Personal recovery in personality disorder – seeking to understand experiences in community and forensic settings

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Abstract

Supporting an individual with experience of mental disorder in their personal recovery is now a stated goal for most mental health services. The meaning of 'recovery', as well as its distinction from traditional concepts of 'clinical recovery' or 'cure', remains unclear however. In the following thesis a variety of methodological approaches are used to explore the lived experience of those receiving a personality disorder diagnosis and accessing care in a variety of institutional settings. Specifically, systematic review and meta-synthesis are used by way of literature sensitisation. Individual interviews and focus groups are used to capture the experience of service users and clinical professionals respectively. Thematic analysis is used to explore findings and to identify overarching themes that encapsulate the essence of the recovery process. Emergent themes suggest that the process of recovery may be considered a form of 'identity work', wherein the experience of mental distress is adopted into the individual's understanding of themselves as a moral agent functioning within various social networks. Findings from the individual interviews, together with the reflections of clinical staff, indicate the particularity of this work in the context of personality disorder and forensic institutions - with diagnostic stigma especially seen as impacting on the process. A model of personal recovery is proposed in light of the findings from the thesis and this is situated in terms of the wider clinical literature. This model highlights the development of personal recovery as a response to varying forms of trauma, and the incorporation of such work into central understandings of personal identity. Findings from the thesis are used to develop proposals as to the manner in which future research could be conducted to allow the adoption of recovery oriented care in day-to-day mental health clinical practice.

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At the time of writing Andrew Shepherd is a higher trainee in forensic psychiatry, working in the North West of England. He is a member of the Royal College of Psychiatrists (MRCPsych) and holds the degree of Bachelor of Medicine, Bachelor of Surgery (BM BCh University of Oxford, 2008). He also holds a Master in Research Methods (MRes University of Manchester, 2013) and Master of Chemistry degree (MChem University of Warwick, 2004).

Chapter 1 - Introduction

The aim of this opening chapter is to establish a background framework for the remainder of the thesis through a discussion of the concept of 'personal recovery' and to locate this as the subject of further research enquiry. An introduction to the concept, and its historical development, is therefore provided at the outset. After this introduction the specific case example of 'personality disorder' is presented and the implications of personal recovery as they relate to this diagnostic category are considered. Finally, a link is made between this background framework, the methodology employed in the reported studies and the overarching aim of the thesis.

The thesis is presented as an alternative format submission - with the results chapters written in the style of academic papers that have either been published within peer review journals, submitted for peer review or are ready for submission. Additional chapters are presented alongside these papers to provide an overarching structure to the thesis as a whole. The methodology chapter within this thesis argues that the act of writing is an integral part of the analysis process - leading to the 'performance' of findings that are specific to the time of their writing and the target audience. As such it is suggested that an alternative format submission is an appropriate format for a project employing a qualitative approach to the phenomena of interest. Presented results chapters therefore represent different investigations, or interpretations, with each relating to the overarching aim of the thesis, as outlined in this introductory chapter.

Personal recovery

The use of the term 'personal recovery' in relation to mental health has increased steadily in both clinical practice and research settings. In the United Kingdom (UK) it has been specifically highlighted as a goal for mental health care service provision; for example, as set out in two successive Department of Health position statements published in 2009 and 2011:

'New Horizons sets out the expectation that services to treat and care for people with mental health problems will be accessible to all who need them, based on the best available evidence and focused on recovery, as defined in discussion with the service user.' (p7 Department of Health, UK, 2009)

'…ensuring that people with mental health problems are able to plan their own route to recovery, supported by professional staff who: help them identify and chief the outcomes that matter to them… put them, and their families and carers, at the centre of their care…' (p16 Department of Health, UK, 2011)

Both of these quotations illustrate an emphasis being placed on the autonomous role of 'the service user', or 'people with mental health problems', in defining their own conceptualisation of recovery. In this light the term personal recovery can be seen as being representative of a shift in the relationship between the clinician, as professional, and the patient - as a person who seeks access to healthcare. The change in this dynamic relationship from the classical representation of the empowered, presumably beneficent, clinician and disempowered patient is representative of a wider reaching change in the relationship that exists between healthcare institutions and their 'consumers'

(McLaughlin, 2009). In this regard the developing use of the term can be seen as tracing a parallel trajectory to the development of other concepts in clinical practice that similarly represent developing change in the sharing of power between clinician and patient - for example the increasing recognition of the importance of 'shared decision making' in relation to clinical care (Barry & Edgman-Levitan, 2012; Elwyn et al., 2012).

At its simplest level therefore the concept of personal recovery can be seen as a valuable representation of a move towards greater empowerment for individuals and their relationship with healthcare providers, however it is also apparent that the shifting terminology is, at least partially, representative of an underlying political process that requires greater critical examination.

Throughout the following argument the terms 'personal recovery' and 'recovery' will be used as being synonymous, where different formulations of the idea of recovery are outlined, for example 'clinical recovery' or 'social recovery' they will be specifically defined.

Origin of a concept

The word 'recovery' is commonly used in relation to ideas of health and illness - but its additional link to the act of 'recovering', or 're-discovering', a previously lost object can be seen as activating very specific symbolic representations of illness; specifically, the absence, or loss, of a previously held state of health. In this manner the origin of the term recovery, as applied to psychiatric disorder, can be seen as drawing on a post-enlightenment framework - whereby 'mental illness' is understood as being something that can be 'recovered from', as opposed to an alternative formulation, in terms of spiritual experience for

example. It can be argued that, even when preceded by the word 'personal', therefore an evaluative concept is introduced through the very use of the word 'recovery' that could be seen as being somewhat in opposition to the position outlined in the statements above, which emphasise the importance of clinicians working with individuals in terms of their own definitions of recovery.

Understanding this conceptualisation of recovery in relation to ideas of health and mental illness is therefore complex - and may be seen as being dependent on a personally held understanding of the terms. The World Health Organisation (WHO) has offered the same definition of health throughout the past 70 years:

'Health is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity.' (World Health Organisation, 1948).

This definition can be criticised however in its apparently static representation of the concept of health - with a claimed clear categorical divide between health and illness, without recognition of the varying dynamic factors that can be seen as impacting on an individual conceptualisation of wellbeing (Bircher, 2005). The question also arises as to whether states of health can be seen as the normal condition, as represented in the above definition, or whether episodes of health, when they exist, are simply brief, transient, performances on a background experience of shifting disequilibrium of social interactions (Williams, 1998)?

Understanding of concepts of health and illness in relation to the idea of 'mental illness' or 'disorder' can be seen as particularly problematic -

and have been subjected to a range of critiques, for example the work of Szasz (for example 1994; 2001) focusses on the moral connotations of labelling aberrant behaviour as illness. Efforts to circumvent this moral critique, based on the evaluative judgements made by those assigning diagnostic criteria, have sought to define mental illness, or psychiatric disorder (Kendell, 2001), in relation to a loss of biological 'fitness' - thereby claiming an objective, value free, perspective in relation to the definition (Kendell, 1975). Concepts of mental wellbeing can be seen as intimately related to social interaction however and therefore the question arises as to whether such experiences can be fully viewed from such a value-free position (Thornton, 2000) and therefore from what position concepts such as personal recovery should be viewed (Thornton & Lucas, 2011).

Deinstitutionalisation and the 'recovery movement'

With the closure of the asylums an influx of the 'mad' into the general community forced a reorientation of the manner in which mental health care and support were provided - with an increase in the availability of community mental health services developing as an alternative to inpatient care (Scull, 2015). The development of this process was complicated however - involving an interaction between different forms of social pressure that risked ostracising individuals in a number of ways. Various social groups can be seen as emerging from this process - including the 'psychiatric survivor' and 'recovery movement' positioning themselves in varying forms of opposition to, or collaboration with, offered psychiatric care (Chamberlin, 1995). The recovery movement therefore did not necessarily oppose the provision of psychiatric care - but instead occupied a position analogous to that outlined by disability rights activists emphasising the need for societal change to meet the needs of individuals with experience of mental

distress. In this manner the recovery movement, together with other social groups, sat alongside the developing anti-psychiatry position as an example of a pressure driving a desire for social change (Crossley, 1998).

In relation to the overall concept of recovery though the recovery movement can be seen as forcing a change in orientation - emphasising the argument that recovery could no longer be seen simply as an individual process, but instead also as one that required change within social institutions and their interaction with 'the mad' (Davidson, 2008).

Recovery in the 1980s and 1990s

In the late 1980s written accounts began to emerge, in various formats, detailing the experiences of 'survivors' in relation to their experience of mental illness. These 'recovery accounts' came to be influential in their representation of the lived experience of mental distress, and began to represent a potential field of criticism in relation to the provision of psychiatric care. Such care was often seen as being too focussed on the external view of the care provider and insufficiently attentive to the needs of the individual. One example of such an account comes from the work of Deegan who wrote of her experience of rehabilitation, or recovery, in comparison to the experiences of a physically disabled man (Deegan, 1988) and also of the sometimes damaging acts carried out by professionals in relation to her care (Deegan, 1990). She offers the following description of her recovery experience:

'The goal of the recovery process is not to become normal. The goal is to embrace our human vocation of becoming more deeply, more fully human. The goal is not normalization. The goal is to become the

unique, awesome, never to be repeated human being that we are called to be.' (p92 Deegan, 1996)

More recent examples continue in this tradition; for example, Dillon (2010) highlights her experience of 'symptoms' as a survival technique in response to extreme personal trauma, the need for social response to these experiences and the need to 'learn from them' (p79 ibid). Similar accounts are to be found on-line, for example a public talk given by Longden which has attracted more than three million 'views' (Longden, 2013). In this account and others (Longden, 2010) she describes her experience as a 'sane reaction to insane circumstances', echoing earlier claims made by Laing (2010).

Reviewing the academic and clinical literature relating to the concept of recovery Anthony (1993) offered a definition which would come to be one of the most commonly cited in the following research and clinical statements, such as those outlined from the Department of Health, above:

'Recovery is described as a deeply personal, unique process of changing one's attitudes, values, feelings, goals, skills, and/or roles. It is a way of living a satisfying, hopeful, and contributing life even with limitations caused by illness. Recovery involves the development of new meaning and purpose in one's life as one grows beyond the catastrophic effects of mental illness.' (p527 ibid)

This statement demonstrates a number of claims in relation to the concept of recovery. The first echoes the idea of recovery as being personally defined - an individual, unique process. The second claim is that recovery will involve some shift in a person's values or social roles.

This, in conjunction with the third claim relating to the living of life despite the limitations of illness, positions recovery as an essentially rehabilitative stance accepting the concept of a form of 'mental illness'. The final phrase repeats the second claim, emphasising the social process involved in the experience of recovery. In its presentation of shifting self-representation and aspiration this definition in some ways outlines the positions of writers such as Deegan, in the quotation above. In other ways however, for example the acceptance and reliance on the concept of mental illness and rehabilitation, the statement can be seen as in tension with the accounts offered by others. Attempts to define recovery therefore begin to show degrees of overlap and disagreement between varying parties - highlighting the complexity of the argument.

Varying conceptualisations of recovery

The background understanding of recovery in terms of its development as a concept, as well as the development of institutional pressure in relation to the delivery of 'recovery focussed care' (G. Shepherd, Boardman, & Slade, 2008), emphasises the need for what Pilgrim (2009) terms 'pre-empirical questions' (p484) relating to the social understanding of 'psychological deviance' (ibid). In other words - if clinical care, or social support, are to become recovery focussed an understanding as to the nature of 'what recovery is' will be required.

A common distinction is made between the concept of personal and clinical recovery - in relation to what factors are deemed important in relation to the process, as well as who holds the power in its definition. Davidson and Roe (2007) term this as a distinction between 'recovery from' as opposed to 'recovery in' mental illness. The former emphasises an improvement in the functional impact of mental distress while the second concept focusses more on the social and individual rights of the

person in relation to self-actualisation and community inclusion. A distinction is also apparent here between the act, or process, of 'recovering' as distinguished from a final state of 'recovery' - of 'having recovered'.

In exploring this issue Pilgrim (2008) initially outlines three identifiable positions in relation to the concept of recovery:

1. Recovery from illness - or response to treatment
2. Recovery from impairment - or rehabilitation
3. Recovery from invalidation - or survival

Later, in returning again to this concept, Pilgrim and McCranie (2013) identify four overarching themes that can be seen as a description of varying accounts of personal recovery:

1. Recovery as personal journey (c.f. Deegan, 1996)
2. Recovery as critique of services (c.f. Dillon, 2010)
3. Recovery as therapeutic optimism (c.f. Slade & Longden, 2015)
4. Recovery and social disability (c.f. Davidson, 2008)

Harper and Speed (2012), in considering the development of understanding in relation to recovery and its application within various institutional settings, highlight three concerns in the emergent discourse:

1. That conceptualisations of recovery, alongside terms such as 'resilience' are adapted within political discourse to emphasise medicalised neoliberal accounts of the individual and their responsibility

2. Discourse risks reframing the idea of 'deficit' as 'strength' and is therefore reliant on a 'deficit based' model

3. That structural factors (e.g. inequality) are marginalised within the conceptual understanding

These critiques will be returned to in greater depth in the closing argument of this thesis (Chapter 9).

Researching recovery

As indicated in the previous section, the concept of recovery has received a great deal of political interest with regard to the development of health care services, but lacks a degree of conceptual clarity regarding the nature of the phenomenon in and of itself. Research is therefore necessary to map the manner in which the concept is enacted clinically, while also providing greater understanding in relation to the implications for an understanding of mental disorder.

From a clinical service provision perspective research has been conducted to explore the manner in which recovery focussed care can be integrated into clinical pathways - two prominent examples of such projects include: Implementing Recovery through Organisational Change (ImROC - http://www.imroc.org.) and REFOCUS (Slade, Bird, Le Boutillier, et al., 2015b). The REFOCUS project represented an effort to develop greater understanding in relation to the theoretical nature of the process of recovery, while identifying specific interventions that could support staff in the delivery of recovery focussed care. The overarching aim was to develop a programme of interventions that would have trans-diagnostic relevance, however most of the research and evaluation focussed on the experience of individuals

who had received a diagnosis of Schizophrenia. The project was divided into three stages:

1. Theoretical exploration
2. Development of an intervention manual
3. Production of the REFOCUS model focussing on the implementation of recovery focussed care

The first stage was conducted through the development of a theoretical framework, which sought to map the existing academic literature relating to the concept of recovery (Leamy, Bird, Le Boutillier, Williams, & Slade, 2011). The authors identified five key factors within the emergent framework:

1. Connectedness
2. Hope
3. Identity
4. Meaning
5. Empowerment

A sixth factor, spirituality, was identified in studies addressing the recovery experiences of Black and Ethnic minority populations. Finally, in this framework development the authors also considered the experience of recovery in comparison to a trans-theoretical model of change, identifying descriptions of experiences matching each of those identified steps (pre-contemplation, contemplation, preparation, action, maintenance) (Prochaska & DiClemente, 1982).

The second stage of the project involved the development of a specific intervention manual, which was produced through collaboration with

groups of stake holders in the form of service users and other experts by training or experience. The delivery of recovery focussed training to community mental health teams was appraised in the form of a cluster randomised controlled trial: - participating clinical teams were randomised with the intervention arm of the study receiving training in the REFOCUS intervention. Randomly selected patients under the care of clinical teams involved in the study were asked to complete a recovery focussed outcome measure (Neil et al., 2009) - data from which was then used as the primary outcome for the trial (Slade, Bird, Clarke, et al., 2015a). Secondary outcomes were collected using tools specifically designed to gauge service user experience. Clinician knowledge was appraised through the use of scales designed to assess recovery orientation in clinical practice. The study showed no change in primary outcome between the intervention and control groups in terms of primary clinical outcome, although some changes were noted in secondary measures with a non-statistically significant trend towards reduced care cost for the REFOCUS arm of the trial. The authors commented on these results highlighting the difficulty of delivering interventions designed to alter clinical practice to clinical teams involved in full time work.

The work conducted in the REFOCUS project is of clear importance in developing the appraisal and delivery of recovery focussed care within clinical settings, while developing an empirically based measure of this intervention. While the outcomes from the clinical trial could be seen as disappointing they are not unduly surprising given the complexity of delivering such interventions with a focus on altering patterns of clinical care. The project also served to demonstrate the importance of considering outcome measures that are specifically tailored to appraise individual understanding of recovery in relation to

clinical care, a consideration that many commonly adopted outcome measures in research have been shown to address only poorly (Andresen, Caputi, & Oades, 2010).

Despite the work of the REFOCUS group it can be seen that a number of research questions, such as those raised by Pilgrim (2009) remain to be addressed. For example, 1) What are the experiences of individuals receiving non-psychotic disorder diagnoses and 2) What is the role of institutional setting in the experience of recovery?

The need for further research

On the basis of the findings from the REFOCUS project and the theoretical arguments relating to the nature of the recovery process outline above for the purpose of the argument outlined throughout this thesis it is proposed that recovery can be viewed as an exercise in 'identity work'. This concept will be returned to in greater detail below in relation to a discussion of the concept of narrative identity, at present however a brief argument is presented to support the thesis.

Identity work can be described as the manner in which individuals engage in a process of making sense of aspects of themselves. The concept can be demonstrated through considering the experience of those suffering from chronic illness. It represents a form of emotional labour undertaken in light of changes to an individual's capacity (Charmaz, 1983; G. Williams, 1984; S. Williams, 2000). For example, in relation to aspects of physical health, Adams, Pill and Jones (1997) write of the manner in which individuals incorporate understandings of their diagnosis of asthma and medication use into their own social identity. Hillman (2013) through ethnographic work, conducted in hospital accident and emergency departments, observed the manner in

which patients could be seen as engaging in a form of identity work to present themselves as 'legitimate' in their need to access healthcare, as seen within a wider political discourse of individual responsibility. This idea of 'legitimacy' is common in the narratives of individual's suffering from chronic disorder, representing a moral pressure to account for one's suffering and need for treatment (Broom, Kirby, Adams, & Refshauge, 2015; Ridge et al., 2015; Sanderson, Calnan, & Kumar, 2015). An analogy can be seen between this process and the 'work' that is undertaken by individuals in relation to their sense of recovery in relation to mental health - both in the rehabilitative sense outlined by Anthony (1993) or in a more political sense (Deegan, 1996; Dillon, 2010; Longden, 2010). Such work can be seen as an aspect of the individual's political identity, one of the many interacting elements which make up the construct (c.f. the experience of women of colour described by Crenshaw, 1991).

As has been discussed, most research into the recovery process so far has focussed on the experience of individuals experiencing psychotic disorders, principally Schizophrenia (Slade, Bird, Le Boutillier, et al., 2015b). Individuals with differing phenomenological experiences, or disorders, may provide an alternative understanding of the concept, or may highlight specific areas of understanding that are particularly pertinent. In this regard, it is suggested that 'personality disorder' represents an area of potentially fruitful research - for the interest of the experience of recovery in relation to this diagnosis in particular but also for the exploration of the concept of 'identity work', as it applies to personal recovery, in more detail.

Personality Disorder

The term 'personality' is derived from the Latin word *personalitas* and can be defined as:

"The quality, character, or fact of being a person, as distinct from an animal, thing, or abstraction; the quality which makes a being human." (Oxford English Dictionary Online)

In reference to the concept of identity, and social enactment, a link can also be seen between personality and the *persona* - a development from Latin meaning performance or mask. With this root the idea of a 'personality disorder' can be seen as immediately complex and potentially problematic. In the following section clinical conceptualisations of personality disorder are considered, while critiques voiced in the academic literature are highlighted. Following this initial discussion, the concept will be accepted for a discussion of epidemiological and prognostic claims made in the clinical academic literature. The concept of recovery will then be considered as it relates to personality disorder.

Clinical definitions of personality disorder

In the International Statistical Classification of Diseases and Related Health Problems 10th Revision (ICD-10) (World Health Organisation, 2003) the WHO defines personality disorder as:

"…deeply ingrained and enduring behaviour patterns, manifesting as inflexible responses to a broad range of personal and social situations. They represent extreme or significant deviations from the way in which the average individual in a given culture perceives, thinks, feels and,

particularly, relates to others. Such behaviour patterns tend to be stable and to encompass multiple domains of behaviour and psychological functioning. They are frequently, but not always, associated with various degrees of subjective distress and problems of social performance." (ICD-10 Chapter V, Mental and Behavioural Disorder F60-69)

Personality disorder is generally seen as having its onset in childhood, and certainly being present by adolescence (Newton-Howes, Clark, & Chanen, 2015a). Eight specific personality disorder classifications are identified within the ICD-10:

F60.0   Paranoid Personality Disorder

F60.1   Schizoid Personality Disorder

F60.2   Dissocial Personality Disorder

F60.3   Emotionally Unstable Personality Disorder

F60.4   Histrionic Personality Disorder

F60.5   Anankastic Personality Disorder

F60.6   Anxious [avoidant] Personality Disorder

F60.7   Dependent Personality Disorder

Two further classifications are included - Other Specific Personality Disorders [F60.8] (Eccentric, 'Haltose' type, Immature, Narcissistic, Passive aggressive, Psychoneurotic) and finally Personality Disorder, unspecified [F60.9]. Within this system diagnoses are presented as categorical - that is they are defined as being present or absent when the specified features are present. An alternative diagnostic system, the Diagnostic and Statistical Manual 5 Edition (DSM-5), published by the American Psychiatric Association, similarly currently adopts a categorical classification system in relation to personality disorder

(American Psychiatric Association, 2013). In clinical practice the most commonly used diagnoses are emotionally unstable personality disorder (typically referred to by its borderline subtype), dissocial and personality disorder unspecified type. Here 'Borderline personality disorder' is used as an example case for discussion.

Classically the term 'borderline' was used to refer to a group of patients seen as occupying a position somewhere between the psychoanalytic concepts of psychosis and neurosis (Stern, 1938), the terminology was subsequently adapted in an effort to yield greater clarity (Kernberg, 1967). Specifically, for borderline personality disorder, the ICD-10 offers the following description:

"…a definite tendency to act impulsively and without consideration of the consequences; the mood is unpredictable and capricious. There is a liability to outbursts of emotion and an incapacity to control the behavioural explosions… characterized in addition by disturbances in self-image, aims, and internal preferences, by chronic feelings of emptiness, by intense and unstable interpersonal relationships, and by a tendency to self-destructive behaviour, including suicide gestures and attempts." (ICD-10 F60.3 Borderline subtype)

In this definition 'self-destructive behaviour' is often seen as referring to acts of self-harm, or deliberate self-injury - for example cutting of the skin, burning or the deliberate fracturing of bones; a collection of highly complex psycho-social acts (Chandler, 2012).

<u>Criticism of the clinical definition of personality disorder</u>

Many criticisms of the classification of personality disorder begin first with a comment on the poor agreement between categorical systems of diagnosis and an underlying presumed nature of general personality, which is generally seen as being more in keeping with a spectrum model (Trull & Durrett, 2005). For example, one of the commonest models of general personality is the, so called, 'big five' system which describes personality according to the following dimensional characteristics: Openness, Conscientiousness, Extraversion, Agreeableness, and Neuroticism (Costa & McCrae, 1992). With respect to such systems categorical definitions can be seen as appealing for their diagnostic simplicity, but can be criticised as poorly referencing their relationship to concepts of normal personality function.

Definitions of personality disorder can therefore be seen as being dependent on their underlying appreciation of personality function. One attempt to overcome the criticism levelled at categorical definitions can be seen in the work of Livesley (2011) - who begins with a general definition of personality disorder in terms of personality function and the assumption that disorder will lie on a continuum with normal functioning. Personality disorder is therefore defined by a failure in one of three defined functions of healthy personality:

1. Stable representation of the self and its relation to the Other
2. Capacity to form intimate attachment relationships
3. Ability to maintain social role

Livesley continues his model through considering the idea of personality types (emotional dis-regulation, dissocial, social avoidance and

compulsivity) as overarching descriptors of personality traits. Finally, consideration is given to four distinct levels of severity:

1. Adaptive personality functioning
2. Personality dysfunction
3. Personality disorder
4. Severe personality disorder

In preparing the most recent revision of the DSM (DSM-5) the personality disorder working group consider possible changes to the classification system - leading to a proposed 'hybrid model' which would have attempted to combine elements of the previous categorical system with an acknowledgement of the spectrum model of personality. Ultimately this proposed model was deemed too complicated for use in routine clinical practice and was as such placed within an appendix designated for further research. This failure to change the underlying classification system has been widely criticised (Frances & Nardo, 2013; Livesley, 2012), along with many other changes within the classification system in relation to other diagnostic systems.

Changes to the classification system have also been proposed for revision to the ICD-10 model (ICD-11) - these proposals suggest that the current system be replaced with a universal definition of personality disorder with a severity qualifier. Five 'domain trait' features are also described which are described as representative of underlying personality function (Negative affective, Dissocial, Disinhibition, Anankastic and Detachment) and are proposed for use in diagnosis by specialist clinicians seeking clarification beyond the severity criteria (Tyrer, Reed, & Crawford, 2015). Commonly used categorical diagnoses, for example borderline personality disorder, are dropped

from this classification. If such proposals are integrated into the classification system, the impact of such a radical split from the DSM-5 system will be uncertain as previously the two systems have mirrored each other relatively closely.

Beyond the theoretical link between personality function and disorder other criticisms have been levelled at the diagnoses with regard to their specific nature. Charland (2006) comments on the manner in which many of the diagnostic traits identified can be classified more as 'moral failings' rather than clinical conditions. This critique has been termed 'neo-Szaszian' in its consideration of the moral nature of mental disorder diagnoses (Zachar, 2011). Other critics point to the manner in which diagnoses such as borderline personality disorder are applied primarily to women who are survivors of extreme personal trauma - suggesting that through a process of medicalisation this act of diagnosis serves to effectively silence the voice of women in dissent (Shaw & Proctor, 2005).

Prevalence of Personality disorder

Variation in the reporting of personality disorder epidemiology globally, as well as differences between various diagnostic measures, has led to estimates of personality disorder prevalence with a wide spread in reported rates. Population surveys in the UK placed the prevalence at approximately 4.4% in the general population (95% confidence interval [CI] 2.9-6.7) (Coid, Yang, Tyrer, Roberts, & Ullrich, 2006), in the United States (US) an estimate of 9% was obtained (Samuels et al., 2002), in Norway estimated prevalence reached 13.4% (Torgersen & Kringlen, 2001), finally in a global survey commissioned by the WHO rates were estimated at 6.1% (Huang et al., 2009).

Personality disorder diagnoses are also observed to occur at high rates of co-morbidity with other psychiatric diagnoses - both psychotic and affective in nature (Coid et al., 2006; Huang et al., 2009). Population studies have shown personality disorder to be associated with an increased standardised mortality ratio (SMR) for death by all causes (Bjorkenstam, Bjorkenstam, Holm, Gerdin, & Ekselius, 2015); of particular note in this report were the increased rates of death owing to substance misuse (in women SMR 11.4 [95% CI 7.2-18.2]), suicide (women SMR 32.8 [30.0-35.8]) and being the victim of homicide (women SMR 5.6 [2.8-11.3]). A case register study based in London estimated the life expectance of women to be shortened by 18.7 years, with a shortening of 17.7 years for men (Fok et al., 2012). Finally, an appraisal of healthcare costs associated with people accessing primary care services estimated that individuals with a personality disorder diagnosis attracted an annual care cost of £3,094 (£1,633 for those without personality disorder) (Rendu, Moran, Patel, Knapp, & Mann, 2002). These increased costs were not independent of other potential cofounders - but a significant correlation was found between the cost of care and the presence of other co-morbid psychiatric diagnoses, which the authors attributed as arising from a possible impact of chronic diagnosis.

Epidemiological estimates of the prevalence of personality disorder show marked variations between institutional settings - with the highest rates claimed within prison populations with 78% of male remand and 64% of sentenced prisoners being diagnosed with a personality disorder for a UK based survey (50% for women prisoners) (Singleton, Meltzer, Gatward, Coid, & Deasy, 1998). In a review of 62 other studies, totalling 23,000 surveyed prisoners, Fazel et al (2002) estimate a

prevalence of 65% for any personality disorder in men and 42% in women.

Outside of epidemiological research there is evidence however that some individuals may remain unaware of having been diagnosed with a personality disorder by their clinical team - for example in a survey of 134 psychiatrists based in the US identified over half of their participants as having previously chosen not to disclose a diagnosis of borderline personality disorder to their patients (Sisti, Segal, Siegel, Johnson, & Gunderson, 2015), including 37% stating that they had experience of a diagnosis had been made but not recorded in clinical records. Perceived stigma and uncertainty regarding diagnostic classification were cited as reasons for this non-disclosure.

Concerns raised relating to the nature and diagnostic credibility of the personality disorder diagnosis mean that such figures cannot be read uncritically - but they are still indicative of a substantial level of personal distress within the population, particularly among prisoners.

Prognosis and treatment

Most research relating to prognosis and treatment in personality disorder has focussed on the experience of those with a borderline personality disorder diagnosis (Bateman, Gunderson, & Mulder, 2015). As described in the survey by Sisti et al. (2015) above there is an association between the concept of borderline personality disorder and ideas of chronicity and their being 'untreatable' that can engender a sense of therapeutic nihilism (Paris, 2012). Longitudinal research has been conducted however, with one cohort now exceeding 16 years of follow up, which suggests that remission of symptoms such that individuals no longer meet the core criteria for diagnosis can be

expected in the majority of patients (Zanarini, Frankenburg, Reich, & Fitzmaurice, 2012). However, within this study the authors highlight that remission cannot be considered synonymous with recovery (which for the purpose of this study is defined as a threshold score on an assessment of psychosocial functioning) with 60% of participants obtaining a two-year period of recovery within the 16 year follow up but only 40% obtaining a period of recovery lasting eight years (Zanarini et al., 2012). Examining factors that may influence this attainment of recovery the group found that two-year recovery was predicted by absence of hospital admission, higher IQ, full-time employment, absence of anxious type personality disorder, as well as high levels of extraversion and agreeableness on personality assessment (Zanarini et al., 2014).

As for all psychiatric disorders available treatment modalities include both psychological and psychopharmacological measures (Bateman et al., 2015). However, most clinical guidelines recommend that psychotherapeutic options be the mainstay of treatment (e.g. National Institute for Health and Care Excellence). A number of specific psychotherapeutic models have been developed in relation to borderline personality disorder - perhaps most significantly dialectical behaviour therapy (DBT - Linehan, 1987) and mentalisation based therapy (MBT - Bateman & Fonagy, 2013) both of which have shown some evidence of superiority in comparison to usual treatment within randomised control trials (Bateman & Fonagy, 2009; Linehan et al., 2006).

The role of pharmacological interventions is more controversial. Different systematic reviews have shown varying findings regarding claims for efficacy with some weak evidence for the role of antipsychotic and mood stabilising psychotropic agents (Ingenhoven, Lafay, Rinne,

Passchier, & Duivenvoorden, 2010; Lieb, Vollm, Rücker, Timmer, & Stoffers, 2009). Notwithstanding these weak evidence claims however prescription of medication is common in the treatment of borderline personality disorder (Martinho, Fitzmaurice, Frankenburg, & Zanarini, 2014).

In spite of the presence of therapeutic nihilism, described at the head of this section, there is some evidence for hope with regard to the prognosis and treatment of symptoms in borderline personality disorder at least, although evidence with regard to the other diagnoses is more limited. Caution should be exercised however in the reading of the evidence base - specifically owing to the lack of conceptual clarity, and opacity of record keeping, described in relation to personality disorder, as well as more generally owing to the risk of corruption and poor quality evidence within the available published literature (Lenzer, 2013).

Recovery and personality disorder

Returning again to the overarching topic of recovery the concept can be seen as becoming still more unclear in relation to personality disorder. For example, if a rehabilitative standpoint is adopted the question emerges as to precisely what level of 'pre-morbid' function can be expected to be reached, given the claimed onset of experience in adolescence, or even childhood? Additionally, returning to the concept of identity work, as the definition of 'personality' outlined above illustrates concepts of personality, persona and identity are intimately linked. What is the process of identity work in relation to a disturbance of 'normal' personality functioning?

Personality disorder, forensic institutions and recovery

As described above epidemiological studies claim that rates of personality disorder are particularly high within prison populations - questions relating to the nature of the diagnosis, its treatment and meanings of recovery are therefore particularly pertinent for mental health practitioners working within such spaces. Provision of clinical care within prison settings is particularly challenging however - a challenge being driven by complexities relating to issues of access to resources and patient autonomy (Birmingham, Wilson, & Adshead, 2006). Working with individuals with a personality disorder diagnosis is recognised as being challenging for clinical staff - with issues of disrupted attachment and strong emotional response being difficult to contain and process emotionally (Adshead, 1998; Watts & Morgan, 1994). Within prison environments prison officers also offer direct frontline support to individuals with experience of mental distress and may therefore experience similar challenges to those described by mental health staff.

Responsibility for the support of personality disordered offenders in the UK is shared between the NHS and National Offender Management Service (NOMS) (Joseph & Benefield, 2012) with hospital environments being made available to those with a co-morbid mental disorder diagnosis and meeting criteria for detention under the Mental Health Act. Psychologically Informed Planned Environments (PIPEs) are being developed throughout the prison service to meet the psychological needs of these individuals (Turley, Payne, & Webster, 2013). These PIPES have been developed to replace previous Dangerously Severe Personality Disorder (DSPD) units (Völlm & Konappa, 2012), which in turn were developed to meet a perceived

significant unmet need within the forensic sector with regard to those receiving a personality disorder diagnosis.

Personality disorder is also significant within the forensic sphere for its role at the interface between ideas of mental health and criminal justice. Criminal law allows for the presence of mental disorder to be taken into account in appraising an individual's culpability in relation to the alleged crime. The position of personality disorder in relation to claims of Insanity, or diminished responsibility in the face of a murder charge, is controversial with some legal jurisdictions acting to exclude personality disorder diagnoses as applicable 'defects of mind' in these cases. Different legal, and clinical, arguments have been presented both in support (Kinscherff, 2010) and opposition (Sisti & Caplan, 2012) to the application of personality disorder diagnoses in this capacity. In this manner the uncertainty relating to the nature and implication of personality disorder diagnoses can be seen as extending into the criminal justice field.

Doubt has therefore been raised within both legal and medical fields of practice with regard to the reliability, or legitimacy, of personality disorder as a construct. As a result, communication of the diagnosis to mental health service users is often left unspoken, or unrecorded - with clinicians citing concerns regarding stigma, or uncertainty in the diagnosis as a reason for this (Sisti et al., 2015). Such lack of clarity may contribute to further difficulty in conceptualising ideas of recovery in relation to personality disorder.

In considering the framework outlined by Leamy and Bird (2011) describing themes associated with the process of recovery (Connectedness, Hope, Identity, Meaning and Empowerment) it can be

seen that each of these themes is impacted on directly by the process of incarceration. The concept of recovery can sit uncomfortably with a number of the ethical questions arising in the practice of forensic psychiatry relating to issues of mental disorder and culpability (Pouncey & Lukens, 2010). The provision of recovery oriented mental health care within forensic institutions can therefore be seen as being particularly challenging (Simpson & Penney, 2011).

In combination the claimed prevalence of personality disorder within forensic institutions, together with the complexity of the concept of recovery as applied to both considerations, indicate the need for greater understanding of both topics within the forensic field. The above arguments have sought to demonstrate the liminality of personality disorder with respect to a number of fields: - Mental disorder / Health; Mental health care / Prison and Mental disorder / Criminal law. On the basis of this liminality, it is argued that the experience of those receiving a personality disorder diagnosis represents a potentially rich field of study in the effort to better explore the concept of recovery. Beyond this however, if the diagnosis of personality disorder is accepted uncritically as an object of distress to individuals then the epidemiological studies indicate that this distress impacts on a significant number of people within the general population, but also particularly the prison population. As such research addressing the concept of recovery in relation to these people's experiences can be seen as being of potential benefit if it informs the manner in which clinical care and support can be provided for them, if desired.

Personal positioning - the role of the author

Before moving on to address the final sections of this chapter a brief interlude is introduced wherein the role of the author in relation to this thesis, and body of research it describes, is considered. In contrast with the remainder of the thesis this section and a similar section in the concluding chapter are presented in the first person. Consistent with the adopted constructivist epistemological approach, described in greater detail in the methods chapter below, this thesis is positioned as a performative piece of writing representing an interaction between myself, the author, and the reader. In this manner I attempt to adopt and perform a specific identity in relation to my role as an academic and researcher (c.f. Ivanič, 1998). I therefore present information in relation to my experience and role in a transparent manner so as to inform the reader's interpretation of this performance.

At the time of writing I am employed within the NHS as a higher trainee in forensic psychiatry and as a doctoral research fellow - the research reported in this thesis was conducted over a three-year period during which I was 'out of programme' with respect to clinical training. As such I occupy a dual role in both academic and clinical fields. This dual positioning was maintained throughout the three-year project as I maintained clinical contact in addition to conducting the research project. I also occupy other roles outside of these spheres (husband, father, son, friend) and while these roles are undoubtedly significant to the construction of this thesis they are not discussed in detail here.

Clinically I have continued to work in a prison setting for one day a week throughout the past three years. This has been in the context of running a psychiatric clinic within a women's prison. Work within the clinic has consisted of assessment, diagnosis, medication monitoring and

occasional report writing when requested by external agencies. This work has principally been conducted within the healthcare unit in the prison, but has also involved visits to the prison wing and to the segregation unit for reviews of women currently held in isolation from the rest of the prison population. I have also remained on an emergency out-of-hours on-call rota principally covering secure hospitals in the North West of England.

In terms of underlying theory, I see my clinical work as being informed principally by psychoanalytic and psychodynamic theory - specifically ideas relating to ideas of attachment (Bowlby, 2005) and Lacanian theory (Fink, 2009). To summarise, this theory posits that we all haven an unconscious life and that manifestations of this unconscious life may give rise to symptoms of distress, that may be termed as evidence of mental disorder. Unconscious life is seen as emerging through the interplay of 'symbolic' and 'imaginary' representations of the 'real' and develops through the interaction of individuals within a linguistic field. Psychopharmacological prescription is made within this model of clinical practice then, not with the intent of 'cure', but instead with the aim of relieving psychic distress (Moncrieff & Cohen, 2005) - however the symbolic interaction between 'doctor and patient' through the prescription of medication must also be acknowledged (Tutter, 2006). The intent of this adopted theory is not to advance a fatalistic, or nihilistic, interpretation of mental distress - but instead to emphasise the normal experience of distress in the face of personal trauma and to minimise this distress where possible.

During core psychiatric training (three years of practice completed two years after graduation from medical school) I was able to secure a degree of academic experience through the support of a NIHR funded Academic Clinical Fellowship award. This allowed me to take a period of three blocks of three months out of full time clinical practice to gain some experience within a research environment. Projects completed in this period included the appraisal of working memory deficits as an endophenotype for Schizophrenia - with working memory deficits modelled through the use of Ketamine, a N-Methyl-D-Aspartate (NMDA) receptor antagonist known to induce working memory deficit, as recorded through electroencephalography (EEG). This project involved the recruitment of healthy volunteers who were exposed to either a ketamine or saline infusion while they completed a series of working memory challenges; EEG was recorded to monitor for changes induced in response to the challenges presented. The hypothesis tested centred on the assumption that the use of ketamine would induce working memory deficits analogous to those observed within patients identified as having a diagnosis of schizophrenia, or high level of 'schizotypy' as defined on standardised diagnostic interview (Koychev, El-Deredy, Haenschel, & Deakin, 2010).

