidance for this question.

The aim of this study is to explore and understand the medium-term impacts of non-residential Democratic Therapeutic Community (DTC) membership. While there is still not a large amount of up to date research on DTCs, there have been a number of studies looking at the mechanisms of change within the DTC, as well as providing some evidence that DTCs are effective interventions for individuals with difficulties typically associated with the diagnosis of borderline personality disorder. However, there is only limited data regarding the medium and long-term effects of having attended a DTC, with follow up periods usually being quite short (e.g. 6 months). The study I am proposing here will build on these findings by developing an understanding of life after leaving a non-residential DTC, focusing particularly on how easy or difficult it is to maintain changes made, what has helped and what has made it difficult.

A6-2. Summary of main issues. Please summarise the main ethical, legal, or management issues arising from your study and say how you have addressed them.

Not all studies raise significant issues. Some studies may have straightforward ethical or other issues that can be identified and managed routinely. Others may present significant issues requiring further consideration by a REC, R&D office or other review body (as appropriate to the issue). Studies that present a minimal risk to participants may raise complex organisational or legal issues. You should try to consider all the types of issues that the different reviewers may need to consider.

It is possible that participants may become emotionally distressed due to some of the topics that will be discussed in the interviews, for example, when discussing any periods of relapse or other difficulty since leaving the DTC. It is unlikely that participants will become significantly distressed during the interview, as the main researcher would be sensitive to when participants appear to be becoming distressed and move to a different topic. If a participant does become more distressed, the main researcher will pause the interview and offer the participant a break and the rest of the interview can be rearranged or ended at that point if needed. The main researcher will explore with the participant their level of distress and establish if they require further support. Participants will be directed to the participant information sheet for sources of support if needed. If a participant is immediately at risk of harm, standard protocol will be followed and the appropriate emergency services would be contacted. For the safety of the main researcher, lone worker guidance will be followed to minimise risk of harm from participants.

3. PURPOSE AND DESIGN OF THE RESEARCH

A7. Select the appropriate methodology description for this research. Please tick all that apply:

- Case series/ case note review
- Case control
- Cohort observation
- Controlled trial without randomisation
- Cross-sectional study
- Database analysis
- Epidemiology
- Feasibility/ pilot study
- Laboratory study
- Metanalysis
- Qualitative research
- Questionnaire, interview or observation study
- Randomised controlled trial
- Other (please specify)

A10. What is the principal research question/objective? Please put this in language comprehensible to a lay person.

The principal aim of this study is to explore and understand the medium-term effects of non-residential Democratic Therapeutic Community (DTC) membership, focusing on participants' experiences of maintaining and possibly continuing change after moving on from the DTC.

A11. What are the secondary research questions/objectives if applicable? Please put this in language comprehensible to a lay person.

A12. What is the scientific justification for the research? Please put this in language comprehensible to a lay person.

There is a paucity of research concerning DTC treatment. While previous quantitative and qualitative research has

found limited evidence to suggest that DTCs are effective interventions for individuals with a diagnosis of personality disorder, the methodological quality of these studies has been weak and they have mostly focused on the mechanisms and processes of change within the DTC and outcomes at the end of treatment, with relatively short follow-up time periods.

It has been suggested that longer follow-up periods be examined and that qualitative and mixed-methods research be used to help better understand the features and processes involved in DTC treatment, in order to better design quantitative studies to evaluate the efficacy of this type of treatment.

My study therefore aims to look at experiences of people who have completed a DTC program between six months to two years ago who feel they benefited from their membership of a DTC to explore what has helped and hindered them in maintaining and possibly continuing therapeutic change.

A13. Please summarise your design and methodology. *It should be clear exactly what will happen to the research participant, how many times and in what order. Please complete this section in language comprehensible to the lay person. Do not simply reproduce or refer to the protocol. Further guidance is available in the guidance notes.*

This study will use a qualitative design. Data will be collected using semi-structured, one-to-one interviews with participants which will then be analysed using interpretative phenomenological analysis (IPA).

Participants will be recruited through several DTCs located in the [REDACTED]. The main researcher will not have access to any patient data. Participants will be recruited from lists of individuals who have completed DTC treatment between 6 months to two years ago held by the services. Information packs will be sent out by a staff member at the relevant DTC service to individuals who meet the inclusion criteria. Information packs will also be made available to individuals who meet the inclusion criteria and are currently attending follow-on or peer support groups or similar.

Information packs will include a participant information sheet and an opt-in form.

Participants will be invited to contact the main researcher if they are interested in taking part. These packs may be sent by email, post or given in person by staff at the DTCs involved in the study (for example, when potential participants attend follow-on groups or similar).

If the first attempt to recruit participants does not yield responses, the information will be sent out a second time. If this second attempt also fails to recruit the number of participants required, the main researcher will attend follow-on or peer support groups in person to invite participants to take part. The main researcher may also attempt to recruit online through social media platforms such as Facebook or Twitter.

Participants will be able to opt-in via several methods including by e-mail, post and telephone.

Between six to 12 participants will be recruited across different DTC services.

Once participants have opted-in to being contacted by the main researcher, they will be contacted and offered the opportunity to ask further questions about the study and taking part. If they are still interested after this a date, time and location for a semi-structured interview will be agreed. These interviews will last approximately one hour. Interviews may be face-to-face either at trust premises, community venues (e.g. GP surgery) or at the participant's home.

Interviews may also be via telephone or Skype. Lancaster University will pay up to £20 for each participant per interview if participants require reimbursement for travel expenses to attend interview.

At the beginning of each interview, the main researcher will introduce themselves and review the participant information sheet, restating the purpose of the interview and the consent form. Consent will be obtained and then demographic information will be collected; including age, gender, ethnicity, which DTC they attended, how long they were there for, how long since they left and whether they have now or in the past been involved in any follow-on or transition groups or similar.

The interview will then take approximately one hour and will be audio recorded. An interview schedule will be broadly followed, which outlines topics to be discussed. The exact questions asked will be dependent on the participant's responses; therefore each interview will be guided partly by what the participant decides is important.

Participants will be offered breaks if needed due to fatigue or distress and if the participant wishes to continue the interview on another day, the main researcher will arrange this if possible.

At the end of the interview participants will be thanked for taking part and provided with a debrief sheet containing contact details for the research team, should they have any questions following the interview or if they wish to withdraw their consent. Participants can withdraw their data up to two weeks after the interview has taken place. The debrief sheet also contains details for sources of support and the main researcher will direct the participant to these details if they appear to be distressed.

Timescale:

October 2017 – ethical and research governance approval

November – January 2017 – conduct interviews

February 2017 – May 2018 – analyse data and write up research paper

May – July 2018 – submit thesis and present findings.

A14-1. In which aspects of the research process have you actively involved, or will you involve, patients, service users, and/or their carers, or members of the public?

Full Set of Project Data

IRAS Version 5.19

- Design of the research
- Management of the research
- Undertaking the research
- Analysis of results
- Dissemination of findings
- None of the above

Give details of involvement, or if none please justify the absence of involvement.

Experts by experience were present at a meeting the main researcher attended to explore the feasibility of the study aims and design. Their views were taken into consideration when designing the study and interview schedule.

The main researcher intends to use a service user consultant who has completed a DTC program themselves to contribute to comments on draft reads of the written report.

The main researcher aims to feedback results of this study to the services and participants involved by a document summarising the findings and/or via a verbal presentation.

4. RISKS AND ETHICAL ISSUES

RESEARCH PARTICIPANTS

A15. What is the sample group or cohort to be studied in this research?

Select all that apply:

- Blood
- Cancer
- Cardiovascular
- Congenital Disorders
- Dementias and Neurodegenerative Diseases
- Diabetes
- Ear
- Eye
- Generic Health Relevance
- Infection
- Inflammatory and Immune System
- Injuries and Accidents
- Mental Health
- Metabolic and Endocrine
- Musculoskeletal
- Neurological
- Oral and Gastrointestinal
- Paediatrics
- Renal and Urogenital
- Reproductive Health and Childbirth
- Respiratory
- Skin
- Stroke

Full Set of Project Data

IRAS Version 5.19

Gender:	Male and female participants
Lower age limit: 18	Years
Upper age limit:	No upper age limit

A17-1. Please list the principal inclusion criteria (list the most important, max 5000 characters).

Individuals who have completed (defined as having a planned discharge from the DTC after completing the expected duration of treatment) the DTC between six months to two years ago.
This is to ensure that participants have had time since completing DTC treatment to process their experience of DTC membership, as well as having sufficient time to have a sense of what has helped or hindered the maintenance and/or continuation of positive changes. The cut off has been set at two years since completing the DTC, as it was felt that participants' experiences within this period would be remembered in enough detail to provide the rich data that is required for this study.

