

The role of stigma and self-stigma in recovery from psychosis.

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by

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Abstract

Stigma is a widely researched concept, with public stigma, courtesy stigma and self-stigma (or internalised stigma) frequently cited as issues for those experiencing mental health issues.

Individuals with experiences of psychosis are some of the most stigmatised in society, and yet the consequences of stigma on outcomes in psychosis are unclear. The four studies presented in this doctoral thesis used mixed methods to examine the impacts of stigma on recovery from psychosis, and the psychological mechanisms through which these effects might occur. It addresses two areas lacking in sufficient research within the stigma literature: clarity in the relationship between experiences of stigma and internalised stigma; and the effects of stigma on outcomes in psychosis. In particular it examines the relationship between stigma and internalised stigma with two diagnoses on the psychosis spectrum: schizophrenia and bipolar disorder.

The study reported in Chapters 3 and 4, was a qualitative investigation based on interviews with 19 individuals who had received a diagnosis of either schizophrenia or bipolar disorder. The objective of the investigation was to explore how individuals processed receiving a diagnosis of schizophrenia or bipolar disorder, and how perceived, experienced and internalised stigma influenced the participants' self-perception, interactions and recovery feelings. Three overarching themes were identified which were negatively affected by stigma: reactions and responses; relationships; and recovery. The study reinforced the notion that stigma is a significant concern for service-users with diagnoses of bipolar disorder and schizophrenia, and was pervasive in all spheres of life; ultimately impacting on hopes for the future.

An unexpected aspect of the qualitative interviews was the participants' focus on the role of mental health services and experiences of treatment, particularly antipsychotic medication. As this is clearly an important aspect of the participants' experiences of living with psychosis, this was written

up separately, forming Chapter 4. Five overarching themes were identified: living with medication; reinforcing stigma; involvement in care; unmet needs; and positive aspects of care. The findings from this study indicated that whilst service-users made positive reports of aspects of both medication and clinical services; they had extensive concerns about the use of medication, and felt limited in their choice of alternatives. Moreover, service-users felt they lacked autonomy, were not involved in care decisions, and thought their contact with services lacked the 'human touch' and could be both invalidating and frustrating.

The study presented in Chapter 5, used an epidemiological, longitudinal dataset (n=80) that formed part of independent research commissioned by the National Institute for Health Research (NIHR) under its Programme Grants for Applied Research scheme (RP-PG-0606-1086). This study aimed to examine how stigma impacts on symptomatic and subjective recovery from psychosis, both concurrently and longitudinally. We also aimed to investigate whether self-esteem and hopelessness mediated the observed associations between stigma and outcomes. In cross sectional regression and multiple mediation analyses of the baseline data, we found that stigma predicted both symptomatic and subjective recovery, and the effects of stigma on these outcomes were mediated by hopelessness and self-esteem. When the follow-up data were examined, stigma at baseline continued to predict recovery judgements and symptoms. However, self-esteem only mediated the effect of stigma on passive social withdrawal.

The study reported in Chapter 6 utilised a clinical sample of 59 service-users with a diagnosis of either schizophrenia or bipolar disorder. The objectives of the study were to assess the impact of stigma on subjective recovery from psychosis, and whether self-esteem and internalised stigma mediates the observed associations between stigmatizing experiences and outcome, thus clarifying the relationship between stigma, self-stigma and recovery. Diagnosis was a persistently significant factor in all analyses, suggesting a negative effect of the term 'schizophrenia' on subjective recovery perceptions. In a multiple serial mediation analysis, experiences of stigma predicated subjective

recovery and this effect was mediated through internalised stigma, which consequently impaired self-esteem.