My second project completed during this ACF rotation focussed on the experience of consultant psychiatrists in relation to decision making in the prescription of antipsychotic medication. This project built on findings from large pragmatic-randomised control trials (P. B. Jones et al., 2006; Lieberman, Stroup, & McEvoy, 2005) and recent meta-analyses (Leucht et al., 2013) which challenged conventional psychiatric practice in terms of the division of antipsychotic medication into so called 'first generation' and 'second generation' drugs (S. Lewis

& Lieberman, 2008); where second generation compounds had been seen as preferential to first in terms of their efficacy and tolerability. The project examined the manner in which psychiatrists negotiated this understanding in terms of their prescription and the practice of 'shared decision making' with patients (Barry & Edgman-Levitan, 2012; Charles, Gafni, & Whelan, 1997; Shepherd, Shorthouse, & Gask, 2014).

Time spent throughout the ACF award allowed for a shift in my theoretical thinking and academic interest - initially this had been focussed on the study and treatment of psychiatric disorders as disease entities, or objects in their own right. Through the second year of the award this understanding and interest shifted however towards the manner in which knowledge is constructed within mental health practice and the implications of this construction for clinical practice and social interaction more generally. This shifting interest, combined with findings from the REFOCUS project (Leamy et al., 2011), led to the development of a doctoral research fellowship application focussing on the recovery experiences of individuals receiving a personality disorder diagnosis.

Academic supervision

In the process of developing the fellowship application, that subsequently allowed this project to be conducted, a research supervisory team was identified comprising members representing a variety of clinical (forensic psychiatry) and methodological (statistical and qualitative methods) positions. In this manner my fellowship was viewed as being analogous to an 'apprenticeship' model allowing me to learn directly from the expertise of the supervisory team. Additionally, however, the supervisory team through the process of discussion, review of research material and draft writing, became directly involved

in the 'construction' of knowledge emerging from the project, as such acknowledgement of the theoretical and clinical expertise of the supervisory team is necessary in considering issues of reflexivity in relation to the authorship of this thesis (Hall, 2005).

Linking theory and methodology

On the basis of the above discussion it is argued that personal recovery can be viewed as an example of 'identity work', in relation to the experience of mental distress, and that further insight into this process can be gained through considering the experience of those who occupy positions that are liminal to the provision of support by mental health services. It has been proposed that those individuals receiving a personality disorder diagnosis occupy such a liminal position with respect to a number of understandings and constructs. An ontological and epistemological orientation are therefore required that are able to address this concept of identity work. This will be discussed in greater detail within the chapter on methodology. An introduction is presented here however to pertinent concepts relating to understandings of identity and identity work.

Theories of identity seek to address questions relating to the manner in which an individual can be recognised as the same person at two distinct time points. This problem is summarised in the classical thought experiment relating to the fate of the Ship of Theseus which, over time, has all of its constituent parts in its hull and other fittings replaced; can it therefore be said to remain the same ship - to retain its identity as Theseus' ship? Many accounts seeking to resolve this problem in the case of personal identity draw on accounts of 'psychological continuity' which claim their origin in an interpretation of Locke's (1997) account of personhood. These theories posit that it is a continuous stream of

conscious experience which knits together the fragmented snap-shots of situational memory. Such theories have been criticised however with alternative accounts being offered, such as that outlined by Schechtman (1990; 2005), wherein it is the reflexive capability of the individual to recognise themselves as a person that is significant to their very personhood. Such theories give rise to the concept of a 'narrative self' - that is an individual who through an act of self-recognition engages in a generative process of developing continuing explanation for their own identity.

Accounts such as that outlined by Schechtman have been challenged as misrepresenting the underlying claims of psychological continuity theorists; suggesting, for example, that these theories are over simplified in her account and that it is the continuity of values, beliefs and desires, not simply memories, that constitute identity (Beck, 2013). Schechtman's response to this argument is to propose that the act of self-narration underscores this process by allowing an act of agency in the development of new beliefs and values (2013). Additional argument has centred on the concept of the 'whole life narrative' and the impossibility of constructing such an edifice, which in turn leads to proposals that a narrative identity is not an overarching structure but instead a bundle of interpretations in relation to different core values that combined together represent the totality (Lumsden, 2013).

An alternative critique of the narrative identity theory can be drawn from an understanding of the psychoanalytic subject - which can only be seen as existing in the richness of conscious and unconscious life in the presence of the Other. Ormay (2013) has referred to this process as the development of the *nos*, or collective unconscious. By positing the

existence of a self-narrating subject there is a risk that the necessity of the Other in the process of reflective self-recognition can be overlooked.

<u>Narrative identity and social science research</u>

The application of concepts of narrative in relation to experiences of chronic illness has led to the development of a rich field of social science research. Such explorations can be seen as emerging from critiques of Parson's (1951) 'sick role' account of illness behaviour - which proposed that the account was of only limited use in the experience of individual's with a chronic experience of illness (Gerhardt, 1990; Mechanic, 1959). Bury (1982) proposed the idea of chronic illness as biographical disruption - that is the disturbance of identity in the face of emerging illness as a point of crisis and contention around which an adapted sense of self would emerge. Williams identified the manner in which individuals would 're-construct' their understanding of their own identity in view of chronic illness experience and in light of social and political considerations (Williams, 1984). Strauss (1982) positioned such 'identity work' as an example of 'sentimental work' undertaken by professionals and their clients in the face of illness experience. Studies of chronic illness narratives in relation to various disease states led to the proposal that certain 'genres' could be seen as arising from these accounts; Heroic and Tragic for example (Kelly & Dickinson, 1997). Frank (2013) has proposed a typology of narrative accounts which he describes as representing a call for understanding in relation to the moral duty of the 'wounded storyteller' to bear witness, or deliver 'testimony' to their experience. His proposed typologies included; Restitution narratives (search for cure or overcoming illness), Chaos narratives (the absence of narrative) and Quest narratives (search for meaning within illness, or use of illness in political opposition). Narratives can also be seen as being closely linked with prevalent social

accounts relating to the nature of individual experience - for example accounts of 'Generativity and Redemption' in the biographical narratives of adult Americans (McAdams, 2006).

With the emergence of increasing volumes of research focussing on the development of illness narratives concerns have also been voiced relating to the manner in which such narratives may be viewed as a representation of 'truth' (Bury, 2001) giving voice to those oppressed by a system dominated by medical power or other forms of dominant discourse (Nelson, 1995), or representing a moral duty to bear witness (Frank, 1997). Bury (2001) emphasises the importance of interpretation by researchers examining illness narratives - pointing, for example, to the performative function that narrative accounts can be seen as playing (Riessman, 2003) and cautioning against an uncritical reading of such performances.

Narrative identity and clinical work in mental health practice

The manner in which individuals relate to and narrate their experiences of distress can be seen as significant to the development of a therapeutic relationship between practitioner and client. In this manner psychotherapeutic practice has been described as a means of supporting the individual in the exploration of their personal story (Holmes, 2008). The therapeutic relationship between participants in the psychotherapeutic process can be seen as central in its allowing this process to develop in a safe and secure fashion (Holmes, 2009) and, while this relationship can be seen as subject to the usual social dynamics that are attendant on all relationships, it can also be seen as representing an especially privileged space within which information can be shared that would not normally be seen as appropriate in a different social context (Wampold, 2015; Wampold & Budge, 2012).

Clinical work has also allowed the extension of this process to consider the function of groups in the development of the psychotherapeutic process (Barnes, Ernst, & Hyde, 1999; Foulkes, 1946) and the concept of developing shared stories within group settings, as they apply to different aspects of personal identity, has been applied in a variety of clinical settings (Adshead, 2011).

In reviewing the change processes associated with psychotherapy research has also focussed on the manner in which narratives relating to the therapeutic process are presented. For example Adler and colleagues (Adler, 2012; 2008) applied quantitative measures of narrative agency and coherence to accounts of experiences of psychotherapy and demonstrated that for those participants reporting greater degrees of subjective wellbeing generated narratives contained a higher degree of personal agency in relation to the management of a discrete problem, while those participants with a higher level of 'ego development' presented narratives that were consistent with an account of personal growth .

For the purpose of the present project it is therefore argued that narrative represents a central facet in the manner that individuals make sense of their own identity, illness experience and also for the manner in which psychotherapeutic processes can be seen as developing. In this way narrative identity can be seen as closely related to recovery as a subject of investigation. However, in keeping with the criticisms raised by Bury (2001), it can also be argued that the concept of narrative should not be observed as an object in its own right - but instead as a manifestation of the shared sense making activity that takes place between agents - whether they be participants in a therapeutic or research process. In this manner the construction of narrative should be

viewed as a social process that is intimately linked with the reflexive, or dynamic, process that emerges between those involved in its elaboration.

Argument, aim and thesis

In this introductory chapter an overview of the concept of 'personal recovery' as it applies to mental health has been provided, together with some indication as to why this is to be considered a significant area for research. In presenting a historical context as background framework it is hoped that the complexity of social forces impacting on the concept have been demonstrated - rendering a simplistic reading of the idea problematic. It has then been proposed that further understanding of the phenomenon may be gained by considering the experience of individuals whose mental distress places them within a liminal situation. 'Personality disorder' is then proposed as an illustrative case to facilitate this exploration. In addition to this line of argument information relating to the author and research supervisory team has been presented in order to inform a reflexive reading of this thesis and as an acknowledgement of the performative aspects in this process. Finally, an overview of narrative identity theory has been provided, together with some examples of its applications within social science research and clinical practice. Limitations of the concept of an 'illness narrative' as an object in and of itself have been highlighted.

The remainder of this thesis seeks to build on argument emerging from these opening statements and to further explore the concept of recovery from a variety of perspectives. In this manner the objective of the research presented in the following chapters is not to test a hypothesis, or seek to disprove the null-condition, but instead to develop greater understanding in relation to the phenomena in question; a process of

hypothesis generation not testing. The overarching aim in the following chapters is therefore to explore the lived experience of recovery as described by individuals receiving a personality disorder diagnosis and accessing support from mental health services in a variety of clinical settings. The manner in which this process is enacted within social institutions is also considered.

Chapter 2 - Methods

The following chapter seeks to outline the methodological approach employed during the thesis project. This begins with an introductory discussion relating to the Ontological and Epistemological approach to knowledge generation employed, before moving on to discuss specific methodological and ethical considerations.

As the thesis is presented in an 'alternative format' style, and includes submitted papers, the intent of this chapter is not to repeat material contained within those papers - but instead to consider more the principles on which methodological decisions were based.

Ontology and Epistemology

As has been discussed above, the precise understanding as to the nature and meaning of personal recovery has not been established and can be seen as varying between parties. For the purpose of this investigation however it is proposed that the concept of personal recovery can be distinguished from one of clinical recovery. It is argued that personal recovery is distinct for the manner in which it incorporates individual understanding, through a process of sense making. In contrast the concept of clinical recovery is often defined in terms of change in measurable phenomena, for example symptom severity. Such individual sense making experience is however a 'private phenomenon' and cannot be accessed, except through shared symbolic representation - for example the development of discourse and language.

Access to such forms of private experience can be seen as sharing some overlap with the application of phenomenological enquiry - that is

philosophical exploration into the nature of experience. For example, in relation to this idea of 'private phenomena' consider the example of Wittgenstein's beetle: - Every person has a beetle in a private box but each has access only to their own beetle, everyone refers to their 'beetle' yet only knows of their own beetle and hence cannot refer to another's - each could in fact refer to some different thing, or nothing (Proposition 293, p100 - Wittgenstein, 1991). The sense making process therefore involves an intimate interaction of social and psychological processes - leading to the development of a subjective knowledge through the actions of a 'psychosocial subject' (Hollway & Jefferson, 2012). Such knowledge cannot be seen as 'real' but instead, to borrow a concept from Lacan, is a 'symbolic' representation of 'imaginary' experience (McConnell & Gillett, 2005).

If an understanding of recovery is to be considered in this manner, then an epistemological approach is necessary that can provide a means of accessing these private phenomena. In assessing notions of clinical recovery positivist empirical approaches have been applied, with great success, for example through the development of the concept of 'evidence based medicine'. Through this approach empirical methodologies, such as the randomised control trial and meta-analysis, are employed in order to measure response to treatment in relation to objective, measurable, phenomena - for example extension in life expectancy through the application of chemotherapy agents in cancer. Such evidence is accumulated together as a resource which is then used by clinicians to aid decision making in relation to clinical practice (Sackett, 1997; Sackett, Rosenberg, Gray, Haynes, & Richardson, 1996). The application of such approaches to private, subjective, phenomena including concepts of personal recovery is however not an immediately suitable approach - with greater exploration of lived

experience necessary if a sufficiently grounded account is to be developed.

Qualitative methodological approaches provide a means of exploring such lived experience, including in the elucidation of the personal significance of phenomena such as personal recovery. A wide variety of such methodologies exist with varying epistemological approaches to their interaction with subject material. Madill and Gough (2008), seeking to present a typographical representation of varying methodological approaches, described each methodology according to the specific procedure applied. Their identified summary overarching methodologies included discursive, thematic, structured and instrumental approaches. In this typology discursive methods are characterised by their focus on representations of the manner of interaction between individuals and the details contained within generated text, or other analytic substrate. Thematic approaches work varyingly with some adopting a 'bottom up' manner seeking to describe 'concepts' that are representative of the phenomenon in question, while others adopt a more deductive methodology. Structured methods, for example Q-methodology, are characterised by their precise methodological approach allowing replication of application between practitioners. Finally, instrumental approaches are defined on the basis of a specific practice ethos, for example feminist approaches.

In considering the phenomenon of 'personal recovery' then it is argued that the idea, while unique in its individual meaning, will share common 'themes', or 'concepts', between individuals - meaning that a thematic approach represents an appropriate avenue of investigation. However, the reporting of experiences of recovery is liable to be greatly influenced by the psychological and social experience, or background, of the

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individual. Its communication will also vary dependent on the nature of the audience, in this case a researcher who is also a practicing psychiatrist. Exploration of this private phenomenon will therefore rely upon a negotiated understanding developed between researcher and participant, with attention given to the manner in which this shared knowledge is evolved. This approach can therefore be seen as adopting a *constructivist* epistemological position - representing the manner in which understanding is built, or constructed, through an iterative interaction of conversation between the researcher and participant, followed by analysis and representation of findings to varying audiences. This approach can be referred to as *contextual constructivism* and relies upon the interaction of subjectivities between researcher, participant and other audiences in the representation of research findings (Madill, Jordan, & Shirley, 2000).

Owing to this need for exploration from different perspectives for the purpose of mapping the concept of recovery it is argued that no one particular methodology is ideally suited and that instead greater clarity can be gained through the application of a range of methodological influences in an eclectic manner. Therefore, in the following sections below each of the employed techniques (systematic review, individual interview and focus group discussion) are considered specifically in terms of the rationale for their application.

Systematic review

Systematic review is generally regarded as being a structured methodological approach whereby the existing academic literature is surveyed in such a manner as to identify relevant studies relating to a specific research question. The act of systematic review, seen as an integral part of the research process, is cited for its ability to minimise

the risk of wasteful reproduction of previous findings (Chalmers & Glasziou, 2009). Within a positivist empirical framework systematic review also allows for the combination of previous findings through statistical methods in the form of a meta-analysis - in this manner previous findings are brought together in order to enhance the strength of the resultant outputs. The reporting of such studies is then guided by publication standards such as the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) statement (Moher, Liberati, Tetzlaff, Altman, PRISMA Group, 2009), ensuring that information is presented in a transparent and complete manner in order to aid interpretation of results.

In contrast the incorporation of systematic literature review into qualitative research studies has not been so clear cut. For example, some methodologists argue that conducting a literature review prior to the research itself risks prejudicing the subsequent enquiry, preventing findings from being sufficiently *grounded* within the data collected (Charmaz, 1990). Counterargument suggests that it is not plausible to view the researcher as an entirely 'blank slate', or alternatively that systematic review is generally accepted as a scoping exercise to delineate the area of study and is largely expected to be completed for funding to be secured. Despite these arguments therefore, methods of systematic review and synthesis have been developed for application within qualitative epistemological frameworks. For example, techniques building on the original work of Noblit and Hare (1988) in their description of meta-ethnography as a means of synthesising, or developing higher order understanding in relation to findings from previous qualitative methods studies. Additionally, in response to the rising number of publications seeking to present findings from such approaches publication standards, analogous to the PRISMA

statement, have been developed - for example the Enhancing transparency in reporting the synthesis of qualitative research (ENTREQ) statement identifies twenty-one core quality items relating to the reporting of systematic review and meta-synthesis studies (Tong, Flemming, McInnes, Oliver, & Craig, 2012). Building on this, in reviewing published meta-ethnography studies, France et al. (2014) highlighted a poor standard of reporting, particularly in relation to the description of the manner in which the synthesis of findings from substrate studies was conducted. It is unclear whether statements such as ENTREQ will be able to address these concerns through developing sufficient focus on the methodology employed within specific studies, owing to the wide range of approaches currently being developed.

In the process of conducting the current research project two initial systematic reviews were carried out - with the aim of identifying existing qualitative methods literature relating to the experience of personal recovery as it relates to personality disorder and also the experience of recovery, in relation to any diagnosis, in forensic institutional settings. The findings from these two reviews are presented in the results section of this thesis but have been previously published elsewhere (2016a; A. Shepherd, Sanders, Doyle, & Shaw, 2016b). In conducting these studies, a background framework was established in relation to existing published research - not with the intention of prejudicing any subsequent analysis but instead to inform the development of the conducted studies in such a way that limitations in the existing literature base could be reduced while also building on existing knowledge and understanding. The conduct of the two systematic reviews can therefore be seen as a form of 'sensitisation' to existing literature in that they allow not only consideration of pre-existing published material in the field, but also consideration of various methodological and theoretical texts

relating to the topic of study. As the methods employed in these reviews are included within the presented papers they are not repeated precisely here; instead a description for the rationale for adopting specific methodological choices is outlined.

Search strategy

Systematic reviews conducted within a positivist framework generally seek to identify all published studies relevant to the research question in order to maximise the population under consideration and increase the statistical strength of findings. Inclusion and exclusion criteria are then applied to identified studies to ensure that target populations and the applied methodology in identified studies are sufficiently homogenous to justify the combination of results through the process of meta-analysis.

Examples of qualitative meta-synthesis studies may similarly seek to be exhaustive in their search strategy (for example - Knowles et al., 2014). However, strategies may also be employed where the search methodology is adapted in a purposive fashion to meet the aims of the study (Benoot, Hannes, & Bilsen, 2016). In keeping with this purposive, or theoretically orientated, sampling techniques have been described as better suited to the 'theory generating' purpose of qualitative research (Finfgeld-Connett, 2016). For example, Suri (2011) proposes 16 purposive sampling strategies to be employed dependent on the synthesis purpose - such as maximum variation sampling and deviant case sampling.

For the purpose of the systematic reviews conducted in this project an iterative approach to the search strategy was initially employed - which demonstrated only a limited number of published studies addressing the

research question for each review. As such a comprehensive sampling strategy was utilised in which all previously published studies were included in the synthesis process. Specific search terms used are outlined in each of the attached reports.

Inclusion criteria were set so as to maximise the representation of individual service user experience in relation to the field of inquiry. Meta-synthesis methodological approaches require access to first order (participant quotation) and second order (primary researcher interpretation) themes - a terminology originally outlined by Schutz (1962). For the purpose of the performed systematic reviews therefore a specific inclusion criterion was set that any reported studies must include transparent access to first order material, such as quotations from interview transcripts. This step was taken in order to ensure that a transparent approach to the synthesis of findings could be taken; the synthesis process is described in greater detail below.

Methodological appraisal of identified studies

In the meta-analysis of quantitative studies detailed methodological appraisal of included studies is conducted to identify potential sources of bias in the substrate studies. Organisations conducting large numbers of systematic reviews, such as the Cochrane Collaboration (http://www.cochranelibrary.com), have published standard methodological appraisal tools which are commonly used by authors in the reporting of reviews (for example Armijo-Olivo, Stiles, Hagen, Biondo, & Cummings, 2010; Higgins et al., 2011).

Similar tools have been developed for the appraisal of qualitative methods studies, with one of the most commonly employed being the Critical Appraisal Skills Programme (CASP - http://www.casp-uk.net)

Qualitative Checklist. This tool seeks to appraise studies according to ten guiding statements (available at- http://www.casp-uk.net/#!casp-tools-checklists/c18f8), the first two of which are intended as 'screening questions' to allow rapid exclusion of studies:

1. Was there a clear statement of the aims of the research?
2. Is a qualitative methodology appropriate?
3. Was the research design appropriate to address the aims of the research?
4. Was the recruitment strategy appropriate to the aims of the research?
5. Was the data collected in a way that addressed the research issue
6. Has the relationship between researcher and participants been adequately considered?
7. Have ethical issues been taken into consideration?
8. Was the data analysis sufficiently rigorous?
9. Is there a clear statement of findings?
10. How valuable is the research?

Figure 1 – CASP criteria for qualitative research

The application of such tools in the appraisal of qualitative research however has been questioned. For example, Dixon-Woods et al. (2007) explored the application of standardised tools in the appraisal of studies by qualitative reviewers and suggested that the application of such instruments may not improve consistency of decision making with regard to the inclusion of papers within systematic reviews. In a stronger critique Barbour (2001) argued that the application of standardised appraisal risked losing some of the individual quality and

insight that can be seen as a strength of qualitative methodological approaches.

For the purpose of the systematic reviews included within the present report the decision was taken to apply the CASP Qualitative Checklist - excluding the second and tenth items from the list. This approach was adopted not with the intention of excluding studies but instead as a means of providing a standardised framework to generate some contextual understanding in relation to the methodology employed in each of the identified studies; therefore, providing the reader with a greater understanding of the nature of the substrate studies employed in the meta-synthesis, informing their own interpretation of the presented findings.

Treatment of results

A meta-synthesis approach, analogous to the meta-ethnography approach described by Noblit and Hare (1988), was adopted. The output of this synthetic approach was a series of 'third order themes' that can be seen as serving as a framework to outline, and build upon, the findings from existing research in this field. As noted above previous reviews of this methodological space have identified the reporting of study methodology as being unclear (Finfgeld-Connett, 2016; France et al., 2014), it is hoped that the reported methods employed in the reported studies in this thesis is clear, although it should be noted that the precise manner in which the methodology employed is reported varies slightly according to the target audience, as indicated by the specific journal in which the findings are published. Five steps were employed in the synthesis process, which were adapted from the classic methodological text (Noblit & Hare, 1988):

1. Reading: - A process of close reading and attention in relation to the results and discussion sections of substrate studies to allow identification of first and second order themes.

2. Study relationship: - Relating the identified studies to each other in terms of their findings and populations.

3. Translation: - The development of first and second order descriptive thematic headings to allow combination of substrate study findings into one synthetic analysis.

4. Synthesis: - A process of reading of primary study material was combined with discussion within supervisory meetings and reading of related published literature to allow the development of novel third order themes in an inductive process derived from the substrate studies.

5. Expression: - Writing and discussion were employed as a means of communicating novel findings until a final form of expression was developed.

Figure 2 – Meta-synthesis process

In presenting a worked example of the meta-synthesis process Britten and colleagues (2002) comment on the difficulty in describing the precise steps employed in the act of synthesis other than to comment that the process begins in the translation of studies into common descriptive headings and that the third order themes can be seen as emerging in an iterative, inductive, process from the analysis. So, for example in the study reported in Chapter 3, first order elements, or quotations, from the second order theme 'Struggling to stay alive by enhancing self-development', identified in the study by Holm and Severinsson (2011), were incorporated into two of the third order themes - 'Safety and containment as a prerequisite to recovery' and 'Identity construction as a process of change' owing to the dual nature

of the processes described - 'struggling to stay alive' and 'self-development'.

Approach to data collection - individual interviews and focus groups

The reported systematic reviews of published studies relating to the experience of recovery in relation to personality disorder and in forensic settings allowed the establishment of a framework understanding relating to the topic of investigation. Additionally, the review process also confirmed that, despite the intimate involvement of social environment in the recovery process (Davidson, 2008), little research attention had been given to this field of enquiry in the published literature relating to personality disorder (Shepherd, Sanders, Doyle, & Shaw, 2016b). The absence of particular attention in relation to the experience of those receiving a personality disorder diagnosis and accessing care within forensic settings is particularly striking given the high claimed rates of such disorders within forensic institutions (Fazel & Danesh, 2002). Further investigation was therefore conducted to explore the experience of personal recovery in relation to personality disorder as described by individuals accessing mental health care in a variety of institutional settings.

In keeping with the overarching aim of the thesis two distinct methodological approaches were adopted in an effort to explore the lived experience of participants. The first of these involved individual interviews with participants who had received a personality disorder diagnosis from their clinical team and were actively accessing some form of mental health care or support. The second approach involved the use of focus group interviews with mental health clinical staff. Professional

focus groups were conducted in order to allow exploration of themes emerging from the individual interviews from a differing perspective, while not implying a primacy of understanding between either professionals or individual interview participants. Thus, while participants were initially invited to consider the concept of 'recovery in personality disorder' as it applied in their own practice illustrative themes from individual interviews were then introduced as a means of reflection and developing further understanding. Overall the incorporation of three methodological techniques (meta-synthesis, individual interview and focus group interview) can be seen as a form of triangulation in the research process.

The concept of 'triangulation' refers to the process whereby varying methodological approaches, or different forms of data, are combined together with regard to the study of the phenomenon of interest. For example, in mixed-methods research, combining qualitative and quantitative paradigms, triangulation as a form of 'corroboration' may be cited as a reason for the combination of different epistemological approaches (Bryman, 2006). Evidence of triangulation has similarly been described as one of the factors indicative of 'credibility' in research and to be judged as a marker of 'quality' (Tracy, 2010). Such approaches risk the conflation of triangulation with a realist epistemological approach however, wherein triangulation is seen as increasing the chance of the adopted methodology zeroing in on the 'true' interpretation of a phenomena. However, triangulation can also be seen as consistent with a constructivist epistemology, which would view the idea of 'a single truth' as problematic. With such an approach the incorporation of varying methodologies, or perspectives, serves to increase the richness of the data available in relation to the field of enquiry (Flick, 1992). In this manner, triangulation has been described

as being one tool available within the 'craft' of social science research (Seale, 1999).

As outlined above the epistemological approach adopted within the thesis is eclectic in nature - therefore, while specific methodologies employed are described in detail within each reported study in the Results section of the thesis, argument is presented below with regard to the rationale for adopting varying approaches to the conduct of individual narrative and focus group interviews.

Individual interview approach

The approach to individual interviews employed in this project draws on a variety of methodological approaches; the influence of these approaches will be discussed here, as well as in the section considering the analytic method adopted.

For the purpose of this investigation the concept of 'recovery' was considered to be a facet of the lived experience of individuals that could be explored through consideration of their talk, generated in response to questions relating to their life and the place of mental disorder within it. The aim of the individual interview process was therefore to allow participants to express their experience in the form of a narrative, with the interviewer seeking to elaborate further understanding through the use of direct questioning. In this manner, understanding in relation to lived experience, and recovery, is generated through a process of co-construction between the researcher and participant.

Epistemologically therefore the interview process is viewed as an act of co-construction between the participant and researcher - as such the role of the researcher in the interview process needs careful

consideration in the conduct of both the interviews and analysis: this impact is discussed in greater detail below, in the section entitled 'Reflexivity'.

It is also important to note however that the term 'recovery' is in itself now widely used within mental health service provision and has therefore taken on a specific connotation within the practice of clinical care. Beyond this, the word itself is also affectively laden in its symbolic meaning - generally being seen as representing the regaining of something that has previously been 'lost', or to return to a 'normal' state of health. The incorporation of the word 'recovery' into materials associated with the research project, such as participant information and consent forms, in itself can be seen as introducing a certain constraining framework to the work of generating understanding as conducted during the interviews. Given this specific use of the word the topic of 'recovery' was therefore approached directly through questioning during the course of the interviews and reflection was also made, through discussion with the participant, between the differences in implicit and explicit reference to the concept.

Inclusion, or sampling, criteria
Participants were selected for individual interview on the basis of three principle criteria:

1. To have received a personality disorder diagnosis through their access to mental health support
2. To have sufficient spoken English language skill to allow engagement with the interview process
3. To be able to offer consent in relation to participation in the study

As was discussed in the introductory chapter several variations of personality disorder diagnoses are recognised within current diagnostic classification systems. Rather than apply specific diagnostic criteria, for example through the application of standardised diagnostic schedules, for the purpose of recruitment in relation to this study it is argued that it is appropriate to approach participants 'as if' they have a personality disorder diagnosis. This is proposed owing to the current diagnostic systems being reviewed in the near future (Tyrer et al., 2015), with the possible removal of specific terms such as 'Borderline' from the system. This argument is continued with the decision to not apply specific diagnostic criteria to the recruitment process - again it is argued that for the purpose of this study what matters is the manner in which participants relate to the concept of 'personality disorder' and endeavour to make sense of it within their self-understanding. Finally, the clustering of individuals who have received any form of personality disorder diagnosis together by professionals, often with pejorative effect and attracting the moniker 'PD', is well recognised and therefore significant to the current investigation (E. S. Jones & Wright, 2015; G. Lewis & Appleby, 1988).

Inclusion criteria relating to the use of spoken English were introduced so as to ensure that participants were able to participate in the study without the use of an interpreter. Such a choice may be seen as exclusive, or even racist, in its connotations - however for the purpose of the current investigation it was argued that the study represented an exploratory investigation and that future research should be conducted to capture the experience of minority ethnic populations and non-fluent English language speakers in detail. This argument will be returned to in the section relating to limitations within the present research and suggestions for future studies.

The final inclusion criterion is present as an ethical consideration and the concept of capacity to consent will be discussed in greater detail within the ethics discussion below.

Participants were recruited from both 'community' and 'forensic' institutional settings. Community settings included participants accessing care from community mental health teams, or currently as an inpatient within a community mental health hospital. Forensic settings included prison, secure hospital and probation approved accommodation premises. All participants were actively involved with the mental health services at the time of their recruitment.

The division between recruitment in community and forensic settings was made for two distinct reasons: Firstly, as was described in the introductory, chapter the diagnosis of personality disorder is over-represented within forensic institutional settings, meaning that research into the experience of personality disorder may be particularly pertinent there. Second, given the overarching intention of this thesis to explore the lived experience of recovery in relation to personality disorder, in varying institutional settings, it is proposed that those accessing mental health care within forensic settings will offer a distinct approach to this concept that is in need of exploration. Ultimately however, the distinction between forensic and community participants would become blurred in that some participants within community settings had previous experience of care within forensic institutions, and drew on this in relating their narrative.

Participant identification and recruitment

As a National Institute for Health Research Clinical Research Network (NIHR-CRN) portfolio registered study (www.nihr.ac.uk) the project

was eligible for support from local clinical studies officers who occupy positions embedded within clinical teams. Support was therefore available in relation to the recruitment of participants recruited from community (secondary care community mental health team, psychological service, or hospital) settings. This support was not available within prison, or secure hospital, settings and forensic recruitment was therefore made through directly approaching clinical teams to discuss potential participants.

Participants were initially identified on the basis of the inclusion criteria above and approached, either by clinical studies officers or members of their own clinical team, in the first instance with information relating to the study. Those individuals expressing an interest in the study were then contacted either directly by the researcher, or through their clinical team again, in order to arrange a time to meet for interview.

The decision was taken that, in order to minimise disruption for participants, the interview would be conducted during the course of a single meeting, although all participants were given the option to terminate, or delay, the meeting at any time - with the opportunity to return and complete the interview at a later date. In practice, aside from occasional short breaks, no participant exercised this option.

Estimates of 'target recruitment values' were required by the NIHR-CRN, as well as the local research and development services, who act as gatekeepers to NHS trusts. The prediction of numbers of participants to be interviewed within qualitative research studies is however complex and not amenable to 'power calculations', as can be conducted within a quantitative paradigm. A conservative estimate was therefore

made, on the basis of advice described by Morse (2000), of 60 total participants for recruitment.

After the initial wave of recruitment, a purposive strategy was introduced to the process - with participants being specifically selected on the basis of characteristics, or experience. This purposive recruitment strategy was conducted primarily through the use of a reflexive journaling approach, used during the conduct of interviews. Journal entries would be used to record personal reflections relating to the interview; including personal responses to the participants' narrative and brief summaries of topics covered. For example, as some early participants spoke about their negative experience of hospital admission this was noted within journal entries and future participants were sought who were currently receiving inpatient care, or who had more extensive experience of previous hospital admission. Other criteria considered in this purposive strategy included; gender, age, length of contact with the mental health services and nature of previous hospital admission (for example intensive care unit placement). Reflexive journal entries were also used to determine saturation, or 'data adequacy' (Morse, 1995), and therefore the number of participants recruited - with saturation being defined as the absence of novel themes emerging over the course of several interviews. Finally, journal entries and themes were incorporated into the analysis process, as described below.

This recruitment strategy produced a population sample (total n=41) that was predominantly female (n=23 women n=18 men) and almost exclusively White (n=40 White, versus n=1 non-White participant). A roughly equal divide developed between community and forensic participants (n=20 community n=21 forensic). The limitations

associated with the adopted recruitment strategy are considered in more detail in Chapter 9 of this report.

Conduct of individual interviews

The overall ethos adopted with regard to the conduct of individual interviews was to support the participant in the narration of their experience in as comfortable and spontaneous a manner as possible. Steps were therefore taken throughout the interview meeting to try and place the participant at their ease and to develop a rapport between the researcher and participant, with the physical environment arranged in such a manner as to allow a non-confrontational approach to the interview, and to facilitate the participants leaving the interview without obstruction should they so choose.

Interviews were conducted in varying locations. For community participants accessing outpatient care a location was agreed within a clinical venue which the participant felt comfortable in attending. For most, but not all, participants this venue was their local community mental health team base. Some participants however elected to meet at a local hospital either owing to its closer proximity to their home address, or for their greater comfort with it as a setting. For those participants receiving inpatient care an interview room within their current ward was chosen. Finally, for participants in prison interviews were either conducted within the prison's healthcare wing, or in an interview room on the participant's residential wing - the choice of location was offered to the participant so far as possible, although some prisoners held under restricted movement control had to be interviewed on the wing out of practical necessity.

Participants were initially offered a copy of the participant information sheet [Appendix 1], which they had received previously, and an opportunity was offered for questions to be addressed relating to the study. When participants indicated that they were satisfied with the responses received the consent form [Appendix 2] was placed on the table and worked through in a manner that both participants were able to clearly see its contents. Once consent was completed the interviewer picked up the Dictaphone and indicated that recording of the conversation would begin.

A semi-structured interview schedule was prepared in advance of the interview phase of the study [Appendix 3]. This was not used for all interviews however, being referred to only in situations where the participant expressed discomfort with the unstructured nature of the discussion. In these cases, the researcher indicated that there were some standard questions that could be completed. In practice no participant requested the use of the interview schedule for a greater length than one question and response phrase.

In relation to the conduct of the interview particular attention was given to points in the discussion which generated an affective response in either party. If the response was experienced by the researcher comment was made at an appropriate ebb in the conversation relating to the affective impact that had been experienced. If it became apparent that the participant was distressed by the conversation care was taken not to immediately move away from the current theme but to try and support them in maintaining their concentration on the thought that had provoked the response. If this led to the participant becoming agitated then either verbal, or non-verbal, cues were used to suggest that the conversation could progress to a different topic. In this manner effort

was made to 'stay with' emotionally salient material, but with careful attention being given to the participant's level of arousal and distress.

The interview was allowed to continue until the participant reached a natural end to their speech. For some this was reached rapidly, while others displayed a greater willingness to speak at length about their experience. In both cases the interviewer attempted to guide the interview such that it terminated after approximately 50 minutes; however, at no point was an artificial ending introduced to the meeting except when the participant had indicated that the interview must end by a specific time.

Written notes were taken by the researcher during the interview - but these were limited to verbatim quotes of the participant's utterances. These quotes were then used later in the interview, if appropriate, so as to mirror the participant's language use when exploring topics in greater detail.

At the end of the interview space was offered for any final comments that the participant wished to offer in relation to the discussion. The researcher then expressed their thanks for the participant's time and offered participants in the community at ten-pound retail voucher, or reward card, which was accepted by approximately half of those so offered. During the closing stages of the interview particular attention was paid to the affective state of the participant - for some, who displayed intense signs of distress at the end of the interview, an opportunity to sit in silence for as long as they wished was offered. This opportunity allowed all participants to return to a position in which they felt comfortable leaving the interview. Some participants made disclosures during the interview in relation to their past life history that

they stated had never been made to a mental health professional. For those participants the researcher recommended that discussing such material with their clinical team could be of benefit. One interview was terminated abruptly at the participant's request. This interview was conducted in a prison setting and before the interview ended consent was sought to discuss this experience with the clinical team. The possibility that confidentiality could have been broken if the researcher felt concern with regard to, for example, the participants risk to themselves was made clear during the consent process and represented part of the protocol established to manage the possibility of emotional distress emerging during the interview's course. This is discussed in greater detail in the 'Ethics' section below.

As has been described the techniques employed during the interview were intended to support the participant in as full a narration of their experience as possible, while also acknowledging the emotional presence of the researcher within the dynamic. Similar interview techniques are described in both research (Riessman, 2008; Smith, Flowers, & Larkin, 2009) and clinical (Bateman, Brown, & Pedder, 2010; Gabbard, 2014) texts. The researcher has received training in communication skills, psychotherapeutically informed interviewing and motivational interviewing during the course of his clinical practice and medical training.

Reflective journal entries

Reflective journal entries were written no less than one, and no more than four, hours after the completion of the interview. In these entries notes were made regarding the participants' appearance and manner during the interview followed by some bullet points to summarise topics of conversation covered. Finally, the researcher's own affective

response to the interview was noted through the use of single word statements (e.g. Anger, fear, unease).

Focus group interviews

The intention behind the focus group portion of the project was to observe the manner in which groups of professionals worked together to make sense of themes emerging from the individual interviews with patient participants. As such the composition of the group and interaction between participants in their discussion was considered important (Halkier, 2010; Kitzinger, 1995). Semi-structured interview schedules were developed [Appendix 4] on the basis of themes emerging from individual interviews, as determined by the use of reflective journaling. The development of this interview schedule represented a substantial amendment to the original NHS research ethics committee application and therefore required approval from the Chair of the ethics committee.

Focus group participants were selected so as to be homogenous in that participants were accustomed to working together as a clinical team (Barbour, 2005). Clinical teams were initially approached on the basis of the researcher's familiarity with their area of clinical practice. As groups were conducted and topics of conversation became repeated between groups recruitment was focussed on teams who were able to offer a different perspective on the given topic. For example, outpatient practitioners referred, on occasion, to inpatient clinical teams as struggling to meet the needs of their patients owing to a number of factors; a meeting with an inpatient team was therefore arranged to address this point of discussion.

A target interview length of 45 minutes was decided as it was believed this would represent a minimum interruption to the clinical working day, yet offer sufficient time for discussion of the research question. An ideal group size of between four and six participants was decided upon. This decision was reached on the basis of the researcher's experience conducting psychotherapeutic groups in clinical practice, and on the basis of the proposed length of interview and amount of material to be covered (Tang & Davis, 1995). Four out of seven groups reached this target size (Table 8, Chapter 6); other group sizes were constrained owing to clinical commitments preventing participant attendance. The number of focus groups conducted was determined by the emergent discussion within the meetings - once all topics spontaneously raised within the groups had been discussed at least one other group meeting the recruitment stopped.