A17-2. Please list the principal exclusion criteria (list the most important, max 5000 characters).

Individuals who are not able to fluently speak and understand English will be excluded, as it is not feasible to fund interpreters or translators for this study. As recruitment will be through DTCs that operate in the medium of English, participants would have to be fluent in English to have engaged in the services, therefore, it is not anticipated that this criterion would unduly affect potential participants' ability to take part in the study.

RESEARCH PROCEDURES, RISKS AND BENEFITS**A18. Give details of all non-clinical intervention(s) or procedure(s) that will be received by participants as part of the research protocol. These include seeking consent, interviews, non-clinical observations and use of questionnaires.**

Please complete the columns for each intervention/procedure as follows:

1. Total number of interventions/procedures to be received by each participant as part of the research protocol.
2. If this intervention/procedure would be routinely given to participants as part of their care outside the research, how many of the total would be routine?
3. Average time taken per intervention/procedure (minutes, hours or days)
4. Details of who will conduct the intervention/procedure, and where it will take place.

Intervention or procedure	1	2	3	4
Seeking consent	1	n/a	10 minutes	Main researcher, either face-to-face or via telephone or Skype
Semi-structured interview	1	n/a	1 hour	Main researcher, either face-to-face or via telephone or Skype
Debrief	1	n/a	10 minutes	Main researcher, either face-to-face or via telephone or Skype

A21. How long do you expect each participant to be in the study in total?

Approximately 1.5 hours. Participants will be offered the opportunity to receive a summary of the results of the study - if they want this, the main researcher will send this out to those participants when the study is complete.

A22. What are the potential risks and burdens for research participants and how will you minimise them?

For all studies, describe any potential adverse effects, pain, discomfort, distress, intrusion, inconvenience or changes to lifestyle. Only describe risks or burdens that could occur as a result of participation in the research. Say what steps would be taken to minimise risks and burdens as far as possible.

It is possible that participants may become emotionally distressed due to the topics that may be discussed in the interviews, for example, when discussing any periods of relapse or other difficulty since leaving the DTC. It is unlikely that participants will become significantly distressed during the interview, as the main researcher would be sensitive to when participants appear to be becoming distressed and move to a different topic. If participants do become more distressed during interviews, they will be offered the opportunity to take a break, or to halt the interview and either discontinue their participation or rearrange a time to complete the interview at a later date if possible. The

Full Set of Project Data

IRAS Version 5.19

main researcher will explore with the participant their level of distress and establish if they require further support. Participants will be directed to sources of support listed in the participant information sheet and the debrief sheet. If any participant is at immediate risk of harm, standard protocol would be followed and the appropriate emergency services would be contacted. Participants can withdraw their data up to two weeks after the interview has taken place, this timeframe has been chosen so that the main researcher can recruit further participants to replace any data that has been withdrawn and to reduce the likelihood that the individual participants' data have not yet been pooled.

A23. Will interviews/ questionnaires or group discussions include topics that might be sensitive, embarrassing or upsetting, or is it possible that criminal or other disclosures requiring action could occur during the study?

Yes No

If Yes, please give details of procedures in place to deal with these issues:

As already discussed, it is possible that participants will become emotionally distressed due to the topics that will be discussed, such as discussing any periods of relapse or other difficulty since leaving the DTC. Although unlikely, it is also possible that criminal or other disclosures requiring action could occur. If such disclosures occur, normal safeguarding procedures will be followed.

A24. What is the potential for benefit to research participants?

There are no direct benefits to participants taking part in this study, although it may be interesting for participants to have an opportunity to discuss their experiences.

A26. What are the potential risks for the researchers themselves? (if any)

As face-to-face interviews will involve the main researcher and the participant only, and may occur in a variety of settings, there may be a risk of harm to the main researcher. The main researcher will follow Lancaster University's Lone Worker policy in order to minimise potential risks; providing details of the time and location of any interviews to the research supervision. The main researcher will develop a plan with the research supervisor regarding how to check in and confirm safety after each interview, and an emergency procedure to follow in the case of failure to check in. This will be particularly relevant for home interviews which will be offered as an option to allow participants who may struggle with transport or caring responsibilities, for example, to be able to take part in the study. Topics to be discussed could also cause the interviewer emotional distress. If this occurs, the main researcher will contact the research supervisor or a member of the DClinPsy clinical staff at Lancaster University for support.

RECRUITMENT AND INFORMED CONSENT

In this section we ask you to describe the recruitment procedures for the study. Please give separate details for different study groups where appropriate.

A27-1. How will potential participants, records or samples be identified? Who will carry this out and what resources will be used? For example, identification may involve a disease register, computerised search of social care or GP records, or review of medical records. Indicate whether this will be done by the direct care team or by researchers acting under arrangements with the responsible care organisation(s).

The main researcher will not have access to participants' medical records. Potential participants will be identified by the services involved from a list of individuals who have completed that particular DTC within the last six months to two years ago. Information packs will be sent/made available to these individuals by the services involved. Once participants have opted-in to receiving more information, the main researcher will be able to make contact and answer questions and arrange an interview.

A27-2. Will the identification of potential participants involve reviewing or screening the identifiable personal information of patients, service users or any other person?

Yes No

Please give details below:

A28. Will any participants be recruited by publicity through posters, leaflets, adverts or websites?

Yes No

If Yes, please give details of how and where publicity will be conducted, and enclose copy of all advertising material (with version numbers and dates).

The participant information sheet will be used to advertise the details of the study and invite potential participants to contact the main researcher.

If attempts to recruit through DTC services and follow-on or transition groups or similar do not yield a sufficient number of participants, the main researcher will attempt to recruit participants through social media platforms such as Facebook or Twitter by posting the participant information sheet and inviting potential participants to contact the main researcher for further information.

A29. How and by whom will potential participants first be approached?

Potential participants will receive an information pack via the DTC services which they attended in the past. This may be by post, email, or in person if the potential participants attend any follow-on, peer support groups or similar associated with the DTC service that they attended.

If this method fails to generate enough participants, the main researcher may attend follow-on and peer support groups in person to talk to potential participants about the study and offer information packs to any individuals who are interested in finding out more about taking part. Participants will be allowed to take the participant information sheets away with them, and will have at least 24 hours to decide if they wish to take part in the research.

If it is necessary to advertise via social media, potential participants will respond to the participant information sheet which the main researcher will have posted on the social media platform in question.

A30-1. Will you obtain informed consent from or on behalf of research participants?

Yes No

If you will be obtaining consent from adult participants, please give details of who will take consent and how it will be done, with details of any steps to provide information (a written information sheet, videos, or interactive material). Arrangements for adults unable to consent for themselves should be described separately in Part B Section 6, and for children in Part B Section 7.

If you plan to seek informed consent from vulnerable groups, say how you will ensure that consent is voluntary and fully informed.

At the beginning of each interview, the main researcher will introduce themselves and review the participant information sheet, restating the purpose of the interview. They will then review the consent form. If the participant agrees to take part, in face-to-face interviews they will provide written consent using the consent form; while in telephone or Skype interviews they will provide verbal consent which will be audio recorded. The verbal consent recordings will be separate files to the audio recordings of the main interview.

If you are not obtaining consent, please explain why not.

Please enclose a copy of the information sheet(s) and consent form(s).

A30-2. Will you record informed consent (or advice from consultees) in writing?

Yes No

If No, how will it be recorded?

For telephone or Skype interviews, consent will be obtained verbally and audio recorded. The procedure will be the same as above regarding the reviewing of the participant information and the consent form. Instead of completing the written consent form however, the main researcher will read out the consent form in full and audio record the participant confirming their agreement to each item.

A31. How long will you allow potential participants to decide whether or not to take part?

Participants will usually have at least 24 hours to decide whether or not to take part. Interviews will be arranged in

Full Set of Project Data

IRAS Version 5.19

advance. The participants will have multiple opportunities to ask questions to aid their decision about taking part. Once they arrive for interview (either in person or over the telephone or on Skype) they will once again be provided with an opportunity to ask questions and decide whether they wish to continue and take part in the study.

A33-1. What arrangements have been made for persons who might not adequately understand verbal explanations or written information given in English, or who have special communication needs?(e.g. translation, use of interpreters)

The interviews will be conducted in English and audio recorded for the purpose of analysis. Funding will not allow the use of translators or interpreters, therefore, recruitment will exclude participants who cannot communicate independently in spoken English.

As recruitment will be through DTCs that operate in the medium of English, participants would have to be fluent in English to have engaged in the services, therefore, it is not anticipated that this criterion would unduly affect potential participants' ability to take part in the study.

A33-2. What arrangements will you make to comply with the principles of the Welsh Language Act in the provision of information to participants in Wales?

If a participant requests a Welsh version of any of the participant documents then they will be provided.