Group meetings were conducted in the participants' normal place of work at a pre-agreed time. The researcher suggested that the discussion begin at a set time and end after a maximum of one hour. Participants were able to enter and leave the group as they wished - although in practice only two participants were unable to remain throughout the meeting. Chairs for participants were arranged in a circle by the researcher prior to the group beginning. An additional chair was provided, so that there would be one more chair than participants, this was intended as a space to which participants could direct comments that were not considered to represent 'part of the group'. For example, some groups spoke negatively about the practice of peers in other clinical teams and such comments were often directed towards these empty chairs. A low table was placed in the centre of the circle, so that all participants could reach it without standing. Recording equipment was placed on this table, together with a box of tissues and paperwork

relating to the study and consent process. The researcher used the time function on the Dictaphone to monitor the length of time spent in the group. During the first two focus groups after 40 minutes of conversation the researcher suggested that in the last five minutes some time might be given to addressing topics that participants had felt unable to discuss so far. It was observed however that this intervention appeared to only stop conversation, as such this was not repeated in subsequent groups.

Interviews began with the researcher introducing the topic of the research and handing out participant information sheets and consent forms. All participants were aware of the nature of the meeting prior to attending. The consent form was then worked through as a group, with opportunity offered for specific questions to be addressed. Once all participants had given their consent the recording equipment was started. A Dictaphone and boundary microphone were used capture of all discussion in the meetings. The groups were conducted by the researcher alone.

As for the individual interview section of the project while a semi-structured interview schedule was prepared this was only used in cases where discussion between participants became limited - in practice this occurred on only one occasion in a group consisting of three consultant psychiatrists. Discussions were commenced by the researcher through the use of an open question relating to the concept of 'recovery' in relation to personality disorder. Opportunity was then given for the group to respond to this question, and to each other. As this discussion continued the researcher made brief notes of verbatim quotes from participants which were then repeated in the form of questions, or to highlight areas of potential discussion between participants. Brief

diagrammatic sketches were also made to indicate dynamics within the group - for example the above description of conversation directed towards empty chairs. As the discussion developed the researcher introduced verbatim quotes from individual interview participants which represented themes identified at that point in the analytic process. Focus group participants in turn commented on these quotes and this allowed the discussion to continue. The researcher adopted a role of active participant within the groups - questioning participants to improve clarity of understanding and to encourage discussion between the participants.

After the group was concluded a final opportunity for questions was offered before the recording was stopped. The researcher then remained in his chair until all other participants had left the room. Journal entries were made immediately following completion of the group noting topics of conversation and interactions within the group that had been observed.

Analysis

The analytic strategy utilised in approaching the information gathered through individual and group interviews was adopted in order to allow an appreciation of the overarching goal of the thesis - to explore the lived experience of individuals in receipt of a personality disorder diagnosis. As outlined in the section headed '*Ontology and Epistemology*' above the concept of personal recovery is seen as representative of a form of private experience accessible only through shared symbolic representation, in the form of discourse, between researcher and participant. Development of understanding is therefore produced in a circular process of construction beginning with the researcher, with their personal, clinical and research experience developed through literature sensitisation as mapped out in the findings of the presented systematic reviews. Further exploration then emerges through the meeting of researcher and participant during the interview process, for both individual and focus group. During these encounters shared understanding is created and developed in an iterative process of data representation and interpretation. The circle is completed by the interaction between the produced data and the researcher, coupled with a return to further theoretical literature, before the process continues in a cyclical manner. In this manner the analytic process draws inspiration from the 'hermeneutic turn' or 'double hermeneutic' described by Smith and Larkin (2009) in relation to the methodology of interpretative phenomenological analysis. In this approach the researcher and participant are both positioned in an act of making sense of a specific phenomenon, with the researcher continually shifting their focus between the phenomenon of interest, the participant and their own appreciation or understanding of the subject in a cyclical, iterative, process of developing greater insight.

Material developed during the course of individual interview encounters was interpreted in the form of a narrative representation of the participant's experience. In this manner the project taps into the long history of narrative research in relation to 'illness experience' (G. Williams, 1984), as discussed in the previous chapter. As such the analytic approach was also informed by the thematic narrative analysis described by Riessman (2008) in her description of the narrative methodological approach. The interpretation of presented narratives is not intended in a naive fashion - but instead seeks to acknowledge that while the presented material is representative of the participant's understanding it also serves a performative function, being a product of the interaction between the participant's experience and the context of the research interview, and attendant issues of reflexivity (Bury, 2001). This mode of understanding in relation to the performance of narrative also overlaps with the concept of the 'defended subject' as described by Hollway and Jefferson (2012). These authors caution against the reading of interview material as a representation of the participant 'telling it like it is' (p8, ibid) and instead propose that research participants be viewed as 'psychosocial subjects' - that is an individual with experience and an unconscious life who will act to produce accounts that serve to adequately contain and defend against their own anxieties. Similarly, the researcher cannot be viewed as a passive recipient of knowledge but must also be viewed as a defended psychosocial subject who will work towards the minimisation of their own distress and anxiety.

Ultimately encounters during the research process are viewed as opportunities for a contextual construction of understanding (Madill et al., 2000) between researcher and participant - with both parties being active in the process of sense making. The analytic interpretation

therefore begins during the interview process, and is captured in the act of reflective journal writing.

Reflective journal entries

As outlined in the discussion pertaining to '*Interview approaches*' - the first step in the analytic process began in parallel with the conduct of interviews through the writing of reflective journal entries. These journal entries consisted of brief descriptions of the research participant, the interview itself, topics emerging during and personal reflections on the researcher's own affective response to the material covered. Topics of discussion noted in this manner were used to inform the purposive recruitment strategy and to define 'saturation' as described above.

Topics identified were also extracted into a summary document that was held for use in conjunction with the coding process conducted at a later stage in the analysis. Reflections regarding the experience of the interview, and affective response, were used as material alongside interview transcripts for the development of *pen portraits* (Hollway & Jefferson, 2012), a device used alongside the coding process in order to maintain a longitudinal, or 'vertical', understanding of the participant.

Transcription of audio recordings

The second stage of the analytic process was represented by the act of transcription from the audio recordings made during the interview process. The intention of this stage of the analysis was twofold: Firstly, to produce an object, the transcript, that was suitable for further analysis and secondly, to further 'immerse' the researcher in the analysis process (Coffey & Atkinson, 1996b). Given these two goals the decision

was taken for the transcription process to be undertaken by the researcher, alongside the completion of the interview recruitment process, and to be viewed as a separate stage in the analysis (Bird, 2005; Lapadat & Lindsay, 1999). In other words, in engaging with the recorded interview material and the production of the transcript an effort was made to move away from the idea of transcription as simple reproduction of material, but instead to represent an analytic move in its own right.

This process therefore involved the production of a transcript that was suitable as a substrate for the analytic methodology employed (Nikander, 2008). As the intended analytic approach was primarily thematic in nature transcripts were produced which represented fully the interaction between researcher and participant, or participants in focus groups, including indications of pauses in speech and non-verbal utterances e.g. [Umm…]; as the audio recording would be kept and listened to repeatedly as part of the analysis however a decision was taken not to produce the micro-level detail seen in transcripts used in a conversation, or discourse, analysis approach.

Transcription was therefore completed using a word processor and audio playback software, together with a foot pedal to allow hands-free control of the audio material. A second computer monitor allowed 'memos' to be recorded relating to thoughts and interpretations arising during the transcription process (Wengraf, 2001). During the transcription process references to individual people and geographical places were removed in order that the transcripts were rendered anonymous, so far as possible.

Coding strategy

The term 'coding' in this context is used to refer to an approach whereby the interview transcripts were fragmented in a manner that allowed the identification of ideas emerging from the material that could then be compared in a horizontal manner between participants and focus groups. The coding process began with the identification of topics discussed and noted in reflective journal writing but was then both combined and adapted through a process of 'line-by-line coding' (Charmaz, 1990; Glaser & Strauss, 1999) such that the coding strategy, while informed by the reflective journals, was primarily 'grounded' in the interview material. Effort was also taken to ensure that 'vertical' understanding of the individual's experience was not lost through the coding process by endeavouring to use the coding strategy to also draw attention to points of conflict within the interview material, which could be taken as manifestations of complications of the manner in which participants interpreted their experience (Hollway & Jefferson, 2012).

The process of coding, and subsequent retrieval of material, was facilitated by the use of computer software, specifically nVivo (Version 11 for Mac, QSR International - www.qsrinternational.com). Interviews were coded initially in chronological order, but then as themes began to emerge reflective journal entries were used to identify interviews, and focus group discussions, which would offer further information on a specific theme.

Pen Portraits

An additional analytic approach adopted alongside the coding strategy involved the writing of 'pen portraits' to describe research participants in their role as psychosocial subjects (Hollway & Jefferson, 2012). Pen

portraits were written in a manner that described the key ideas identified through the coding process and from reflective journal writing while positioning these ideas contextually through linking them to the autobiographical narrative presented by participants. Thus, for example - a code linking to a participant's mother's interpretation of their experience would be linked to comments made by the participant relating to their childhood, adolescent and adult relationship with their mother. Notes made in relation to the researcher's affective response to interviews were also incorporated into the writing of pen portraits. In this manner the pen portraits can be viewed as analogous to formulations used in clinical mental health practice (Cabaniss, Moga, & Oquendo, 2015; Cabaniss, Cherry, Douglas, Graver, & Schwartz, 2013). The pen portraits were intended as a means of maintaining 'vertical' orientation in relation to specific participants, in contrast with the horizontal inter-participant coding strategy, such that the individual nature of the participant's narrative would not be lost in the analysis process.

Thematic network mapping

This stage in the analysis process allowed the consideration of the output from the coding and pen portrait steps to be combined together in a process of abstraction - whereby overarching 'themes' or 'concepts' were elaborated from the developed codes. The process involved two stages which, while presented sequentially, should be viewed as a combined act of interpretation:

1. *Writing as description and interpretation*: - An iterative writing process was adopted wherein brief descriptions of identified codes were combined together with pen portrait descriptions to

identify the disposition of codes in relation to each other and to allow the development of overarching descriptive themes.

2. *Thematic mapping*: - Identified codes were combined together in a schematic representation of a two dimensional space. Within this representation the inter-relationship of specific codes could be considered, together with their relationship to organising thematic headings (Attride-Stirling, 2001). Computer software (Scapple for Mac - Literature and Latte; http://www.literatureandlatte.com) was used to facilitate this process and to allow ready consideration of the relationship between concepts.

An example thematic map, developed in relation to a consideration of the relationship between narrative understanding of self and mental disorder, is presented in Figure 3.
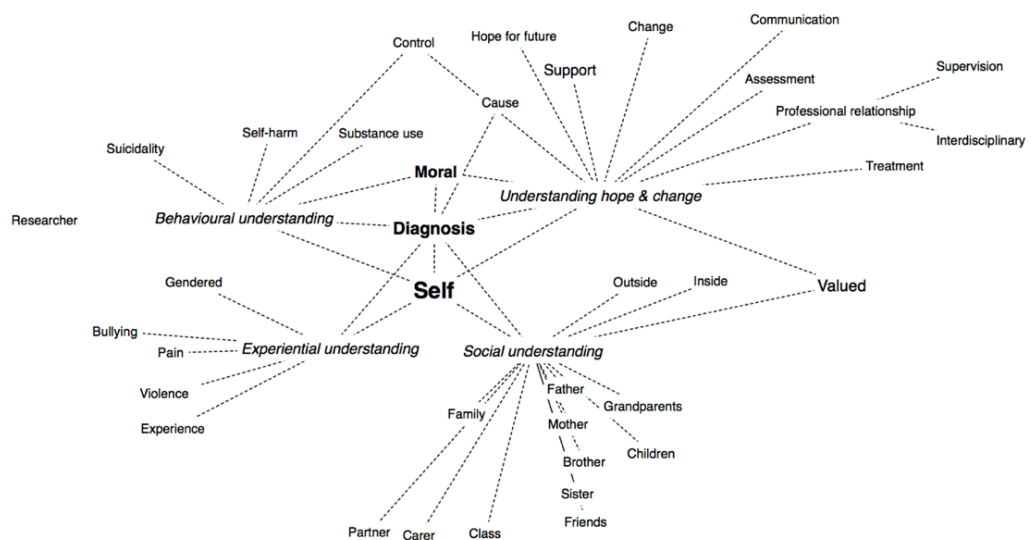
Figure 3 – An example thematic network map

Writing as part of the analytic process

As indicated in the previous section writing, as a means of expression, was integrated into the analysis process. In this way an iterative approach to writing allowed a refinement of expression and description in relation to emergent themes and concepts (Coffey & Atkinson, 1996b). The process of writing began on an individual basis, being utilised by the researcher in considering individual interviews in relation to reflective journal entries and subsequently in considering the relationship between emergent codes and themes identified in the analysis process. Writing was also used during research supervision meetings, as discussed below. The final step in the analytic process then involved the production of written material initially in abstract form for submission to conferences, in the process of draft writing for submission of papers to peer review publications and ultimately in the production of this thesis.

Research supervision, project advisory group and the analytic process

Research supervision, held on a monthly basis throughout the three-year project, was incorporated throughout the analysis process. Research supervisors initially provided commentary on emergent ideas and themes, developed from reflective journal entries and then from the coding process. These themes were presented, 'defended' and developed in a process of multi-disciplinary discussion drawing on the expertise of members of the supervisory team. As writing in the analytic process developed, feedback from the supervisory team was incorporated into future draft writing allowing further refinement of the presentation of analytic material.

At the outset of the project an advisory group of mental health service users was recruited. The membership of this group varied somewhat over the course of the project, but was defined primarily by individuals volunteering their time to discuss the development of the project. In this manner the advisory group was able to inform the development of the research protocol, ethics application and initial interpretation of findings from interviews and focus groups. Participants in the advisory group were offered twenty pounds in cash by means of thanks for their participation in each meeting; their travel expenses for attending meetings were also reimbursed.

Reflexivity

As has been argued throughout this chapter, the overall epistemological approach to the project has been to consider the encounter between researcher and participant, or purely data in the context of systematic review, as a constructivist scenario - whereby both parties are seen to act as agents in the development of understanding. In keeping with this approach it is therefore important that issues of reflexivity are considered -that is a "…*deconstructive exercise for locating the intersections of author, other, text, and world, and for penetrating the representational exercise itself*." (p35 Macbeth, 2001).

Information relating to the author's clinical and theoretical background is presented, alongside information relating to the supervisory team, in the 'Introduction' chapter of this thesis - further information is presented in the 'Discussion' chapter indicating the manner in which the researcher experienced their position as shifting during the course of the three-year project. This information is presented in order to aid the reader in their consideration of the presented findings. Specific issues of reflexivity as they pertain to the individual and focus group

interview processes, as well as process of analysis and writing, are discussed in greater detail below.

Individual interview encounters

Within the individual interview a power differential can be seen as existing between the researcher and participant. While this differential may be seen as undesirable an alternative interpretation, discussed by Ben-Ari and Enosh (2013), proposes that acknowledgement of this discrepancy allows an analytic focus to be established which considers the research encounter as a triadic relationship between researcher - participant and phenomena of interest. Recognition of this relationship allows the nature of the power differential between participant and researcher to be considered for the impact that it may have on the construction of understanding during the encounter. Reflexivity then becomes an important issue for the manner in which it informs the actions of both researcher and participant, together with its impact on the generation of knowledge through their encounter (Enosh & Ben-Ari, 2016). In considering the research encounter as a vehicle for the generation of discourse the significance of the participant and researcher as actor and audience needs to be acknowledged - in this manner discourse can be viewed as performative, or strategic, for the manner in which it is utilised to develop a specific representation of the encounter (Riessman, 1990; 2003).

Certain characteristics affecting the dynamic of the research encounter can be considered but not concealed from participants - for example the gender and ethnicity of the researcher. These factors can be seen as significant - particularly when working with survivors of sexual abuse or physical violence. The researcher's role as a psychiatrist was also not hidden from participants - this knowledge can be seen as impacting on

the construction of narratives, and reference is made by participants to both the researcher's clinical role and their previous encounters with mental health professionals. This observation is in keeping with previous research relating to the perceived role of the researcher where participant responses to clinician researchers were noted as being markedly different from the response to a non-clinician researcher (Richards & Emslie, 2000). From the researcher's perspective both clinical and personal experience can be seen as impacting on the encounter, while the role of doctoral student - with motivations in terms of academic credibility and the desire to produce a meaningful thesis on completion of the project will also be significant. Participant motivation requires consideration for its impact on the interaction - it is unlikely that all participants agreed to the research encounter solely through a process of altruism. For example, some participants disclosed motivations, including providing a critique of their experience of care and a desire to voice dissatisfaction with their experience. The impact of the researcher's role on the interview and analysis process is returned to in greater detail in Chapter 8.

Focus group interview encounters

Previous research, considering the experience of being involved in qualitative research conducted by a fellow clinician, has demonstrated varying responses from participants; for example, with some participants perceiving the exchange as a test of knowledge, or opportunity for education being positioned as 'expert' (Coar & Sim, 2006). The nature of the information elicited during a research interview has also been observed to vary dependent on the participant's knowledge of the clinical role of the researcher (Chew-Graham, May, & Perry, 2002).

Given this background it is likely that for focus group participants knowing the role of the researcher, and in some cases having worked together in a clinical capacity, will have impacted on the evolution of the discussion within the group sessions. The induction of a power differential, different to that experienced in clinical practice, may have been discomforting for some participants - and likely contributes to the manner in which knowledge is developed and performed in the encounter. For example, one consultant psychiatrist, who would customarily adopt a position of hierarchical superiority to the researcher, approached the researcher following their taking part in a focus group requesting a certificate to indicate their participation for use in their clinical portfolio - demonstrating pressures outside of the desire to altruistically contribute to research that motivate potential participants.

Reflexivity and the process of writing and analysis

Academic writing can be seen as being performative in its construction - a process through which the author seeks to convey some aspect of their sense of identity as an 'academic' (Ivanič, 1998). Due to its performative manner then, in thinking about the process of writing, attention needs to be given to the role of both the actor and the audience in the production. A parallel here can be drawn with the writing of forensic psychiatric reports - and their performance on varying stages, for example in the courtroom (Griffith, Stankovic, & Baranoski, 2010; Griffith & Baranoski, 2006).

In academic writing therefore consideration is given to two principle factors - the identity that the author wishes to convey and the purpose of the performance in relation to the role of the audience. In writing, the author generally seeks to convey a sense of conscientiousness and

credibility - but the precise style, and language, adopted will be greatly influenced by the audience: For example, in writing an abstract for presentation at conference language is selected that is felt to best match the stated goals of the conference organisers. Similarly, when writing for peer reviewed publication language is selected that matches the target journal's audience, although this will also be considered alongside the suitability of the target publication. In writing this thesis the author seeks to convey the usual qualities outlined above, and also to identify with the role of varying potential audiences, not least the process of examination.

As has been indicated in the discussion above, relating to analysis, the act of writing as a form of expression is seen as central to the analytic process. However, other factors are also considered within this dynamic, for example the link between research findings and the theoretical literature. Engagement with research data in a constructive process of developing understanding must therefore be seen as a dynamic process. Written representations of this process are therefore 'snap-shots', or static crystallisations, of the on-going process, designed to communicate understanding generated at the specific moment of writing.

Ethical considerations

Ethical issues in relation to medical research are generally considered in the context of the principles outlined in the Declaration of Helsinki (1964 revised in 2013). This framework was established in order to recognise the need for an organised consideration of the ethics of conducting research with human subjects. The original statement has now been revised seven times, most recently in 2013 - with changes in the latest revision recognising the need to acknowledge harm caused to participants inadvertently during the research process whilst also supporting efforts to include rarely researched groups within the process (Arie, 2013). The Declaration of Helsinki is directed primarily towards medical professionals and draws on statements relating to the role of clinicians in relation to their patients, as set out in the Declaration of Geneva (World Medical Association, 1948).

Such statements, as produced by governing or other authoritative bodies, seek to outline ethical 'principles'; that is a series of tenets that are taken as being universally held. Such statements therefore reflect the need to protect individual's from harm, while also acknowledging the importance of research in the development of clinical care, and providing clarification regarding the 'rights' of research participants. In this manner the principles espoused share much in common with the four principles of biomedical ethics outlined by Beauchamp and Childress (2001):

1. Beneficence
2. Non-maleficence
3. Respect for autonomy
4. Justice

In the following discussion ethical considerations taken in relation to the current project are outlined.

Ethical approval within the National Health Service

Addressing the needs outlined in the Declaration of Helsinki in the United Kingdom research involving participants drawn from National Health Service settings requires approval from a Research Ethics committee. Application for such approval is handled centrally through the Integrated Research Application Service (IRAS - www.myresearchproject.org.uk). This service provides researchers with a series of standardised questions which determine the level of scrutiny required for a project. In the case of the current research, which involved prisoner participants, a full committee review process was required.

IRAS application is structured in such a way as to require researchers to consider their proposal from a variety of perspectives; the core ethical concerns identified during this process, and subsequent discussion at the ethics committee hearing are outlined below. Ultimately ethical approval was granted for the project (Reference 14/EE/0029 - approval attached in Appendix 5): a substantial amendment was submitted in relation to this application following the development of the interview schedule for the focus group interview stage of the project.

Risk to participants

The principle of non-maleficence illustrates the necessity of working to ensure that any discomfort, or risk, experienced by research participants is proportionate to potential benefit gained through the research process (although not necessarily personal benefit as the

concept of a 'social good' is recognised in this consideration). The core issues identified in this regard for the current project related to the potential impact of the interview process on participants, and the need to maintain confidentiality in relation to personal information.

1. Impact of the research exercise on the participants' mental state
   - Participation in an interview process, particularly one relating to a concept such as mental distress, risks the participant being exposed to an intense affective process and this needs to be considered in the research process (Bahn & Weatherill, 2013; Cowles, 1988). In order to address this, issue a protocol was outlined whereby the affective response of participants would be judged throughout the interview and on conclusion of the meeting. This monitoring involved initial attention to the participant's emotional state - observing for signs of persistent distress, or any other change in the participant's mental state. Varying responses were available to such changes - beginning with simple reassurance, progressing through suggestion that the individual make contact with their clinical team or GP to finally recommending transfer to hospital for emergency assessment. As the development of intense emotional distress during the interview process could potentially lead to the breaking of participant confidentiality this possibility was clearly outlined in information provided in relation to the study.

2. The participants' right to confidentiality
   - In keeping with any encounter in which personal information is disclosed to a medical professional the participants had a right to expect that their data be handled

in a respectful and confidential manner. At its simplest level this involved the research being conducted in keeping with NHS data protection standards through the use of secure electronic media and encryption of files, with separation of personal identifiable information from interview transcripts. As the methodology employed involved the development of personal narratives it was also important that effort be made to ensure that any representation of this material maintained the anonymity of the participant. This statement risks developing a tension in comparison with the analytical concept of the psychosocial subject however - where information relating to the participant's historical experience is pertinent to the analysis, but could also risk the loss of their confidentiality if presented in a poorly considered manner. This risk is perhaps particularly pertinent to prisoner, or other forensic, participants - for whom some information relating to their past offending behaviour may be present in the public domain (Adshead & Brown, 2003).

Potential benefit for participants

A direct claim of personal benefit for participants included in the project would be controversial - although there is some emerging evidence that the participation in qualitative interview research may be of some emotional benefit, and that the impact of participation certainly seems to be greater than the impact of exclusion (Biddle et al., 2013; Rivlin, Marzano, Hawton, & Fazel, 2012). For the purpose of this project's ethics committee discussion a claim was made that participants could expect to gain a form of social benefit through the development of

greater understanding which, it is to be hoped, may inform the development of clinical care in the future.

Consent process

In order to participate in the current research project participants were required to offer informed consent prior to the interview taking place. The granting of consent to take part in a research study is a dynamic process - involving a continuing interaction between the researcher and potential participant in which information is provided by both parties and consent to participation is gauged. An important additional concept relating to the offering of consent is that of 'capacity' - a legal term developed in relation to the protection of individuals from assault in relation to clinical care. Individuals are assumed to have capacity in relation to specific decisions until evidence is offered to the contrary; the demonstration of capacity involves the ability to absorb offered information, to retain and weigh such information in order to reach a decision and finally to communicate that decision. Recent changes relating to case law as it applies to the process of consent particularly highlight the central role of information provision in this process (Sokol, 2015).

In order to support the consent process a participant information sheet was developed, alongside the consent form used to record acquiescence to participation (Appendix 1 and 2). Consent was considered to be a dynamic process - not one that was finalised on signing of the offered form, but one that continued throughout the interview process with on-going consent being gauged through questioning and measuring of the participant's response.

Risk to the research team

Carrying out qualitative research is recognised as representing a potential form of emotional labour on the part of the research team (Bergman Blix & Wettergren, 2015). This fact was acknowledged in preparing for the project and it was proposed that the need could be adequately addressed through the research supervision process, with meetings held on a regular basis throughout the three-year period.

As discussed in Chapter 8 ultimately the process of managing emotional labour through discussion in research supervision was more complex than anticipated - suggesting that in future projects an alternative space for this work be considered.

A second risk identified involved the process of conducting interviews in various different institutional settings. Training was completed within the University relating to the role of the 'lone worker' in order to address this need.

Participant remuneration

The decision was taken to offer participants involved in interviews in the general community a ten-pound retail voucher by way of thanks for their participation. This statement is presented separately from the section on 'potential benefit' as the act was not intended as a payment for participation, but instead as a statement of thanks. This decision can be seen as somewhat controversial since not all participants, notably those interviewed in prison, could be offered the voucher. Not all participants accepted the offered voucher, and as such it is possible that in future research projects this decision could be re-visited.

National Offender Management Service (NOMS) approval

As the project involved participants who were also prisoners NOMS approval was also required in addition to that of the NHS research ethics committee. Application for NOMS approval was conducted in parallel with IRAS application, but awaited the final research ethics committee approval before NOMS approval could be granted. In addition to the criteria set out in the IRAS form applications to NOMS are also considered against specific principles relating to the proposed research (https://www.gov.uk/government/organisations/national-offender-management-service/about/research):

1. Are there enough links to NOMS priorities?
2. What are the likely demands on resources e.g. staff time, officer requirements, data providers?
3. Is there an overlap with other current or recent research?
4. How appropriate and able is the methodology?
5. Are there any data protection / security issues?
6. Are there any ethical considerations?
7. What is the extent of the applicants' research skills and experience?

A statement addressing these points, in addition to the IRAS form, was produced and NOMS approval was granted (Reference 2013-282 Appendix 6).

Following central NOMS approval individual prison governor approval was required for each prison identified as a research site. Obtaining this involved directly approaching governors to outline the proposed research and seek approval for access. This gatekeeping

contact was mediated through discussion with integrated mental health teams working in each identified prison.

Chapter 3 - Personal recovery in personality disorder: Systematic review and meta-synthesis of qualitative methods studies

Andrew Shepherd, Caroline Sanders, Michael Doyle and Jenny Shaw

In this chapter and those that follow findings from the research conducted during this project are presented. Each chapter represents a complete 'paper' written for a specific target journal and as such a degree of overlap and repetition is unavoidable. Chapters 3 and 4 have been published and are presented following a peer review process. Formatting of these chapters has been maintained as for the remainder of the thesis for a consistent style. The remaining chapters have either been submitted, or are approaching readiness for submission - details are given at the beginning of each chapter.

This chapter draws on findings reported in the International Journal of Social Psychiatry, published in 2016 (A. Shepherd, Sanders, Doyle, & Shaw, 2016b). Copyright agreement for the inclusion of this chapter is included in Appendix 7.

Abstract

Background and aims: Support of personal recovery represents the aim for many modern mental health services. There is a lack of conceptual clarity around the application of the term however and this is particularly problematic with regard to the personality disorder diagnoses. This study sought to review the existing qualitative methods literature in relation to the experience of personal recovery in personality disorder.

Methods: A systematic literature search was conducted. Identified studies were incorporated through meta-synthesis in order to develop higher order descriptive themes representative of the individual experience described within included studies.

Results: Three studies were identified and incorporated into the meta-synthesis. Three novel higher order themes were developed: Safety and containment as a prerequisite to recovery, social networks and autonomy in the recovery process and identity construction as a process of change.

Conclusion: Personal recovery in personality disorder is revealed as a complex process reflecting both personal and social experiences or desires. These findings have important implications for clinical practice – emphasising the need to work closely with individuals and to develop an understanding of both their social experience and networks. Further research, taking greater account of social context in the recovery process, is necessary.

Background

The support of personal recovery now represents a stated goal for many modern mental health services. The meaning of the term personal recovery is, however, complex and not always clearly defined (Pilgrim, 2008). With its origins in the deinstitutionalisation process of the United States, the idea of a *recovery movement* was adopted by mental health service users with an emphasis on personal empowerment, self-expression and overcoming restrictions within social structures (Davidson, 2008; Deegan, 1996; Dillon, 2010). However, mental health services and professional bodies commonly cite descriptions of personal recovery as being more in keeping with a rehabilitative understanding, for example, living a satisfying life despite the limitations of illness (Anthony, 1993). The tension between these two positions has been described as understanding the distinction between descriptions of recovery *from* versus recovery *in* mental disorder (Davidson & Roe, 2007).

Despite these differences in position, most descriptions of personal recovery emphasise the idiographic nature of the process. Understanding the preferences of individuals seeking support in relation to mental distress is important as there is evidence that commonly used measures of clinical outcome do not match with the individual expectations of mental health service users (Andresen et al., 2010).

Research conducted considering the recovery experience of those with a mental disorder diagnosis has highlighted key themes of connectedness, hope, identity, meaning, empowerment and spirituality (Leamy et al., 2011). This framework, developed by Leamy et al., emerged from the consideration of recovery narratives across a range of

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mental disorder diagnoses. However, they did not consider the specific experiences of those with personality disorder diagnoses where it can be argued that most of the pertinent themes they described may have been impacted upon in a chronic manner. This observation is important as longitudinal studies have demonstrated that while symptomatic remission occurs relatively commonly in those receiving a diagnosis of borderline personality disorder (BPD) longer term recovery, in terms of psychosocial functioning, is rarer (Zanarini et al., 2012). Reviewing the development of new treatment interventions in the care of BPD, calls have been made for a greater focus on the clinical and research understanding of the concept of recovery in personality disorder to be developed (Nehls, 2000).

The concept of personal recovery in personality disorder is therefore not without problems and requires further research and clinical understanding. In order to address this concern, this study seeks to identify qualitative methods studies exploring the experience of personal recovery in personality disorder. While numerous quantitative methods studies exist exploring treatment outcomes in personality disorder, it can be argued that qualitative methods offer a valuable understanding of the personal recovery process from an idiographic perspective. In this manner, the concerns raised by Andresen et al (2010) can be addressed. Such approaches also provide one means of addressing an identified research need to identify appropriate outcome measures as described in a recent publication by the UK-based National Institute for Health and Care Excellence (NICE, Borderline Personality Disorder Treatment and Management). For the purposes of this review, the term 'personality disorder' is used in place of any specific diagnostic term; it is argued that this is appropriate given concerns raised regarding existing classification systems and proposed

changes to future classification (Frances & Nardo, 2013; Tyrer et al., 2015).

A literature search and meta-synthesis were therefore conducted with the aim of identifying existing qualitative research to allow the development of an adequate thematic map to outline findings in this area.

Methods

The review was registered prospectively with the PROSPERO database – reference CRD42013006839. This report is structured in keeping with guidance for enhancing transparency in reporting the synthesis of qualitative research (Tong et al., 2012).

Systematic search strategy

An electronic search strategy was adopted in order to identify studies meeting the following inclusion criteria:

1. English language publication
2. Peer reviewed publication with online access to full text
3. Qualitative methods approach with transparent representation of service user experience

Exclusion criteria included the following:

1. Purely clinical definition of recovery (e.g. change in symptom rating scale)
2. No presentation of service user experience (e.g. no access to primary source material through quotation)

3. Literature relating solely to recovery in substance use disorder

The following databases were accessed: EMBASE, Medline, PsycINFO, Applied and Complementary Medicine Database (AMED), Social Policy and Practice, Applied Social Science Index and Abstracts (ASSIA), British Humanities Index, Social Services Abstract, Sociological Abstracts and Sage publications. Search terms were adapted to meet the requirements of individual search engines but such that the overall semantic meaning was not altered. The following terms were used for the search:

Personality disorder AND recovery

Search outputs were imported directly into electronic reference manager software, which allowed for the removal of duplicate material (Papers 3 for Apple OS X, www.papersapp. com).

Review of titles and abstracts allowed exclusion of identified papers of clear irrelevance to the search strategy; editorial and opinion commentary pieces were also identified at this stage. Full-text versions of remaining hits were obtained and reviewed according to the inclusion and exclusion criteria defined above.

Reference lists of identified reports and editorial commentaries were also searched to broaden the search strategy.

Critical appraisal of identified papers

Included papers were reviewed according to the standard criteria set out by the Critical Appraisal Skills Programme (CASP – www.casp-uk.net). The application of standardised assessments to qualitative

methods studies is complex, however, and risks limiting the value of the findings (Barbour, 2001). As such, the purpose of critical appraisal in this review was not to exclude papers on methodological grounds but to incorporate this review into the analysis process through further clarification of the methodology, limitations, rigour and setting for each study. Critical appraisal was led by AS with close discussion being held regularly with the remaining authors.

Meta-synthesis

Meta-synthesis allows the combination of qualitative methods studies in a manner so as to develop overarching, third-order, themes that develop further understanding grounded in the material of the included studies. For this synthesis, an approach analogous to that of meta-ethnography was employed (Noblit & Hare, 1988) that has previously been described by other authors (Britten et al., 2002). Guidance relating to the writing of meta-synthesis reports, such as that described by (Tong et al., 2012), does not focus on the specific synthesis methodology and this report is presented in light of findings from critical review of meta-ethnography publications (France et al., 2014).

The synthesis process was conducted over five stages with the first two authors, AS and CS conducting the first three stages and all authors being involved in the remaining analysis stages:

1. *Reading*: studies were initially read and then separated in order that results and discussion sections of reports could be incorporated into the analysis process.
2. *Study relationship*: reading of identified reports allowed the initial identification and comparison of related material and themes

3. *Study translation*: a descriptive coding method was adopted in order to allow translation of the included studies. First- and second-order themes were developed according to the tradition of Schutz (1962). First-order themes represented original participant understanding, in the form of quotations, while second-order themes represented original author interpretation of findings. Descriptive codes were applied in order to capture understanding of these themes. Codes were used across all studies in order to complete the translation process. Summary tables of coding first- and second-order themes were developed.

4. *Synthesis of translations*: understanding of first- and second-order themes was combined through further reading and author discussion in order to develop third-order themes as described by Britten et al.(2002)

5. *Expression of synthesis*: writing as a form of expression and analysis was incorporated into the final two stages of the analysis process (Coffey & Atkinson, 1996b). An iterative approach to writing and discussion, involving all authors, was adopted to the expression of findings in this report.

Results and Discussion

Identified studies and critical appraisal

Figure 4 summarises the search process. The initial search identified a total of 5510 hits – with 818 duplicate papers then being removed by electronic reference management software. Review of title and abstract alone allowed for exclusion of a further 4668 papers; therefore, full-text versions of 24 papers were retrieved. Application of the full inclusion and exclusion criteria led to exclusion of a further 21 papers. Reference list review yielded no additional papers but showed cross-referencing

between the included papers. Reasons for exclusion of papers following full-text review included the following: case study presentation only, not focussed on the experience of those with a personality disorder diagnosis and representation of personal recovery through quantitative scale definitions only.
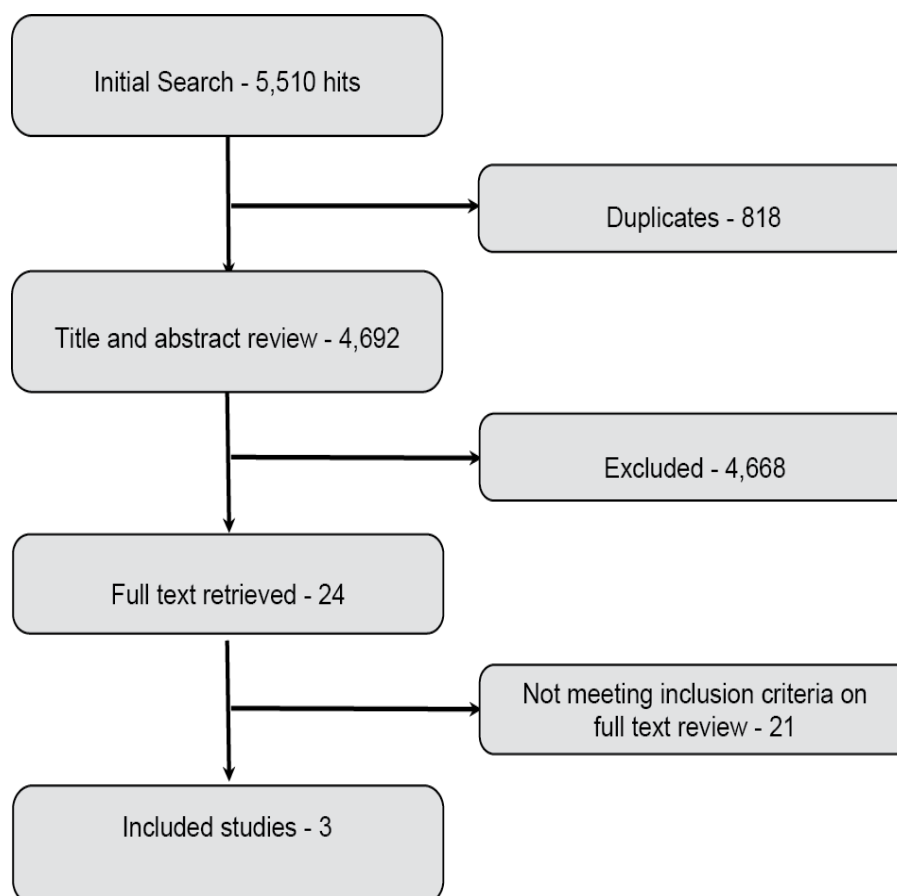
Figure 4

Three papers were therefore identified for inclusion in the meta-synthesis analysis (Castillo, Ramon, & Morant, 2013; A. L. Holm & Severinsson, 2011; Katsakou et al., 2012).

Study characteristics are summarised in Table 1, and appraisal findings according to CASP criteria are shown in Table 2. The CASP statements, 'Is a qualitative methodology appropriate' and 'How valuable is the Research', are omitted from this appraisal.

Study	Location and setting	Participants and diagnoses (*n* =)	Age (mean (range))	Methods
Holm and Severinsson (2011)	West Coast Norway; 'varied clinical settings'	13 women – borderline personality disorder	39 (25–53)	Exploratory qualitative methods design
Katsakou et al. (2012)	London, UK; specialist personality disorder service, community mental health teams and psychological therapy service	48 (39 women) – borderline personality disorder and history of self-harming behaviour	36.5 (standard deviation 10.38)	Exploratory design, grounded theory and thematic analysis
Castillo, Ramon, and Morant (2013)	Specialist personality disorder service, UK	60 (47 women) – any personality disorder diagnosis	Mean not stated – implied range 18–65	Participatory action research framework – thematic analysis

Table 1

Overall, the findings from included studies were clearly represented. Theoretical considerations were given little description, however, in either the description of the research process or analysis. Clear incorporation of theory within qualitative research is essential to informing the reader's interpretation of findings (Bradbury-Jones, Taylor, & Herber, 2014; Wu & Volker, 2009). Descriptions of possible reflexivity on the interview process and analysis were also limited – this may be particularly pertinent in the report by Castillo and colleagues where the role of service users in the analysis process was unclear (Macbeth, 2001). However, it should be acknowledged that further efforts in relation to reflexivity may have been undertaken but were omitted from published reports owing to reporting constraints.

CASP statement	Holm and Severinsson (2011)	Katsakou et al. (2012)	Castillo, Ramon, and Morant (2013)
Was there a clear statement of the aims of the research?	Stated aim to explore a recovery process in relation to self-harming behaviour.	To explore participants' view of 'recovery'.	How do participants define recovery; what factors support this process; and does the provided specialist service facilitate recovery.
Was the research design appropriate to address the aims of the research?	Explanation of method utilised, no account of choice of method used.	No explanation of theoretical methods employed.	Reference to participatory action research and thematic analysis but no explanation of choice for method used.
Was the recruitment strategy appropriate to the aims of the research?	Targeted diagnosis based selection – no indication of how number of participants determined.	Purposive sample to address diagnosis, self-harming behaviour and range of demographic characteristics.	All those attending specialist service eligible with purposive sampling in order to represent unit population.
Were the data collected in a way that addressed the research issue?	Individual interviews with questions to promote discussion in relation to change and suicidal behaviour. No evidence of adapting recruitment to analysis. No indication of saturation process.	Semi-structured individual interviews with interdependent recruitment and analysis. No evidence of discussion of idea of saturation.	Individual interviews and focus groups. No indication of how different data handled in analysis process. No discussion of interaction between analysis and recruitment. No mention of data saturation.
Has the relationship between researcher and participants been adequately considered?	Authors' dual role as psychiatric nurse and researcher acknowledged in report.	Description of academic and clinical roles with the assertion of likely lack of impact on analysis process.	First author also employed as chief executive of organisation. No discussion of reflexivity from participatory action research framework.
Have ethical issues been taken into consideration?	Clear discussion of ethical approval and consent process.	Clear discussion of ethical approval and consent process.	Description of consent forms but no description of ethical approval or consent process.
Was the data analysis sufficiently rigorous?	Thematic analysis on basis of textual reading and researcher discussion.	Grounded theory approach with constant comparison method. Evidence of triangulation through discussion with service user advisors.	Participant involvement in analysis as per participatory action framework but no detailed explanation of analysis process.
Is there a clear statement of findings?	Presentation of themes and supportive quotations.	Presentation of themes and supportive quotations.	Diagrammatic representation alongside presentation of themes and supportive quotations.

Table 2

Synthesis findings are summarised in Table 3 and discussed in more detail below together with relevant existing literature in order to illustrate the context of findings. Illustrative first- and second-order themes are provided within Table 3 for each superordinate, third-order, heading.

Safety and containment as prerequisite for recovery

Participants described that in order for personal change to occur, it was necessary for them to feel safe, or contained, and that this allowed them to express their distress in a more manageable fashion. Such containment could be delivered through individual relationships (professional and peer), social networks or environments. This containment was described as being essential for the recovery process – with environments, or relationships with others, that were perceived as being toxic, or rejecting, leading to an impeding, or regression, in desired change.

This finding is in keeping with previous research literature that has emphasised the role of trusting therapeutic relationships as being essential in support of personal recovery (Adshead, 1998). Attachment theory (Bowlby, 2005) provides one means of understanding this phenomenon – by suggesting that during times of distress, individuals will seek out attachment sources, mirroring behaviour in early life. Fonagy and Luyten (2009) argue that BPD is characterised by a lowered threshold for activation of attachment behaviour, with accompanying loss of 'mentalisation'. As professionals also display varying attachment styles, the interaction between the professional and the individual seeking help is necessarily complex (Bucci, Seymour-Hyde, Harris, & Berry, 2015).

Synthesised third-order themes	Second-order themes	Illustrative quotation (first order)	Source
Safety and containment as a prerequisite to recovery	Struggling to stay alive by enhancing self-development	'This place was different from other institutions. I felt safe here; they believed I could manage the same things as the others. This was a turning point and my way to freedom'.	Holm and Severinsson (2011)
	A sense of safety and building trust	'The Haven has taught me to trust again. I don't have to hide behind a smile anymore. I can come in and cry. The important thing is that coming here makes you safe enough to change'.	Castillo, Ramon, and Morant (2013)
	Feeling cared for and creating a culture of warmth	'It's been excellent, a kind ear, a cuddle, cup of tea, respite when I need it'.	Castillo et al. (2013)
	Learning the boundaries – love is not enough	'I feel safe at the Haven because I know you're not allowed to get away with stuff like cutting while you're here, which means I don't try. It's about being protected from the negative parts of yourself'.	Castillo et al. (2013)
Social networks and personal autonomy in the recovery process	Struggling to assume responsibility for self and others	'I have to do something, not escape from life anymore. This was a turning point. I must manage to take care of myself and not leave the responsibility to others'.	Holm and Severinsson (2011)
	Balancing personal goals of recovery versus service targets	'I was trying to get over my divorce and also my relationship with my mum and men, and I was trying to work through it but it [DBT] was all about other things, it was about self-harming, it was about mindfulness ...'	Katsakou et al. (2012)
	Hopes, dreams and goals and their relationship to recovery	'I look to the future more than I ever did. It exists now'.	Castillo et al. (2013)
	A sense of belonging and community	'It's all about human contact. I think a lot of people here realise what it's like to be lonely, we all know what it's like so we all make an extra effort to be friendly'.	Castillo et al. (2013)
Identity construction as a process of change	Struggling to assume responsibility for self and others	'They asked me why I did it and why I did not think about them. I had no answer. I could not explain why I wanted to kill myself and could find no words to explain my pain'.	Holm and Severinsson (2011)
	Struggling to stay alive by enhancing self-development	'They told me I was unstable and that it was best that I was in hospital. "Your disorder is the reason why you try to kill and harm yourself". I stayed alive and for this I was grateful, but nobody saw me or spoke to me as a person'.	Holm and Severinsson (2011)

Personal goals and/or achievements during recovery	'I feel more confident. I keep on doing something and then thinking "well I wouldn't have done that last year". I'm stronger in myself, with relationships, with anything'.	Katsakou et al. (2012)
	'I just want to be able to ... like if I'm miserable then I'm just down, I'm not wanting to die kind of thing. And then if I'm happy I'm just cheerful, not kind of flying off the walls like I've taken drugs; just to feel normal emotions'.	Katsakou et al. (2012)
Problems with the word 'recovery'	'I can't imagine not having BPD. I don't remember a time in my life when I didn't feel this way. So recovery, cure ... no, I don't think so. Learning how to deal with it, I'm very positive about ... I don't think it will every go away. I'd have to have a personality transplant for that to happen ...'	Katsakou et al. (2012)
	'I think recovery is a very difficult word particularly with mental illnesses and I think you can recover, but I suppose I'm naturally worried that if I go and recover, I would be worried that I could think I'm wonderful now and then all of them fall from the rails, cause I'm not keeping a check of myself ...'	Katsakou et al. (2012)
How recovered do people feel?	'I think it's still there, so as to recovering ... I actually don't see it as before and after, you can have a diagnosis of depression and then move through that depressive phase ... it feels a bit more like who I am ...'	Katsakou et al. (2012)
Hopes, dreams and goals and their relationship to recovery	'We can only learn to live alongside our illnesses by re-thinking the way we think, to re-train the way we go about our daily lives and to learn to use our past experiences to guide us to where we want to be in life rather than carrying on the way we do'.	Castillo et al. (2013)
Achievements, identity and roles	'I still dislike myself. I don't know if it will ever change, it's always as far as I can remember for such a long time ago, that's just how I feel about myself'.	Castillo et al. (2013)
	'Although there are still good days and bad days, if you learn to love yourself you can begin to help others'.	Castillo et al. (2013)

Table 3

The idea of safety and containment, however, raises additional concern around the experience of leaving, or moving between, environments. This was described by participants in the identified studies with discharge or transfer being a point of care requiring particular care and attention. Transitions between clinical and community environments are recognised as being problematic with potential impact on the individual's sense of personal identity – illustrating a potential overlap between this third-order theme and the idea of identity as a change process (Coffey, 2012).

Social networks and personal autonomy in the recovery process

Recovery was represented as a developing exercise of personal autonomy – with descriptions of 'turning points' wherein individuals recognised that change was necessary and took steps to secure this. In this manner, people were able to develop hope for future change. However, there was also a recognition that any change necessarily occurred within social spaces and would be influenced by others, for example, family members, significant relationships and professionals. There was also tension here, however, with participants in the study by Katsakou et al. describing difficulty with differences between their priorities and those of the mental health services – for example, with individuals wishing to address difficulties within personal relationships, while feeling that professionals instead focussed on domains related purely to risk, such as self-harming behaviour.

Social network support is known to play a key role within any change process. Perry and Pescosolido (2015) demonstrate that the strategic activation of social networks is a key component in help-seeking behaviour in response to distress; furthermore, they describe how activation of stronger ties, or ties with others who display a pro-

healthcare orientation, results in more profound and lasting changes over time. Cohen and Wills (1985) suggest that social networks may have both direct and indirect effects on the experience of distress – allowing improved response to disorder but also providing a buffering effect against social stress. Social network support for individuals with experience of mental distress tends to be less than that for individuals with physical illness, however – with individuals receiving a diagnosis of schizoaffective disorder reporting less satisfaction with and lower perceived support from social networks than individuals with a diagnosis of diabetes (Nettelbladt, Svensson, Serin, & Öjehagen, 1995). This disruption of social network support may also expand to the family members of individuals with mental disorder diagnoses (Magliano, Fiorillo, Malangone, De Rosa, & Maj, 2006). Stigma in relation to experiences of mental distress are also likely significant here and may result in marginalisation of individuals from family and professional support (Bonnington & Rose, 2014).

Identity construction as a process of change

Identity construction appeared to be central to the experience of personal recovery in each of the identified studies. Participants described a process of 'identity work' – that is, the manner in which experience is incorporated into the sense of self alongside other competing identities (S. Adams et al., 1997). For some, this involved the complex task of working to understand previous acts, or behaviours, and to make sense of these experiences. This could involve the adoption of an 'illness identity' to account for their experience – however, others described the stigmatising effect of this pathologisation of their behaviours, an experience that may be particularly pertinent in relation to help seeking for those with a personality disorder diagnosis (Bonnington & Rose, 2014). Recovery then became about moving

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beyond this state and developing hope for a future identity – a stronger, more confident, self or one who was simply able to experience 'normal' emotion. This process was complicated, however, with participants expressing difficulty with the idea that one could 'recover from' personality disorder – instead suggesting that this would become a permanent facet of their identity and that a guard should be maintained against destructive, or self-injurious behaviour.

The manner in which individuals manage experiences of distress and the resultant narratives they construct are known to have lasting influence for the individual's sense of self, or identity (M. L. Crossley, 2000). Such narrative identities can also be seen as being performative in nature informed by both the audience and individual, emphasising again the role of social networks in the recovery process and providing a link between the second and third overarching themes described in this report (Riessman, 2003). Thoits (1985) hypothesises that individuals may 'self-label' in response to distressing experiences and behaviours and that this leads to help-seeking behaviours. However, such labelling of individuals, either by the self or others, may also act as a barrier to change and engagement with services, possibly raising concerns about the firm manner in which some individuals incorporated the identity of 'disorder' into their sense of self (Scott, 1973a; 1973b). Adler and colleagues (2012; 2008), working with individuals who had received psychotherapy, identified that the manner in which an individual incorporates his or her understanding of therapy and distress into a personal narrative can have implications for on-going psychological health.

Conclusion

This article aimed to review the existing qualitative literature relating to personal recovery in personality disorder and develop a thematic map representing the material identified. Three overarching and interdependent themes were synthesised. These themes show some overlap with existing recovery frameworks (Leamy et al., 2011) but also display unique properties indicative of the distinct experiences and difficulties faced by those receiving a personality disorder diagnosis. The focus of each of the identified themes represents domains of function likely to be particularly disrupted, or complicated, in this population. These findings may also echo previous research (Andresen et al., 2010) in demonstrating the inadequacy of many outcome measures used in clinical practice and research in relation to personality disorder diagnoses – focus on symptomatic rating does not appear to be sufficient in representing the recovery process. This is also in keeping with the findings of longitudinal studies, described above (Zanarini et al., 2012), which demonstrate that while 'symptom remission' is not uncommon in individuals with a diagnosis of BPD, lasting psychosocial recovery is rare. One possible alternative approach, acknowledging these tensions, is the adoption of tailored measures that seek to adequately capture personal meaning with regard to quality of life and to allow interventions to be adapted to meet personally significant aims (Wallcraft, 2011).

Limitations

The greatest limitation of this report is the small number of identified substrate studies for inclusion in the meta-synthesis. Further research is indicated to assess these themes in more detail and in different social settings. The included studies were of good methodological quality; however, little attention was apparently given to reflexive issues during

the data collection and analysis process. Theoretical influences on the analysis process similarly receive little description. Given the relationship of findings in this report to ideas of personal identity and the complexities of working with individuals with experience of personal mental distress, these domains should receive greater consideration in future work.

Each of the identified studies was conducted within a general community setting. However, personality disorder diagnoses are represented with differing prevalence in different social settings; for example, prevalence rates in forensic populations are recognised as being particularly high (Fazel & Danesh, 2002). The social setting may therefore require further consideration in future studies.

Much of the existing published academic literature in the study of personality disorder relates specifically to the experience of those receiving a diagnosis of BPD, and two of the three studies in this review similarly focussed on this diagnosis. This imbalance in the research base also needs to be addressed in future studies (Bateman et al., 2015).

Issues of reflexivity in the current analysis were addressed through involvement of a multidisciplinary research team throughout the analysis process. Regular research meetings were held with discussion of emergent themes, and the incorporation of an iterative writing process allowed further exploration of themes. The analysis was grounded within a contextual constructionist epistemology – that the experience of phenomena is determined by interactions between the research participant, researcher and other audiences (Madill et al., 2000). Triangulation of findings was considered through research meetings and sensitisation to the existing theoretical literature with

developing theoretical understanding through further literature reading in the light of synthesis findings.

Implications and future work

The findings have implications for both clinical practice and research. From a clinical perspective, there is evidence that interventions offered by mental health services do not fully address the needs of individuals with a personality disorder diagnosis. By focussing on the domains identified in these recovery narratives, services will better be able to meet the needs of these people. Support of interpersonal relationships with both professionals and non-professionals appears crucial to providing the sense of safety necessary before identity work may occur. The interplay between professional and client attachment style may also have to be taken into consideration. The demands of such relationships on professionals are well recognised and services may be required to adopt close supervision facilities, if these are not currently available, in order that clinical staff may better continue to fulfil their roles (Adshead, 1998). A review of outcome measures to allow identification of those most closely aligned with domains of significance to personal recovery is also necessary.

Further qualitative research studies, paying particular attention to issues of reflexivity, are necessary to address the small number of studies directly addressing the experiences of individuals in receipt of a personality disorder diagnosis. Given the implication of social networks and spaces in the recovery process, these studies should also seek to review the experiences of individuals within a variety of social settings.

Chapter 4 - Personal Recovery within forensic settings - systematic review and meta-synthesis of qualitative methods studies

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This second results chapter again represents an already published report (A. Shepherd, Doyle, Sanders, & Shaw, 2016a). The copyright agreement relating to its reproduction here is included in Appendix 7.

Abstract

Background: The support of personal recovery represents a stated goal for many modern mental health services. The role of personal recovery within forensic institutions however raises additional ethical and practical considerations, for example the appropriate degree of personal empowerment and its balance with support for personal risk management.

Aim: The current project aims to develop a framework description of the personal recovery processes for people receiving mental health care within a forensic setting.

Methods: A systematic literature review was conducted and meta-synthesis approach utilised in order to develop a framework description.

Results: Five studies were identified through the search process and combined through meta-synthesis. Three key overarching themes were synthesised: - Safety and security as a necessary base for the recovery process, The dynamics of hope and social networks in supporting the recovery process and Identity work as a changing feature in the recovery process.

Conclusions: The identified themes from this study serve to map out the existing literature on personal recovery within forensic settings and highlight areas for future research such as the interaction between personal risk and safety, the role of social networks and the importance of developing sense of personal identity to the recovery process.

Introduction

The support of personal recovery in mental disorder now represents a frequently stated goal for modern mental health services (G. Shepherd et al., 2008). Published statements relating to recovery goals commonly draw on ideas described by Anthony - where recovery is related as a means of achieving quality of life, despite the limitations imposed by illness (Anthony, 1993). Such descriptions can be seen as being somewhat in tension with service user definitions however, which offer a more humanistic description centring on personal choice of recovery definition (Deegan, 1996). Reviewing the existing literature describing personal recovery Leamy and Bird (2011) developed a conceptual framework outlining key themes described in the recovery process: Connectedness, Hope, Identity, Meaning, Empowerment and Spirituality.

The support of personal recovery within forensic mental health practice presents specific challenges - particularly in relation to the support of personal autonomy in balance with the need to manage risk of potential recidivism (Pouncey & Lukens, 2010). Further research has been called for in order to adequately understand the concept of personal recovery in forensic practice and to enhance the delivery of care in forensic settings (Dorkins & Adshead, 2011; Simpson & Penney, 2011).

Much academic literature focusses on definitions of recovery grounded in the use of clinical outcome measures, or symptom rating, scales, yet these measures have been shown to correlate poorly with service user defined recovery measures (Andresen et al., 2010). Most accounts of the recovery process highlight the idiographic nature of the process - research is therefore required that is better positioned to the capture of this essentially personal experience. Qualitative research methods seek to develop understanding of phenomena, often through an inductive process that grounds itself in the experience of research participants (Pope, 2009). Such methods therefore seem ideally placed for exploration of the nature of the personal recovery process within forensic mental health services.

Research aim

The current study sought to develop a framework that could adequately describe the existing qualitative literature relating to the experience of personal recovery in forensic settings.

Methods

The systematic review and combination of existing qualitative studies is a well-recognised research methodology and the current report is structured in keeping with published guidelines for Enhancing transparency in reporting the synthesis of qualitative research (ENTREQ) (Tong et al., 2012). A synthetic approach analogous to the classical meta-ethnography described by Noblit and Hare (1988) was adopted in order that existing research findings could be considered and developed into higher level understanding in relation to the recovery process. Ultimately qualitative analysis is a subjective process and the purpose of this report is to provide an audit trail to support readers in

their own interpretation. Literature searching, appraisal and analysis were undertaken by AS with review of coding strategy and meta-synthesis provided by the remaining authors.

The review protocol was registered prospectively in the PROSPERO database (CRD42013006840).

Systematic literature search strategy

The adopted search strategy sought to identify qualitative methods studies in peer reviewed publications. Grey literature material including conference abstracts and other non-peer reviewed communications were deliberately excluded from the strategy. Inclusion criteria for the review were:

1. English Language publication
2. Peer reviewed publication with online access to full text
3. Transparent representation of service user experience (e.g. direct quotation)

Exclusion criteria included:

1. Substance use disorder related recovery only
2. Clinical recovery definition (e.g. change in symptom rating scale score)
3. No clear access to service user experience in original publication

On-line electronic search engines were used to access the following databases: EMBASE, Medline, PsycINFO, Applied and Complementary Medicine Database (AMED), Social policy and practice, Applied Social Science index and Abstracts (ASSIA), British Humanities Index, Social Services abstract, Sociological abstracts and Sage publications. The following search terms were used.

Recover* AND (Forensic OR Prison OR Offend*) AND (Mental OR Psych*) AND (Disorder OR Illness OR Health OR Problem)

Terms and search format were adapted to meet the requirements of individual search engines, but the overall content of the search was not altered. The search was conducted on the 4th December 2013. Reference lists of included papers and editorial commentaries were also reviewed.

Search outputs were directly imported into electronic reference manager software (Papers 3 for OS X www.papersapp.com). The software allowed removal of duplicate hits from the search. Paper titles and abstracts were screened to allow exclusion of articles of clear irrelevance to the search strategy. Full text copies were reviewed for remaining articles and the inclusion and exclusion criteria outlined above were applied.

Critical quality appraisal

The application of standardised criteria to the review of qualitative research is not uncontroversial and risks losing the understanding that can be obtained from a detailed consideration of the relationship between observed material and theoretical stance (Barbour, 2001). Given these limitations a quality appraisal process was applied not with the intention of excluding potential studies but to gauge the transparency of the reported methods and findings. Criteria described by the Critical Appraisal Skills Programme (www.casp-uk.net) were used for this process.

<u>Meta-synthesis</u>

For this study a process analogous to the meta-ethnography described by Noblit and Hare (1988) was employed. Studies identified for inclusion were repeatedly read; themes identified within each report were then tabulated to include first order themes (direct participant quotations) and second order themes (original researcher interpretation). Second order themes were translated and combined under summary headings that allowed their consideration within a common language framework. Combination of second order translations in an inductive process allowed the development of third order constructs - which served as the output of the synthesis process.

The meta-synthesis was conducted primarily by AS and detailed discussion was held with the supervisory team in relation to coding strategies and study appraisal. Disagreements were resolved through discussion and where appropriate alteration of the coding framework. An iterative narrative approach to qualitative data representation and interpretation was adopted through an analysis that involved writing as a means of expressing findings for discussion (1996b).

Results

A total of 6,581 initial hits were identified - removal of duplicates reduced this to 4,982. Title and abstract review excluded 4,954 further papers - full text was therefore reviewed for 28 articles. This allowed exclusion of 23 further papers - reasons for exclusion at this stage included; no qualitative data presented, no transparent presentation of qualitative findings from participants, pure substance misuse recovery description, individual case reports only. This process is summarised in Figure 5. Five studies were ultimately included in the appraisal and

synthesis stages of the study; their characteristics as well as the diagnosis and index offence, where known, of participants are outlined in Table 4 (Ferrito, Vetere, Adshead, & Moore, 2012; Laithwaite & Gumley, 2007; Mezey, Kavuma, Turton, Demetriou, & Wright, 2010; O'Sullivan, Boulter, & Black, 2013; Stanton, Simpson, & Wouldes, 2000). Reference lists from editorial commentary and these studies identified no missed studies and text within each study referred to the sparsity of literature within this field, suggesting that the search strategy had been comprehensive.
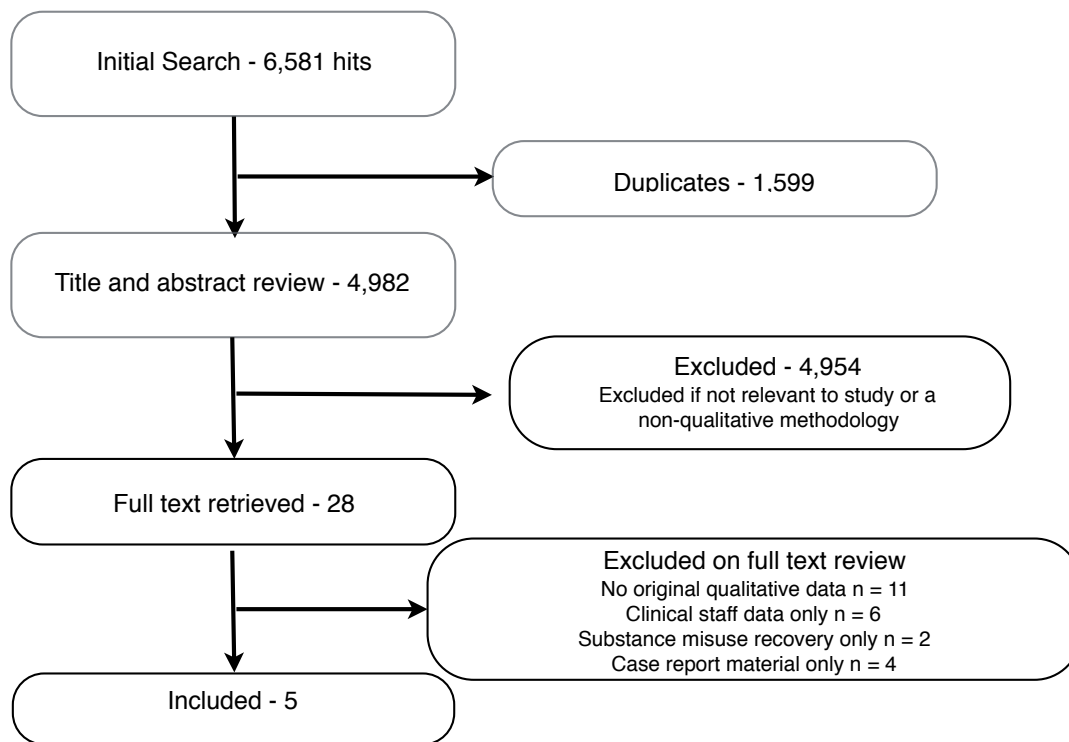
Figure 5

Critical appraisal criteria were applied in keeping with the CASP framework. Anchor statements from this framework and comments relating to each included study are presented in Table 5. Statements 'Is a qualitative methodology appropriate' and 'How valuable is the Research' are omitted from this appraisal. In assessing the aims of the

included studies direct quotations from the original papers are presented.

Meta-synthesis

Three significant tertiary themes were identified through the meta synthesis process. These themes are presented in Table 3, illustrative first order and second order themes are presented together with summary themes and the synthesised third order, synthetic, themes.

Safety and security as a necessary base for the recovery process

This theme describes the need for a sense of safety as being prerequisite for any recovery process to occur. The descriptions offered by participants in each of the studies highlighted the experience of threat - that may have been present throughout much of the individual's life. This sense of safety, security or asylum could be provided both by the physical environment or through a relationship with a care giver. In this manner the physical environment itself was presented as having therapeutic possibilities. This sense of safety, while viewed as essential, also represented a possible hindrance to recovery progression however - the fear of loss of asylum was considerable for many participants. Conversely the physical environment itself could become toxic - for example if there was inadequate space to distance oneself from peers. Lack of clarity in relation to routes out of care could also be perceived as claustrophobic; emphasising that while a secure environment could be supportive it could also be overly restrictive.

Study	Location and setting	Participants and diagnoses (n=)	Average participate age (range)	Index Offence	Methods
Stanton 2006	New Zealand	6	Not stated	Maternal Filicide	Naturalistic paradigm - constructivist epistemology, thematic analysis
		Schizophrenia - 3			
		Schizoaffective disorder - 2			
		Major depressive disorder - 1			
Laithwaite 2007	High security hospital, UK.	13	39 (22-60)	Assault, Manslaughter, Murder, Sexual offence	Grounded Theory approach
		Bipolar affective disorder - 3			
		Schizophrenia - 10			
Mezey 2010	Medium security hospital, UK	10	37 (24-56)	Arson, Assault, Manslaughter, Sexual offence	Grounded theory approach
		Schizophrenia - 7			
		Schizoaffective disorder - 3			
Ferrito 2012	High security hospital, UK.	7	31 (25-46)	Homicide	Interpretative phenomenological analysis
		Schizophrenia - 4			
		Schizophrenia and borderline personality disorder - 1			
		Schizoaffective disorder and psychopathic disorder - 1			
		Psychopathy and antisocial personality disorder - 1			
O'Sullivan 2013	Medium security hospital, UK	5	36 (26-42)	Not listed	Interpretative phenomenological analysis
		Schizophrenia and substance abuse - 3			
		Schizoaffective disorder and substance abuse - 2			

Table 4

CASP statement	Stanton 2006	Laithwaite 2007	Mezey 2010	Ferrito 2012	O'Sullivan 2013
Was there a clear statement of the aims of the research?	As a base to developing understanding of any phenomenon adequate description is required. The purpose of this study was to access the perpetrators' frame of reference.	The current study presents a user's perspective on being a patient in a high-security setting and the factors he/she considers important in his/her recovery.	The aim of this study was to explore forensic psychiatric patients' perceptions and experiences of recovery and to identify whether they had different narratives and emphases from non-offender patients, that could inform service planning and interventions.	This study sought to explore the processes of 'recovery' and redemption in the narratives of a sub-group of homicide perpetrators who were admitted to a secure hospital for treatment.	The overall aim of this research was to explore the experiences of individuals in MSUs with dual diagnosis who have been recalled, in order to inform treatment for this poorly understood population.
Was the research design appropriate to address the aims of the research?	Yes explanation for methodological choices	Review of epistemological approach and outline of justification for grounded theory	Explanation for choice of qualitative methods - limited description as to particular theoretical approach	Exploration of service user voice through qualitative methods - IPA	Explanation of qualitative methods - not IPA in particular
Was the recruitment strategy appropriate to the aims of the research?	Purposive sampling of specific group of participants	Purposive sampling for diagnostic and experience criteria. Development	Purposive sampling within specific population	Purposive sampling within target population	Convenience sampling

		of recruitment in light of findings.			
Were the data collected in a way that addressed the research issue?	Exploratory study - not seeking to draw theory or generalisation, no theoretical sampling and no saturation.	Explanation for method. Development of interview to findings. Description of method clearly laid out.	Clear discussion of appropriate analysis method	Purposive sample based on predefined criteria. Individual interviews to discuss topics.	Clear description of approach and involvement of analysis
Has the relationship between researcher and participants been adequately considered?	No clear discussion of reflexivity	Discussion of possible impact of own role on interviews and interpretation of data.	Involvement of service users in analysis process but no clear description of reflexivity issues	No clear discussion of reflexivity	No clear discussion of reflexivity
Have ethical issues been taken into consideration?	Ethical approval received	Ethical approval received	Ethics approval received	Ethics approval received	Ethical approval received
Was the data analysis sufficiently rigorous?	Clear description of data analysis	Clear description of analytic method	Working between service users and researchers to identify themes and codes.	Clear description of IPA approach	Clear description of analysis process
Is there a clear statement of findings?	Clearly stated	Clearly stated	Clearly stated	Clearly stated	Clearly stated

Table 5

3rd order theme	Summary theme (translation)	2nd order theme	Illustrative quotation (1st order theme)	Source
Safety and security as a necessary base for the recovery process	Safety	Relationships and a Changing Sense of Self	Being in here was a rest initially. I—when you say it has been a rest, how has it been restful for you? P9—nae violence, hallucinations. Quiet, quiet.	Laithwaite 2007
		What helps to bring about recovery	I'm really glad to be here at the moment, I feel safe, I feel I have a roof over my head, everything's taken care of and the nurses are lovely . . . . . . we get a cozy bed, with a duvet, you know and it doesn't cost much, so you know it's important'	Mezey 2010
The dynamics of hope and social networks in supporting the recovery process	Hope	Definitions and understandings of recovery	I'm actually in the process of trying to find hope again, you know I'm coming to that point, but you know if you haven't got hope then it really hinders your recovery'	Mezey 2010
		I have got no choice': disempowerment	I said to them 'at the end of the day how many people have they done these groups on that they've come back? More than the people that haven't come back in innit', and they're like 'yeah but, but, but, we can help you rarara' [laughter] It's not going to help me. (Seán)	O'Sullivan 2013
	Support	Relationships and a Changing Sense of Self	…the relationships are still strong, but I want to see my wee brother, I want to do well by my wee brother and give him help and support.	Laithwaite 2007
Identity work as a changing feature in the recovery process	Constructing self	Role as a mother	And I just went to pass [baby] to her and she said, "oh no, you hold her if you want to.", or something, I can't really remember, but I just remember looking at [friend] I had tears running down my eyes, and I said to her, I said, "you don't know what that means to me."	Stanton 2006
		Internal integration	If I make a better life for myself then I haven't wasted two lives. If I kill myself then I would have wasted my life as well and if I make a success of my life then I think somehow the person I killed has helped me.	Ferrito 2012
	Disorder	Managing illness	I was able to admit that I was severely depressed—I mean you know, and then to find that severe depression is a sickness is such a relief you know. [Crying]	Stanton 2006

	Definitions and understandings of recovery	If you don't understand what illness you have got then and what it is about then you are just going round with blinkers on, or a blindfold and err what's the point of having the treatment if you are not going to understand what the problem is'	Mezey 2010
	I was not really an addict': transition of the self as substance user	People made out I'd done more than them, but they'd done more than me really ... I wasn't much of a user. I was more of a binger, a few days, I'd leave it alone for another three weeks, four weeks. I wasn't really an addict, it wasn't like every single day I had to have it.	O'Sullivan 2013
Making sense	Managing the Horror of the Memories	When I woke up there was a detective there and I knew I had done something. I said, "how many", and he said "two" and I said "two what" and he said "two boys". Oh, you don't know what it was like.	Stanton 2006
	What helps to bring about recovery	because what I done was pretty serious. I mean I know that, I'm really, really sorry, I mean I wish . . . it's the worst mistake of my life I wish I could take it back. But I can't and'	Mezey 2010
	The role of past experience	There would be hugs and kisses. There would be love, presents at my birthdays, get together at Christmas, so they were loving parents. But then it suddenly goes bad, it gets really bad, beatings, starvations, humiliations, more beatings, acute beatings, fucked up stuff.	Ferrito 2012

Table 6

The dynamics of hope and social networks in supporting the recovery process

Two main factors were emphasised as being important in supporting the recovery process. The most significant of these was the development of hope in relation to personal experience and future aspiration. Allowing the expression of, or providing support for, personal autonomy was seen as significant in the fostering or dissolution of hope.

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Supportive relationships provided by family, friends or professionals were described as being essential. These relationships were perceived as providing concrete material support but also having a role by providing a mirror within which personal change could be viewed. There was also a risk however in that relationships perceived as unsupportive were detrimental to the individual's sense of progress and could undermine potentially therapeutic relationships with others.

Identity work as a changing feature in the recovery process
The final theme described the overarching change occurring within the recovery process - the developing sense of personal identity. This change contained three principal components; making sense of past experience, understanding the role of disorder and constructing a sense of self. The process could be described as identity work - seeking to make sense of a complex interplay between past and possible future selves (S. Adams et al., 1997). Recollections of personal trauma, particularly childhood memories, were prevalent in many of the presented descriptions; integration of these experiences together with developing understanding of offending behaviour seemed to be crucial to the process.

The representation of mental disorder within accounts was complex. Generally, disorder was presented as an object external to, and somewhat independent of, the individual - a problem to be directly identified and addressed through treatment that could provide some account for the nature of offending behaviour. The stigma of mental disorder and particularly of being a mentally disordered offender was represented and addressed as a barrier to accessing support and care within a community setting.

For those participants with a dual diagnosis mental and substance use disorder the interplay between disorder and self was still more complex with varying representations of the individual's status as potential addict and cultural representations of substance use - for example the use of cannabis in religious ritual.

The importance of an individual's past and future social role within communities was also apparent; for example, the ability of an individual to maintain a role within their family was crucial to the individual's sense of self. In the report by Stanton vivid descriptions were offered by participants of incidents where the participant was allowed to adopt a maternal role and did so despite the horror of their previous acts, although it should be noted that not all the women opted to again take on this role. For participants in other reports the separation of personal identity from offending behaviour was also of importance; with further descriptions of the need to develop social roles that could represent some form of future repayment to society.

Discussion

Through a review and meta-synthesis of the available qualitative methods literature the current study sought to develop a framework to represent the themes described in relation to the experience of personal recovery in forensic settings.

Recovery within forensic settings

The third order theme *Safety and security as a necessary base for the recovery process* can be considered as representing a basic human need (Maslow, 1943), however for participants in the included studies, who offered

extensive narratives of personal trauma, this process appears particularly pertinent. Forensic hospital environments may provide such safe environments through the nature of the institution itself and also through the ability of clinical staff to provide close, supportive relationships (Adshead, 1998). The theme of safety is not described within the framework outlined by Leamy and Bird (2011) and its presence here may represent the differing experiences of patients accessing care in forensic settings in comparison with the community. In addition feelings of insecurity and threat may represent a destabilising environment, to which some individuals may respond violently as a means of managing their anxiety, or re-enactment of previous traumas (Yakeley & Adshead, 2013), highlighting further the need for a safe base from which the individual may begin their recovery process. The loss of such a safe environment on return to the community is recognised as a complex process in need of careful management and support (Coffey, 2012)

Through incarceration people receiving support within forensic environments may experience isolation from their natural social, and support, networks. Lack of clarity around length of stay or pathways out of care can also lead to a loss of hope (Durcan, Hoare, & Cumming, 2011). These factors are represented in the theme *the dynamics of hope and social networks in supporting the recovery process*. The emphasis on interpersonal support within the recovery process highlights the need to explore the nature of social networks surrounding those who experience mental distress. The manner in which social network support is activated, as well as the constituent components of such networks are known to be of importance within the recovery process (Perry & Pescosolido, 2015). In forensic mental health practice this situation is compounded by the societally sanctioned separation of those who have

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offended from their family and community support networks (Dorkins & Adshead, 2011). Finally, in this theme the desire for the expression of personal autonomy was also described - this represents a further tension for the provision of forensic mental health care as the balance between personal autonomy and the necessary containment of risk is a fragile one.

The remaining synthesised theme highlighted the concept of *identity work as a changing feature in the recovery process*. Within forensic mental health care this process is again necessarily complex as individuals attempt to incorporate disparate identities; for example, their offending history and understandings of experiences of mental disorder. The role of therapeutic interventions in supporting individuals in such work has been described in both general (Holmes, 2008) and forensic settings (Adshead, 2011). Working towards the understanding of mental disorder, and its implications, within forensic settings is complex and can have important implications in terms of risk of recidivism (Keers, Ullrich, Destavola, & Coid, 2014). Many of the descriptions identified in this study sought to externalise the experience of mental disorder. The relationship between the experience of mental disorder and sense of self can adopt varying approaches, for example integrative or "sealing over" (McGlashan, 1987); in this approach McGlashan distinguishes between those who "seal over" their experiences by viewing experience as alien to themselves and seek to encapsulate it, in contrast those adopting an integrative approach describe a psychic continuity that displays awareness of the maintenance of self throughout the experience and any attendant recovery. These different approaches to understanding mental distress may be significant in relation to both treatment and risk formulation in forensic settings as working with individuals to support understanding of personal experience may allow

issues of risk, recidivism and the potential role of disorder to be addressed.

<u>Strengths and Limitations</u>

A strength of the current study is that, through review of the available literature, it has allowed expansion of previous work into the experience of personal recovery and developed a particular focus on that experience within forensic settings. The search, review and analysis process were conducted by AS under direct supervision from the remaining authors. A multidisciplinary supervisory team minimised the impact of personal theoretical bias on this process.

The greatest limitation of the current study is the small number of studies identified for inclusion. While a degree of convergence was apparent between the findings of each included study further qualitative studies are necessary to further explore the described phenomena. The studies included in this report were of generally high methodological quality, however their attention to the role of reflexivity in the data analysis process was, with the exception of the report by Laithwaite, somewhat limited leaving them open to accusations of possible bias (Macbeth, 2001).

Conclusions and future work

The framework developed within this study shows considerable overlap with similar frameworks developed in community mental health settings, but also highlights crucial differences and tensions that require special attention in forensic practice. The limited number of identified studies demonstrates the need for further research to better understand

the subjective experience of the recovery process - the themes identified within this study may serve as a framework to guide this research; for example, emphasising the role of interplay between mental disorder and personal identity, the role of social network support within forensic environments and the experience of transition between secure and community settings. The emphasis on identity work as the possible central change process within personal recovery also emphasises the need for review of outcome measures used in the research of mental disorder - are clinically focussed measures sufficient, or are novel, recovery orientated measures more appropriate?

Chapter 5 - Seeking to understand lived experiences of personal recovery in personality disorder in community and forensic settings – a qualitative methods investigation

Andrew Shepherd, Caroline Sanders and Jenny Shaw

Abstract

Background: Understandings of personal recovery have emerged as an alternative framework to traditional ideas of clinical progression, or symptom remission, in clinical practice. Most research in this field has focussed on the experience of individuals suffering with psychotic disorders and little research has been conducted to explore the experience of individuals with a personality disorder diagnosis, despite the high prevalence of such difficulties. The nature of the personality disorder diagnosis, together with their high prevalence rates in forensic settings renders the understanding of recovery in these contexts particularly problematic. The current study seeks to map out pertinent themes relating to the recovery process in personality disorder as described by individuals accessing care across a variety of clinical settings.