A35. What steps would you take if a participant, who has given informed consent, loses capacity to consent during the study? Tick one option only.

- The participant and all identifiable data or tissue collected would be withdrawn from the study. Data or tissue which is not identifiable to the research team may be retained.
- The participant would be withdrawn from the study. Identifiable data or tissue already collected with consent would be retained and used in the study. No further data or tissue would be collected or any other research procedures carried out on or in relation to the participant.
- The participant would continue to be included in the study.
- Not applicable – informed consent will not be sought from any participants in this research.
- Not applicable – it is not practicable for the research team to monitor capacity and continued capacity will be assumed.

Further details:

CONFIDENTIALITY

In this section, personal data means any data relating to a participant who could potentially be identified. It includes pseudonymised data capable of being linked to a participant through a unique code number.

Storage and use of personal data during the study

A36. Will you be undertaking any of the following activities at any stage (including in the identification of potential participants)?(Tick as appropriate)

- Access to medical records by those outside the direct healthcare team
- Access to social care records by those outside the direct social care team
- Electronic transfer by magnetic or optical media, email or computer networks
- Sharing of personal data with other organisations
- Export of personal data outside the EEA
- Use of personal addresses, postcodes, faxes, emails or telephone numbers
- Publication of direct quotations from respondents
- Publication of data that might allow identification of individuals

Full Set of Project Data

IRAS Version 5.19

- Use of audio/visual recording devices
- Storage of personal data on any of the following:
- Manual files (includes paper or film)
 - NHS computers
 - Social Care Service computers
 - Home or other personal computers
 - University computers
 - Private company computers
 - Laptop computers

*Further details:***A37. Please describe the physical security arrangements for storage of personal data during the study?**

Personal data in this study will be contact details that participants provide when they opt-in to be contacted by the main researcher and recordings of participants voices during the interviews. The contact details will be stored securely on Lancaster University VPN or another secure storage facility approved by the University (e.g. Box). Data held on portable devices will be encrypted when possible; if data cannot be encrypted, any identifiable data, such as recordings of participants' voices, will be deleted from the device as quickly as possible (e.g. when transferred to a secure medium, such as a secure storage facility approved by the university (e.g. Box)) and the device will be stored securely in the meantime. Once participants have completed the interview and been sent their copy of the summary of results or details about any verbal presentations of the findings, their personal data will be securely deleted. Any participants who withdraw from the study will have their personal data deleted at the point of withdrawal.

A38. How will you ensure the confidentiality of personal data? Please provide a general statement of the policy and procedures for ensuring confidentiality, e.g. anonymisation or pseudonymisation of data.

Personal data (e.g. contact details of participants) will be kept separately to the research data. Identifying numbers will be allocated to participants to allow their data to be linked to contact details if necessary, for example, if participants request for their data to be withdrawn from the study.

The files for written or verbal consent will be securely stored separately to the audio recordings of the interviews and the files of the transcribed interviews. All digital files will be appropriately labelled.

The transcribed interviews will be anonymised to ensure participant confidentiality.

A40. Who will have access to participants' personal data during the study? Where access is by individuals outside the direct care team, please justify and say whether consent will be sought.

Only the main researcher, the research supervisor and the field supervisor will have access to the participants' personal data during the study.

Storage and use of data after the end of the study**A41. Where will the data generated by the study be analysed and by whom?**

The data generated by the study will be analysed primarily by the main researcher at Lancaster University. The research supervisor and field supervisor may also be consulted during the analysis of the data.

A42. Who will have control of and act as the custodian for the data generated by the study?

Title	Forename/Initials	Surname
Professor	Bill	Sellwood

Full Set of Project Data

IRAS Version 5.19

Post	Programme Director, Doctorate in Clinical Psychology, Lancaster
Qualifications	University PhD
Work Address	Division of Health Research Furness College, Lancaster University Lancaster
Post Code	LA1 4YG
Work Email	b.sellwood@lancaster.ac.uk
Work Telephone	01524593398
Fax	01524592401

A43. How long will personal data be stored or accessed after the study has ended?

- Less than 3 months
 3 – 6 months
 6 – 12 months
 12 months – 3 years
 Over 3 years

A44. For how long will you store research data generated by the study?

Years: 10
Months:

A45. Please give details of the long term arrangements for storage of research data after the study has ended. Say where data will be stored, who will have access and the arrangements to ensure security.

Digital files of the audio recordings of the interviews (and verbal consent in the case of telephone or Skype interviews) will be deleted from the recorder as quickly as possible after the interview has concluded, when it will be transferred to a secure file storage site (e.g. the VPN. Box or other secure facility approved by Lancaster University). At that point the files will be deleted from the recorder. Whilst the files are still on the recorder, this device will be stored securely by the main researcher.

Written participant consent forms will be scanned as quickly as possible after the interview has concluded and stored on a secure file storage site, as described above. The original hard copies will be securely destroyed (shredded). The interviews will be transcribed by the main researcher. These files will also be transferred to a secure file storage site approved by Lancaster University.

Once the written report for the study is complete and has been examined, digital files of the audio recordings of the interviews will be securely destroyed.

The scanned participant consent forms and the audio files of verbal consent for any telephone or Skype interviews and the files of transcribed anonymised interviews will be kept securely by Lancaster University for either 10 years or 10 years after publication, whichever is longest. After this, all files will be deleted. Secure storage refers to storage on Lancaster University server. Storage and deletion of data will be the responsibility of the DClinPsy Research Co-ordinator, under the line management of the Programme/Research Director.

INCENTIVES AND PAYMENTS**A46. Will research participants receive any payments, reimbursement of expenses or any other benefits or incentives for taking part in this research?**

- Yes No

If Yes, please give details. For monetary payments, indicate how much and on what basis this has been determined. Lancaster University will reimburse travel expenses to attend interview if required by participants up to £20 per participant per interview.

Full Set of Project Data

IRAS Version 5.19

A47. Will individual researchers receive any personal payment over and above normal salary, or any other benefits or incentives, for taking part in this research?

Yes No

A48. Does the Chief Investigator or any other investigator/collaborator have any direct personal involvement (e.g. financial, share holding, personal relationship etc.) in the organisations sponsoring or funding the research that may give rise to a possible conflict of interest?

Yes No

NOTIFICATION OF OTHER PROFESSIONALS

A49-1. Will you inform the participants' General Practitioners (and/or any other health or care professional responsible for their care) that they are taking part in the study?

Yes No

If Yes, please enclose a copy of the information sheet/letter for the GP/health professional with a version number and date.

PUBLICATION AND DISSEMINATION

A50-1. Will the research be registered on a public database?

Yes No

*Please give details, or justify if not registering the research.
No suitable register exists.*

*Registration of research studies is encouraged wherever possible.
You may be able to register your study through your NHS organisation or a register run by a medical research charity, or publish your protocol through an open access publisher. If you are aware of a suitable register or other method of publication, please give details. If not, you may indicate that no suitable register exists. Please ensure that you have entered registry reference number(s) in question A5-1.*

A51. How do you intend to report and disseminate the results of the study? Tick as appropriate:

- Peer reviewed scientific journals
- Internal report
- Conference presentation
- Publication on website
- Other publication
- Submission to regulatory authorities
- Access to raw data and right to publish freely by all investigators in study or by Independent Steering Committee on behalf of all investigators
- No plans to report or disseminate the results
- Other (please specify)

A research report will be produced as part of the thesis for the Doctorate of Clinical Psychology at Lancaster University. Study findings will also be presented to the other Clinical Psychology trainees and staff and service users on the Lancaster Programme. Participants will be able to either attend a presentation or be provided with a written summary

Full Set of Project Data

IRAS Version 5.19

of the findings of the study. Finally, research may also be published in academic journals/ presented at conferences.

A52. If you will be using identifiable personal data, how will you ensure that anonymity will be maintained when publishing the results?

The interview data will be anonymised. Any quotes used in the report or any published articles will be chosen carefully in order to protect participants' confidentiality.

A53. How and when will you inform participants of the study results?

If there will be no arrangements in place to inform participants please justify this.

Participants will be offered a summary of the study's results. Results may also be presented in person at the services involved.

5. Scientific and Statistical Review

A54-1. How has the scientific quality of the research been assessed? Tick as appropriate:

- Independent external review
- Review within a company
- Review within a multi-centre research group
- Review within the Chief Investigator's institution or host organisation
- Review within the research team
- Review by educational supervisor
- Other

Justify and describe the review process and outcome. If the review has been undertaken but not seen by the researcher, give details of the body which has undertaken the review:

This research proposal has been peer-reviewed by members of the research staff on the clinical psychology programme at Lancaster University.

For all studies except non-doctoral student research, please enclose a copy of any available scientific critique reports, together with any related correspondence.

For non-doctoral student research, please enclose a copy of the assessment from your educational supervisor/ institution.