Methods: Individual qualitative interviews were utilised in order to explore the lived experience of those receiving a personality disorder diagnosis and accessing mental health care in either community or

forensic institutional settings. Thematic analysis was conducted in order to identify shared concepts and understanding between participants.

Results: 41 individual participant interviews were conducted across forensic and community settings. Recovery was presented by participants as a developing negotiated understanding of the self, together with looked for change and hope in the future. Four specific themes emerged: 1. Early lived experience as informing sense of self 2. Emotional control and the embodiment of distress 3. Diagnosis as linking understanding and hope for change 4. The role of mental health services.

Conclusions: Through considering personal recovery in personality disorder as a negotiated understanding between the individual, their social networks and professionals this study illustrates the complexity of working through such a process. Clarity of understanding in this area is essential to avoid developing resistance in the recovery process. Understanding of recovery in a variety of diagnostic categories and social settings is essential if a truly recovery orientated mental health service is to be developed.

Keywords – Personal Recovery, Personality Disorder, Qualitative Research

Background

Personal recovery is increasingly recognised as a principle goal for mental health services (Department of Health, UK, 2011). Understanding in this area is by its very nature idiographic, however efforts have been made to synthesise pertinent themes into framework conceptualisations (Leamy et al., 2011) and to develop measures through which recovery orientated clinical practice may be enacted

(Slade, Bird, Clarke, et al., 2015a; Slade, Bird, Le Boutillier, et al., 2015b). So far most research into the recovery process has been conducted with individuals with psychosis and the application of this developed understanding to the experience of individuals with other diagnoses requires further exploration.

Despite the high prevalence of personality disorder (Tyrer et al., 2015) a recent systematic review identified only three qualitative methods studies specifically focussed on the experience of recovery in relation to these diagnoses (A. Shepherd, Sanders, Doyle, & Shaw, 2016b), in contrast to 89 studies identified through systematic review in relation to recovery in schizophrenia (Andresen, Oades, & Caputi, 2003). Understanding this process with regard to personality disorder is further complicated by the high prevalence of the diagnoses within forensic settings (Fazel & Danesh, 2002), a setting where particular issues and tensions can be seen as arising in relation to issues such as autonomy and empowerment that are crucial to the process of recovery (Pouncey & Lukens, 2010; Simpson & Penney, 2011). While recovery focussed frameworks have been developed for care provision within forensic settings (Doyle, Logan, Ludlow, & Holloway, 2011) there has been little exploration of the theoretical underpinning, or lived experience, of this process (A. Shepherd, Doyle, Sanders, & Shaw, 2016a).

Research into the recovery process is essential in order that therapeutic support needs can be recognised and appropriately met through structured interventions (Slade & Hayward, 2007). Research can also facilitate the development of shared understanding between clinicians and patients - a necessary step if new interventions are to become standard for clinical services (Murray et al., 2010).

Therefore, with this background framework, the current study aimed to better map the lived experience of those receiving a personality disorder diagnosis, focussing on their understanding of personal recovery and the experiences of individuals accessing mental health care across a variety of institutional settings.

Methods

These findings are from a doctoral research project supported by funding from the National Institute for Health Research, registered with the UK Clinical Research Network (Reference 15934). A qualitative methodological approach was adopted in order to adequately address the aims of the project. In contrast to methodologies adopting a positivist epistemology, qualitative methods studies offer the opportunity for in-depth exploration of the personal aspects of health experience and illness narratives (Kuper, Reeves, & Levinson, 2008; Pope & Ziebland, 2000). Individual interviews were conducted with mental health service user participants - with participants initially identified on the basis of their having received a personality disorder diagnosis. Subsequent rounds of recruitment were conducted in a purposive manner to address emergent themes. Focus groups were conducted with clinical staff in order to reflect, from an alternative perspective, on emergent themes from individual interviews. Findings from these focus groups will be reported elsewhere.

The research was conducted in clinical settings and prisons within the North of England. Participant anonymity is protected through the use of pseudonyms and the removal of any personal identifiable information from interview transcripts.

Individual interviews: - Participant recruitment and interview process

Participants were selected on their having been identified as having received a personality disorder diagnosis and having sufficient spoken English language skill to enable them to participate in the interview process. Potential participants were initially identified through approaching clinical teams with information relating to the study. Teams were asked to identify potential participants, and to provide them with information describing the role of participants in the study. Initial contact with participants by the researcher was therefore mediated through clinical teams. No structured diagnostic interviews, or other such steps, were taken to verify personality disorder diagnosis and no specific subtype of diagnosis were sought. For the purpose of this research project it is argued that, on the basis of recent discussions of personality disorder diagnostic criteria (Livesley, 2012; Skodol, Morey, Bender, & Oldham, 2015; Trestman, 2014) and possible future changes (Frances & Nardo, 2013; Tyrer, 2013; Tyrer et al., 2015; Tyrer, Crawford, & Mulder, 2011), the present administration of specific personality diagnoses is uncertain - and therefore a pragmatic approach to diagnosis was adopted with no specific exclusion criteria set. A recruitment strategy was therefore adopted where participants were being treated by their clinical team 'as if' they had a personality disorder diagnosis. This diagnosis could be seen as primary or secondary in any formulation and participants were not excluded on the basis of any co-morbid diagnoses. No specific exclusion criteria were applied; excepting that participants were required to be able to offer informed consent for participation.

Individual interview recruitment and analysis were conducted in an iterative fashion, such that recruitment could be informed in a theoretical manner. For example, early references to adverse inpatient

experiences and the importance of consistent therapeutic contact lead to participants being identified with varying lengths of contact with the mental health services and experience of contact in a variety of clinical settings (inpatient open ward, psychiatric intensive care unit, community care, prison and secure hospital). Recruitment continued until data saturation had been reached. The applied definition of saturation is discussed in the analysis section below.

As described above potential participants were approached with information relating to the study by members of their clinical team. After expressing interest participants were then contacted by the first author and an appointment was arranged for the interview to be conducted. Interviews were conducted at clinical locations with which the participants expressed familiarity and comfort in attending. Prior to commencing the interview proper further opportunity was provided for participants to ask questions relating to the research. Consent for participation in the study was then obtained with a consent form being signed at this stage - although the consent process was viewed as being dynamic in nature, continuing throughout the period of the interview and beyond. Consent and interview were both undertaken at the same appointment so as to minimise disruption for participants.

Interviews were conducted in an open style, with initial questioning conducted in a fashion that encouraged the elaboration of personal story (Riessman, 2008). Semi-structured interview schedules were developed but were used only for participants who indicated they desired a greater degree of prompting to elicit their experience. Interviews were audio-recorded and then stored, electronically, in an encrypted file format in keeping with NHS data protection standards.

<u>Analysis</u>

Analysis was theoretically informed by a contextual constructivist approach to knowledge generation (Madill et al., 2000). In this manner responses to questions were taken as representative of the participants' understanding, but with consideration being given to the emergence of discourse as being a co-constructed phenomenon between researcher and participant.

The first step in the analysis process began with the writing of reflexive journal entries following each individual interview and focus group meeting. Journal entries allowed the capturing of significant themes based on initial reflection on the interview such that these could be explored in more detail during subsequent interviews, and during subsequent analysis steps. These initial themes were developed through reflection on subsequent interviews and further transformed throughout the analysis process. Data saturation was defined by the emergence of no novel themes within these journal entries over the course of sequential interviews.

Transcription of interviews was completed by the first author and represented the second phase in the analysis process, allowing an 'immersion' in the data (Lapadat & Lindsay, 1999). The third step in the analytic process involved a coding strategy conducted in a manner so as to 'fragment' the transcribed data allowing horizontal comparison between interviews (A. Coffey & Atkinson, 1996a). Memo-writing (Wengraf, 2001) was used to capture descriptions and links between coding and to allow the development of emergent themes (Charmaz, 1990). Data analysis was supported through the use of qualitative data analysis software NVivo (QSR International version 11). The fourth stage of the analysis process involved the construction of thematic maps

(Attride-Stirling, 2001), which allowed the relationship between themes to be reviewed. Descriptive writing was then also incorporated into the analysis process.

Transcripts and emergent themes were reviewed with the second and third authors during research supervisory meetings. Themes were also discussed at meetings with a mental health service user advisory group conducted throughout the research project. In this way analysis was reviewed from a variety of standpoints with regard to theoretical experience and role. Issues of reflexivity, that is the impact of the role of the researcher on the research process (Mauthner & Doucet, 2003), were also discussed during supervision and advisory group meetings in order to allow that they be sufficiently addressed.

Ethical approval

Ethical approval was sought from the National Research Ethics Service East of England - Essex (Reference 14/EE/0029). Access to prisons was approved by the National Offender Management Service, National Research Committee (Reference 2013-282); specific Prison Governor approval was granted for prisons from which participants were recruited.

Results

A total of 41 individual interview participants were recruited across both community and forensic settings. Most participants self-identified as having been diagnosed with an Emotionally Unstable or Borderline Personality Disorder, with some also reporting a diagnosis of Dissocial Personality Disorder. Demographic details of interview participants are

summarised in Table 7. Individual interviews lasted between 15 and 79 minutes (mean 53 minutes).

In discussing their understanding of recovery, participants described an overarching process involving a balance between developing an 'understanding of self' together with 'looked for change' or hope for the future; this process was not simply an individual act however but involved a close negotiation of understanding between the individual, their host social network and other agents, such as professionals, with whom they developed contact. Within this overarching understanding four further themes are presented below: 1. Early lived experience as informing sense of self 2. Emotional control and the embodiment of distress 3. Diagnosis as linking understanding and hope for change 4. The role of mental health services. Each of these four themes is explored in greater detail below; illustrative quotations are used for the richness of their description and, where possible, to represent counter-arguments or statements.

<u>Early lived experience as informing sense of self</u>

Most participants framed their understanding of their experiences within a description of their early life within their family, particularly their sense of belonging and the interpretations of their behaviour made by key family members.

Interviewer: "What was that like, being the youngest in that family?"

Participant: "I always felt there was a lot of pressure on me to do very well, because my brothers are both very bright and had done well at school and I always felt compared to them when I went to primary school I was 'oh you're M and B's sister', not 'you're C' I was always theirs, known as their sister and for that reason I went to a different secondary school to them"

Code	Interview Setting	Age	Gender
Int001	Secure hospital	48	Male
Int002	Secure hospital	28	Female
Int003	Prison	42	Male
Int004	Prison	38	Male
Int005	Prison	27	Male
Int006	Prison	46	Male
Int007	Prison	35	Female
Int008	Prison	21	Male
Int009	Prison	20	Male
Int010	Prison	38	Male
Int011	Prison	41	Female
Int012	Prison	36	Female
Int013	Secure hospital	47	Male
Int014	Secure hospital	36	Male
Int015	Community	37	Male
Int016	Prison	19	Female
Int017	Prison	33	Female
Int018	Prison	24	Female
Int019	Prison	27	Female
Int020	Prison	54	Female
Int021	Prison	42	Female
Int022	Community	38	Male
Int023	Community	41	Male
Int024	Community	31	Female
Int025	Community	21	Female
Int026	Community	51	Female
Int027	Hospital	57	Male
Int028	Hospital	49	Female
Int029	Community	29	Female
Int030	Community	32	Female
Int031	Community	45	Female
Int032	Community	43	Female
Int033	Community	34	Male
Int034	Hospital	22	Male
Int035	Community	45	Female
Int036	Community	30	Female
Int037	Hospital	50	Male
Int038	Community	50	Female
Int039	Community	18	Female
Int040	Community	31	Female
Int041	Community	20	Male

Table 7

Later in the interview this respondent reflected on her current sense of self:

> *Interviewer: "How are you as an individual now, what have you found in yourself?"*
> *Participant: "It's difficult because I sometimes feel like my illness has kind of defined who I am, I'm just like the one who's got all the problems and I've not really found who I am yet." [Int036]*

> *Interviewer: "She [mother] said you were mentally ill?"*
> *Participant: "Yeah but going back all them years ago, they didn't really recognise it that I was mentally ill."*
> *Interviewer: "What made you mentally ill at that time do you think?"*
> *Participant: "I had a lot of depression and down days, when I think back now just not fitting in even the foods that I liked were totally different I had nothing in common with the family that I lived with and brought up with. Not in the food, nothing." [Int038]*

Within the context provided by their social networks, participants saw some elements of behaviour as constituting a destructive aspect of themselves, emerging as a response to violence and pain and impacting on their ability to trust in others and form relationships:

> *"I won't let many people in, I choose my circles… who I speak to even smaller… I still choose not to speak to a lot of people about it. Just mainly because I kind of deal with it, or I've dealt with it and I don't feel like bringing it up." [Int019]*

Participant accounts of their experience were therefore intimately framed within the understanding of their social networks, often reaching back to early life experiences of family life - accounts which were often coloured by experiences of violence or abuse within the family environment.

Emotional regulation and the embodiment of distress

Many participants, when discussing hoped for change, described their wish for greater control of their emotional life, as a process of developing a more coherent understanding of their experience. This then became an intimate part of the 'recovery process' - a greater sense of stability, of self-control:

"I do have a lot more awareness than I used to do in the past, and I don't do things, impulsively go off and drink and then go off on one and then go and have a drink, do you know what I mean, any of those sort of things, self-injure, so I think in terms of, like, recovery, in terms of being able to have a degree of self-control and being able to think ahead about the consequences of things so that rather than having a big blow up." [Int033]

Participants engaging in acts of self-harm, or suicidal behaviours, such as those described in the quotation above, positioned these as emerging directly from experiences of trauma, or distress, and representing a potential relief from conflict; linking their emotional distress to a particular sense of embodiment:

Interviewer: "What type of things lead to you feeling you need space"
Participant: "because my emotions go up and down where I'm angry and then really really mad, then I feel suicidal it's like a volcano with me. At the moment I'm like level but let anything change tonight and it goes."
Interviewer: "What makes it change, what type of things set off the volcano?"
Participant: "It's when I don't feel safe and stuff I just don't feel like I can do it no-more and basically at the end of the day, it's just like, like I said before, I just wish I was dead, because it would stop all the arguing with everybody." [Int040]

Diagnosis as linking understanding and hope for change

For the majority of participants the application of a personality disorder diagnosis represented an important step in the understanding of their

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experience. An appreciation of diagnosis allowed them to begin a process of engagement and to develop a sense of hope for the future:

"That helped knowing a little bit and then I didn't really get a lot of support with regards to what I had, I did an awful lot of research myself […] But then by having that that opened up other avenues, other courses of treatment and having regular CPN was great, really but it was good to be diagnosed with something anyway, because I knew it was something worse [than depression]." [Int023]

"They gave me the diagnosis of emotionally unstable personality disorder. So I was put on, obviously, several antipsychotic drugs and antidepressants which were linked with an anti-anxiety as well and I started going to a hearing voices group, which was near where I lived, so that made things a lot easier knowing that I was with like-minded people." [Int025]

For a minority of participants however the diagnosis of personality disorder was seen as unhelpful - representing a direct comment on them as a person, or as a representation of their previous behaviour, not a 'mental illness' per se:

Participant: "It felt like a bit of an attack to me own, everything about me, you know, everything that I am do you know?
Interviewer: "That your personality is who you are?"
Participant: "Yeah" [Int003]

"Well the doctor said I've got an antisocial personality disorder, I'm not antisocial so where do they get that from? […] Well technically, that could be right I suppose, you know, it's like antisocial burgling and crime, stuff like that isn't it but you know does every Tom, Dick and Harry who's in [prison] now have an antisocial personality disorder just because they're in?" [Int013]

This understanding was particularly pertinent in forensic settings where diagnosis was seen as being used, through expert witness testimony, to

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inform the judicial process or as a means of excluding some from care within the hospital setting.

For a small minority of participants the recovery process was seen as being one of radical change, representing an adaption in self-understanding beyond that offered within a diagnostic framework:

"I changed quite a lot to be fair, I pretty much did become a completely different person. […] I gained empathy, I gained compassion, I gained understanding these were things that were lacking, even before my mental health problems really, they were just accentuated with my mental health problems." [Int023]

<u>The role of the mental health services</u>

Relationships with professionals in a therapeutic setting were seen as being crucial in allowing the individual an opportunity to reflect on experience and plan for future change; the opportunity for such therapeutic relationships was seen as becoming increasingly constrained by resource restrictions however:

Participant: "The counsellor that I saw was the best person.
Interviewer: "What was best about the counsellor, what was it about them?"
Participant: "We had a great rapport
Interviewer: "So the relationship with the counsellor was important to you?"
Participant: "Yeah, very important, and I trusted her […] It let me open up more to her and to know that she cared, and she really did care, and she was very interested in me and my thoughts…" [Int025]

Others described how their relationships with professionals had been dismissive, or even bullying, in nature:

"I felt hang on I feel more bipolar, than I do, with that symptom included, and I look back how I was as a kid, because sometimes I get quite hyper. I tried hanging myself at 14 as well so I was suicidal from a young age and I don't

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know it just fits more. He [psychiatrist] said it was so I could get out of going under this team at [region] […] which I've been fighting not to go under 'cause [social worker] I don't get on with him, I don't find him useful, I find him patronising and not at all good, and I'm not the only one with that opinion so he was saying I was just doing it, saying it so I wouldn't, didn't have to go under them and I wasn't" [Int040]

"But within the illness it's difficult for me to understand it I just try and go along I got the understanding that people don't trust it or they say it's a cop out. But I don't care about it I know I'm ill I know the things I've done, I know I wouldn't be in this service if there was nothing wrong with me" [Int015]

Within prison settings participants reflected on the role of prison officers and their interaction with prisoners during times of mental distress. Prison officers were seen as representing the front line of support in some cases, but also as not appreciating the complexity of distress that they witnessed:

"…the prison officers and that were pretty good with me, because they knew I was mentally unwell. So even though I was locked in my room, because if you don't go to workshops and stuff in prison you get what's called basic salary and you don't get near normal, amounts, but because they knew I was unwell they gave me enhanced and they gave me a television even though I wasn't going to workshops and they took me out each day to get me a shower and at exercise times, so they were quite good to me…" [Int001]

"I understand that they're not emotionally connected to me, they don't really give a shit, it's a job - everything. Well to some extent they do, they've got a duty of care, you know, if I died tonight I'd be forgot in a week, do you know what I mean, it's all it really is nobody gives a shit in here…" [Int003]

Discussion

The present study sought to explore the experience and personal meaning of recovery in relation to individuals receiving a personality disorder diagnosis and accessing care in either community or forensic settings. Overall the process was revealed as a negotiation of understanding between those experiencing mental distress, their social networks and clinical (or other) professionals. In keeping with previous research, recovery was identified not as a discrete outcome but instead as an on-going process (Slade & Longden, 2015). The manner in which this process was understood and reflected was determined largely by the individual's sense of themselves and their reflection on their lived experience. Social networks, as in other studies, were seen as playing an essential role in this 'sense-making' activity (Leamy et al., 2011; A. Shepherd, Doyle, Sanders, & Shaw, 2016a; A. Shepherd, Sanders, Doyle, & Shaw, 2016b).

Diagnosis, for the majority, represented a route through which understanding of past distress could be linked to current experience, although this was not a universal understanding with other participants viewing the diagnosis as inherently stigmatising or as leading to an exclusion from health service support, a finding consistent with other studies comparing the experience of those receiving a personality disorder diagnosis with other forms of mental disorder (Bonnington & Rose, 2014). This difficulty was perhaps particularly noteworthy when considered in the context of forensic healthcare settings where a few participants experienced the diagnosis of personality disorder being used as a means to exclude them from care options, such as hospital transfer. Despite these difficulties when considered in the light of individual past experience many found the act of diagnosis to be a

powerful act allowing an alternative perspective to be adopted and hope for future change to develop.

Mental health services were seen as supportive in their ability to offer therapeutic relationships that allowed participants to work through their understanding of recovery in a negotiated manner. However, the capacity to develop these relationships was seen as being impinged upon by tensions between modes of sense making - with many participants detecting uncertainty from clinical staff in terms of their understanding of the diagnosis of personality disorder; such uncertainty impacted on the individual's ability to foster feelings of hope in relation to change. Within prison settings other professionals, principally prison officers, were seen as fulfilling an essential role in the support of those with experience of mental distress. The impact of this emotional labour on officers can-not be directly commented on from the findings in this study, although - given the described impact of such work on clinical professionals - it can be hypothesised that this will represent a significant burden. Caution is necessary to ensure that the well-recognised difficulties of working with individuals with disrupted attachment experience (Adshead, 1998), as is often characteristic of forms of personality disorder, does not lead to a process of exclusion for 'difficult patients' (Sulzer, 2015b).

Strengths and Limitations

Systematic review has revealed the limited amount of research conducted in relation to the concept of recovery in personality disorder; what research has been conducted has generally focussed on the experience of participants accessing care within community settings. By focussing on the experience of individuals across a variety of setting this

study builds on, and adds to, this previous knowledge and understanding.

Reflexivity represents the manner in which the researcher teams' own theoretical experiences and understandings interact with the analysis of the available material (Macbeth, 2001; Mauthner & Doucet, 2003). All interviews and the majority of the analysis process for this study were undertaken by the first author; a higher trainee in forensic psychiatry and doctoral research fellow. The author's role as a psychiatrist was known to all participants in the study and may have impacted on the emergent discourse (Richards & Emslie, 2000). This impact was considered during research supervisory meetings with the remaining authors together with coding approaches and emergent themes. Themes were also discussed and developed through meetings with a service-user advisory group recruited at the outset of the project. In this manner interpretation of findings was considered in a multi-disciplinary fashion, acknowledging the impact of the researcher role on the investigation, acknowledging its impact and moving to prevent a one-sided reading of the data (Hall, 2005).

The vast majority of participants within the present study were White; this is significant as it is known that race and ethnicity are factors that influence the understanding of personality disorder diagnoses (McGilloway, Hall, Lee, & Bhui, 2010; Mikton & Grounds, 2007). Additionally it is recognised that cultural heritage may produce different appreciations of the recovery process (Leamy et al., 2011; Slade, Bird, Le Boutillier, et al., 2015b). A decision was taken in this study not to focus on race or ethnicity within the purposive sampling strategy: - on the basis of the complexities outlined further research is required specifically focussing on the experience of race in relation to personality

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disorder and personal recovery and with particular attention paid to issues of reflexivity.

<u>Future work</u>

A novel theme emerging from this study is the manner in which understandings of recovery are negotiated between the individual with experience of mental distress, their social networks and clinical staff or other professionals. An intimate sensitivity to the language used is apparent in this process and further understanding relating to the dynamic nature of this process is required. Studies focussing on the development of dialogue and discourse between agents are therefore required to explore and map this process.

As discussed above the experience of Black and Ethnic Minority individuals with a personality disorder diagnosis are in need of further exploration - studies should be developed in order to capture this missing experience in an in-depth fashion.

Finally, the role of prison officers in supporting individuals experiencing mental distress within prison settings was also highlighted. Further research should be undertaken to explore the nature of this process in greater detail - focussing particularly on the impact of such emotional labour on officers and the availability of appropriate support, or supervision, to allow this role to be fulfilled.

Conclusion

The recovery process, in relation to the experience of those diagnosed with a personality disorder, was revealed to be one of developing self-understanding in relation to one's biographical experience - with an emerging sense of greater control in relation to emotional experience.

This understanding involved negotiation between the individual and their host social networks, as well as clinical professionals and other agents providing support. For some however this process was disrupted by the varying attitudes of clinical staff that were at times perceived as being almost hostile in their manner, an experience that was seen as being particular to the diagnosis of personality disorder. The understanding and support for the process of personal recovery in relation to mental disorder is complicated by varying understandings of its implications among professionals (Le Boutillier et al., 2015; 2014).

The findings from the current study highlight the difficulty in the development of a negotiated understanding between clinical professionals and individuals who receive a personality disorder diagnosis. Emergent tensions in relation to the understanding and communication of diagnosis further complicate this process. Lack of clarity in this area risks the development of stigmatised narratives leading to a sense of exclusion and hopelessness. The central role of social networks in the recovery process also requires attention from mental health services; this may represent a particular problem for those offering care within forensic settings where individuals may be divorced, or separated by great distances, from original networks.

Research into the process and meaning of personal recovery is crucial for the continuing development of clinical mental health services. This understanding may be particularly complex in the case of personality disorder. The current study highlights the importance of attention to communication and collaboration between professional and patient to allow the development of mutual understanding. Developing understanding of recovery in a variety of diagnostic categories and

social settings is essential if a truly recovery orientated mental health service is to be developed.

Chapter 6 - Working to support personal recovery in personality disorder: Findings from focus group interviews with clinical professionals

Andrew Shepherd, Caroline Sanders and Jenny Shaw

Abstract

Background: 'Personal recovery' involves a negotiation of understanding between clinicians and service users.

Material: Clinical staff focus groups were conducted, in a variety of clinical settings, to explore the concept of personal recovery as it applies to personality disorder.

Discussion: Thematic analysis revealed themes relating to recovery as a process of identity work - characterised in the case of personality disorder by the complexity of diagnosis, risk of therapeutic nihilism and necessity for the containment of distress within the professional relationship.

Conclusions: Support of personal recovery in personality disorder represents a process of emotional labour for clinicians requiring training and close supervisory support.

Keywords

Personal recovery, Personality disorder, Clinical practice, Qualitative research, Focus groups

Background

The support of personal recovery now represents a specific goal for mental health care professionals within the UK (Department of Health, UK, 2011) and internationally (for example Department of Health, 2013). Research has been conducted into the mapping of the recovery process (Leamy et al., 2011) with the intention of clarifying understanding of the process and its differentiation from other concepts and goals in clinical care provision (Slade & Hayward, 2007). Work has also begun with regard to interventions designed to support the delivery of specifically recovery orientated clinical care models (Slade, Bird, Clarke, et al., 2015a).

Despite such investigation a lack of clarity still exists regarding the nature, or conceptualisation, of 'recovery'. Most research in this area has been conducted in community settings with individuals suffering from psychotic disorders (Slade, Bird, Le Boutillier, et al., 2015b), other diagnoses, for example personality disorder, can be seen as raising the complexity further, yet little research has been conducted to explore the lived experience of individuals receiving these diagnoses (Shepherd, Sanders, Doyle, & Shaw, 2016b).

Ultimately, recovery oriented care is generally presented as involving a negotiation of understanding between service users, clinical staff and their surrounding social milieu (Anthony, 1993; Davidson, 2008; Deegan, 1996; Pilgrim, 2008). Professional conceptualisations are therefore significant in this process. Research exploring this understanding has indicated a high degree of uncertainty both in terms of the defining the underlying meaning of the concept and the recognition of driving forces affecting its implementation (Le Boutillier

et al., 2014; 2015). Further research of clinical staff perspectives is necessary if a recovery oriented clinical care system is to be enacted.

With this background framework the current study therefore seeks to build on previous research by exploring the understanding of clinical staff, working in both community and forensic settings, in relation to the provision of recovery oriented care for service users receiving a personality disorder diagnosis.

Methods

Focus groups allow for a construction of understanding between participants (Barbour, 2005; Halkier, 2010; Kitzinger, 1994; 1995) and were therefore selected as an appropriate methodology for this study. Ethical approval for the study was granted by the NHS National Research Ethics Service Committee East of England Essex (Reference 14/EE/0029) and by the National Offender Management Service National Research Committee (Reference 2013-282).

Analysis and group recruitment were conducted in parallel such that the process could continue until saturation, defined as no novel themes emerging over two interviews, was reached. An initial semi-structured interview schedule was developed on the basis of findings from individual service user interviews (conducted as another phase in a larger study). This schedule was adapted for subsequent interviews to address newly emerging themes. Potential participants were approached on the basis of their experience in relation to emergent themes of discussion in previous interviews.

Group sessions were audio recorded and a reflective journal was maintained (Malacrida, 2007). Transcription of recordings was followed by thematic analysis adopting a coding strategy which sought to fragment transcripts to allow comparison of material between group discussions. Issues of reflexivity, such as the impact of the researcher's clinical role as a psychiatrist, were addressed during analysis and through group discussion with other members of the research team.

Seven focus groups were conducted in total, details of which are presented in Table 8.

Focus group code	n=	Duration (minutes)	Setting	Roles
CSFG001	6	46	Community outpatient	Psychology and nursing staff
CSFG002	4	48	Community outpatient	Psychology, probation and service user consultant
CSFG003	6	42	Community inpatient	Psychology and nursing staff
CSFG004	2	55	Community outpatient	Psychology
CSFG005	3	40	Community inpatient and outpatient	Psychiatrists
CSFG006	6	42	Prison mental health	Psychology and nursing staff
CSFG007	3	41	Prison mental health	Nursing staff

Table 8

Results

Four overarching themes emerged from the analysis: Recovery and change, the complexity of diagnosis, treatment and the risk of therapeutic nihilism, the professional relationship and containment of distress. Illustrative quotations are selected for the thickness of their description, or where possible to illustrate counterfactual argument. Brackets and anonymised participant initials are used to indicate different speakers where appropriate.

<u>Recovery and change</u>

Participants outlined their understanding of recovery as a process of change in personal identity:

"(Interviewer - what changes during the recovery process?)…what changes exactly, something to do with identity…" [CSFG002]

For many this process was linked to the experience for service users of coming to terms with previous personal trauma and gaining understanding in their life:

"…coming to terms with experiences that have happened to you and, in some sense, I guess putting that behind you and, I guess, functioning again…"
[CSFG005]

"I think recovery allows us to get away from a more diagnostic notion of disease and cure by thinking about a process of coming to terms with, or living with optimally, something that is described, rightly or wrongly, as personality disorder." [CSFG002]

This process of change was described as being manifest in the way people related to others within their social networks and institutions; therefore, the change was seen as being social in nature and its reflection within groups was seen as necessary to allow its identification, as it may otherwise have escaped individual notice:

"I'm really busy trying to really distil and I suppose it's, I suppose I'm coming up with a number of words about understanding, awareness, formulating like I suppose, something historic, but also how feelings are managed, how

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relationships are managed, relationships with others, relationships with self…"
[CSFG004]

"…people might make some subtle changes, but don't always see that they're in a process of recovery but others around them can see it happening…" [CSFG002]

Group participants also perceived a potential tension however between observable change, or recovery, in clients and the maintenance of staff optimism - with lack of apparent therapeutic change seen as being damaging to the motivation of staff.

A further important facet of the identity work described by participants in this study, and its application to the recovery process, is the manner in which individuals work to make sense of medical aspects, specifically diagnosis. Participants identified such shifting understanding as a crucial process of change:

"…but I think you're right, that it is part of a process, people do generally come in with the idea that they've got an illness, don't they, and they're quite, it takes a while for them to start moving beyond that and to start thinking about relationships and their feelings and I guess their humanity really, over time… ([R] - I think what we were talking about before, in the group, is about how it does, that can become somebody's identity and if you struggle to know who you are then that can become that person's identity so you, maybe recovery is about discovering an identity beyond that label…)" [CSFG002]

The complexity of diagnosis

Building on the idea of a shifting understanding of the self during the recovery process, as was highlighted in the first theme, focus group participants described the manner in which diagnosis could provide a form of symbolic stabilisation, or validation of personal suffering, within a framework of mental disorder:

"It always has been, hasn't it, a form of validation, for some, for some people and I think that's a really important thing to hold onto, because it can help make sense of what somebody experiences, or I now feel as if this is being recognised in some way, it's difficult because it can also hold a stigma…" [CSF004]

This sense of validation, or normalisation of experience, for some extended into the act of diagnosis removing a degree of accountability for one's actions and experiences, taking on a moral dimension where the diagnosing clinician was almost able to provide a form of absolution:

"But I think when it comes back to EUPD [Emotionally unstable personality disorder] or borderline the impact really it's taking away from them you know, it wasn't your fault, what was done to you, what caused you to be this way and we recognise it, we're going to try and support you, so I find, I don't like the word disorder, in terms of personality disorder - I tend to say personality difficulties, it seems an easier pill to swallow, but in the end it's the same thing that I'm trying to get across that it's something about the way they are as a person that's been affected by what's happened to them…" [CSFG005]

However, these views were seen as controversial among focus group participants:

"I try to steer clear of discussion with someone who has, I suspect, a personality disorder, and try to emphasise more of a personal responsibility, than that I'm here to fix something or that somebody's to blame, for what's happening, because I think clearly that externalising the blame, that external locus of control, that doesn't help, that only perpetuates their understanding that I'm not responsible for anything, somebody else has done this to me and poor me, so they tend to adopt a sick role…" [CSFG005]

"…I think you can make matters worse because they will start to believe that, instead of tackling what could be their own past, they may have sought other diagnoses - and that's then something else they can then blame, so it removes responsibility from themselves and places it on a rather nebulous concept of some other problem…" [CSFG007]

In relation to other, 'severe mental illness', diagnoses the idea of personality disorder was viewed by some professionals as being unclear - with differences framed in terms of understandings of 'organic' illness in opposition to personality disorder:

"…I had a trainee, who was meeting with one of my medical colleagues, say well psychosis is a proper brain disease, whereas PD isn't… so I think there is that thought that it's an organic… [A - Like a chemical element, D2 receptors and all that…]" [CSFG003]

In comparison with other diagnoses communication relating to the meaning and nature of the personality disorder diagnoses was perceived as being poorly understood and conveyed between professionals and

service users. For others personality disorder was seen as being a diagnosis at risk of exclusion from clinical care:

"I've done a lot of work with community mental health teams I see them all, very similarly, operating the same type of exclusion processes where these clients can't access the right type of service easily - some do but not many." [CSFG002]

The reasons behind this perceived exclusion were varied, often relating to ideas of clients being 'un-treatable' owing to their apparent lack of response to psychopharmacological agents:

"Historically psychiatrists, because it's not a disorder that responds well to medication, I think therefore, you know, psychiatrists in particular decided it wasn't something that was treatable, so there's no point bringing somebody into hospital for treatment when there isn't any, this is something that is untreatable, so I think that when you're face with, that kind of view with it - there's an issue: I can remember when I first started working here, donkeys' years ago, one of the consultants, who had a position here, like yourself, he often used to say to me - you know it's pointless, PDs, which is you know the pejorative term that we all use, it's pointless bringing them into hospital, prison is the best place to help the people with PD, because they have, you know, behavioural problems and it's best off them being managed in prisons…" [CSFG006]

Perceptions reached beyond these ideas however with some at times accessing discourse reminiscent of media representations of the 'deserving' and 'undeserving' (Valentine & Harris, 2014):

"But then there's the other side of it as well, which is where the, what do you call it, the person is like portraying PD traits, just to come in because they've got

nowhere to live, obviously, and they want their benefits and we've had quite a few

[N - Just abuse the system.] yeah." [CSFG003]

Treatment and the risk of therapeutic nihilism

Many participants framed their approach to treatment and personality disorder in terms of perceived lack of response to psychopharmacological agents, as outlined above, and this fed into understandings of the diagnosis as distinct from other forms of mental disorder, while also challenging the validation that could be achieved through ideas of treatment in response to diagnosis. Others emphasised the primacy of psychological treatments, but also highlighted a constraint on resources, particularly time and training, in this regard:

"Sometimes it may only be, you can only offer a once a month appointment, you know, it's difficult, with the best will in the world it's difficult to build therapeutic rapport, isn't it, when you only see somebody for an hour a month [Interviewer - Absolutely] Yeah, but - It's a difficult one isn't it? There are people you sit and you think, I could do a lot, [Others - General agreement] I could do a lot, in this room, if I had the time to do it…" [CSFG001]

Regardless of treatment options however it was the potential therapeutic relationship between clinician and client that many identified as being most significant for supporting the process of change, but that this was something that services were seen as not adequately configured to recognise and work with:

"…the longer I've gone on the less I am persuaded about the sort of technique if you like of therapy and its applicability to a person. I think this applies to a disorder, a set of beliefs or something and it loses the person and it's why I no

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longer feel I'm a therapist, although I hope I'm therapeutic, so the medium is the relationship with the person, rather than the therapy applied to some part of that person and I know that's an over simplistic thing, but for me that is close to some part of recovery that it's no longer an expert thing that you do to or with someone it's much more complicated, and I don't think we're very, I think statutory services are really struggling..." [CSFG002]

Other clinicians cautioned however regarding the role of 'dependency' within the therapeutic process, which was seen as at risk of removing agency, and the capacity for recovery, from the patient:

"I think as a clinician we should be very clear, about our role, I think sometimes we feel like we end up rescuing someone, because day-to-day job involves treating, or managing, personality disorder and it probably is one of our comfort zone to talk about medication, to talk about other things with a view ok - let's rescue this person here, who's really struggling, so day-to-day things like you end up detaining them, doing rapid tranquilisation, and I know sometimes it's very difficult because we have to manage risk at the same time that is the moment in time when we shift our focus away from recovery, more to an immediate rescuing mode, and I think the clinician should be mindful of that we should foster individual's internal... repairing mechanism I would say, rather than rescuing them, because it creates dependency..." [CSFG005]

<u>The professional relationship and containment of distress</u>

The central role of the therapeutic relationship in the provision of care, with the caution raised regarding the risk of 'dependency', emphasises the importance of understanding the professional's role in work with clients - this relationship was seen as taking an emotional toll on clinicians, a toll that was not readily acknowledged and often even avoided:

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"…there's almost no attempt to provide continuity, it gets reframed as dependency everything's always about getting people out because attachment is seen as being suspect from a boundary point of view, because it's just too difficult, because it means we might actually have emotions about people that we work with, it might be that we actually have real relationships, it might be that we're not entirely different from people that have personality based difficulties it's just that it's too discomforting, so I think that it's just at any number of levels, political and personal and intrapsychic, that there's massive resistance and massive anxiety about this whole area of work…" [CSFG002]

Emotional work on the part of the clinician was seen as complex, being informed by institutional attitudes which were framed as 'pejorative' in their attitude towards the personality disorder diagnoses. There was a recognition that the complexity of this work at times risk interfering with emotional experience outside of the work environment:

"(F: - …it's the nature of the job, isn't it? That you're going to take that stuff on board, that you're going to carry it with you, your own personal coping mechanisms as well outside of work.) [General agreement] N: - I think you have to take care of yourself a bit. You can manage if your home life is manageable, but if your work life and your home life are disrupted then, or you've got extra stresses - I can remember stepping off a course, for 6 months, just because I was dealing with somebody who was describing a lot of traumatic stuff, you know, and it didn't feel as if I could do both at once." [CSFG001]

For some groups clinical supervision was seen as an essential means of managing this process, of allowing reflection and sharing of responsibility. However, such supervision was seen as a constrained resource, increasingly limited with restrictions on professional time and

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other resources. This risked the process of supervision becoming formulaic, not adequately addressing the needed emotional work:

"J:- …I know if I want some supervision I'd go and ask for it, but setting me a supervision date once every three months, or once every two weeks is pointless to me, I'd rather ask for it. (T: - Yeah, especially downstairs I mean we have bitching sessions, 'fucking hell have you heard her', but that's the way I deal with it, if I've had a hard day I swear and fucking run, and I find that more beneficial than sitting down with somebody and them telling me what to do…) J: - But counselling supervision you would look at elements of yourself, when I was in counselling supervision. It would be aspects of myself I'd be looking at, what winds me up about that person, what is it about yourself [laughs] take a look at yourself, what are the triggers. (G: - [Laughs]) So that's how I view proper supervision. (Interviewer - But that's not what's?) J: - No. And it's should be yourself and all that aspect really I think, and I think we should have proper supervision in this environment." [CSFG007]

Finally, in relation to the professional relationship, participants reflected on the impact of external agencies within their working environment and the potential impact this had on their work. This was especially pertinent to those groups working in prison environments where interactions with Uniformed Officers and Governors were seen as representing significant pressure and demand on their time - as they felt they increasingly had to move in order to support the work of these other professionals:

"…take somebody who's chaotic, doesn't know where they stand with life, bring them in here and they see the same faces every day and they establish a boundaried rapport and learn what is and what isn't acceptable… it just works well, it's not perfect, not by a long chalk, you get officers that are far too involved

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and all kinds of weird and wonderful things going on in relationships, but… as a whole prison officers unwittingly manage the bulk of people with a personality disorder, in prison, on a very basic level, i.e. keeping them safe, most of the time…" [CSFG006]

Discussion

Many of the aspects of the recovery process outlined by participants overlapped significantly with the conceptualisation with frameworks outlined in the wider academic literature (for example Leamy et al., 2011). This was particularly apparent in relation to the process of sense making, or identity work, undertaken by individuals. Identity work can be seen as a form of 'sentimental work' conducted between clinicians and service users (Strauss et al., 1982). That is, an incorporation of the understanding of concepts of 'illness' or 'disorder' into one's sense of self (Adams et al., 1997; Corbin & Strauss, 1985). Diagnosis, in this process, was seen as taking on a symbolic role with the power to convey a degree of normalisation in relation to experience.

In common with findings from other studies focus group participants reported a complexity in the manner in which the diagnosis of personality disorder was understood (Bonnington & Rose, 2014; Jones & Wright, 2015; Lewis & Appleby, 1988). This involved varying staff conceptualisations of the nature of personality disorder and also the perceived impact of working with such clients on the professionals themselves. Clinical supervision was seen as necessary to address this issue - but this was viewed as a restricted resource within services. The impact of unmet emotional need led to an alienation of clinical staff towards their clients – resulting in the potential exclusion of individuals from care on the basis of their 'un-treatability' (Sulzer, 2015b) or their 'incorrigibility' (p139 Pilgrim & McCranie, 2013). In this manner any

ideas of hope for recovery accessed through diagnosis risk being diminished through ideas of therapeutic nihilism.

Finally - a perceived restriction on available resources, specifically time and psychotherapeutic treatment options, suggested a risk of models of recovery being driven by 'service defined recovery', defined by the limitations of service provision (Le Boutillier et al., 2014; 2015).

Limitations

A strength of the reported study lies in its efforts to explore the experiences of clinical staff working in a variety of institutional settings. However, restriction on the recruitment of practicing teams for practical reasons, such as availability of participants, may indicate that participants consenting to give up their time may not be representative of wider practice within mental health services. The overlap of findings with pre-existing literature speaks somewhat against this limitation.

Focus groups were conducted by an individual researcher who took on the role of group conductor. While interactions between participants were noted and attention was directed, where feasible and appropriate, to address these interactions it is possible that some elements of interaction may not have been captured through this process. Additionally the researcher's role as a psychiatrist was known to all focus group participants which in turn may have influenced the nature of the information generated (Chew-Graham et al., 2002; Coar & Sim, 2006). Such issues were addressed during supervisory discussions with the remaining members of the research team and a close coding strategy to identify such points of reflexivity has been utilised; this approach demonstrated that while participants did acknowledge the researcher's

role there was no apparent evidence of altered discourse, or quieting of critique, in response to this knowledge.

Conclusion

The most significant findings from the current study is the manner in which lack of clarity around professional conceptualisations of personality disorder jeopardise the negotiation of understanding between professionals and service users – imperilling any act of recovery. From a research perspective the negotiated nature of the recovery process requires greater understanding with regard to understanding the manner in which it is enacted in varying institutional settings. Observations studies, drawing on ethnographic understanding, represent one potential means through which greater knowledge may be developed (Pilgrim, 2009).

From a clinical perspective it is apparent that clinicians occupy a powerful role in their ability to support, or restrict, the process of recovery. Working with individuals with disordered attachment experience, as is the case for many personality disordered individuals, is challenging (Adshead, 1998; Whittle, 1997) and close clinical supervision is indicated. The identification of such supervision as a restricted resource risks inadequate acknowledgement of the emotional labour (Strauss et al., 1982) involved in clinical care. Further training and adequate supervision would seem necessary to clarify the role of professionals within a recovery oriented care framework, while acknowledging the emotional demand of such work.

Chapter 7 - Identity work and 'personal recovery' in mental disorder – considering the case of personality disorder

Andrew Shepherd, Jenny Shaw and Caroline Sanders

Abstract

Enabling 'personal recovery' in relation to mental disorder is commonly presented as an aim for mental health services. Varying definitions of the concept are presented, and often held in distinction from traditional notions of 'cure'. A common factor seems to be the process of identity work undertaken in the face of distress. However, little research has been conducted to consider the manner in which such identity work is conducted in relation to contested understandings of mental disorder. The current report seeks to better understand this concept through considering the case example of 'personality disorder'. Semi-structured interviews were conducted in a variety of institutional settings. The process of recovery was revealed to consist of a shifting understanding of 'self' versus 'disordered self' with individuals seeking to represent themselves as legitimate moral agents within a framework understanding relating to concepts of mental disorder. The findings from this study suggest that recovery can be viewed as a performative act of identity construction through which the individual projects an understanding of their sense of self in relation to concepts of mental disorder. This process can be restricted by the actions of professional

agents however, imperilling the development of a legitimate sense of personal identity.

Background

Modern mental health practice is increasingly framed as being focussed on a 'personal recovery' orientation to care (Department of Health, UK, 2011). The concept of recovery takes on a particular meaning in mental health that is distinct from notions of 'cure'. For example, Davidson and Roe (2007) describe 'recovery *from*' in contrast to 'recovery *in* serious mental illness' [emphasis added]. The most commonly cited definition of recovery is drawn from the work of Anthony "…*a way of living a satisfying, hopeful, and contributing life even with limitations caused by illness*…" (p527 Anthony, 1993). This definition's focus on the '*limitations caused by illness*' risks distancing it from the work of 'psychiatric survivors' who, in critiquing the role of psychiatric care, emphasise the risk of de-humanisation inherent in the diagnostic act (Deegan, 1990) and instead shift the emphasis of the process as being one that is a "vocation of becoming more deeply, more fully human" (p92 Deegan, 1996).

Consensus with regard to the understanding of recovery has been sought through the systematic review of published literature (Leamy et al., 2011), highlighting themes such as connectedness, hope, identity, meaning, empowerment and spirituality. Interventions, arising from developed framework understanding, have been produced to allow the delivery of recovery focussed care (Slade, Bird, Le Boutillier, et al., 2015b). Despite these developments the core understanding of recovery remains uncertain - with different healthcare agents adopting varying positions (Le Boutillier et al., 2014; 2015). This complexity challenges

the implementation of any change to clinical care models (Pilgrim, 2008).

Personal recovery as identity work

Themes outlined by Leamy and colleagues (2011) articulate around a central concept of *identity* - suggesting an overlap between the concept of 'recovery' and that of *'identity work'*, a form of emotional labour conducted in the face of disruptive illness experience (Adams et al., 1997; Bury, 1982; Strauss et al., 1982).

Illness narratives represent one means of seeking to understand the manner in which people make sense of physical or emotional distress; a representation of the intra and interpersonal negotiation of understanding conducted in the face of an illness experience (G. Williams, 1984). Recognition of this process is seen as being of importance to clinical practitioners in allowing them to consider their role and impact on this sense-making work (Greenhalgh & Hurwitz, 1999), underlining the role of professionals in this emotional labour - as originally described by Strauss (1982).

Different typologies have been proposed in relation to the nature and content of illness narratives. For example, Frank (2013) outlines three classifications of narrative, which he sees as representing a means of drawing attention to the experience of the 'wounded storyteller' and their moral duty to offer 'testimony' in relation to their experience: Restitution narratives, described as the combined individual and social desire for the return of health, can be seen as close in meaning to many descriptions of recovery in mental health. In contrast survivor narratives can be seen as closer to Frank's description of the quest narrative - which "meet suffering head on; they accept illness and seek

to *use* it" (p115 ibid). Chaos narratives, distinct from both restitution and quest accounts, are characterised by their absence of narrative order; they are not a 'proper' story (p97 ibid). Frank's typology is grounded in the experience of individuals diagnosed with cancer; the applicability of such forms to the recovery narratives of individuals experiencing mental distress is therefore uncertain.

The development of illness narratives involves an intimate interaction between understandings of both personal and social self, together with the development of 'legitimate' representations of suffering (Broom et al., 2015). Narratives can therefore be seen as strategic, or performative, in their representation of the individual (Riessman, 1990). Such performance illustrates the interplay between actor and audience and also raises the question: - in what manner do such narratives represent claims to truth (Bury, 2001)? The complexity of such interactions imply that "*…links between chronic illness and self-identity are neither self-evident or unproblematic.*" (p281 ibid)

Development of narrative understanding in mental disorder has been proposed as being intimately linked to the development of a 'therapeutic process' (J. M. Adler & McAdams, 2007). Although such readings of narrative should not be viewed as un-complicated, given the difficulties outlined by Bury (2001) and others, as the relationship between performative and experienced notions of health can be seen as highly complex (S. J. Williams, 1998).

<u>The case of 'personality disorder'</u>

Survivor narratives, for example in relation to cancer experiences, can be seen as representative of efforts to deal with changes to one's 'pre-existing' sense of self. In the context of mental disorder however this demarcation is not so clear cut - particularly in the case of a diagnosis such as 'personality disorder' where ideas of the onset of disordered experience become problematic.

Debate continues as to the precise nature of 'what is disordered' in personality disorder (for example Livesley, 2011; Millon, 2016) and this uncertainty is represented by failed attempts at reform in diagnostic systems (Frances & Nardo, 2013) as well as proposed changes to future systems (Tyrer et al., 2015). At present however personality disorder is presented as '…*enduring behaviour patterns, manifesting as inflexible responses to a broad range of personal and social situations*…' (F60-69 Organisation, 2010). Such experiences are seen as having their onset in genetic heritability, childhood temperament and life experience and as being manifest from childhood or adolescence (Newton-Howes et al., 2015a).

Prevalence claims from epidemiological studies vary between 4-15% (Coid et al., 2006; Torgersen & Kringlen, 2001; Weissman, 1993) and wide variation in prevalence is noted in different institutional settings - with claimed prevalence reaching approximately two-thirds in populations of sentenced-male-prisoners (Fazel & Danesh, 2002).

Such variation in prevalence represents one form of the myriad of critiques levelled at the personality disorder diagnoses, described by some as being inherently 'moral' in nature in their labelling of 'undesirable' traits in individuals (Charland, 2006; Pearce, 2011). Other

critiques point to the high level of female survivors of abuse diagnosed in this manner, arguing that the diagnosis represents a means of silencing female narrative (Shaw & Proctor, 2005).

Notwithstanding this uncertainty the personality disorder diagnosis continues to be applied to large numbers of individuals experiencing significant mental distress and seeking support from mental health care professionals. As such understandings of 'recovery' for this group are important, yet little research has been conducted to explore their lived experience (Shepherd, Sanders, Doyle, & Shaw, 2016b). Returning to the concept of identity work as it applies to recovery the question arises as to how this work will be enacted by individual's diagnosed in this manner? This becomes particularly pertinent for those accessing care in forensic institutional settings, given the 'double' stigma that may be applied to them under the label of being a 'mentally disordered offender' (Edwards, 2000). Such stigma can be felt as a pressure for normalisation by individuals (Whitley & Denise Campbell, 2014) and will have an effect on the recovery process. Exploration of the lived experience of individuals with a personality disorder diagnosis therefore becomes highly pertinent as a case study allowing development of understanding into the process of identity work and personal recovery in response to mental disorder.

Methods

Given this background contextual framework the current study sought to further explore the concept of personal recovery through considering the enactment of identity work undertaken by individuals who have received a personality disorder diagnosis and accessed mental health care in either community, prison or secure hospital settings.

Participants were recruited from National Health Service and prison settings in the North of England. Ethical approval was granted for the study by the National Research Ethics Service East of England - Essex (14/EE/0029). Prison access was granted by the National Offender Management Service National Research Committee (2013-282) and through discussion with local Governors in individual prisons.

Interview process

Participants were identified on the basis of their having received a personality disorder diagnosis and accessed care within either a community (community mental health team, psychological service or hospital) or forensic (prison, secure hospital, probation approved accommodation) setting. A purposive sampling strategy was employed with participants sought on the basis of gender, age, length of contact with the mental health services as well as setting in which clinical care was accessed. Interviews were conducted in a clinical setting of the participants choosing, with the exception of those receiving care in hospital or currently serving a prison sentence where an appropriate meeting room was selected within the institution. A semi-structured interview schedule was produced, but this was used only sparingly; instead an open questioning style was used to elicit participant response and follow up questions were used to allow the participant to offer a personal account of their experience.

Recruitment and initial analysis of interview material were conducted in parallel in order that recruitment could be informed by emergent analytic themes. This process continued until saturation was reached - defined by the emergence of no novel themes, identified in reflective

journal entries, over the course of sequential interviews. Owing to the wide variation in experience and clinical settings a large sample, comprising 41 total participants, was recruited (20 in community settings, 21 in forensic). Community participants were drawn from community mental health team client lists and in-patient ward settings. Forensic participants were similarly drawn from community mental health teams (servicing probation approved accommodation settings) but also secure hospitals and prisons. The majority of the participants were women (n=28) and the average age of the participants was 36 years. Interviews lasted 53 minutes on average. Participants were not ethnically diverse, with most being White.

Analysis

The overall analytical strategy was thematic in nature - seeking to identify the manner in which participants represented their experience and made sense of their 'recovery'. A situational constructivist approach was adopted (Madill et al., 2000) where interviews were viewed as a joint process of construction between the researcher and participant (Ben-Ari & Enosh, 2013).

The analysis process began with the writing of reflexive journals following interview encounters (Malacrida, 2007). In these journals emergent themes from discussion were recorded alongside commentaries describing the researcher's personal emotional response to interviews. Journal entries from individual interviews were used to guide the recruitment process and to define saturation, as described above. The second phase of analysis involved the transcription of audio recordings by the first author. Memo writing was employed at this stage in the analysis to begin to capture emergent themes, alongside those

recorded in reflective journals (Wengraf, 2001). Transcripts were then coded so as to fragment the information and allow horizontal comparison between transcripts. Thick vertical descriptions of interviews were also maintained through the use of reflective journal entries and the development of 'pen portraits' (Hollway & Jefferson, 2012) - in this manner the coherence of interview material was maintained, with particular attention paid to points of tension within the emergent discourse. This vertical analytical method was used in a complementary fashion alongside the horizontal coding strategy, with the intention of offsetting the fragmentary aspect of the coding approach. Emergent themes were combined into schematic diagrams, or representations, which allowed their respective dispositions to be considered in a process of conceptual mapping (Attride-Stirling, 2001). Writing in response to themes was incorporated into the analysis drawing together the preceding analytic steps into a representation of the final overarching concepts as they emerged (A. Coffey & Atkinson, 1996b).

The second and third authors were involved in the development of emergent themes through a process of discussion of transcripts during supervisory meetings. The interdisciplinary nature of the research team allowed different understandings to be considered in relation to the analysis process. A service user advisory group was recruited at the outset of the research process and was consulted in relation to the development of interview schedules and the consideration of emergent themes.

In keeping with a constructivist ontological and epistemological approach the role of reflexivity is considered in the interaction between the researcher, participant and phenomena of interest (Enosh & Ben-Ari, 2016). The first author works clinically as a psychiatrist, employing a psychoanalytic model of understanding in relation to the experience of mental distress (Gabbard, 2014). Remaining authors are drawn from a background of medical sociology (CS) and clinical psychiatry (JS). The researcher's role as psychiatrist was known to interview participants - the impact of this knowledge, and the inherent power relationship, on the dynamics of the research encounter was considered through adopting an alternative coding strategy focussing on the exploration of this interaction - the findings from which are considered in detail in an accompanying paper.

Findings

Emergent themes from the interview process can be seen as centred on the construction of representations of 'self' - versus 'disordered self' and the implications of these representations in terms of the individual's identity as a legitimate moral agent. Three core themes emerged in relation to this process: Embodiment of emotional distress, Developing social understanding and contextualisation, Diagnosis as potential understanding. Development of ideas relating to hope for the future can be seen as intimately linked with each of these themes. Themes are presented below, together with illustrative quotations and contextual descriptions to situate this material in relation to the participants' experience. Illustrative excerpts are selected on the basis of their thickness of description, counterfactual illustrations representing

different approaches to understanding are also presented throughout. Pseudonyms are used to represent participants.

Embodiment of emotional distress

For most participants their experience of emotional distress was impossible to articulate verbally. They were overwhelmed with feeling and left desperate for help and support. For some this experience was externalised through the use of violence against others. Jeremy was held on community license in relation to an assault charge and described episodes of emotional distress that led to a complete fragmentation of his sense of self, to which he would respond by articulating several distinct personal identities that he recognised within himself. Each of these identities, with their own name, was recognised as a constituent part of him, but the thought of their combining into a unified whole left him uncomfortable:

"(Int:… when would Leon be your main personality?) If I was extremely annoyed, extremely, not angry, but pissed off and I push past that point, you know, when I'm getting really stressed and stuff it's a lot easier for him to take control… (…that personality, is taking over from Jeremy?) he comes to the front, I can still see, I can still feel everything, I can still see all the movements - but it's not me making the movements, I'm in the background…"

"In an ideal world I'd like to all just smush it all together and then plonk it down on the table and start moulding… (Int: …You said in an ideal world, so is that something you would like to do?) That's a good question, yes and no, yes because you know I think that would be quite good, but no because if I didn't have the separate personalities as they are and it all got pushed into one then, you know,

your moods going to be all over the place, for one. Two, could become an

extremely violent person..."

For the majority of participants however emotional experience was felt as trapped internally and in need of some form of expression. For Clare acts of self-harm came to represent a form of relief, an indication of her need to take care of herself. As a young child Clare described struggling to emerge from the shadow of her older brothers. Ultimately it would be her emotional distress, emerging following being the victim of a sexual assault at the age of fourteen, which she saw as differentiating her. The feelings of protection this engendered in her parents were experienced as smothering however and she would later find herself trapped within her family home and infantilised by their actions:

"(Int: How are you an individual now, what have you found in yourself?) It's difficult because I sometimes feel like my illness has kind of defined who I am, I'm just like... the one who's got all the problems and I've not really found who I am yet..."

"...to me it just felt like, everything did stop, and it just felt like a relief really. (Int: A relief of what?) Stopping all the pressure building up inside me and all the emotions that I didn't know what to do with... I didn't know how to express them in other ways, so by self-harming it kind of released those emotions and I guess in a way I was able to, after I'd done it, sort of take care of myself, in a way, in a way that I would normally never do."

For David, a young man on community license following his conviction for a firearms related offence, self-harm similarly came to represent a release of emotion - however there was also an element of memory in his

acts whereby he would trace scars and recall incidents that had preceded each act:

"When you do it it's like [sighs] and you look at it and it's like your frustration, and your anger, it comes out and you carry on and you carry on 'till you get to that point where, right, that's alright… I look at it and it's like every cut is like… that's for what happened there, that's for what happened with that, that's for what happened with that…"

Many participants who engaged self-harm experienced themselves as being rejected by clinical services in relation to these acts. For example, Blake, having begun to work on a mental health ward in a support capacity, commented on the differing reactions between professionals and service users in response to his scars:

"That's an attitude I've come across with some staff, not all of them, that's the kind of feeling I get and you know it's the kind of thing that you've got no idea that one of your colleagues, that you're working with, that you think quite highly of… I just say it was a long time ago and I'm better now and the other thing is that there have been a few patients that've commented on it, and that's been ok, and without delving into why I did that, or asking them about…"

Self-harm and acts of violence therefore came to represent an articulation of emotional distress a communication both to the individual, and to others around them. This process has been described as being an act of emotion work (Chandler, 2012), and the social aspect of this ritual communication has often been overlooked in the clinical literature (Chandler, Myers, & Platt, 2011). In this context the embodiment of distress, and its expression through self-harm or

violence, grounds the sense of personal identity and complicates its communication to others, and to the self, through intelligible means.

Developing Social Understanding and Contextualisation

The idea of social understanding in relation to experience could be seen as directly impacting on each process and theme discussed by participants. These background social frameworks were initially established in early childhood and adolescence through the individual's interactions within family dynamics. In later adolescence and adult life these frameworks expanded further to include peer groups or other adult relationships. Many participants however described a disjunction in this experience - with their family dynamic being characterised by separation, loss or violence. For example, Karla - a fifty year old woman had made contact with the mental health services in relation to acts of self-harm and efforts to end her life - described how as a child she struggled to place herself within her family and how her mother would frame her acts in this context as a form of illness, eventually taking her for psychiatric assessment:

"…I didn't like having my photograph taken, on family photos, I used to cringe, I hate it I don't want to be on this picture, I used to hide away… (Int: Why was that do you think?) Because I didn't belong to them… I used to have thoughts - Oh I've got a nice mum and dad, she's not even my mum, she's not fit to be a mother… I wonder if she left me on a doorstep, she's picked me up all these thoughts and dreams and nightmares this longing of, you know, of the perfect family…"

"…I rebelled at fourteen anyway… my mother, at fourteen, took me to, my memory of it, I didn't know it was classed as a psychiatrist, I thought it was a

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doctor, because she said there was something not right about me… this guy had a
white coat on and he asked me did I want to talk about any problems and I said
that I hadn't got any problems, I don't know why my mother's put me here…"

This sense of displacement from her family was initially framed as
"*something not right*" through interaction with her mother - the
introduction of psychiatric assessment shifted this understanding into a
pathological domain. As an adult reflecting on her experience of 'illness'
Karla commented in relation to her diagnosis of personality disorder:

"…I've been like this through childhood. So it answers a lot of questions for me -
that I wasn't naughty I was ill and that's what it means, and coming to terms
with everything and being happy with life."

Her recovery is then presented in the form of a restitution narrative -
she overcome this experience and developed a sense of herself as valued
in her family and professional roles - a 'fighter':

"(Int: Is there a point when you will say 'I'm better', 'I'm no longer ill'?) There
is… after I had the counselling I remember going back to work, on a part time
basis, I worked on a helpline for disabled children you can imagine I was getting
all the doom and gloom… But I was good at what I did, everybody said you are
great at what you do, that's you the fighter… If I'm not fighting, a cause, then I
sulk, if I'm not fighting for somebody."

The hopes participants described in their future were clearly varied -
but most identified specific social roles that they hoped to occupy, such
as valued family positions or occupational roles. Such narratives
mirrored the restitution narratives described relation to hope for
recovery in chronic physical illness conditions (Ezzy, 2000; B. Smith &

Sparkes, 2005). There were also those whose experiences were too disjointed, where the future was unimaginable - linking with Frank's (2013) conceptualisation of the 'Chaos Narrative': For example, Sian was a young woman who conceptualised her difficulties as emerging following the death of her father and neglectful care from her mother. She was serving a prison sentence in relation to aggravated assault on another young woman:

"(Int: What do you hope for?) To be normal… I wouldn't hear voices, I wouldn't be in prison, I wouldn't have all these scars, I wouldn't have none of them, and I'd just, when I'm, when I'm upset I'd just have a cry and then that would be it… (But you have a chance to turn it round?) I don't I've fucked it up - who wants to employ somebody that'll flip out and stab somebody, who wants to employ a loop-e-doop that tries killing themselves every five fucking minutes - I wouldn't want to employ me…"

Others spoke of being constrained by their personal social networks. Samantha, who was serving a prison sentence in relation to a charge of assault, spoke of how she felt that her sense of herself outside of prison was restricted by the expectations of others, she therefore saw her identity as constrained - forced into being that of a 'violent person'. Prison was seen as paradoxically liberating in that it separated her from these previous social groups:

"…I'm worried about going home, because people will remember psycho-Samantha, people will remember the Samantha who didn't give a shit… the Samantha who'd do anything for anyone… I'm not that Samantha no more… I've really changed and I'm worried about if they'd let me be this person…"

Accounts of identity and hoped for change can therefore be seen as directly rooted in individual experience yet also as serving a performative function - allowing the individual to develop a sense of themselves that can be tested in various social settings. In Samantha's case this test will come on her release from prison and she is uncertain as to how this will play out. Identity is seen as needing to be acceptable not only to the individual, but also to other agents within social networks. In this regard there is overlap with the descriptions of individuals with physical health conditions - for example Broom and colleagues (2015) address the experiences of women living with chronic pain who similarly raise concerns regarding the legitimacy of their experience in relation to their personal social networks (Broom et al., 2015). Fullagar and O'Brien (2014) similarly describe the impact of social milieu on the experience of middle-aged women suffering from depression. Wider social discourse influences experience in relation to the 'cancer survivor' as well, a label rejected as inappropriate by many (Kaiser, 2008). For ex-offenders a complex social discourse emerges in relation to their offender identity and the manner in which this interacts with conceptualisations of mental illness that can be seen as forcing any attempt at identity construction.

Diagnosis as potential for understanding

Faced with overwhelming emotional distress, which they struggled to articulate, and the need to develop a form of performative identity participants sought a means of capturing their experience in a symbolic manner that could be adequately conveyed to others. Most chose to articulate this understanding within a framework of 'mental illness' and 'diagnosis'.

Representations of diagnosis for participants carried highly significant meanings, which allowed them to address issues relating to the perceived moral nature of their acts. For Alice, a middle-aged woman who accessed community mental health care, her difficulties began following the death of her mother but only came to a head following a period of ill physical health in her thirties. She had attempted to end her life numerous times and carried a noose of rope in her bag as reassurance that she could kill herself at any time she chose. Alice articulated a highly intellectualised idea of 'illness', and at times struggled to wed this with her own experience:

"...if I don't believe that I'm ill, if I can't believe that this is an illness, and even personality disorder, if I can't believe it's an illness then it makes it even worse. Because it makes it that, I'm doing this to myself. That for some reason I can't control the way I feel and if it's not an illness then, then I'm a really, really seriously bad person."

Accepting the personality disorder diagnosis allowed Alice to address this moral concern, arguing that her behaviour is emptied of its moral significance when labelled as disordered (Scott, 1973a; 1973b). Those who accepted the diagnosis were able to access a form of restitution narrative - accompanied by feelings of hope for recovery with the aid of psychological and psychopharmacological treatment. Many participants however experienced their conceptualisation of themselves as 'ill' as being resisted by clinical professionals - who, in some cases, were seen as dismissive, or as withholding needed treatment. David experienced this form of rejection in his care:

"I got the understanding that people don't trust it [diagnosis] , or they say it's a cop out, but I don't care about it, I know I'm ill, I know the things I've done, I know I wouldn't be in this service if there was nothing wrong with me…"

In this manner David's experience of rejecting clinical care led him to resist the threatened act of 'de-medicalisation' (Sulzer, 2015b) which imperilled his efforts at developing a stable self-representation.

A significant minority of participants responded to the process of diagnosis with an act of resistance - challenging it as incorrect, a 'misdiagnosis', which resulted in their receiving inadequate, or incorrect, treatment. Nancy spoke about arguments with her psychiatrist where she had challenged the diagnosis:

"…maybe I have got borderline personality disorder, maybe I have got bipolar, but I want to know for certain and he said that, it's not, headaches is not a symptom of bipolar and if I'm going to read stuff I should read the right stuff… (Int: what is the role of diagnosis then - because you said you wanted to get it right?) I'd get the right treatment, I don't know, I just want them to to get me better…"

A smaller minority of participants, all accessing care within forensic institutions, refuted the diagnosis of personality disorder as incorrect. Khalid, a young man interviewed in secure hospital, had spent much of his prison sentence in hospital and expressed anger in relation to his personality disorder diagnosis and the manner in which he perceived a diagnosis such as schizophrenia (which he believed would have allowed him to avoid conviction at criminal trial) was being withheld:

"(Int: What does that idea of a personality disorder mean to you?) Doesn't really mean much to me, to tell you the truth, just a made up name given by doctors, just to accomplish their type of ways where people they don't think behave in a way they want them to behave… (So it's an idea that you reject?) I reject it, but I have to accept it in order to make progress and I'm being truthful now, I'm just going on with it saying whatever, you think that I've got it I'll work with it… now my doctors saying you should have had diminished responsibility… but during my appeal [Doctor], who is my doctor, and [Second Doctor], who was the junior doctor, said [Khalid] did, nothing is wrong with [Khalid] and he acted like an average person would act, in that situation… after all these years, they're saying I'm mentally ill, I need to be on medication, I'm saying - hold on a minute [Doctor] clearly said nothing's wrong with me, I would not act differently from an average person, so why do you want me on medication, I do not need medication…"

For some therefore the concept of diagnosis was a valuable means of organising their sense of identity and orientating with notions of 'recovery as cure'. For others however the diagnosis was experienced as a rejection from professionals, as inaccurate, or as a 'cultural construction' that simply represented 'bad behaviour'.

Discussion

Through the findings presented in this paper have sought to represent the act of identity work enacted by individuals in relation to a diagnosis of personality disorder and the concept of recovery. The process was developed on a background of significant personal trauma, overwhelming emotional experience and its expression, for many, through acts of self-harm or, more rarely, violence. In this manner self-harm came to represent an embodied act of emotional work (Chandler,

2012) with violence possibly fulfilling a similar function (Logan & Johnstone, 2010; Robinson & Gadd, 2016). Such acts are complex in their impact on the individual's social experience (P. A. Adler & Adler, 2007) and risk marginalisation - either indirectly through rejection by others (J. Harris, 2000) or directly through incarceration (Crewe, 2011).

In the face of trauma and marginalisation individuals, in keeping with other forms of disorder (Broom et al., 2015), sought a representation of themselves as 'legitimate'. In articulating this act as an understanding of 'self versus disordered self' through interaction with mental health services the person becomes subject to a 'biopolitical' identity (N. Rose, 2001) that can possibly provide the sought legitimacy. 'Diagnosis' then becomes significant for its functional symbolism (E. Jones, 1918) in conveying ideas of suffering and need for support - treatment and positive therapeutic relationships can be seen as reinforcing this process (Tutter, 2006).

In this manner professional agents are manifest with a significant degree of power in their ability to support or thwart the development of personal legitimacy. Individuals receiving a personality disorder diagnosis are commonly seen as 'difficult', challenging conceptualisations relating to the border between 'health and illness', and risk rejection from clinical professionals (Bonnington & Rose, 2014; Sulzer, 2015a; 2015b) - likely, at least partially, as a result of the intense emotional labour involved in care provision (Adshead, 1998; Watts & Morgan, 1994). Charmaz's (1999) formulation of the moral status of suffering may also be significant here in its identification of the characteristics of 'high moral status' on the basis of emergency medical situations, involuntary onset of distress and the blamelessness of the

sufferer. In contrast chronologically protracted moral claims, with required negotiation of understanding, are seen as possibly leading to the questioning of claims and eventual diminishment of moral status. Uncertainty regarding diagnostic formulation and detrimental clinician attitudes therefore risk derailing the search for legitimacy. Thus, while many of the participants displayed clear use of restitution narrative (Frank, 2013) others saw their agency in this area as curtailed and experienced themselves as marginalised, or overtly controlled by the mental health services - restricting and forcing their access to narrative representation of themselves to one's of resistance, or even more chaotic representations.

Such representations of 'self as moral agent' take on a particular resonance when considered in relation to the experience of those accessing mental health care within forensic institutional settings. These individuals will also have to access a symbolic understanding of 'self as offender' and the interplay between this concept with that of being either a moral agent or being diagnosed as suffering with mental disorder is clearly complex. This was apparent in Khalid's case, as outlined above, as he struggled to come to terms with ideas of accepting or rejecting the diagnosis and offered support.

Overlap can be seen here for forensic participants seeking to make sense of their experience in terms of agency, offending and disorder in comparison with the act, undertaken by those avoiding future crime, of 'abandoning' an offender identity. Maruna (2001) has described the process of 'desistance' from crime, proposing that 'desistance transformation narratives' can be seen as having three distinct components: 1) Good core self 2) Generative Motives 3) Individual agency. The concept of identity work as it applies to recovery in mental

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disorder can be seen as impacting on this process through its impact on both the ideas of 'core self' and 'individual agency'.

A negotiation of legitimacy and understanding is not unique to experiences of mental distress, or personality disorder specifically, and can also be seen in other forms of (dis)ease - for example the covert nature of suffering and need for analgesia in Broom et al's (2015) diary study led to a complex moral negotiation. However, the manifestation of personal distress described by participants in the current study, together with the need to develop an identity capable of resisting enforced alienation from social groups, can perhaps be seen as a particularly complex process of contested negotiation.

Limitations

A strength of the current study relates to the variety of institutional settings from which participants were drawn, complementing previous research which has primarily focussed on experiences within general community settings. Given the claimed prevalence of mental disorder within forensic institutional settings further work is clearly indicated to better explore this space. However, while participants were drawn from a variety of institutional settings it is likely that the use of clinical teams as the primary means of recruitment will have limited the discovery of counter-narratives; given the resistance displayed by some future research studies seeking to identify participants outside of clinical frameworks are necessary.

In utilising only one interview it was intended that minimum disruption and potential distress be inflicted on participants. However, given the dynamic nature of the narrative process described it can be argued that future research will benefit from drawing on repeated interviews

separated over a longitudinal period. The findings in the present study are likely impacted on by the role of the first author as a psychiatrist, of which all participants were aware. Reference was made to participants in relation to the author's role and as such the performative nature of the emergent narrative will have been affected. The likely impact of this power dynamic is discussed in greater detail in a further paper.

Finally, it is known that participants from different cultural backgrounds access understanding of mental distress in varying ways, additionally cultural variations and biases are apparent in the diagnosis of personality disorder (McGilloway et al., 2010; Mikton & Grounds, 2007). As the majority of participants in the current study were white - further research is necessary to explore the impact of different cultural experience in relation to this group of individuals.

Conclusion

In keeping with other forms of identity work the process of personal recovery can be seen as an act of developing negotiated legitimacy for the individual sense of self. Further research, including observational methods (Pilgrim, 2009), is necessary to better understand the manner in which this process is enacted within clinical interactions. Improved understanding in this area is important as there is a risk that the interruption of this process may lead to lasting personal distress and suffering for a significant proportion of individuals seeking clinical care and support. The performative social aspect of personal recovery is also significant for its emphasis on the role of community and the possibility of providing a 'space' where suffering can be adequately met and responded to.

Chapter 8 - Psychiatrist as qualitative researcher: Reflexive issues arising from an individual interview study with mental health service user participants

Andrew Shepherd, Jenny Shaw and Caroline Sanders

Abstract

Qualitative research methods are of use in the exploration of areas of problematic understanding within mental health practice. Understanding of issues of power and inter-personal relationships are important in both psychiatric practice and qualitative research. Despite this, little conducted research reports on the reflexive positioning of clinician researchers in relation to their study, in particular no studies specifically address the role of psychiatrist as qualitative researcher. The current report seeks to illustrate potential reflexive issues emerging for the psychiatrist as researcher in relation to the study of mental distress, through considering the example of a study examining the lived experiences of personal recovery in personality disorder. Specific reflections are drawn out relating to the ethics of such research, the clinician's insider / outsider status and the blurring of clinical and academic roles. The findings illustrate the importance of consideration of power dynamics within research encounters.

Introduction

Writing more than 100 years ago, Karl Jaspers described psychiatry as a 'hybrid discipline', one that must address two specific aims: - The description and observation of patterns of behaviour (erklären) as well as the exploration of meaning making and signification within behaviour (verstehen) (Jaspers, 1997). In modern psychiatry, as disputes over the application of diagnostic systems continue (Frances & Nardo, 2013; Insel et al., 2010), Jaspers' description remains highly pertinent to clinical practice (de Leon, 2014). Modern mental health services increasingly emphasise the importance of concepts such as 'personal recovery' which are seen as distinct from traditional notions of 'cure' in relation to illness, instead emphasising a sharing of understanding between patient and practitioner (Anthony, 1993; Department of Health, UK, 2011). Such statements are reminiscent of long standing calls for 'patient centred medicine', focussing on personal experience over concepts of illness orientated medicine (Balint, 1969). The sharing of power and decision making responsibility within mental health practice is complex however (Seale, Chaplin, Lelliott, & Quirk, 2006; Shepherd et al., 2014) and longstanding practices and perspectives of psychiatric 'illness' and its treatment remain pertinent (Pilgrim & Rogers, 2009; Rogers et al., 1998).

With this background framework the ability of qualitative methodological approaches to develop understanding that is grounded firmly in individual experience (Charmaz, 1990) would suggest that such studies are of essential importance to the understanding of mental health practice and its enactment (Pilgrim, 2009). However, despite an increasing recognition of the importance of qualitative enquiry being outlined within mainstream biomedical literature (Pope, 2009; Pope & Mays, 1993) and calls for more research to address perceived deficits in

the current research evidence base (Greenhalgh, Howick, Maskrey, for the Evidence Based Medicine Renaissance Group, 2014), qualitative research appears to remain relatively marginalised within psychiatric practice (Crawford, Ghosh, & Keen, 2003). Recent systematic review findings suggest that little has changed since Crawford et al's paper (2003) with publication of qualitative findings remaining rare within mental health practice (Shepherd, Doyle, Sanders, & Shaw, 2016a); possibly representative of resistance to the publication of such research within many biomedical journals (Greenhalgh et al., 2016).

Despite these limitations calls persist for a greater presence of qualitative research within medical research (Noyes, 2010) and also within psychiatric practice (Brown & Lloyd, 2001). Methodological accounts of the practice of such research have therefore been published in high impact biomedical journals (Pope & Ziebland, 2000). Alongside these publications there has also been an increase in the number of papers addressing the appraisal of qualitative studies (Kuper & Lingard, 2008) as well as checklists to enhance the 'rigour' of reporting and critique (Hannes, Lockwood, & Pearson, 2010; Tong et al., 2012; Tong, Sainsbury, & Craig, 2007) - although caution has also been raised regarding the use of checklist approaches (Barbour, 2001). Within these 'quality statement' guidance papers issues of reflexivity are commonly presented as being a means of recognising the inability to 'completely avoid personal bias…' (p351 Tong et al., 2007) and that through the reporting of factors such as occupation, gender and training the 'credibility' of findings can be transparently enhanced and communicated.

Such claims of credibility and the avoidance of bias's may imply a realist approach to empirical study - wherein the objective nature of

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phenomena may be determined. Through a process of reflexive consideration it should be possible for the researcher to 'bracket' their findings - that is to engage in *'a scientific process where a researcher suspends or holds in abeyance his or her presuppositions, biases, assumptions, theories, or previous experiences to see and describe the essence of a specific phenomenon'* (p63 Given, 2008). Beyond this idea of bracketing however issues of reflexivity can be seen as having a far wider impact on the conduct of research - representing intimate negotiations of power balance between participants in the research process (Enosh & Ben-Ari, 2016) and a conscious form of 'work' to be conducted as part of the project that needs to be presented transparently to inform any subsequent reading (Mauthner & Doucet, 2003). With its particular attention to the social positioning of the researcher, or research team, and their relationship to the research process the concept of reflexivity can be seen as having some overlap with the ideas espoused in psychoanalytic theories of psychic life - wherein individuals are seen as having an unconscious life, formed through early life experience, that may manifest in the form of distress, conflict and symptom at a later stage in the individual's life (Bateman et al., 2010), with the impact of the clinician's own psychic experience being represented in the 'countertransference' generated in clinical encounters. Commentators have begun to approach this possible site of interaction, seeking to gain analytic traction in this recognition (Hollway & Jefferson, 2012; Midgley, 2006).