A59. What is the sample size for the research? How many participants/samples/data records do you plan to study in total? If there is more than one group, please give further details below.

Total UK sample size: 12

Total international sample size (including UK): 12

Total in European Economic Area:

Further details:

A60. How was the sample size decided upon? If a formal sample size calculation was used, indicate how this was done, giving sufficient information to justify and reproduce the calculation.

This study aims to recruit between six to 12 participants. The lower end of this range is in line with what is considered to be an appropriate amount for conducting professional doctorate IPA studies. However, to maximise publishability, the higher end of the range will be aimed for as many academic journals require larger sample sizes for qualitative research to be accepted for publication.

A62. Please describe the methods of analysis (statistical or other appropriate methods, e.g. for qualitative research) by

Full Set of Project Data

IRAS Version 5.19

which the data will be evaluated to meet the study objectives.

This will be a qualitative study. Data will be collected using semi-structured interviews which will be transcribed and anonymised by the main researcher. The data will be analysed by the main researcher using interpretative phenomenological analysis (IPA). This method of analysis involves an initial close reading of the transcripts, followed by indentifying initial themes which are then refined and clustered into the final themes. Links are made between the resulting themes and a narrative developed about how they interconnect.

IPA produces detailed accounts of lived experience. This method is explicitly idiographic; examining each case in depth before developing into a more general account of the themes within the data set. Described as a set of flexible guidelines to be adapted to particular research aims, IPA is a particularly useful methodology when examining emotionally laden and complex topics such as in this study.

The research supervisor and field supervisor will be consulted during the analysis phase of the study to ensure that particular areas of the data are not being overrepresented.

6. MANAGEMENT OF THE RESEARCH

A63. Other key investigators/collaborators. Please include all grant co-applicants, protocol co-authors and other key members of the Chief Investigator's team, including non-doctoral student researchers.

	Title	Forename/Initials	Surname
Post	█	█	█
Qualifications	████████████████████		
Employer	█		
Work Address	████████████████████		
Post Code	██████████		
Telephone	██████████		
Fax	██████████		
Mobile	██████████		
Work Email	████████████████████		

A64. Details of research sponsor(s)

A64-1. Sponsor

Lead Sponsor

- Status: NHS or HSC care organisation
 Academic
 Pharmaceutical industry
 Medical device industry
 Local Authority
 Other social care provider (including voluntary sector or private organisation)
 Other

Commercial status:

If Other, please specify:

Full Set of Project Data

IRAS Version 5.19

Contact person	
Name of organisation	Lancaster University
Given name	Becky
Family name	Gordon
Address	Research Services, Lancaster University
Town/city	Lancaster
Post code	LA1 4YH
Country	United Kingdom
Telephone	01524592981
Fax	
E-mail	ethics@lancaster.ac.uk

A65. Has external funding for the research been secured?*Please tick at least one check box.*

- Funding secured from one or more funders
- External funding application to one or more funders in progress
- No application for external funding will be made

What type of research project is this?

- Standalone project
- Project that is part of a programme grant
- Project that is part of a Centre grant
- Project that is part of a fellowship/ personal award/ research training award
- Other

Other – please state:

A66. Has responsibility for any specific research activities or procedures been delegated to a subcontractor (other than a co-sponsor listed in A64-1)? Please give details of subcontractors if applicable.

- Yes No

A67. Has this or a similar application been previously rejected by a Research Ethics Committee in the UK or another country?

- Yes No

Please provide a copy of the unfavourable opinion letter(s). You should explain in your answer to question A6-2 how the reasons for the unfavourable opinion have been addressed in this application.

A68-1. Give details of the lead NHS R&D contact for this research:

Full Set of Project Data

IRAS Version 5.19

	Title	Forename/Initials	Surname
Organisation			
Address			
Post Code			
Work Email			
Telephone			
Fax			
Mobile			

Details can be obtained from the NHS R&D Forum website: <http://www.rdforum.nhs.uk>

A69-1. How long do you expect the study to last in the UK?

Planned start date: 20/11/2017

Planned end date: 31/05/2018

Total duration:

Years: 0 Months: 6 Days: 12

A71-1. Is this study?

- Single centre
 Multicentre

A71-2. Where will the research take place? (Tick as appropriate)

- England
 Scotland
 Wales
 Northern Ireland
 Other countries in European Economic Area

Total UK sites in study

Does this trial involve countries outside the EU?

- Yes No

A72. Which organisations in the UK will host the research? Please indicate the type of organisation by ticking the box and give approximate numbers if known:

- NHS organisations in England 2
 NHS organisations in Wales 1
 NHS organisations in Scotland
 HSC organisations in Northern Ireland
 GP practices in England
 GP practices in Wales
 GP practices in Scotland

Full Set of Project Data

IRAS Version 5.19

<input type="checkbox"/> GP practices in Northern Ireland <input type="checkbox"/> Joint health and social care agencies (eg community mental health teams) <input type="checkbox"/> Local authorities <input type="checkbox"/> Phase 1 trial units <input type="checkbox"/> Prison establishments <input type="checkbox"/> Probation areas <input type="checkbox"/> Independent (private or voluntary sector) organisations <input type="checkbox"/> Educational establishments <input type="checkbox"/> Independent research units <input type="checkbox"/> Other (give details)	
Total UK sites in study:	3

A73-1. Will potential participants be identified through any organisations other than the research sites listed above?

Yes No

A74. What arrangements are in place for monitoring and auditing the conduct of the research?

The main researcher will meet monthly with the research supervisor and will have email and phone contact with the field supervisor as needed with the option of meeting if required.
 Research and field supervisor will offer advice and supervision during the study regarding data collection and analysis of data and any other relevant issues that arise.

A76. Insurance/ indemnity to meet potential legal liabilities

Note: in this question to NHS indemnity schemes include equivalent schemes provided by Health and Social Care (HSC) in Northern Ireland

A76-1. What arrangements will be made for insurance and/or indemnity to meet the potential legal liability of the sponsor(s) for harm to participants arising from the management of the research? Please tick box(es) as applicable.

Note: Where a NHS organisation has agreed to act as sponsor or co-sponsor, indemnity is provided through NHS schemes. Indicate if this applies (there is no need to provide documentary evidence). For all other sponsors, please describe the arrangements and provide evidence.

- NHS indemnity scheme will apply (NHS sponsors only)
 Other insurance or indemnity arrangements will apply (give details below)

Lancaster University legal liability cover will apply.

Please enclose a copy of relevant documents.

A76-2. What arrangements will be made for insurance and/ or indemnity to meet the potential legal liability of the sponsor(s) or employer(s) for harm to participants arising from the design of the research? Please tick box(es) as applicable.

Note: Where researchers with substantive NHS employment contracts have designed the research, indemnity is provided through NHS schemes. Indicate if this applies (there is no need to provide documentary evidence). For other protocol authors (e.g. company employees, university members), please describe the arrangements and provide evidence.

NHS indemnity scheme will apply (protocol authors with NHS contracts only)

Other insurance or indemnity arrangements will apply (give details below)

Lancaster University legal liability cover will apply.

Please enclose a copy of relevant documents.

A76-3. What arrangements will be made for insurance and/ or indemnity to meet the potential legal liability of investigators/collaborators arising from harm to participants in the conduct of the research?

Note: Where the participants are NHS patients, indemnity is provided through the NHS schemes or through professional indemnity. Indicate if this applies to the whole study (there is no need to provide documentary evidence). Where non-NHS sites are to be included in the research, including private practices, please describe the arrangements which will be made at these sites and provide evidence.

NHS indemnity scheme or professional indemnity will apply (participants recruited at NHS sites only)

Research includes non-NHS sites (give details of insurance/ indemnity arrangements for these sites below)

Please enclose a copy of relevant documents.

A78. Could the research lead to the development of a new product/process or the generation of intellectual property?

Yes No Not sure

PART C: Overview of research sites

Please enter details of the host organisations (Local Authority, NHS or other) in the UK that will be responsible for the research sites. For further information please refer to guidance.