Issues of reflexivity also become particularly apparent in considering research relating to areas of 'sensitive' enquiry (Cowles, 1988), with calls for attention to be paid not only to the need of research participants but also to the potential impact on researchers themselves (B. Johnson & Clarke, 2003). Studies within healthcare settings will almost universally represent an investigation into sensitive material and

reflexivity therefore becomes particularly pertinent when considering clinical qualitative research. In this regard some attention has been given to the role of the 'clinician as qualitative researcher', particularly within primary care settings where the majority of such clinical qualitative research has been conducted. Specifically considering the role of doctor as researcher attention has been given to the potential impact on the interview process with patient participants (Hoddinott & Pill, 1997; Richards & Emslie, 2000) and medical peers (Chew-Graham et al., 2002; Coar & Sim, 2006). No reported research exists, however, specifically examining the role of psychiatrist as qualitative researcher from a reflexive position.

This absence from the literature is significant as the clinical practice of psychiatrists, despite shared medical training, has historically developed along a different route from other medical practitioners (Scull, 2015). While not exclusively the preserve of psychiatrists public perception does very much invest the role of psychiatrist with the existence, and application, of mental health legal frameworks (Pilgrim & Rogers, 2005). However with the emergence of concepts such as 'personal recovery' the role of the psychiatrist is increasingly emphasised as one which brokers negotiated understanding between clinician and patient (Anthony, 1993). Qualitative research methods are clearly significant to the field of mental health and the role of psychiatrist as qualitative researcher requires exploration.

The current paper therefore seeks to explore the role of psychiatrist as qualitative researcher through considering the example of one study into the experiences of personal recovery described by participants receiving a personality disorder diagnosis and accessing mental health care in either community or forensic (prison, secure hospital or

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probation approved accommodation) settings. This discussion begins with an overview of the methodology employed within the study, before moving on to a review of the manner in which the first author's role as a psychiatrist could be seen as impacting on the research process.

Methodology

The current report draws on findings developed from a larger project with the overall aim of exploring the lived experiences, in terms of 'personal recovery' (Anthony, 1993), described by participants who had received a personality disorder diagnosis and accessed mental health care within either community or forensic (prison and secure hospital) settings. The project represents the research portion of a Doctoral Research Fellowship award funded by the National Institute for Health Research, UK (Reference DRF-2013-06-122). Ethical approval for the project was granted by the National Research Ethics Service Committee East of England Essex (Reference 14/EE/0029). Access to prisons was granted nationally through the National Offender Management Service (NOMS) (Reference 2013-282) and locally through negotiation with individual prison governors.

Findings from the individual interview stage of the project are discussed here; focus group sessions with clinical staff were conducted to explore emergent themes from individual interviews from an alternative perspective. The findings of these focus group meetings are reported elsewhere.

<u>Individual interviews</u>

Participant identification and recruitment

Potential participants were identified, with the aid of local clinical research support networks in the North West of England, on the basis of their having received a personality disorder diagnosis. Participants were approached initially by members of the research support network, or the potential participant's own clinical team, with information relating to the study. Those expressing an interest in taking part were contacted by the lead author and offered an opportunity to discuss the project in detail before a meeting was arranged. At this meeting informed consent for participation was obtained and the interview was conducted. A single interview was used so as to minimise disruption for the participant. Those participants recruited in the community were offered a ten-pound retail voucher by way of thanks for their time; NOMS guidance restricts the use of such measures within prison settings and therefore no participants recruited from within forensic institutions could be offered this.

Participant recruitment was conducted in two principle waves - with community participants (n=20) being recruited before forensic (n=21). An overlap developed between the two recruitment waves, with two participants being recruited from probation approved accommodation settings while still subject to license following criminal conviction. Two participants within the community cohort had experience of accessing care in forensic settings, while most participants in the forensic cohort had also accessed general community care.

Beyond the identification of participants on the basis of diagnosis a theoretical sampling strategy was employed wherein recruitment was directed to allow emergent themes to be addressed in subsequent

interviews. This theoretical sampling was directed through the use of reflexive journal entries written after each interview in which emergent themes from discussion were noted and used to inform recruitment, this process of reflexive journal writing is discussed in greater detail below. Participant recruitment was influenced by factors including; gender, experience of inpatient care, age and length of contact with the mental health services.

Women constituted the majority of the sample (n=23, men n=18), participants ranged in age between 18 and 57 years with the mean age being 36 years. The majority of the recruited participants were White; for the purpose of the current project it is argued that, on the basis of known discrepancies in the diagnosis of personality disorder and access to forensic mental health care among ethnic minority populations (Coid, Kahtan, Gault, & Jarman, 2000; McGilloway et al., 2010; Mikton & Grounds, 2007), as well as different cultural constitutions of the meaning of personal recovery (Leamy et al., 2011), a separate project will be required to address the needs and experiences of ethnic minority groups attracting a diagnosis of personality disorder. It is likely that the recruitment strategy employed may also have led to the exclusion of certain voices from the research project - on the basis of using clinical teams, or research support networks, as mediators and also owing to the clinical role of the first author (Kristensen & Ravn, 2015). The impact of such issues on the nature of the findings obviously cannot be commented on directly in this report but further research is indicated employing alternative recruitment strategies.

Conducting interviews

Meetings between the researcher and participant were opened with an introduction of both parties and the role of the research project, space was then offered for the participant to have any questions arising answered before a consent form was completed and the interview proper began. As discussed below consent was viewed as a dynamic process extending throughout the interview process and any subsequent contact between the researcher and participant. The researcher's role as a psychiatrist was known to all participants - principally through information provided to them during the recruitment process, for example by members of the research support network. During interviews the researcher elected to use their first name as well as stating their role as both psychiatrist and researcher by way of introduction.

A semi-structured interview schedule was developed on the basis of the findings from the initial systematic review and accompanying literature reading. This schedule was intended for use if interview participants indicated discomfort with the free-form interview process and preferred a more directional questioning style. Ultimately, this was not the case for any participant and the schedule was referred to only at the beginning and end of the interview to collect basic demographic information.

Interviews were conducted in the same manner as the clinical interview setup normally used by the first author - specifically with chairs of equal level, set at an angle so as to easily allow eye contact or breaking of such contact. A low lying table was placed slightly off centre between conversation participants with a clock, and recording equipment, clearly visible to both parties. This set-up was achieved for all interviews, including those in prison settings. A chaperone, third party

professional, was available if the participant requested - and three individuals did so. In each case this person was a female member of nursing staff, or research support officer, who sat slightly removed from the principle parties in the interview, behind the researcher and did not participate actively in the interview.

Interviews were recorded on two digital Dictaphone and participant consent was sought for recording being initiated and stopped. Interviews lasted 53 minutes on average (range 13 to 79).

Analysis

A principally thematic approach to analysis was adopted (Madill & Gough, 2008), with a situational constructivist theoretical underpinning being employed. That is, research encounters were viewed as opportunities where participants would present representations of their understanding and experience which would then be developed in a process of joint construction of knowledge through conversation between parties during the interview process (Madill et al., 2000). Continued construction of understanding after the interview process was taken on by discussion within the research team.

Reflexive journal writing

On completion of each interview a reflexive journal entry was made by the first author. In this entry significant themes of discussion in the interview were noted alongside reflections on the interview process itself and the researcher's emotional response to the meeting (Malacrida, 2007). Notes relating to themes of discussion were used to inform future recruitment in an inductive manner. These themes were

also used to define saturation - identified on the basis of no novel themes emerging after a sequence of interviews.

Transcription

The second stage of the analysis process involved the transcription of interview recordings, which was completed by the first author in parallel with the recruitment process. Transcripts were produced so as to represent the conversation between participants but without specific structural elements as would be expected in a discourse analysis approach (Lapadat & Lindsay, 1999). Transcription was viewed as a part of the analysis process, representing an immersion of the researcher in the data (Coffey & Atkinson, 1996b) and allowing analysis to be conducted that began to build on the reflexive journaling process (Bird, 2005). Memos were recorded during the transcription process to inform subsequent analysis (Wengraf, 2001).

Coding

Coding was employed as a strategy to allow fragmentation of the interview transcripts and cross comparison between participants and focus groups in relation to specific codes and themes. The coding strategy sought to build on the initial themes noted within reflexive journal entries and to allow their evolution in light of the more in-depth analysis process. Specific to the current report a coding strategy was also applied to identify incidents in which issues specifically relating to the role of the researcher as a clinician became apparent. Computer software (nVivo for Mac - http://www.qsrinternational.com/product/nvivo-mac) was employed to support the storage and retrieval of the output from the coding process.

Pen portraits

While the coding strategy employed allowed fragmentation and 'horizontal' comparison of interviews. 'Pen portraits' (Hollway & Jefferson, 2012) were employed to allow some form of 'vertical' understanding of the participant as 'psychosocial subject' to be maintained. Thick descriptions of individual interview participants were therefore written, in conjunction with researcher responses recorded in reflexive journals, to maintain this sense of context.

Thematic mapping and writing as conceptualisation

Themes emerging from the coding process were arranged in a two dimensional spatial representation and then manipulated so as to allow their relationships to be considered (Attride-Stirling, 2001). Visual representations of these maps were incorporated alongside descriptive writing of emergent concepts in presentations to the remaining members of the research team.

Research supervision and reflexivity in the analytic process

Members of the research supervisory team (JS and CS) brought experience of varying professional and theoretical backgrounds such that supervision meetings represented multi-disciplinary discussions during which transcripts, coding strategy and descriptive writing were discussed and fed into the analysis process (Barry, Britten, Barber, Bradley, & Stevenson, 1999).

With regard to the preparation of this report particular attention was paid within supervision meetings to the role of reflexivity in the research and analysis process. In this manner issues emerging during the interview process were discussed, while findings emerging from the analysis process relating specifically to researcher role were also

addressed. Such issues were then captured for future consideration through a parallel process of memo writing during supervision meetings as well as during specific analytic stages. A parallel, or 'meta-analytic', process of analysis was therefore adopted to allow the identification of issues of reflexivity. Again descriptive writing was used to capture and illustrate this process.

Findings and Discussion

In terms of the overall findings from the research project a process of identity construction was revealed wherein participants sought to make sense of their experience in the face of extreme levels of personal mental distress and trauma. For many 'diagnosis' served a symbolic role in this process, acting as a means of capturing their experience within a principally medical framework of understanding. However, many participants experienced themselves as excluded from this process by the attitudes and actions of clinicians, who were perceived as adopting a negative attitude towards the diagnosis of personality disorder.

Specific to the issue of reflexivity in the research process three overarching themes emerged, which interacted with each other as well as with the central concept of 'recovery' outlined by participants. These themes were: Informed consent and the ethics of research participation, insider or outsider status, and the blurring of clinical and academic roles. These themes are discussed in greater detail below; illustrative quotations are selected on the basis of their richness of content.

<u>Informed consent and the ethics of research participation</u>

Participation within research projects clearly involves a necessary process of informed consent - wherein participants are invited to consider the risks and benefits of their participation (World Medical Association, 1964). Information provided to potential participants is therefore central to this process in allowing a decision to be reached. Such information was provided to participants in advance of the interview being conducted, additionally participants were given space to ask additional questions relating to the process before interviews commenced. However, during the course of several interviews it became apparent that the participants were seeking some form of additional 'benefit' from their participation that was not in keeping with the dynamic of a research interview. For example, Nancy was a 31-year-old woman who had been left with chronic back pain and reduced mobility, requiring use of a wheelchair, following a suicide attempt. She described an uncertainty in relation to her diagnosis of borderline personality disorder - believing instead that she should be recognised as suffering with bipolar affective disorder. Such differentiation represents a common, challenging, clinical discussion (Bayes et al., 2016) - compounded by differing attitudes of clinicians towards the different diagnoses (Bonnington & Rose, 2014; Dudas, 2014). During the interview Nancy outlined feelings of antagonism towards her psychiatrist - whom she perceived as dismissive of her concerns in relation to her diagnosis. This dynamic, together with her perception of the researcher's potential role as a third party within it, became particularly apparent in the closing stages of the interview:

"(Interviewer - When you were thinking about today was there anything that you thought we'd talk about, or hoped we'd talk about at all?) No… Can you give an opinion on my diagnosis? (I'm afraid that's not why I'm here) I know

that's not why you're here (That would be umm… overstepping my role as a…
I'm sorry I know that feels like I'm pushing you away.) Right. (Well I am
pushing that away… it wouldn't be appropriate for me to comment on that) The
thing is I can, I think they said I could write for a second opinion, can I ask you
to be my second opinion doctor?"

In this excerpt the interviewer's discomfort at this direct request is apparent and an alternative framework for the interview becomes apparent - in that Nancy is seeking support in relation to her opposition of the 'imposed' diagnosis. A careful exploration of her understanding of the role of the interview was then repeated to ensure that given this 'rejection' of her aim by the researcher she was still willing to be involved in the project.

David was held on community license in relation to a firearms offence at the time of his interview. He spoke about his negative experience in relation to a personality disorder diagnosis, and how he perceived his not being 'trusted' by clinical staff - he extended this suspicion to the researcher, but went on to explain one reason for his participation in the research project:

"I'll be honest with you now, I don't trust you, one bit (Interviewer - Why should
you? You've never met me before I'm just a man.) Yeah but in this minute in
time I'm aware of what I'm doing and I've accepted that I'll come and do this.
(What do you hope to gain from this?) Understanding. I mean I'm not being
towards people that like have my care, but my understanding is that you're a lot,
I don't know if this is the right word, but you're a lot higher up than most people
I've dealt with…"

This, unjustified, hierarchical positioning of the researcher again frames the purpose of the interview in a different manner and necessitates an exploration of the purpose of the project, and David's continued willingness for participation.

Participant expectations in relation to the potential role of the psychiatrist researcher within the encounter therefore apparently lay outside of the parameters outlined by the information provided at the outset of the project. This act by participants is unsurprising, particularly given the central concept of legitimacy in relation to diagnosis and the perceived precariousness of the personality disorder diagnosis, but represented a radical shift in power within the interview dynamic. Such processes served to emphasise the importance of considering consent to be a dynamic process, not simply a static procedure at the outset of the interview. A continuous process of 'checking in' with participants was adopted to ensure that the consent to participation was maintained even in the face of potentially distressing material, or a shift in participant expectation as in the above examples.

Insider or Outsider Status

The expectation as to the researcher's role as a clinician can also be seen as informing the dynamic of the interview with regard to the manner in which participants anticipate that the researcher will perform within the interview. For example, Rebecca first accessed mental health care following a suicide attempt while in her second year at university. Following this she experienced herself as unsupported by her family and linked this to her experience as a child where she felt her Mother was emotionally distant and that she was expected to take on much of the

'maternal' caring duties for her younger siblings. She receives support from a psychiatrist, but struggles in her relationship with him:

"I don't really get on very well with my psychiatrist… I find that he doesn't listen to me and I feel a lot of scepticism from him, I don't feel like he believes a lot of the things I say to him…"

Later in the interview she links this relationship with her psychiatrist with her expectations of the research interview:

"As I was coming in here I was thinking I hope he doesn't treat me like a patient, because I would just, I don't, I don't respond to that I really don't like it. (Interviewer - How would I treat you like a patient, what would that be like?) If you were, stoic, with me if you were, just, I don't know what the word is, I don't know if you were condescending I suppose I feel that from a lot of doctors…"

Here then Rebecca positions her expectations of the interview in relation to her, historically negative, experience of doctors - predicting a particular reaction and manner to be adopted during the interview. The degree to which the interviewer meets, or hopefully confounds, this expectation will impact on the manner in which information is disclosed.

The researcher's insider status can also be seen as potentially impacting on disclosures from interview participants relating to their previous experience of clinical care. For example, returning again to David's experience and his relationship with his psychiatrist:

"I was under Dr X (Interviewer - I know Dr X - yeah) and he's very tough person, he's very hard, but he's very fair, and it took a good few years for an understanding between me and him, I was violent to him, I was nasty to him, as

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I've been told, I wasn't the same with him as he was me, he was very abrupt, and it took a long time, people going and telling me, as an instance Jane was my CPN and she was saying, like, well he's a very, what's the word, he's a very hard person, but he's very good at his job and he's fair and he'll come across as if he doesn't care, or he's not listening to you…"

David discloses the difficulties that he has experienced in this therapeutic relationship - he appears to remain candid in this disclosure, however the impact of the researcher's spontaneous disclosure of personal acquaintance with Dr X is unclear. This utterance from the researcher can be seen as unguarded and, given the tone of the interview at this point, may be indicative of the researcher's discomfort at being considered in the light of David's previous experiences.

In other interviews the participants' perception of the researcher as outsider was highlighted by their decision to disclose information that they reported they had not previously revealed to their clinical team. Disclosures of perceptions of poor clinical care were relatively common among the participants, a form of potentially discomforting information for the researcher to manage in their dual role as clinician and researcher. Participants knew of the researcher's potential familiarity with members of their clinical team and the possible need to disclose some information, pertaining to issues of 'risk', outside of the research encounter had been covered during the consent process. As such participants were aware that the researcher would be weighing the decision to disclose conveyed information - suggesting a possible degree of performative intent to their disclosure, perhaps further representing their dissatisfaction with the care they were receiving.

Blurring of clinical and academic roles

Researcher and clinical practitioner both have a responsibility to ensure that their interactions with patients, or participants, occur in a manner that is safe for all parties - to work with the individual in a framework that is able to meet their needs while adequately containing any risk issues that arise. As such, in monitoring the impact of the research interview on the participant, a degree of overlap exists with psychiatric clinical practice. This was particularly apparent for some interviews in which a significant amount of participant distress was disclosed, accompanied by thoughts of self-harm which the researcher was required to respond to: *"Like today I know I'm going to ligature, I'm not going to tell the officers, 'cause they won't care…"*. In one instance the level of the participant's distress could not be contained within the interview setting, resulting in an abrupt termination of the interview. Such disclosures manifested a blurring of the clinician and researcher role and prompted a process of risk exploration and 'safety netting' - a process of exploring available support and prompting help seeking behaviours from the participant (Almond, Mant, & Thompson, 2009; C. H. D. Jones et al., 2013).

During the course of the research project participants disclosed significant levels of mental distress, thoughts of suicide or self-harm, as well as personal histories containing significant experience of personal trauma. While acknowledging such personal distress for participants it is also necessary to recognise the impact of this on the research team - as has been described in other fields of qualitative enquiry (Johnson & Clarke, 2003). The emotional distress engendered during the context of this project was at times experienced as significant and also quite distinct from the experience of working with mental distress in a clinical capacity. This distinction in the quality of professional distress likely

relates to differences in perceived role - with the clinical role being seen as better able to offer immediate support and aid versus the more deferred goal of research. Specific stages of the research process, such as transcription which were conducted with the aim of 'data immersion' were also experienced as distressing owing to the repetitive nature of the task and the in-depth focus maintained on the precise language used to convey experience (Gregory, Russell, & Phillips, 1997).

The potential impact of working with sensitive material has been discussed in the methodological literature (Malacrida, 2007) with proposals being made for the best manner in which to deal with such experiences, for example through group supervision and discussion (Barry et al., 1999; Woodby, Williams, Wittich, & Burgio, 2011). The supervisory process in research is often hierarchical in nature however and the presentation of emotional material within such meetings is not always seen as appropriate, or simple to manage. In the context of the current study research supervision was supportive, yet still necessarily hierarchical and complicated by an intersection of clinical and academic responsibility. As such alternative means, such as group psychotherapy (Foulkes, 1946), were sought by the first author to allow emergent emotional experience to be discussed outside of an academic framework.

Recruitment too involved an interaction between clinical and research roles with participants being identified through collaboration with clinical staff according to the potential participant having received a personality disorder diagnosis and being recognised as likely willing to participate in the research process. On one occasion this process led to the researcher being co-opted into a disagreement with regards to diagnosis between nursing and medical staff. In this instance the

participant had been expressing longstanding visual hallucinatory experience and had been referred to hospital from prison to facilitate assessment of this experience. Nursing staff disclosed, following the research interview, however that they were not in support of this referral - believing that symptoms were 'feigned' and that the individual should remain in prison. Referral into the study of this participant was seen by staff as representing a second medical opinion in relation to the hospital transfer which they perceived as being likely to support their position.

Finally, one participant, following on from the research encounter, spoke with nursing staff in the prison where the researcher worked in a clinical capacity requesting referral for assessment in the researcher's clinic - citing their having already disclosed much information during the research encounter and their satisfaction with the initial 'therapeutic relationship' that had emerged. After close consultation with clinical colleagues it was decided that, given the end of the participant's involvement in the research process, this request would be supported.

Conclusions

In the current paper an attempt has been made to review the potential impact of the role of the psychiatrist as qualitative researcher on the construction of understanding emerging during the conducting and analysis of findings from individual interviews. The principal discussion relates to the manifest impact of the researcher's clinical role on the generation of material in the interview, as well as the potential ethical implications of this effect. In the context of the larger study from which this discussion is drawn this observation is important as a significant finding related to the manner in which individuals seeking mental health

care desired to experience a form of legitimacy in relation to their suffering, accessing the use of diagnosis in a strategic, or symbolic, manner to manage their professional distress. Professionals were seen by many as interrupting this act through a pejorative and stigmatising attitude towards the experiences of those receiving a personality disorder diagnosis. The researcher's role is clearly therefore significant in this process and the manner in which previous therapeutic, or non-therapeutic, encounters and relationships are re-enacted within the dynamic of the interview scenario is apparent. Considering this observation alongside the ethical implications emerging relating to the blurring of expectation in the research encounter begs the question as to whether the researcher's professional identity should have been revealed to participants, given that they are present in the role of researcher not clinician? For the purpose of the current study the response to the above question was considered self-evident, in that any effort to hide the researcher's dual-role was seen as unethical; however, the impact of disclosure is apparent and will inform any reading of findings from the study. The precise manner in which this disclosure manifests remains unclear in the absence of a comparator, or 'control state'. For example, it is possible that the presence of the psychiatrist as researcher may have either facilitated or inhibited communication of distress for some participants. Ultimately the existence of a power dynamic between researcher and participant is inevitable within research scenarios and can be seen as driving the construction of understanding (Ben-Ari & Enosh, 2013).

The final theme reported, the blurring of clinical and academic roles, in a sense represents a continuation of this impact on the research dynamic, but also raised an additional pressure for consideration within the research team. The decision, for example, to continue to meet

clinically with a research participant, was taken pragmatically after extensive discussion - but cannot be viewed as unproblematic for its impact on this role boundary.

Such interactions, together with the emotional labour necessary for the containment of affective response elicited in witnessing the narration of significant personal trauma, raise questions relating to the supervisory process necessary in such projects. Technical questions of praxis are often readily approached through conventional supervision, although dual supervision and demands between clinical and academic roles raise further issues in this regard. The representation and management of emotional material generated through research does not sit so comfortably within traditional supervisory processes however and in this regard this paper adds emphasis to previous calls for institutional processes that recognise and support the emotional labour inherent in research practice (Malacrida, 2007; Woodby et al., 2011).

In summary effort has been made to highlight the epistemological overlap between qualitative research and psychiatric practice - emphasising the importance of such research to developing understanding in relation to the experience and support of mental distress. Reflexive issues arising in the role of psychiatrist as qualitative researcher have been highlighted, not as a means of bracketing, or enhancing the 'credibility' of the findings reported, but instead to emphasise the nature of both clinical and research encounters as a process of knowledge construction, enacted between agents both of whom bring an experience and expectation of power within the interaction.

Chapter 9 - Discussion and Conclusion

In this final chapter the findings reported in Chapters 3 to 8 are summarised and presented alongside pertinent new literature published since the two reported systematic reviews were completed. Results are then considered in light of the original aim of the thesis, as set out in Chapter 1: - *'to explore the lived experience of recovery as described by individuals receiving a personality disorder diagnosis and accessing support from mental health services in a variety of clinical settings.'* Two principle conceptualisations of personal recovery are then outlined as a summary of the arguments raised in previous chapters before counterarguments relating to the the concept are discussed. Limitations of the methodologies employed are described, in addition to the limitations sections included within presented results chapters. A personal reflection is then offered to consider the manner in which the author's experience has modified in light of the findings from this project. Finally, some implications of the research project are considered in terms of future clinical and research practice.

Synthesis of study findings and consideration of their relationship to the wider literature

Systematic review findings

The two conducted systematic reviews, reported in this thesis, aimed to develop a synthesis of the existing qualitative academic literature relating first to the concept of personal recovery in forensic settings and second to those diagnosed with personality disorder. The two reviews were separated as it was recognised, from an initial literature search, that no previous research had specifically addressed the recovery

experience of those with a personality disorder diagnosis accessing mental health care in forensic settings. Significant overlap was identified in the findings between the two reviews, which can be summarised in three overarching themes found in common between the two studies:

1. The necessity for feelings of safety, or containment, for any recovery process to occur
2. The importance of social networks in contextualising the process
3. Identity work as the underlying process of change

Systematic reviews, once conducted, come to occupy the position of a static representation of the authors' interaction with the academic and theoretical literature at a particular time. Additional evolution in both the authors' thought and the substrate literature is therefore to be expected. In keeping with this an on-going engagement was made between the author and the emergent literature through the use of automated search strategies (for example the application 'PubCrawler' - allows an automatic literature search to be conducted, of the Medline database, at a specified time interval; http://pubcrawler.gen.tcd.ie). Pertinent journal outputs were monitored through the use of 'Rich Site Summary' (RSS) feeds collated with an electronic application (Reeder 3 for MacOS X - http://reederapp.com/mac/). These resources allowed the identification of newly published material of relevance to the development of the project. Specifically, one newly published systematic review was identified, addressing the concept of personal recovery in forensic clinical settings (Clarke, Lumbard, & Sambrook, 2015), while two additional primary studies, exploring the concept of recovery in personality disorder, were also found (Gillard, Turner, & Neffgen, 2015; Larivière et al., 2015).

The identified systematic review sought to explore the concept of recovery in relation to the experience of forensic mental health patients (Clarke et al., 2015). This study identified eleven mixed or qualitative method studies which were combined through a thematic analysis. The authors identified six superordinate themes through their analysis process, specifically highlighting two of these themes as of special significance owing to their prevalence within the identified substrate studies (indicated by italics in the list below):

1. *Connectedness*
2. *Sense of self*
3. Coming to terms with the past
4. Freedom
5. Hope
6. Health and intervention

Considerable overlap clearly exists between this review and those reported in this thesis and there is a great degree of shared methodology, although the search and inclusion / exclusion strategies vary slightly. Owing to this a number of the studies identified by Clarke et al have been excluded from the report included in this thesis. Reasons for exclusion included the lack of direct relevance to the research question, the absence of original qualitative data and presence of only clinical staff data. The reason for this variation can be attributed to an emphasis placed on the individual lived experience in the review reported in Chapter 4. Similar to the findings reported in Chapter 4 Clarke et al described a particular absence of reference to the interaction between research teams and interview participants as a limitation in their substrate studies. This absence of reflexive consideration may be particularly pertinent given the impact of clinician experience, or

attitude, described by participants as reported in the results chapters 5, 6 and 7.

Gillard, Turner and Neffgen (2015) report on the findings from their analysis of interviews with six participants who had received any personality disorder diagnosis. They adopted a thematic and framework analysis approach to their data. In contrast to other studies identified within Chapter 3 the authors devoted a high degree of attention to the relationship between researcher and participant - specifically describing the role of clinician, service user researcher and academic researcher in relation to the analysis process. In terms of findings the authors described the recovery process as representing a reconciliation between experiences in the individuals' understanding of their internal and external worlds; specifically, the authors highlighted conflicts between these two interpretations as leading to feelings of ambiguity, conflict and harm to the self. The internal world was seen as being isolated and detached, while the external world was described as unpredictable and hostile. 'Diagnosis' was seen as only allowing a poor agreement to be met in this process, or as reinforcing feelings of 'not fitting in' (p9 ibid.). The authors comment on the risk of employing an uncritical reading of the experience of recovery in others from 'mainstream mental health services' (p10 ibid.) in working with those who receive a personality disorder diagnosis.

Finally, Larivière et al. (2015) address the experiences of twelve women who had received a borderline personality disorder diagnosis and accessed two years of treatment in a specialist unit within the province of Quebec, Canada. Their methodology involved the use of two interviews where the women were supported in the expression of their life narrative through the development of a collage, consisting of

magazine clippings, and the choice of an object that was representative of the individual's recovery experience. Findings, or dimensions of recovery, were then fitted to a framework derived from the Person-Environment-Occupation model of occupational functioning (Law et al., 1996). The authors highlight that many current interventions, for example DBT, focus primarily on the 'person' facet of the process but that a more considered approach to the environment and occupational aspect of recovery could be beneficial - a point that has resonance with care models such as Nidotherapy (Tyrer, 2008), which propose alteration of the individual's environment rather than any intrapsychic process that would be more in keeping with other treatment modalities.

As in other studies the relationship between the researchers and participants was not addressed in detail in the discussion - which, given the participants familiarity with the offered treatment programmes following two years of attendance, may have impacted on the findings.

Again overlap can be seen between the findings of these two studies and those reported in both Chapters 3 and 4 - with representations of internal and external worlds (Gillard et al., 2015) being analogous to the concept of identity work and sharing the significance of social networks, while Larivière et al also highlight the importance of this interaction.

Given the significant degree of overlap between the findings of each of the newly identified studies with the reviews reported in this thesis it is argued that the three core themes outlined above remain pertinent as conclusions on the basis of these additional findings. Furthermore, it is proposed that each of these studies adds weight to the suggested need for additional exploration into the manner in which the diagnosis of

personality disorder and access to clinical care in different institutional settings impacts on the enactment and understanding of the concept of personal recovery.

Individual interview and focus group findings

The studies reported in Chapters 5 to 7 sought to build on the findings from systematic review in varying ways. The first study specifically explores described recovery experiences in relation to personality disorder in a variety of institutional settings and the role of mental health services in the support of this process. Focus group interviews, as reported in Chapter 6, allowed further exploration of the manner in which the understanding of self, necessary for the identity work process could either be fostered or impeded, identifying in particular the impact of the stigma that is apparent in relation to this diagnosis. Such stigma can be seen as adversely impacting on the recovery process and this has implications for clinical care. In Chapter 7 it was proposed that personal recovery could be viewed primarily as a form of identity work, in keeping with the findings from the reported systematic reviews. Personality disorder was used as an example to consider the manner in which this work was conducted and its relation to understandings of narrative constructions of illness identity and their performance. Finally, Chapter 8 reviewed the role of the researcher in the generation of this understanding, highlighting the manner in which the author's role as a psychiatrist informed the conducting of interviews and the material generated therein. It is proposed that this last chapter serves to illustrate some of the issues relating to reflexivity as they arose in the study process. Given the reported precarious nature of the personality disorder diagnosis, and the impact this has on personal recovery, it is

suggested that this interaction was a crucial one requiring particular attention.

A proposed model of recovery as it relates to personality disorder

On the basis of these investigations a model of personal recovery is proposed, as it relates to personality function and disorder - this is represented in Figure 6.
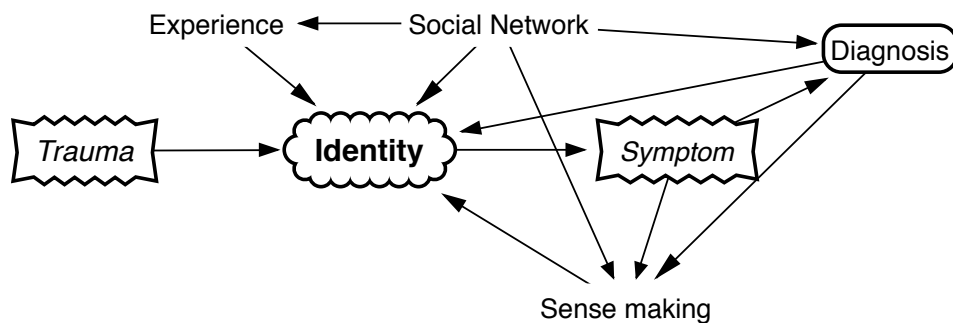
Figure 6 – Modelling the recovery process

In this model the individual is seen as developing a core sense of self as a moral agent - that is their sense of 'identity'. Identity can be related to ideas of personality functioning as outlined by Livesley (2011) - that is that personality functioning represents three distinct processes: A stable self-representation, the capacity to form attachment relationships with others and finally the ability to maintain social role. An individual's sense of identity is therefore informed by heritable characteristics as well as their experience in both early and adult life, particularly in relation to attachment formation, but is also intimately related to their positioning within various social networks - with the size and heterogeneity of these networks varying at different stages of life.

Personal identity therefore represents an internal construct forged through interaction and experience within a social field (consisting of a combination of network constituents as well as particular social institutional environment) - this construct can also be seen as being analogous to the representation of psychic life by a constellation of internalised interacting 'objects' (c.f. Fairbairn, 1963). This conceptualisation of personal identity clearly shows a great deal of overlap with thinking in terms of the individual having a narrative sense of personal identity (Schechtman, 2005) - but the emphasis of social network placement as a constituent part of this identity speaks against the idea of an underlying core life narrative, being more in keeping with Lumsden's (2013) proposal for a core construct of various bundles of narrative that are articulated in different social spheres and at different times.

Identity, or personality functioning, therefore allows the individual to move through multiple social fields and to exercise their agency in varying social roles. 'Trauma' can be seen as representing a force, experienced at any point in the life course, that moves to disrupt, or challenge, this process - and may therefore vary in its intensity. Faced with such challenge the individual engages, through a series of conscious and unconscious moves, in a process of absorbing and processing the problematic material. Incomplete processing of this material manifests as 'symptom' - which can be seen in varying forms of intrapersonal, interpersonal or social conflict in keeping with personality functioning. 'Recovery' then represents an effort to make sense of symptom, and to incorporate this knowledge back into the core identity - perhaps through a process of symbolic representation. In this conceptualisation 'diagnosis' represents an external model, occupying a symbolic function, that may aid, or hinder, the recovery process through

its impact on the sense making activity, referred to as 'identity work' in the preceding papers and discussion. Treatment, in the form of either psychotherapy or psychopharmacological intervention, may similarly be seen as occupying such a symbolic function, in addition to any 'direct' effect that they may engender.

Situating findings in relation to existing literature

The above proposed model offers a framework through which to consider the findings outlined in this thesis and, in its equating personality functioning and identity work, draws heavily on ideas relating to much of psychoanalytic thought (outline in Bateman et al., 2010). It is suggested that a great deal of overlap exists between the overarching themes identified in the current project and those emerging from the exploration of experience for people with other forms of mental distress - for example as outlined in the framework by Leamy, Bird et al. (2011); their concepts of connectedness, hope, identity, meaning, empowerment and spirituality can be seen as closely related to the identified concepts of identity constituting the sense of moral agency [c.f empowerment] as emerging from experience and social network placement [c.f connectedness]. 'Sense making', as a representation of recovery, is clearly related to their use of the term 'meaning'. The concept of 'hope' is important to the concept of recovery and in a sense can be seen as informing many stages in the process, although its representations are varied and complex (Ezzy, 2000; B. Smith & Sparkes, 2005). Understandings of spirituality will also inform the manner in which the sense of self is constituted both for the individual and their social role within the communion.

In their exploration of ideas of recovery, as applied to personality disorder, Gillard, Turner and Neffgen (2015) emphasise that caution, or critical thinking, must be applied in drawing on findings from recovery literature as it applies to other forms of mental distress. This cautionary statement is grounded in much current thinking which differentiates the experience of those receiving a personality disorder diagnosis from forms of 'mental state disorder' (Newton-Howes, Mulder, & Tyrer, 2015b). However, epidemiological studies exploring the incidence of traumatic experience in personal history have demonstrated a possible correlation between experiences of childhood trauma and later life psychotic experience (Bendall, Jackson, Hulbert, & McGorry, 2007; Read, Os, Morrison, & Ross, 2005; van Os, Kenis, & Rutten, 2010; van Os, Linscott, Myin-Germeys, Delespaul, & Krabbendam, 2008). Such findings indicate that some form of personal response to trauma, with accompanying sense making activity, may be significant in many forms of mental distress. There is also a need to caution against simplistic views of a clear separation between ideas of personality dysfunction and other forms of 'major mental illness'. Findings indicating a common traumatic root to much mental distress may provide some indication as to the reason for a great degree of overlap between recovery experiences in response to varying forms of disorder.

An alternative account of the overlap between recovery experiences can be developed by considering its relationship to the emotional wellbeing literature. Ryff (2014), for example, has developed the concept of Eudaimonia (personal flourishing), with its origins in Ancient Greek philosophical thought, as a model for psychological wellbeing made up of six constituent, theoretically informed, dimensions:

1. Autonomy
2. Self-acceptance
3. Personal growth
4. Environmental mastery
5. Positive relationships
6. Personal growth

Individuals are seen as moving along a spectrum of experience, between high and low attainment, in each of these domains at varying points in their life and in response to various challenges. Parallels can be drawn between such models with the accounts of recovery experiences and there is a clear link between the concepts. Such understanding returns us to the idea the recovery is not simply something to be engaged in by the 'mentally ill' but instead represents an act that is simply 'human' in its nature (Deegan, 1996); a process of self-actualisation (Maslow, 1943). Such a move towards the understanding of the recovery process as an inherently human one in the face of, admittedly extreme, psychic distress challenge conceptualisations of health and illness - raising questions as to precisely what it is that represents distress and disorder. 'Health' can perhaps move towards being viewed more as a social act of performance in keeping with social morays and taboos (S. J. Williams, 1998). Within such formulations expectations of health become linked with a moral demand to produce a performance of 'successful illness', in keeping with societal demands (Frank, 1997). Such claims have clear resonance with those made by participants in the current study in seeking explanation and support in the face of their 'bad' behaviour.

In this process of identity work professionals occupy a powerful role in their ability to offer support as well as a degree of normalisation to experience. With respect to this the concept 'diagnosis' occupies a

symbolic function in its ability to activate differing modes of understanding in relation to personal distress, to tie together bundles of narrative or to act in the unifying role of the 'synthome' as described by Lacan (Fink, 2009; Leader, 2011). Treatment and medication within this formulation may similarly come to represent the role of containing, or 'transitional', object (Tutter, 2006). Appeals to diagnosis therefore come to occupy powerful social roles in their ability to offer an account of an individual's experience - both to the individual themselves and to their wider social networks (Mechanic, 1962; Parsons, 1975). The potential for clinicians to act in a rejecting manner in relation to the distress described by those receiving a personality disorder diagnosis, as described by both individual and focus group interview participants, is therefore concerning but also resonates with other descriptions in the literature (Bonnington & Rose, 2014; Sulzer, 2015b). If care is to be offered to this group of people further work is required to identify means in which clinical staff can be supported in its provision. Diagnosis is however not unique in its ability to provide a unifying symbolic role. Other actions of social acceptance and unification may fulfil a similar function, for example through the role of group work and peer support groups such as are provided within Hearing voices support groups (http://www.hearing-voices.org). There is also resonance here with the call for a 'narrative turn' in psychiatric clinical practice - recognising the multitude of different forms of narrative that can be used to support and interpret mental distress (B. Lewis, 2014).