Investigator identifier	Research site	Investigator Name
IN1	<input checked="" type="radio"/> NHS/HSC Site <input type="radio"/> Non-NHS/HSC Site Organisation name [REDACTED] Address [REDACTED] Post Code [REDACTED] Country [REDACTED]	Forename Nina Middle name Family name Hewitson Email n.hewitson@lancaster.ac.uk Qualification (MD...) Country United Kingdom
IN2	<input checked="" type="radio"/> NHS/HSC Site <input type="radio"/> Non-NHS/HSC Site	Forename Nina Middle name

Full Set of Project Data

IRAS Version 5.19

	Organisation name Address Post Code Country	[Redacted] [Redacted] [Redacted] [Redacted]	Family name Hewitson Email n.hewitson@lancaster.ac.uk Qualification (MD...) Country United Kingdom
IN3	<input checked="" type="radio"/> NHS/HSC Site <input type="radio"/> Non-NHS/HSC Site		Forename Nina Middle name Family name Hewitson Email n.hewitson@lancaster.ac.uk Qualification (MD...) Country United Kingdom
	Organisation name Address Post Code Country	[Redacted] [Redacted] [Redacted]	

Research Protocol

Name of applicant and main researcher: Nina Hewitson, Lancaster University

Research supervisor: Suzanne Hodge, Lancaster University

Field supervisor: Lucy Morris, Clinical Psychologist

Version: 1

Introduction

Therapeutic communities (TCs) have been defined by psychodynamic therapists as interventions where the community is the primary therapeutic instrument that is consciously designed to harness the social and group processes (Roberts, 1997). TCs are used in approximately 60 countries worldwide including the United Kingdom and the United States (Pearce & Haigh, 2017). There are two main models of TC; the concept or hierarchical and the democratic TC model. Concept TCs have been extensively studied and are most frequently used in prison settings and to treat drug and alcohol addiction. This study will focus on the democratic TC model.

Democratic therapeutic communities (DTCs) are a psychosocial intervention using a collaborative and deinstitutionalised approach to the therapeutic relationship between staff and service users and emphasise empowerment, personal responsibility, shared decision-making and participation in communal activity (Campling, 2001). Haigh (1999) identified five qualities that create a DTC: attachment, containment, open communication, involvement and agency. In the UK this intervention has been used for the treatment of individuals with a personality disorder diagnosis (Pearce & Haigh, 2017) with the aims of reducing self-harming behaviour, aggression, impulsive behaviour and use of services (i.e. in-patient and out-patient

treatment related to their mental health difficulties) and increasing wellbeing, decision making and interpersonal functioning. Originally developed as residential services, the model has been extended to non-residential DTCs, due to issues around cost, which led to many residential DTCs being closed (Pearce & Haigh, 2017).

The effectiveness of the DTC approach has been researched. A meta-analysis by Lees, Manning and Rawlings (2004) found that, although the quality of the studies included was not high, there was evidence to support the effectiveness of the approach. Their paper also recommended further quantitative and qualitative research into the DTC approach, to produce stronger evidence.

Subsequently a study by Barr et al. (2010) looked at the DTC approach in one-day a week communities and found that group members demonstrated improvements in mental health and social functioning. This study also looked qualitatively at the experiences of group members attending these DTCs and findings indicated that group members became less dependent on self-harm as a coping strategy and developed improved methods of relating to others (Hodge et al., 2010). Subsequent research by Morris (2014) looked qualitatively at the process of change in non-residential DTCs. The findings described a reciprocal process by which individuals gradually take on the identity of a group member and work on both sides of the therapeutic relationship to support each other's progress.

Pearce et al. (2017) reported the results of a recent randomised controlled trial (RCT) looking at non-residential DTC treatment. In this study, participants who were confirmed as meeting the criteria for personality disorder were randomly assigned to either a DTC or crisis planning plus treatment as usual (TAU). Participants were followed up at 12 and 24 months and findings showed that levels of self-harm, aggression and satisfaction with care were significantly

improved in the DTC condition, compared to the TAU group. Pearce et al. (2017) however, also concluded that a longer follow-up time was required to robustly demonstrate the effectiveness of DTC at improving outcomes in individuals with a personality disorder diagnosis, partly due to the length of a DTC intervention, which is comparatively longer than other interventions, but also because of constraints such as the occurrence of waiting lists to enter DTC groups. Levy (2008) called for longer-term follow-up studies to demonstrate the significance of different psychotherapeutic interventions for improving outcomes in individuals with a borderline personality disorder diagnosis. Research has already suggested the DTC approach can lead to long-term, sustained benefits in outcomes. Pearce et al. (2017) stated that they were carrying out a 5-year follow-up RCT study, which may build upon their current quantitative findings.

There is not currently any research that has qualitatively examined the medium to long-term experiences of individuals who have completed and moved on from non-residential DTCs. The current study aims to fill this gap and provide rich data concerning what helps and hinders the maintenance and continuation of change after leaving a non-residential DTC.

The aim of this study is to explore and understand the medium-term impacts of non-residential Democratic Therapeutic Community (DTC) membership. Previous quantitative and qualitative research has suggested that DTCs are an effective intervention for individuals with personality disorder diagnoses. Research so far has mainly focussed on the mechanisms and processes of change within the DTC and outcomes at the end of treatment, with shorter follow-up times. There is little research examining the experiences of individuals after leaving DTCs. The study I am proposing will look at the experiences of people who have completed the DTC program between six months to two years ago, who feel they have benefited overall from their

time in the DTC. It will focus on participants' experiences of maintaining and possibly continuing change after moving on from the DTC.

Method

Design

A qualitative design will be used in this study. Data will be collected using semi-structured interviews which will be analysed using interpretative phenomenological analysis (IPA) (Smith & Eatough, 2016).

Participants

Participants will be recruited through several DTCs located in the north-west of England and north Wales. The main researcher will not have access to service users' personal data, therefore individuals on the services' lists of past service users and individuals currently attending follow-on, transition or peer groups or similar who match the inclusion criteria will be sent information about the study by staff at the TCs involved in the study and invited to contact the main researcher if they are interested in taking part. Inclusion criteria will be individuals who have completed (defined as having a planned discharge from the DTC after completing the expected duration of treatment) the therapeutic community treatment between six months to two years ago. This is to ensure that participants have had time since completing DTC treatment to process their experience of DTC membership, as well as having sufficient time to have a sense of what has helped or hindered the maintenance and/or continuation of positive changes. The cut off has been set at two years since completing the DTC, as it was felt that participants' experiences within this period would be remembered in enough detail to provide the rich detail that is required for the chosen method of analysis in this study.

Individuals who are not fluent in understanding and speaking English will be excluded from this study, as it will not be possible to fund interpreters or translators for this study. As recruitment will be through DTCs that operate in the medium of English, participants would have to be fluent in English to have engaged in the services, therefore, it is not anticipated that this criterion would unduly affect potential participants' ability to take part in the study. However, in accordance with the Welsh Language Act, if a participant requests a Welsh version of any of the participant documents then they will be provided.

Between six to 12 participants will be recruited across the different DTC services. The lower end of this range is in line with the number of participants thought to be appropriate for conducting professional doctorate IPA studies (Thompson, Larkin & Smith, 2011). However, many academic journals require larger sample sizes for qualitative research to be accepted for publication. As it is hoped that this research will be making a novel and valuable contribution to an area of practice for which there is currently little evidence, it is particularly important that its publishability is optimised. Thus, the higher end of the sample range will be aimed for if possible.

Materials

For the semi-structured interviews an interview schedule will be used (see appendix D). Other materials to be used in this study are: participant information sheet, opt-in form, consent form and debrief sheet.

Procedure

A pack containing a participant information sheet and opt-in form will be sent out by the participating DTCs to individuals who have completed the DTC between six months to two years ago. These packs may be sent by email, post, or in person (for instance when potential

participants attend follow-on or peer support groups) by staff at the TCs involved in the study. If the first attempt to recruit participants does not yield any responses, the information will be sent out a second time. If this second attempt also fails to recruit participants the main researcher will attend follow-on or peer support groups to invite participants to take part. The main researcher may also attempt to recruit online through social media platforms such as Facebook or Twitter by posting the participant information sheet and inviting potential participants to contact the main researcher for further information. There will be several methods for opting in to be contacted by myself (the main researcher) including by e-mail, post and telephone. Once an individual has opted in, I will contact them and at this point they can ask further questions about the study and taking part. After this, if they are still interested in taking part, a date and time for a semi-structured interview lasting approximately one hour will be agreed. Interviews may be face-to-face at either trust premises, community venues (e.g. GP surgery) or at the participant's home, or a telephone or Skype interview. Lancaster University will pay up to £20 for each participant per interview if participants require reimbursement for travel expenses to attend the interview.

For face-to-face interviews, when the participant arrives for the interview I will introduce myself and review the participant information sheet (appendix A), restating the purpose of the interview. We will then review the consent form (appendix C) and if the participant agrees, they will then provide written consent.

For telephone or Skype interviews, at the beginning of the call I will introduce myself and review the participant information sheet, restating the purpose of the interview. Then we will review the details on the consent form and the participant will provide verbal consent which will

be audio recorded. The recordings of verbal consent will be separate files to the audio recordings of the main interview.

Necessary demographic information will be collected at the beginning of the interview. This information will include age, gender, ethnicity, which TC they attended, how long they were there for, how long since they left and whether they have now or in the past been involved in any follow-on or transition groups or similar. The interview will take approximately one hour and will be audio recorded. The interview schedule (appendix D) outlines the topics to be discussed, however the exact questions will be dependent on the participant's responses; therefore, each interview will be guided in part by what that participant deems to be important. Break periods will be offered if the participant becomes tired or distressed and if the participant wishes to continue the interview on another day, this will be arranged. At the end of the interview the participant will be thanked for their participation and provided with a debrief sheet (appendix E) containing contact details for the research team, should they have any questions following the interview, or if they wish to withdraw their consent. Participants can withdraw their data up to two weeks after the interview has taken place, this timeframe has been chosen so that the main researcher can recruit further participants to replace any data that has been withdrawn and to reduce the likelihood that the individual participants' data have not yet been pooled. The main researcher will direct the participant to sources of support detailed on the participant information sheet if they appear to be distressed.

Digital files of the audio recordings of the interviews (and verbal consent in the case of telephone or Skype interviews) will be transferred from the recorder as quickly as possible after the interview has concluded to a secure file storage site (e.g., the VPN, Box or other secure facility approved by Lancaster University), and at that point they will be deleted from the

recorder. Whilst the files are still on the recorder, this device will be stored securely. The main researcher will transcribe and anonymise the audio recordings of the interviews and the digital files will be labelled with numerical identifiers and stored securely. Identifying numbers will be allocated to participants to allow their data to be linked to contact details if necessary, for example, if participants request for their data to be withdrawn from the study. Participant contact information will be kept for up to 12 months, as participants will be offered the choice of receiving a summary of the findings of the study or attending a presentation of these findings. Once this has occurred, participant contact details will be permanently deleted. Digital files of the audio recordings of the interviews will be deleted when the written report for the study is complete and has been examined. The scanned participant consent forms (and audio recordings of verbal consent for any telephone or Skype interviews) and the transcribed anonymised interviews will be kept securely by Lancaster University for either 10 years or 10 years after publication, whichever is longest, after which they will be destroyed. Audio recordings and anonymised transcripts of the interviews will be separately stored securely by Lancaster University. Secure storage in this case refers to storage on Lancaster University VPN or another secure storage facility approved by the University (e.g. Box). Storage and deletion of data will be the responsibility of the DClinPsy Research Co-ordinator under the line management of the Programme/Research director.

Personal data in this study will be contact details that participants provide when they opt-in to be contacted by the main researcher. These details will be stored securely as described above. Once participants have completed the interview and been sent their copy of the summary of results or details about any verbal presentations of the findings, their personal data will be

securely deleted. Any participants who withdraw from the study will have their personal data deleted at the point of withdrawal.

The raw data from the study will be accessed by the main researcher, the research supervisor and the field supervisor only.

Proposed analysis

IPA will be used to analyse the data in this study, following the method described by Smith and Eatough (2016). IPA produces detailed accounts of lived experience. This method is explicitly idiographic; examining each case in depth before developing into a more general account of the themes within the data set. Described as a set of flexible guidelines to be adapted to particular research aims, IPA is a particularly useful methodology when examining emotionally laden and complex topics such as in this study. The stages of analysis described are: initial close reading of transcripts; identifying initial themes, checking them against the data and clustering them; refining and condensing themes and making links between the themes; producing a narrative around the themes and how they interconnect with one another. An audit trail of the steps taken in the analysis process including notes on initial thoughts following interviews and early read-throughs of the transcripts, to the coding of the data and steps taken to identify themes.

Practical issues

- The research supervisor and field supervisor will listen to the recording of the first interview to provide feedback/advice regarding the interview style and questions asked.
- The research supervisor and field supervisor will be consulted during the analysis phase to ensure that certain areas of the data are not being overrepresented.

- Costs of photocopying and posting information packs to potential participants if necessary will be funded by the Lancaster University Doctorate of Clinical Psychology programme.
- Several DTCs in the north west of England and north Wales have indicated they would be willing to be involved in the study.

Ethical concerns

It is possible that participants may become emotionally distressed due to some of the topics that will be discussed in the interviews, for example, when discussing any periods of relapse or other difficulty since leaving the DTC. It is unlikely that participants will become significantly distressed during the interview, as the main researcher would be sensitive to when participants appear to be becoming distressed and move to a different topic. If a participant does become more distressed, the main researcher will pause the interview and offer the participant a break and the rest of the interview can be rearranged or ended at that point if needed. The main researcher will explore with the participant their level of distress and establish if they require further support. Participants will be directed to information in the participant information sheet or debrief sheet for sources of support if needed. If a participant is immediately at risk of harm standard protocol will be followed and the appropriate emergency services would be contacted.

The main researcher will follow lone worker guidance to minimise risk of harm from participants. This will be relevant when conducting home interviews, which is an option that will be offered to participants. This option has been included to facilitate participation for those who may struggle with transport, caring responsibilities or similar, for whom getting to another location would prohibit taking part in the study.

Timescale

October 2017 – ethical and research governance approval

November – January 2017 – conduct interviews

February 2017 – May 2018 – analyse data and write up research paper

May – July 2018 – submit thesis and present findings.

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Ethical Approval Letters**North West - Liverpool East Research Ethics Committee**

Barlow House
3rd Floor
4 Minshull Street
Manchester
M1 3DZ

Please note: This is the favourable opinion of the REC only and does not allow you to start your study at NHS sites in England until you receive HRA Approval

05 March 2018



Dear Miss Hewitson

Study title: A qualitative study of the experience of moving on from a non-residential Democratic Therapeutic Community
REC reference: 18/NW/0036
IRAS project ID: 235003

Thank you for your letter of , responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Vice-Chair.

We plan to publish your research summary wording for the above study on the HRA website, together with your contact details. Publication will be no earlier than three months from the date of this opinion letter. Should you wish to provide a substitute contact point, require further information, or wish to make a request to postpone publication, please contact hra.studyregistration@nhs.net outlining the reasons for your request.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

Conditions of the favourable opinion

The REC favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements. Each NHS organisation must confirm through the signing of agreements and/or other documents that it has given permission for the research to proceed (except where explicitly specified otherwise).

Guidance on applying for NHS permission for research is available in the Integrated Research Application System, www.hra.nhs.uk or at <http://www.rdforum.nhs.uk>.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of management permissions from host organisations

Registration of Clinical Trials

All clinical trials (defined as the first four categories on the IRAS filter page) must be registered on a publically accessible database within 6 weeks of recruitment of the first participant (for medical device studies, within the timeline determined by the current registration and publication trees).

There is no requirement to separately notify the REC but you should do so at the earliest opportunity e.g. when submitting an amendment. We will audit the registration details as part of the annual progress reporting process.

To ensure transparency in research, we strongly recommend that all research is registered but for non-clinical trials this is not currently mandatory.

If a sponsor wishes to request a deferral for study registration within the required timeframe, they should contact hra.studyregistration@nhs.net. The expectation is that all clinical trials will be registered, however, in exceptional circumstances non registration may be permissible with prior agreement from the HRA. Guidance on where to register is provided on the HRA website.

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Ethical review of research sites

NHS sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Non-NHS sites

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

<i>Document</i>	<i>Version</i>	<i>Date</i>
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [PL & EL & PN]	0.1	30 June 2017
IRAS Application Form [IRAS_Form_19122017]		19 December 2017
IRAS Checklist XML [Checklist_19122017]		19 December 2017
Letter from sponsor [Letter from sponsor]	0.1	07 December 2017
Other [Opt-In-Form]	0.1	30 November 2017
Other [Debrief Form]	0.1	30 November 2017
Other [Semi-structured Interview Schedule]	0.1	30 November 2017
Other [Demographic information questions]	0.1	28 December 2017
Other [Response to Validation]		28 December 2017
Participant consent form [Consent Form]	0.1	30 November 2017
Participant information sheet (PIS) [Participant Information Sheet]	0.1	30 November 2017
Research protocol or project proposal	3 Clean	01 March 2018
Summary CV for Chief Investigator (CI) [Chief Investigator CV]	0.1	19 December 2017
Summary CV for supervisor (student research) [Supervisor CV]	0.1	19 December 2017

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Reporting requirements

The attached document "*After ethical review – guidance for researchers*" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments

- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The HRA website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website:

<http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/>

HRA Training

We are pleased to welcome researchers and R&D staff at our training days – see details at

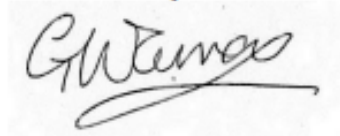
<http://www.hra.nhs.uk/hra-training/>

18/NW/0036

Please quote this number on all correspondence

With the Committee's best wishes for the success of this project.