Considering the model outlined above together with the interaction between experience, social network and identity reveals the particular complexity of the situation faced by those who also have to negotiate an understanding of the 'offender identity' in addition to any concept of mental disorder or distress. The enforced identity of 'offender', applied

through the judicial system, can be seen as 'spoiling' or 'forcing' the individual's sense of self in a form of stigmatisation, a concept returned to in greater detail below. Beyond this however, the individual conceptualisation of self as moral agent can be seen as an intimate negotiation for the offender between personal and social understanding of themselves. Any change in understanding of personal identity will require a negotiation of these varying self-aspects. As was outlined in the discussion above lay understandings of mental disorder may function to empty an act of its moral significance, thereby providing one strategy wherein the individual may lessen their own potential sense of moral discomfort in relation to an offending behaviour. This may provide an alternative path to desistance which, returning to Maruna's conceptualisation (2001), can be seen as impacting on the individual's core sense of self and their sense of agency. Maruna and Ramsden (2004) expand on this idea further in their consideration of the development of a 'redemption narrative' in the process of offender rehabilitation. Development of such a narrative by offenders in the face of mental disorder can therefore be seen as being conducted in parallel with, as well as being complicated by, the central understanding of self that develops both in relation to offending behaviour and mental distress.

In concluding this section emphasis is returned to the role of social networks in both the experience of personal identity and the expression of distress. This observation is important in its recognition that in labelling mental distress there is a risk that the subject is labelled as 'deviant', in need of correction or control, and activating concepts of stigma in relation to their behaviour and identity (Scambler, 2009). Care is needed therefore to emphasise the recovery as a process is informed deeply by the social milieu within which the individual lives - and that

therefore their recovery may be as much about social movement as it is personal change (Davidson, 2008). As one participant in a recent online social media conversation, relating to the role of mental health care, stated:

"...I know all you have is meds & talk. But pls acknowledge that sometimes the world needs changing, not me." (p6 Shepherd, Sanders, Doyle, & Shaw, 2015)

For the 'offender' this process is again complicated and will require change within host social institutions on a number of fronts (Barry 2015). One possible strategy, which requires further exploration, to address this issue can be seen as being adopted by some ex-offenders who develop supportive roles for other offenders, adopting the identity of 'wounded healer' (LeBel, Richie and Maruna 2014).

Conceptualisations of personal recovery

The following section seeks to build on the synthesis of findings in the previous section by outlining two formulations of the concept of personal recovery. While divided into distinct sections it is important to note that substantial overlap exists between these conceptualisations - for example, as has been illustrated in previous chapters, to divorce the personal representation of the self from its social considerations risks losing the core concept of personality and identity - that is the voiced articulation of the self within the social field.

Personal meaning and personal recovery

In the preceding section a model of personal recovery was proposed, situating the experience as an act of identity construction in the light of traumatic events. In considering the findings from reported studies, in

light of the pre-existing literature relating to the concept experience of recovery, it was suggested that the overlap in findings could be seen as an indication of the fundamental human nature of the process. A link to the concept of Eudaimonia was then outlined as a framework for consideration (Ryff, 2014).

Considering the personal experience described by participants, the act of identity work can be seen as a process of gaining perceived moral legitimacy in relation to one's distress and behaviour. This is an inherently social act and will be determined through interaction with various agents within social networks, in addition to the actions of health professionals offering support. For individuals with a personality disorder this process may be seen as particularly difficult and the integration of social experience represents a core difficulty emerging from this disruption (Livesley, 2011). This disruption has been referred to as 'epistemic mistrust' (Allison & Fonagy, 2016; Fonagy, Luyten, & Allison, 2015), a construct emerging from the interaction between temperament and early life attachment experience. This concept is particularly vulnerable to disruption through the 'violation of trust' inherent in the experience of trauma, or abuse, described by many participants in the current study (Knox, 2016).

Developing sufficient epistemic trust to allow the process of recovery to proceed may then represent a fundamental difficulty for individuals suffering with personality disorder, or indeed mental disorder in general. Means of supporting the development of epistemic trust will therefore require consideration if the process of personal recovery is to be supported.

The social meaning of personal recovery

The use of the phrase 'personal recovery' risks situating the process entirely within the realm of individual experience, and ultimately individual responsibility. The findings reported in this study however highlight the intimate social awareness, or pressure, attendant within the process. Recovery in this sense becomes a performative act of developing a representation of the self that is 'fit' for use within varying social settings. This therefore relates to the ability both of the individual to project themselves within society, but also for society to be able to accommodate their experience and distress. Adopting the analogy of the theatre - the actor's performance will fall flat if the audience is non-responsive, or hostile.

Two readings of this situation are possible. The first represents a disability rights model of understanding wherein the individual is seen as limited in their functioning only in so far as capacities within society restricts their day-to-day activities. By adopting a more inclusive model society may move towards the promotion of recovery in mental distress (Davidson, 2008). An alternative formulation lies in the absolute rejection of deficit models; an emancipatory act wherein the conceptualisation of 'illness' is removed and the individual moves on as an 'expert by experience' or 'survivor' of their past (Pilgrim, 2008). These formulations should not be seen as mutually exclusive and both would require societal change in order for the recovery process to occur.

On a micro-level therefore recovery is enacted within close social networks around the individual and will be driven by the acceptance of the individual within family units or other social groupings. For the participants in this study divorce from social groups, or divorcing from social ties through incarceration, restrict this development through a

process of alienation. Work will be required to address this and allow the individual's re-integration, or the establishment of new social ties, if that is what is desired.

From a more macro-perspective, these micro-level interactions will be driven by social attitudes and experiences at the wider community level. Recent commentary relating to the 'parity of esteem' between mental and physical health care represents one potential driver for social change in this regard (Bailey, Thorpe, & Smith, 2013). Public conceptualisations of mental distress, as portrayed in the general media and other outlets, are significant in this regard and will inform the experience of individuals throughout their social network interactions. Stigma in relation to mental health related care is well recognised (Huxley & Thornicroft, 2003) and those with a personality disorder are not excluded (Sheehan, Nieweglowski, & Corrigan, 2016) from its influences. Public level interventions have been developed with a view to addressing this.

Normalising interventions, such as the 'mental illness is an illness like any other' approach, seek to represent mental distress as a phenomenon in parallel with other forms of distress, and sharing a physical grounding in 'biological dysfunction'. The intention behind such interventions is to promote help seeking behaviour and social inclusion for those diagnosed with mental disorder, the impact of such interventions is complex however. Angermeyer and colleagues (2013) demonstrate that over a period of two decades public attitudes, in Germany, relating to diagnoses of Schizophrenia, Depression and Alcohol dependence, shifted - with respondents to their survey becoming more likely to endorse a biological explanation and need for mental health assessment over time. Alongside this change was also noted a trend towards greater

social distance - with more respondents likely to endorse statements that they would reject having an individual with a diagnosis of Schizophrenia as a neighbour, or having them marry into their family. Biologically grounded anti-stigma interventions seems therefore to risk increasing the representation of those suffering with mental distress as 'other' to the general community (Read, Haslam, Sayce, & Davies, 2006); that in being 'biologically ill' the individual is in some way fundamentally alien in their experience, and therefore to be avoided, or isolated.

For those in contact with the criminal justice system the enforced 'offender' identity similarly represents a spoiling of the sense of self that is marginalised, or rejected as fearful, by society as a whole (Moran, 2012). For the 'mentally disordered offender' the constriction on personal identity is increased still further in the form of 'double' (Edwards, 2000) or even 'triple' manifestations of stigma (Hartwell, 2004).

In some investigations individuals with experience of mental disorder report the 'actual' manifestations of stigma as relatively rare in their day-to-day lives. What is more apparent however is the perceived pressure on one's identity and agency to appear 'normal' - for example increased ability to 'pass' as normal can be seen as a marker of strength, agency and recovery (Whitley & Denise Campbell, 2014). Ultimately therefore it may be the 'felt' nature of stigma that is most significant - enforcing a process of 'self-stigmatisation' on the individual through perceived societal pressure (West, Vayshenker, Rotter, & Yanos, 2015).

Social representations of recovery in relation to mental distress are therefore complex and well-intended interventions risk unintended

consequence. Varying responses to this situation are proposed, for example the role of 'solidarity' as opposed to normalisation (Corrigan, 2016a; 2016b) - that is the acceptance of 'difference' within society in an act of 'standing together' with those who experience distress. Critique has been levelled at some examples of interventions however - citing the risk that messages can become distorted in the light of the desires of interested groups (Pilgrim & Rogers, 2005); for example, in adopting roles within anti-stigma campaigns, professionals may be seen as seeking to shore up their own authority and power in relation to the control of deviance.

Returning to the specific instance of 'personality disorder' conflicting attitudes amongst professionals, as demonstrated in the focus groups reported in this thesis, risk complication of any message conveyed in relation to the experience of personality disordered individuals. Ultimately the implication of a social understanding of recovery places the discourse at a political level, as well as personal, with coherent action and collective decision making required to address the experience of those suffering from varying forms of mental distress.

Arguments against recovery

In the opening chapter of this thesis the arguments outlined by Harper and Speed (2012) were presented as a means of illustrating the complexity of understanding concepts of personal recovery. Their argument is now returned to, in light of the formulations of recovery, outlined above, in an effort to answer their criticism. Briefly their arguments are set out here (paraphrased from p10 ibid):

1. Recovery and resilience are inherently individualistic concepts
2. In reframing deficit as strength the concepts are inherently reliant on a deficit based model
3. Structural factors (for example social inequality) are diminished in light of the neoliberal reading of 'identity politics'

These points are each approached in turn in light of the findings from the current study and the presented conceptualisation of the recovery process.

1. <u>Recovery as an individualistic concept</u>
   Harper and Speed (2012) cite several sources in building this strand of their argument including the definition outlined by Anthony (1993):

   "*Recovery involves the development of new meaning and purpose in one's life as one grows beyond the catastrophic effects of mental illness.*" (p527 ibid)

   In this formulation it is argued that the acceptance of '*mental illness*' and its inherent deficits are necessary for the individual to discover '*new meaning and purpose*'. There is a possible overlap here with the identity construction understanding of recovery outlined

above. However, it can be argued that in referring to the social, performative, understanding of personal identity, the concept is immediately moved beyond an individualistic focus. Identity construction is presented as involving a negotiation of individual understanding between agents and their social milieu and as such recognises the restrictions inherent within such interactions. This is not to say that the process cannot become 'forced', as experienced by individuals who felt that they had been wrongly diagnosed in the reported findings. This again is representative of a social processes enacted by agents within constraining fields. The performative nature of the recovery process therefore requires change to occur at a societal or political level as well as an individual - to move beyond a focus on the individual to a recognition that society also must change if an individual is to be accepted.

2. <u>The model is implicitly deficit focussed</u>

In the conceptualisation of recovery outlined the process of identity construction is framed as arising in response to challenge, or trauma, arising within the social milieu. While acknowledging the impact of personal trauma it is proposed that this approach is not inherently deficit focussed. Instead the process is framed as being a shared human endeavour in keeping with the experience described by Deegan (1996) and the concept of Eudaimonia (Ryff, 2014). Clinical care then becomes a process of working to support the individual in this natural act. The deficit driven model is hard to completely dismiss however in relation to personality and identity; for example, the concept of epistemic mistrust (Fonagy et al., 2015). It is argued that in being an inherently trans-diagnostic formulation the emphasis is moved away from a

diagnostically led formulation, avoiding the criticisms that are levelled at such an approach (Szasz, 1994). Ultimately though in some manner experience of distress may represent some underlying deficit in experience that requires addressing, even if the precise nature of that deficit is unclear (Millon, 2016).

3. <u>The impact of structural factors is downplayed</u>

   Structural inequality within the social environment is not approached as a specific potential source of trauma in the presented formulation. Instead it is proposed that in intimately embedding the idea of identity construction as a social process structural factors remain closely linked and recognised in the approach. Again recovery in this account becomes a political endeavour, not simply a process of personal adaptation.

Limitations and Methodological reflection

A strength of the current study lies in the manner in which it examines the experiences of individuals seeking mental health support within a variety of institutional settings - therefore expanding the previous appreciation of the role of social networks in the recovery process. A number of limitations are present in the methods employed however and these are reviewed in the following section.

<u>Recruitment strategy</u>

Recruitment of participants for individual interview involved a process of close collaboration with local clinical teams and research support networks. Indeed, this was a feature that attracted discussion during the ethical review approval process with questions arising from the ethics committee regarding the manner in which the ability of participants to engage safely with the research process would be gauged. The adopted recruitment strategy may have necessarily led to the exclusion of certain voices (Kristensen & Ravn, 2015), for example those who are alienated from the experience of mental health care. Many participants were however 'critical' of the care they received and it is uncertain as to what further information would have emerged if more alienated participants could have been identified.

The recruitment strategy also led to a large number of participants being interviewed and it is argued that this large sample size is representative of the breadth of experience sampled. It is also possible however that the recruitment of a sample of this size has led to some loss of sensitivity in the analysis process. The impact of this is unclear. An alternative reading is that the large sample size is representative of an issue of

reflexivity and the sample size generally expected for the epistemological approaches in which the author was initially trained.

A decision was taken to approach recruitment in four different waves of recruitment: Community individual interview, community focus group, forensic individual interview and forensic focus group. In terms of individual interview participants, recruited in both waves, a great deal of overlap in experience was identified - with some 'community' participants having experienced care within forensic institutions, and almost all forensic participants having had experience of community mental health care. The division of participants into 'community' and 'forensic' cohorts may have therefore induced an artificial separation of experience into the analytic process, for example through an unspoken, and unrecognised, assumption in relation to 'forensic participants'.

Individual interviews

During planning and ethics application for the project it was considered that the most appropriate means of investigation would be a single, one-off, interview with participants. The rationale for this decision was to allow a reasonable depth of interview, while minimising distress for participants. This choice of recruitment strategy may also have partially been driven by concerns relating to difficulties in recruitment and possible loss to follow up, problems that are recognised as barriers to recruitment within mental health research (Patel, Doku, & Tennakoon, 2003). While it is argued that the selected interview strategy was appropriate, and that it produced rich data for analysis and discussion, it is possible that an alternative interview paradigm may have added to the analysis. A strategy involving sequential interviews over a period of time may have introduced a degree of reflection on the part of the

participant between interviews, further enriching the analysis process (Wengraf, 2001). Alternatively, a more in-depth phenomenological exploration across a series of interviews may have provided a potentially valuable perspective (Smith et al., 2009). Given the dynamic nature of the recovery process the separation of multiple interviews across a period of time could also have been of value - for example allowing the separation of interviews at varying stages of clinical contact, such as during hospital admission (Lee, Vlaev, King, Mayer, & Darzi, 2013).

Focus group interviews

At the outset of the project it had originally been planned to conduct focus groups with returning participants from individual interviews. A process for recruitment to this stage of the project was proposed whereby consent to be re-contacted by the researcher would be sought at the end of the individual interview process. During the course of the individual interviews however few participants offered such consent, and questions were also raised regarding what could be gained through interviewing participants again in a heterogeneous group setting, especially as many had voiced concern about group experiences during their interview. A decision was therefore taken to omit this portion of the project to allow greater focus to be maintained on individual interviews with service users and focus group meetings with clinical staff.

The intention of focus groups conducted with clinical staff was not to position these groups as 'expert opinion' in relation to the process of recovery, but rather to allow an alternative reflection on the themes emerging from individual interview. The development, and observation, of group dynamics within focus group meetings is a significant strength

to the use of groups as a means to explore areas of interest (Barbour, 2005; Kitzinger, 1994) - this is particularly pertinent within fields of enquiry where group dynamics and co-constructed modes of understanding are significant, as in the current project. While effort was made to observe interactions during group meetings by the researcher these efforts were limited by the researcher conducting the groups alone: introduction of a second researcher within the focus groups would have improved the ability to observe and capture such information. Additionally, while the use of homogenous focus groups, in the form of clinical teams accustomed to working together, was of use in terms of ease of recruitment and arranging times for meetings - it is possible that the deliberate construction of partially heterogeneous groups, through inviting participants from different clinical teams, may have allowed for different findings to emerge outside of the familiar dynamics of practicing clinical teams. It is suggested however that this does not necessarily represent a 'limitation' of the adopted methodology, merely that an alternative perspective would be expected to provide different information.

Issues of reflexivity are again pertinent to the conducting of focus group meetings with clinical professionals. Research with clinical professionals working in primary care settings has demonstrated that the role of the researcher impacts on the nature of discussion and information provided, with professionals feeling potentially more 'judged' when interviews are conducted by a fellow professional (Chew-Graham et al., 2002). As for individual interviews the author's role as a psychiatrist was known to focus group participants, some of whom had worked with the author in a professional capacity. Such knowledge will have undoubtedly impacted upon the dynamic developed within the group meetings, but is difficult to comment upon as no comparator exists to

allow conclusions to be drawn. As for individual interviews however it is likely that a performative aspect to the interviews exists, as would be supported by previous findings in the methodological literature (Coar & Sim, 2006).

Service-user advisory group role

As discussed in the methodology section above a service user advisory group was recruited in order to allow an additional space for discussion relating to methodology and development of findings. Ultimately this group, consisting initially of five members, was consulted during the development of interview schedules, following completion of community interviews and once more following completion of forensic interviews. During this time the number of participants agreeing to attend the group decreased to one participant for a variety of reasons - specifically ill health, changing professional role and change to personal circumstances. Group discussions provided additional discussion relating to topics of interest, as was anticipated, however there was a sense in which the group could have been more active in the research process. This raised tensions in terms of the role of the various parties involved in the research project, particularly in relation to the analysis process. Increasingly research designs allow for the incorporation of varying parties in the research process - for example as in Participatory Action Research approaches (Baum, 2006). Such approaches present novel means of overcoming traditional hierarchical power structures, with emergent issues of reflexivity, and are therefore particularly pertinent to the study of phenomena such as recovery (Gill, 2012). For the purpose of the current project this service user researcher role was not considered at the outset as it was intended that, while aiming to be rigorous in its approach, the study also served as a traditional

'apprenticeship' experience for the author, in keeping with its position as a project funded through a personal development fellowship. The impact of more direct involvement of experts by lived experience in the research process requires further exploration in future studies.

Personal reflection

In the introductory chapter I presented my clinical and academic experience in order to inform the reader with regard to possible influences on the conduct of interviews and the analysis process. Chapter 8 expanded on this concept by considering the manner in which my role as psychiatrist and researcher impacted on the findings in a reflexive manner. In keeping with that opening section this personal reflection is presented in the first person.

Briefly in this closing chapter the impact of the research process on my clinical practice is returned to. As was stated throughout the past three years I have maintained a clinical role, principally working in a weekly prison clinic in a women's prison while also providing 'out-of-hours' emergency cover as part of a rota of junior doctors. This clinical contact has provided an opportunity for reflection in relation to the emergent findings from the project. As was explained I view my practice as being informed by a psychodynamic model of understanding (Gabbard, 2014), while acknowledging that, in line with Leader, *'a psychoanalytic theory of psychosis doesn't mean that psychoanalysis will - or even should - take place'* (p3 Leader, 2011).

Throughout the past three years the primary area of practice in which the research has impacted upon my practice lies in the manner in which information is generated and shared between clinician and patient. In

keeping with the situational constructivist epistemology described in this report (Madill et al., 2000) I have increasingly come to see the interaction between doctor and patient as an opportunity for construction of shared understanding, an act that raises important questions as to the role of 'truth' and its impact on the clinical interaction (Greenberg, 2016). This has led to my effort to practice in a manner informed by formulation of experience, as opposed to a principally diagnostically led mode of understanding (Cabaniss et al., 2013; 2015) while recognising that varying models of understanding are necessary, dependent on the needs of the individual seeking support and their current experience of crisis or clinical demand (B. Lewis, 2014). I also hope that in this regard my practice has become more 'strengths based' in its manner and also more optimistic with regard to the act of recovery as communicated in the clinic.

Implications of findings

Throughout the results chapters of this thesis potential avenues of further enquiry have been presented in keeping with the 'journal style' of presentation. In this final closing section some further implications are considered in terms of both future clinical and academic practice.

Clinical implications

Clinical services represent a bridge between the personal and social formulations of recovery outlined above; tasked as they are with the delivery of care to individuals at times of distress, whilst also meeting the varying social forces and policy pressures that inform the manner in which this care is delivered. For example, the public demand that mental health care be delivered in such a way as to contain the 'danger' inherent in the 'mentally ill' (Pouncey & Lukens, 2010).

Delivery of recovery focussed support is in many ways in keeping with the 'biopsychosocial' nature of care described by many mental health service providers (Engel, 1981). However, this model of practice has been criticised as at times becoming too fragmented, or eclectic, in its manner - losing any specificity in its ability to inform compassionate care in relation to personal distress (Ghaemi, 2009). Other critiques position the approach as simply being descriptive and failing to acknowledge the intimate link between the biological, psychological and social (Cabaniss et al., 2015). Recovery oriented practice with its requirement to bridge personal and social conceptualisations of health / disorder may therefore be seen as a challenge to traditional clinical care provision models.

The development of recovery orientated clinical practice requires changes at a variety of organisational levels. Working at an individual level the desired outcomes of clinical care require consideration. At present most measured outcomes relate primarily to symptomatology, with other outcomes, such as social engagement, frequently positioned as secondary measures or considerations. Provision of recovery orientated care requires a redressing of this focus - with the adoption of outcome measures that consider not only symptom severity but also the patients' perspective, as well as that of their social networks and wider societal implications (Arfken & Balon, 2014). This is significant as many routinely used measures of clinical outcome do not capture information that is described as in keeping with the process of personal recovery by patients (Andresen et al., 2010). One possible means of addressing this difficulty is through the use of individualised outcome measures, where choice is provided for the individual to specify outcomes of significance to them in particular and for changes to be gauged in response to these 'goals attainments' and 'personalised primary outcomes' (Pesola et al., 2015). Incorporating such measures into existing research epistemologies, most significantly the randomised controlled trial, would allow the development of evidence for efficacy that is pertinent through its direct relation to personal experience.

Particular to the experience of personality disorder, if the concept of identity work is to be considered as a process of change in recovery then therapeutic relationships must be fostered that are capable of supporting this change, while allowing the individual a sense of 'safety' in their experience. Fonagy and Allison (2014) propose three stages in the development of such a therapeutic relationship:

1. Communication of knowledge, or understanding, to indicate that the therapist represents a reliable source of information

2. Increasing mutual understanding (referred to as robust 'mentalisation')

3. Social learning

Overlap exists here with Wampold's (2015) conceptualisation of the therapeutic process, referred to as the 'contextual model':

1. The real relationship (therapeutic relationship)
2. Expectations in relation to experience
3. Specific ingredients for change

Many individual interview participants commented on the central importance of such the therapeutic relationship to their experience of recovery - the adoption of a recovery oriented mental health service therefore needs to acknowledge this need and to adopt sufficient supervisory processes that the challenges of the work can be met (Adshead, 1998; Watts & Morgan, 1994). Clinical staff taking part in focus groups, reported in Chapter 6, highlighted the difficulty of working in such a manner - with the therapeutic relationship seen as being constrained by the availability of the resources necessary to allow its support, while also acknowledging the lack of supervisory support to allow the emotional labour inherent in such a relationship to be conducted safely. There is therefore a risk here that recovery focussed care becomes defined by the limitations inherent within existing clinical situations (Le Boutillier et al., 2014; 2015).

Focus group participants in the current study also expressed concern regarding the role of the personality disorder diagnosis alongside

concepts such as 'treatability'. A risk of conflating treatment with solely biomedical intervention was also apparent in some exchanges during focus group discussion. Such uncertainties illustrate the importance of collective, organisational, understanding by institutions in relation to concepts such as personality disorder (Bloor & Dawson, 1994). Such institutional cultural understandings also interact closely with the understanding held within other agencies, which in turn display their own organisational culture, for example in the case of prisons (Farkas & Manning, 1997). Professional education programmes (such as the Personality Disorder Knowledge and Understanding Framework - www.personalitydisorderkuf.org.uk) may offer one means of addressing such issues and incorporating different models of working into clinical institutions. However, many of the barriers identified by participants exist at higher levels, relating to institutional awareness and the availability of support - in resource constrained times, when boundaries of clinical responsibility become firmly defined. There is therefore a risk that work done to offer inclusive models of care may become threatened (National Institute for Mental Health in England, Personality disorder: No longer a diagnosis of exclusion, 2003).

The social nature of the recovery process also highlights the importance of working not only with individuals in isolation from their social environment, but also in trying to support the inclusion of family or other forms of social support where appropriate. Such an intervention is clearly challenging, and the work of exploring psychological dynamics within social networks is a challenging area of practice.

Working to support recovery in forensic institutions

Considering the experience of those seeking mental health support within prison environments also raises considerable complications. Participants in the reported study identified similar expectations and concerns in both forensic and community settings, but the experiences of those in forensic institutions are necessarily tinged with a different filter. Incarceration is associated with significant personal distress, sometimes referred to as the 'pains of imprisonment' (Crewe, 2011). Under such circumstances experience of mental distress is common and prisoners show various psychological endeavours in their attempt to make sense of their experience, particularly in the face of long sentences (Wright, Crewe, & Hulley, 2016). Agents seeking to make sense of concepts of mental distress in such scenarios are therefore faced with a complex scenario (Galanek, 2012; 2015). Further exploration is necessary to determine the best manner in which mental health service support can be delivered within such settings.

Unfortunately, it is possible that prison environments may simply be seen as anti-therapeutic for individuals with a personality disorder. As described in Chapter 1, in recognition of this efforts have been made to establish alternative pathways within the prison service which provide environments more conducive to an individual's needs (Turley et al., 2013). Such environments are intended to allow the cycle of repeat offending, wherein individuals become trapped within prison institutions, to be broken. Initial explorations of the delivery of training to professionals within prison environments demonstrated positive changes in both staff attitudes and in measures of prisoner behaviour (Bruce, Horgan, Kerr, Cullen, & Russell, 2016).

Adopting a model of recovery oriented care

Recovery oriented care provision therefore requires professionals, and their host institutions, to adapt to novel ways of thinking and to induce change within organisations, an inherently complex and challenging process (May, 2013). Efforts to introduce models of recovery orientated care have met with mixed fortune with early randomised control trials demonstrating complex findings following staff training activities within specific models of practice (Mueser, 2015). The authors cite the difficulty of inducing practice change in transient populations of professionals with high levels of service demand, and in a parallel review identified potential barriers at both high and mid-level institutional organisation (NHS and local trust), as well as individual practitioner level, to the introduction of new practice (Leamy et al., 2014).

Models such as Normalisation Process Theory (Murray et al., 2010) provide frameworks for identifying potential barriers to institutional change:

1. Coherence: - The clarity of purpose and benefit from an intervention, together with its distinction from other interventions.
2. Cognitive participation: - The acceptance of target professionals with regard to the role of the intervention
3. Collective action: - The impact of change on practice and any activity required on the part of agents within the system
4. Reflexive monitoring: - How will professionals perceive the intervention following its implementation, will this provide further evidence for its benefit.

Application of this model of understanding has been used to explore the implementation of a variety of models of care (for example Gask et al., 2010). A toolkit developed in light of the underlying theory allows organisations to identify their own readiness for change and potential work still required (May et al., 2011).

Focussing on the implementation of a recovery oriented practice model it can be argued that in terms of *coherence* the differentiation of recovery focussed care from previous models of care may be difficult which may in turn restrict the *cognitive participation* of professionals. At present there is an absence of research evidence to support the implementation of such practice change. Steps such as awareness change and the introduction of practitioners in roles of 'recovery champion', including service user consultants or peer support models, may provide one such means of beginning this introduction. Such models are a powerful example of the potential of recovery focussed care provision (Austin, Ramakrishnan, & Hopper, 2014). Robust evidence for the role of such interventions is lacking however, with some findings supporting implementation in certain experiences and clinical settings (e.g. inpatient care for depression Pfeiffer, Heisler, Piette, Rogers, & Valenstein, 2011), but not others (e.g. Lloyd-Evans et al., 2014). Additionally, a number of potential barriers to the implementation of such models exist, (Repper & Carter, 2011; Solomon, 2004) particularly within forensic institutions (Devilly, Sorbello, Eccleston, & Ward, 2005).

Research implications and possible future studies

The findings from the current study go some way to illustrating the complexity of the understanding and enactment of a concept such as personal recovery, when applied to non-psychotic disorders where the

majority of research has been conducted. The results described here indicate the intimate social nature of the process and the importance of experience within social and institutional environments. To better explore this process then further research is necessary, adopting a variety of methodologies (including observational, or ethnographic studies) to allow observation of the manner in which recovery oriented care is enacted by professionals and service users (Pilgrim, 2009). Further research is also required to explore the manner in which mental health care is provided and experienced within forensic settings, such as prison institutions. Again observational studies would be of use in this regard.

Broadening the field of enquiry beyond the experience of the specific individual experiencing mental distress to their social networks may also provide a fruitful field of enquiry to explore the means in which concepts of mental disorder are made sense of and enacted within varying social fields. Such exploration could also be of direct clinical benefit in informing means of better incorporating personal social support into clinical care practice.

If recovery practice is to be implemented into clinical care models then further research is needed, in keeping with the areas of discussion outlined above. Specifically;

1. Coherence and understanding: - clinical training models must be developed to allow the communication of models of recovery oriented care to practitioners. Such training must clearly communicate the intent of recovery oriented care models to allow practitioners to recognise the manner in which it could be seen as altering their current practice.

2. Outcome measures: - the applicability of individually defined outcome measures within research and clinical settings requires exploration; such measures may provide a means of addressing many of the current limitations in the evidence base for mental health practice (Greenhalgh et al., 2014), although further research is clearly necessary to develop the applicability of this approach across a variety of clinical scenarios. Such research may be valuable however in demonstrating the efficacy of recovery oriented care.

3. Integration into practice: - Further research is necessary to better map and understand the potential benefits and barriers to the inclusion of peer support and other models of clinical care.

Once the decision to implement recovery oriented care has been taken models, such as normalisation process theory, may be of use to specific institutions in mapping which areas of need are most pertinent to their specific situation. Generally, it can be argued however that a greater body of evidence, as well as models of practice, are required if the initial stage of *coherence* is to be met. The research outlined above may provide some means of addressing this.

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Appendix 1 – Individual interview participant information sheet

The front page from the PIS is shown below – the full form is available at www.recoverypd.wordpress.com

Greater Manchester West **NHS**
Mental Health NHS Foundation Trust

MANCHESTER 1824
The University of Manchester

Experiences of Personal Recovery in Personality Disorder

Research team - Dr Andrew Shepherd, Chief investigator, Dr Michael Doyle, Dr Caroline Sanders and Professor Jennifer Shaw

We would like to invite you to participate in our research study. The following information will provide you with details relating to the project. Prior to your agreeing to participate in the project you will be given an opportunity to discuss this information with a member of the research team. Should you have any questions these will be addressed. If you agree to participate in the research you will be asked to sign a consent form indicating that you have read and understood this information and agree to take part. Please pass on this information to others who may be interested in participating.

This project is being conducted as part of a doctoral research degree (PhD) and is supported by the University of Manchester.

What is the purpose of the study?

Personal Recovery in mental disorder is described as a unique process of making sense of personal experience and change in the context of mental distress. Understanding ideas of personal recovery in mental disorder is therefore essential to allow the best support for individuals throughout their contact with the mental health services. Research has been conducted trying to understand recovery in mental disorders such as Schizophrenia and Depression. Despite personality disorder being a common disorder, affecting 1 in every 25 people in the general community, very little research has been conducted trying to understand the recovery process for these people.

The current project seeks to better understand the experience of those with a personality disorder. The research will consist of individual interviews with people who have received care from the mental health services in either community, hospital, prison, probation or secure hospital settings. Later in the project focus group meetings will be used to talk through findings from the individual interviews.

Community participant information sheet v 5. Protocol v 4. 19th February 2014

Appendix 2 – Participant consent form

Greater Manchester West **NHS**
Mental Health NHS Foundation Trust

MANCHESTER
1824
The University of Manchester

Study Number: DRF-2013-06-122

Participant Identification Code:

CONSENT FORM FOR INDIVIDUAL INTERVIEW

Title of Project: Personal Recovery in Personality Disorder - seeking to understand service user experiences in community and forensic settings

Name of Researcher: Dr Andrew Shepherd

Please initial all boxes that you consent to

1.   I confirm that I have read and understand the information sheet dated 19th February (version 5) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.

2.   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.

3.   I understand that relevant sections of any data collected during the study, may be looked at by individuals from the University of Manchester, from regulatory authorities or from the NHS Trust, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records.

4.   I understand that any interviews in which I participate will be audio recorded.

5.   I understand that anonymous brief quotes from these interviews may be used in publications associated with this project.

6.   I agree to take part in the individual interview portion of the study and for interview information to be used in representations of research findings; with any restrictions that I have set in place.

_____   _____   _____
Name of Participant   Date   Signature

_____   _____   _____
Name of Researcher   Date   Signature

Consent form date of issue:
Consent form version number: 4 19th February 2014

Appendix 3 – Individual interview schedule

Interview Topic guide

Participant ID Code	
Participant Age	
Gender	▢ Male ▢ Female
Ethnicity (participants' own term)	
Length of contact with mental health services	

Introduction

- Explain purpose of research project

- Ask if participant has had opportunity to read information provided

- Check they are happy to participate

- Ask regarding audio-recording

- Ask if there are any questions arising from the information sheet

- Prompt for questions

- **Offer consent form and work through with participant**

Interview themes

The aim of the interview is to support the participant in offering a narrative description of their experiences, contact with mental health services and hopes for future change.

Topics to be covered:

Guide	Illustrative questions
Impact of mental distress	1. What experiences first led to you making contact with the mental health services? 2. When did you first have these experiences? 3. How have they affected your life?
First contact	1. Can you talk through your first contact with the mental health services? 2. What happened next? 3. What are your thoughts on this contact now?
Treatment offered	1. What support or treatments were you offered? [Psychological, Pharmacological, Social] 2. What support do you receive now from the services? 3. What helps most with your difficulties?

Guide	Illustrative questions
Goals treatment	1. What do you hope for from your contact with the mental health services? 2. Do you have any goals you have set yourself? 3. Do you feel your goals match with the support offered?
Recovery	1. What does recovery mean to you? 2. Have you accessed any specific services that supported you in this?

Who provides support	1. Can you describe anyone who has given you support?
	  A. Relationships
	  B. Family
	  C. Friends
	  D. Colleagues
	  E. Charities
	  F. Mental Health professionals
	  G. Other professional agencies?
	2. Who would you say is your closest support?
	3. Do you have someone you feel comfortable to confide in?
	4. Is this type of support important to you?
	5. What support is most helpful to you?

What has changed	1. Thinking back to before your contact with the mental health services, what change do you notice in yourself? 2. Have you noticed any change in yourself since your contact with the services? 3. Is this positive change?
Hoped for change	1. Thinking to the future - are there any changes you would like to see? 2. What support would you like to receive to reach this desired change?
Any further material	1. Is there anything you would have liked to discuss today that you feel we haven't touched on?

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Appendix 4 – Focus group interview schedule

Experiences of personal recovery in personality disorder

Focus group topic guide

Focus group meeting	
Focus group setting	
Participant Descriptions / ID	

Introduction

- Explain purpose of research project

- Ask if participants have had opportunity to read information provided

- Participation is voluntary and can be withdrawn at any time

- Material discussed within the group should be treat as confidential to the group

- Please respect the experiences and opinions of others - all are valid and there are no right and wrong answers

- We wish to hear everyone's views

- Ask regarding audio-recording

- Ask if there are any questions arising from the information sheet

- **Offer consent form and work through with participants**

Interview themes

The aim of this focus group is to discuss the experience of personal recovery in personality disorder. We may draw on some examples of topics covered during the individual interviews in this discussion.

Guide	Summary for discussion
What is personal recovery in personality disorder?	
Recovery from what?	*Understandings of personality disorder?*
	Understanding and recovery?
	Difficulties with moral implications?
	Stigma?
What changes?	*Stability*
	Recovery of normality
	Making sense of self
Role of the mental health services	*Professional relationship*
	Admission
	Drug treatment
	Discharge - when does treatment end?

Appendix 5 – NRES approval

03 March 2014

Dr Andrew Shepherd
National Institute for Health Research Doctoral Research Fellowship
GMW Mental Health NHS Foundation Trust
Research and Development Office, Room F.036, Harrop House
GMW Mental Health NHS Foundation Trust
Bury New Road, Prestwich, Manchester
M25 3BL

Dear Dr Shepherd

Study title:	**Personal Recovery in relation to Personality Disorder - Seeking to understandservice user experiences in community and forensic settings**
REC reference:	**14/EE/0029**
IRAS project ID:	**138470**

Thank you for your letter of 19 February 2014, 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 Chair.

We plan to publish your research summary wording for the above study on the HRA website, together with your contact details, unless you expressly withhold permission to do so. Publication will be no earlier than three months from the date of this favourable opinion letter. Should you wish to provide a substitute contact point, require further information, or wish to withhold permission to publish, please contact the REC Manager, Alka Bhayani.

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.

Appendix 6 –NOMS approval

Ministry of JUSTICE
National Offender Management Service

Dr Andrew Shepherd
GMW Mental Health NHS Foundation Trust
Research and Development Office,
Room F.036, Harrop House,
GMW Mental Health NHS Foundation
Trust,
Bury New Road,
Prestwich,
Manchester
M25 3BL
andrew.shepherd3@nhs.net

National Offender Management Service
National Research Committee
Email: National.Research@noms.gsi.gov.uk

12 February 2014

<u>**APPROVED SUBJECT TO MODIFICATIONS – NOMS RESEARCH**</u>

Ref: 2013-282
Title: Experiences of personal recovery in Personality Disorder

Dear Dr Shepherd,

Further to your application to undertake research across NOMS, the National Research Committee (NRC) is pleased to grant approval in principle for your research. The Committee has requested the following modifications:

- The following should be included in the participation information sheets/consent forms:
  o   It must be made clear to research participants that they can refuse to answer individual questions and that this will not compromise them in any way.
  o   Participants should be informed for how long their data will be held.
- The following should also be included in the participation information sheet/consent form for offenders:
  o   It needs to be clear that the following information has to be disclosed: behaviour that is against prison rules and can be adjudicated against, illegal acts, and behaviour that is potentially harmful to the research participant (e.g. intention to self-harm or complete suicide) or others.
  o   Potential avenues of support should be specified for those who are caused any distress or anxiety.
- It is recommended that a recording device with encryption technology is used. Recordings should be wiped from this device once successfully transferred to the secure University of Manchester server.

Please note that there will be a transition from Probation Trusts to the National Probation Service/Community Rehabilitation Companies on the 1st June which could impact upon the assistance provided for the running of the study. Please also note (as set out in the NOMS Research Applications Instruction) vouchers should not be given to offenders while under prison or probation supervision. Payment will only be considered in very exceptional circumstances – there will need to be strong evidence that response rates have become problematic in the approved study before seeking approval through the NRC for payments to be made.

Before the research can commence you must agree formally by email to the NRC (National.Research@noms.gsi.gov.uk), confirming that you accept the modifications set out above and will comply with the terms and conditions outlined below and the expectations set out in the NOMS Research Instruction

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Appendix 7 – Copyright agreements

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Appendix 8 – Alternative format submission approval

THE UNIVERSITY OF MANCHESTER

Faculty of Medical and Human Sciences

PERMISSION TO SUBMIT A PHD THESIS IN ALTERNATIVE FORMAT
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We confirm that the following student in the Faculty of Medical and Human Sciences, has been granted permission by his/her supervisor to submit a PhD thesis in alternative format approved under the regulations, including sections which are in a format suitable for submission for publication or dissemination.

Name: Andrew SHEPHERD

Degree programme: PhD Medicine (BBMH)

Registration Number: 7849836

School: Medicine

This form should be submitted with the thesis.

Signed: _____   Date: 04.02.16
                    Faculty Graduate Education Manager
                    Faculty of Medical and Human Sciences Graduate Office

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