Yours sincerely



PP
Vice-Chair
Miss Kimberley Saint

Email: nrescommittee.northwest-liverpooleast@nhs.net

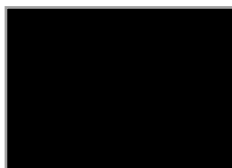
Enclosures: "After ethical review – guidance for researchers"

Copy to: Ms Becky Gordon
Pauline Parker, Mersey Care NHS Foundation Trust



Health Research Authority

Email: hra.approval@nhs.net



06 March 2018

Dear Miss Hewitson

Letter of HRA Approval

Study title: A qualitative study of the experience of moving on from a non-residential Democratic Therapeutic Community
IRAS project ID: 235003
REC reference: 18/NW/0036
Sponsor: Lancaster University

I am pleased to confirm that **HRA Approval** has been given for the above referenced study, on the basis described in the application form, protocol, supporting documentation and any clarifications noted in this letter.

Participation of NHS Organisations in England

The sponsor should now provide a copy of this letter to all participating NHS organisations in England.

Appendix B provides important information for sponsors and participating NHS organisations in England for arranging and confirming capacity and capability. **Please read *Appendix B* carefully**, in particular the following sections:

- *Participating NHS organisations in England* – this clarifies the types of participating organisations in the study and whether or not all organisations will be undertaking the same activities
- *Confirmation of capacity and capability* - this confirms whether or not each type of participating NHS organisation in England is expected to give formal confirmation of capacity and capability. Where formal confirmation is not expected, the section also provides details on the time limit given to participating organisations to opt out of the study, or request additional time, before their participation is assumed.
- *Allocation of responsibilities and rights are agreed and documented (4.1 of HRA assessment criteria)* - this provides detail on the form of agreement to be used in the study to confirm capacity and capability, where applicable.

Further information on funding, HR processes, and compliance with HRA criteria and standards is also provided.

It is critical that you involve both the research management function (e.g. R&D office) supporting each organisation and the local research team (where there is one) in setting up your study. Contact details

IRAS project ID	235003
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and further information about working with the research management function for each organisation can be accessed from the [HRA website](#).

Appendices

The HRA Approval letter contains the following appendices:

- A – List of documents reviewed during HRA assessment
- B – Summary of HRA assessment

After HRA Approval

The document “*After Ethical Review – guidance for sponsors and investigators*”, issued with your REC favourable opinion, gives detailed guidance on reporting expectations for studies, including:

- Registration of research
- Notifying amendments
- Notifying the end of the study

The HRA website also provides guidance on these topics, and is updated in the light of changes in reporting expectations or procedures.

In addition to the guidance in the above, please note the following:

- HRA Approval applies for the duration of your REC favourable opinion, unless otherwise notified in writing by the HRA.
- Substantial amendments should be submitted directly to the Research Ethics Committee, as detailed in the *After Ethical Review* document. Non-substantial amendments should be submitted for review by the HRA using the form provided on the [HRA website](#), and emailed to hra.amendments@nhs.net.
- The HRA will categorise amendments (substantial and non-substantial) and issue confirmation of continued HRA Approval. Further details can be found on the [HRA website](#).

Scope

HRA Approval provides an approval for research involving patients or staff in NHS organisations in England.

If your study involves NHS organisations in other countries in the UK, please contact the relevant national coordinating functions for support and advice. Further information can be found through [IRAS](#).

If there are participating non-NHS organisations, local agreement should be obtained in accordance with the procedures of the local participating non-NHS organisation.

User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please use the feedback form available on the [HRA website](#).

IRAS project ID	235003
-----------------	--------

HRA Training

We are pleased to welcome researchers and research management staff at our training days – see details on the [HRA website](#).

Your IRAS project ID is **235003**. Please quote this on all correspondence.

Yours sincerely

Joanna Ho
Assessor

Email: hra.approval@nhs.net

*Copy to: Becky Gordon, Sponsor Representative, Lancaster University
Pauline Parker, Lead NHS R&D Contact, Mersey Care NHS Foundation Trust
Dr Suzanne Hodge, Academic Supervisor, Lancaster University*

Chapter 5 Appendices

Appendix A Participant InformationHealth &
Medicine**Participant Information Sheet**

A qualitative study of the experience of moving on from a non-residential Democratic Therapeutic Community

My name is Nina Hewitson and I am conducting this research as a student on the Doctorate of Clinical Psychology programme at Lancaster University.

What is the study about?

The aim of this study is to explore and understand the medium-term impacts of non-residential Democratic Therapeutic Community (DTC) membership. As part of a previous clinical psychology research project which involved a number of DTCs in the region a few years ago, Lucy Morris, a former Lancaster trainee, developed a model to understand the process of change in non-residential DTCs. This model showed how the various elements of the DTC model work together to enable individuals to make positive changes. The study I am proposing here will build on these findings by developing an understanding of life after leaving a non-residential DTC, focusing particularly on how easy or difficult it is to maintain changes made, what has helped and what has made it difficult.

Why have I been approached?

You have been approached because you have attended a DTC and moved on between six months to two years ago and this study is interested in the experiences of individuals who have completed DTC treatment and moved on. Those who are now attending a follow-on group or peer support group are also eligible to participate. I am hoping to recruit a maximum of 12 individuals to take part in this study.

Do I have to take part?

No. It's completely up to you to decide whether or not you take part in this study. If you decide not to take part, there will be no negative repercussions in relation to any treatment you receive.

What will I be asked to do if I take part?

If you decide you would like to take part, you would be asked to attend a one-to-one interview with the researcher, which will last for approximately one hour. If you are unable to attend a face-to-face interview, a telephone or Skype interview can be arranged.

APPENDICES

In the interview, you will be asked to discuss your experiences of life since leaving their DTC, focusing on the changes that being part of a DTC enabled them to make, and what it has been like maintaining those changes since moving on.

Once you have completed your interview, if you wish to withdraw permission for me to use your interview in my study, you can do so up until two weeks after you interview has taken place. After this time, your data may have been pooled with the data of other participants. This is also to allow the main researcher to recruit further participants to replace any data that has been withdrawn.

Will my data be Identifiable?

The researcher will not have access to any of your client records held by the DTC service that you attended.

The information you provide as part of the study will be anonymised and pooled with the information from other participants, however anonymised quotes from your interview may be used in the report and may be published in the future.

The data collected for this study will be stored securely and only myself (Nina), the Research Supervisor and my Field Supervisor will have access to this data:

- Audio recordings will be securely destroyed and deleted once the project has been examined.
- Lancaster University will keep typed, electronic copies of the interviews for 10 years after the study has finished or 10 years from publication, whichever is the longer. At the end of this period, they will be securely destroyed.
- The files on the computer will be encrypted (that is no-one other than the researcher will be able to access them) and the computer itself password protected.
- The typed version of your interview will be made anonymous by removing any identifying information including your name. Anonymised direct quotations from your interview may be used in the reports or publications from the study, so your name will not be attached to them.
- Personal data collected by the researcher will be confidential and will be kept separately from your interview responses.

There are some limits to confidentiality: if what is said in the interview makes me think that you, or someone else, is at significant risk of harm, I will have to break confidentiality and take appropriate action. If possible, I will tell you if I have to do this.

What will happen to the results?

The results will be summarised in a research report and may be submitted for publication in an academic or professional journal and presented at academic or professional conferences. They will also be presented to the DDTC Umbrella Group verbally and/or in written form. If you have participated in the study, you will also be offered a written summary of the findings.

Are there any risks?

APPENDICES

There are no risks anticipated with participating in this study. However, if you experience any distress following participation you are encouraged to inform the researcher and contact the resources provided at the end of this sheet.

Are there any benefits to taking part?

Although you may find participating interesting, there are no direct benefits in taking part.

Who is organising and funding this study?

I am a trainee clinical psychologist and I am conducting this study as part of my doctoral training. The research is funded by Lancaster University Clinical Psychology Doctorate Programme.

Who has reviewed the project?

This study has been reviewed by National Health Service REC.

Where can I obtain further information about the study if I need it?

If you have any questions about the study, please contact the main researcher or research supervisor:

Main researcher: Nina Hewitson
E-mail: n.hewitson@lancaster.ac.uk
Phone: 07508 375665

Research supervisor: Suzanne Hodge
E-mail: s.hodge@lancaster.ac.uk
Phone: 01524 592807

Complaints

If you wish to make a complaint or raise concerns about any aspect of this study and do not want to speak to the researcher, you can contact:

Bill Sellwood Tel: +44 (0)1524 593998
Chair in Clinical Psychology; Email: b.sellwood@lancaster.ac.uk
Clinical Psychology
Furness College
Lancaster University
Lancaster LA1 4YG

If you wish to speak to someone outside of the Clinical Psychology Doctorate Programme, you may also contact:

Professor Roger Pickup Tel: +44 (0)1524 593746
Associate Dean for Research; Email: r.pickup@lancaster.ac.uk
Faculty of Health and Medicine
(Division of Biomedical and Life Sciences)
Lancaster University

APPENDICES

Lancaster LA1 4YG

Thank you for taking the time to read this information sheet.

Resources in the event of distress

Any participants that feel they need psychological support, or need to talk to someone, as a result of any distress caused by the study or at some time in the future, may find the following resources helpful:

- **Staying safe:**
 - If you are suffering emotionally, mentally or physically, contact your GP.
 - If you are feeling suicidal or need to speak to someone contact the Samaritans:
 - Samaritans Helpline: 116 123
You can call this number free from any phone, 24 hours a day.
 - Website: www.samaritans.org
 - You can also contact Mind:
 - Mind infoline: **0300 123 3393**
This line is open 9am to 6pm, Monday to Friday (except bank holidays).
 - Mind website: <https://www.mind.org.uk/>
This website is full of information and has advice on how to access support in a crisis.
 - **If you feel at serious risk of harm or suicide attend your nearest A&E or dial 999.**

Appendix B Participant Consent

Version 0.1, Date: 30/11/2017

Doctorate in
Clinical Psychology



Appendix C Consent Form

Study Title: A qualitative study of the experience of moving on from a non-residential Democratic Therapeutic Community

We are asking if you would like to take part in a research project to examine the experiences of individuals who have completed DTC treatment and moved on.

Before you consent to participating in the [study](#) we ask that you read the participant information sheet and mark each box below with your initials if you agree. If you have any questions or queries before signing the consent form please speak to the principal investigator, Nina Hewitson.

- | | Please initial each statement |
|---|-------------------------------|
| 1. I confirm that I have read the information sheet and fully understand what is expected of me within this study | <input type="checkbox"/> |
| 2. I confirm that I have had the opportunity to ask any questions and to have them answered. | <input type="checkbox"/> |
| 3. I understand that my interview will be audio recorded and then made into an anonymised written transcript. | <input type="checkbox"/> |
| 4. I understand that audio recordings will be kept until the research project has been examined. | <input type="checkbox"/> |
| 5. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected. | <input type="checkbox"/> |
| 6. I understand that I can withdraw my data up to two weeks following the interview. | <input type="checkbox"/> |
| 7. I understand that the information from my interview will be pooled with other participants' responses, <u>anonymised</u> and may be published. | <input type="checkbox"/> |
| 8. I understand that my data will be shared and discussed with the Research Supervisor and Field Supervisor. | <input type="checkbox"/> |
| 9. I consent to anonymised information and quotations from my interview being used in reports, <u>conferences</u> and training events. | <input type="checkbox"/> |
| 10. I understand that any information I give will remain strictly confidential and anonymous unless it is thought that there is a risk of harm to myself or others, in which case the principal investigator will need to discuss this information with the Research Supervisor and/or Field Supervisor to determine if further action needs to be taken. | <input type="checkbox"/> |
| 11. I consent to Lancaster University keeping typed transcriptions of the interview for 10 years after the study has finished or 10 years from publication, whichever is the longer. | <input type="checkbox"/> |
| 12. I consent to take part in the above study. | <input type="checkbox"/> |

Name of Participant _____ Signature _____ Date _____
Name of Researcher _____ Signature _____ Date _____

APPENDICES

Appendix C – Opt-in form

Opt-In FormHealth &
MedicineLancaster
University

Study Title: A qualitative study of the experience of moving on from a non-residential Democratic Therapeutic Community

I am contacting you to invite you to take part in a study, which will be looking at people's experiences of life since leaving their DTC, focusing on the changes that being part of a DTC enabled them to make, and what it has been like maintaining those changes since moving on. I am hoping to conduct interviews with people who have completed DTC treatment and moved on between six months to two years ago. I am hoping to recruit a maximum of 12 participants.

If you wish to find out more about taking part, please contact the main researcher, Nina Hewitson, using one of the methods indicated in the bottom half of this form.

Yours sincerely,

Nina Hewitson

I understand that Nina Hewitson is conducting the above study.

I would like to opt-in to be contacted by the main researcher, Nina Hewitson, to discuss taking part in the study.

Name: _____

Contact phone number: _____

Please return this form by e-mail or contact the main researcher on the number below:

Phone: [to be confirmed]

E-mail: n.hewitson@lancaster.ac.uk

APPENDICES

Appendix D – Interview Schedule

Semi-structured interview schedule

This interview schedule describes topic areas to be covered in the interview and example questions and suggested prompts. The exact questions asked will depend on each participant's responses, with the focus of each interview being partly guided by what is considered important by each individual participant.

Introduction

Introduce self. Review participant information sheet and purpose of interview. Review consent for and obtain written or verbal consent (depending on whether the interview is face-to-face or telephone/Skype) from participant. Collect any necessary demographic information.

Experience in the DTC

In this section of the interview, the interviewer will explore what led to the participant attending the DTC and their experiences of the DTC treatment.

Sample questions:

How did you find out about the DTC? What led to your referral?

How was your psychological wellbeing at that time?

What was your previous experience of mental health services/treatment?

Did you have any expectations about what the DTC would be like or how/if it would help you?

Did it differ to these expectations? If so, how?

Looking back how do you feel about the DTC? Was it helpful? If so what about it helped? Why?

Did you notice any changes in yourself/your wellbeing through your DTC experience?

APPENDICES

Was there anything you would have liked to be different? If so, why?

Experience of leaving the DTC

In this section of the interview, the interviewer will explore the participant's experience of coming to the end of their time in the DTC.

Sample questions:

What are your memories of the last few weeks at the DTC? Thoughts? Feelings? Worries?

How was the ending prepared for? By the group and personally?

Did you have any expectations about what leaving would be like?

Did you feel ready to leave?

Was there anything you found particularly helpful? If so, why?

Was there anything you found unhelpful/would have liked to be different? If so, why?

Immediately after leaving the DTC

In this section of the interview, the interviewer will explore experiences in the first few weeks after leaving the DTC.

Sample questions:

What are your memories of the first few weeks after leaving the DTC? Thoughts? Feelings? Any significant events?

How did the change in routine affect you?

Did you have support available to you? If so, what were your views on that support?

Life after the DTC

In this section of the interview, the interviewer will explore what the participants' life was like in the medium term after leaving the DTC, focusing on what helped/hindered the maintenance of benefits gained through the DTC.

APPENDICES

Sample questions:

Do you feel there have been any changes in yourself/your wellbeing as a result of being a member of the DTC? (perceived benefits – prompt if necessary) – This may have been covered already in the beginning of the interview.

Prompts on types of change:

- Different coping strategies
- Changes in self-harm behaviour
- Changes in interpersonal interactions - relationships
- Problem solving and decision making skills
- Assertive communication regarding needs and wishes
- Coping with strong emotions
- Wellbeing and self-esteem
- Feelings of empowerment and self-agency
- Occupation
- Use of services

Do you feel you have been able to maintain [the changes they have spoken about]? What helped you do this? What has been a barrier to you doing this? (For each of the changes reported).

How important do you think these changes have been to you?

Has your time as a member of the DTC had any other effects on your life?

How are things in your life now? Are you happy with how things are now? Are there any other changes you would like to make?

Is there anything else you would like to tell me or you think I should know?

Conclusion

APPENDICES

In this section of the interview, the interviewer will thank the participant for taking part. The interviewer will ensure the participant has not been distressed by the interview and if necessary will direct the participant to sources of support on the participant information sheet/debrief sheet.

Appendix E Debrief

Debrief Form

Study Title: A qualitative study of the experience of moving on from a non-residential Democratic Therapeutic Community

The purpose of this study was to explore people's experiences of individuals who have completed Democratic Therapeutic Community (DTC) treatment and moved on

Please contact the main researcher, Nina Hewitson, or the research supervisor, Suzanne Hodge if you have any questions regarding this study using the contact details below.

Thank you again for taking part in this study.

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Phone: [to be confirmed]

Research supervisor: Suzanne Hodge
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Phone: 01524 592807

Resources in the event of distress

Any participants that feel they need psychological support, or need to talk to someone, as a result of any distress caused by the study or at some time in the future, may find the following resources helpful:

- **Staying safe:**
 - If you are suffering emotionally, mentally or physically, contact your GP.
 - If you are feeling suicidal or need to speak to someone contact the Samaritans:
 - Samaritans Helpline: 116 123
You can call this number free from any phone, 24 hours a day.
 - Website: www.samaritans.org
 - You can also contact Mind:
 - Mind infoline: **0300 123 3393**
This line is open 9am to 6pm, Monday to Friday (except bank holidays).
 - Mind website: <https://www.mind.org.uk/>
This website is full of information and has advice on how to access support in a crisis.
 - **If you feel at serious risk of harm or suicide attend your nearest A&E or dial 999.**