Findings from these studies suggest that stigma reduces individual's perceived ability to recover, impairs individual's perceptions of their progress in recovery, and negatively impacts on psychosis symptoms. These effects occur predominantly through the internalisation of stigma, causing devaluation of self-image and consequently reducing self-esteem. The findings further suggest that whilst the experiences of individuals diagnosed with bipolar disorder and schizophrenia are predominantly similar, 'schizophrenia' is an inherently negative term which affects subjective recovery perceptions even when controlling for symptoms. Finally, it is evident that help-seeking is not always helpful, and there are numerous issues with medication and mental health services that can create feelings of hopelessness and reinforce stigmatising stereotypes of severe mental illness.

Overall, the findings have significant clinical implications. Internalised stigma is an important psychological mechanism in recovery, and directly links to experiences of stigma. There is a need for clinical services to work in a stigma-informed way in an effort to reduce the impact of stigma post-diagnosis, as well as the development of interventions aimed at preventing stigma from being internalised. Interventions aimed at improving self-esteem and reducing hopelessness for psychosis-spectrum service-users are needed to further reduce the effects of stigma on recovery. Moreover, there is a need for clinical services to reduce behaviours that reinforce stigma, and work collaboratively and transparently with service-users; ensuring that goals for treatment correspond between clinicians and consumers to provide a more patient-centred approach to care.

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INSTITUTE OF PSYCHOLOGY, HEALTH AND SOCIETY
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DECLARATION IN HIGHER DEGREE THESES

DECLARATION

This thesis is the result of my own work. The material contained in the thesis has not been presented, nor is currently being presented, either wholly or in part for any other degree or qualification.



Signed (candidate)

Date30/11/2016..... (candidate)

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Chapter 1:

Psychosis: Approaches, influences and outcomes.

1.1. Abstract

This review aims primarily to examine the different approaches to the determinants of psychosis, particularly in relation to schizophrenia and bipolar disorder, by presenting the some of the conventional and non-traditional theories, evidence and criticisms in the current literature. The second aim of the review is to discuss the issues and controversies around diagnosing psychotic experiences, by challenging the use of diagnostic categories in terms of reliability, validity, heterogeneity of symptoms and comorbidity with alternate diagnoses. Latterly, in light of the presented theories, the review aims to explore what the concept of 'recovery' means in relation to psychosis, and how this might be perceived differently between clinicians, individuals with experiences of psychosis, and their support networks.

*“Much madness is divinest sense
To a discerning eye;
Much sense the starkest madness.
'T is the majority
In this, as all, prevails.
Assent, and you are sane;
Demur,—you 're straightway dangerous,
And handled with a chain.”*

Emily Dickinson, 1924

1.2. Historical context of psychosis

Current concepts of bipolar disorder are commonly thought to originate from two mid-nineteenth century French psychiatrists: Jules Baillarger and Jean-Pierre Falret. Baillarger described a mental illness defined by recurrent oscillations between excitement and depression which he termed “folie à double forme” (dual-form madness). Around the same time Falret described a similar condition “folie circulaire” with the distinction of defined periods of symptom-free recovery between each cycle of depression and mania (Azorin et al., 2011; Haustgen & Akiskal, 2006; Koukopoulos et al., 2006). Falret also noted that the illness appeared to be clustered in families, and suggested a genetic origin.

Some years later German psychiatrist Emil Kraepelin began to categorise and study the natural course of mental illness in patients under his care. Through his observations he began to cluster symptoms together with a view to developing distinct diagnoses, one of which was ‘manic depressive psychosis’ (Bentall, 2009). As with Falret, Kraepelin also noted that periods of acute illness in manic-depressive patients were followed by relatively symptom-free intervals. This was a critical distinction with what Kraepelin referred to as ‘dementia praecox’ (premature senility), and what we today call schizophrenia which he understood to be a progressive neurogenerative disease, without remission (Decker, 2004). Kraepelin further distinguished manic-depression from dementia praecox, suggesting that it did not lead to the same loss of cognitive functions and had a better prognosis (Ebert & Bär, 2010).

However, Carl Gustav Jung was the first to distinguish different types of manic-depression. In 1903 he presented a number of case studies of patients who exhibited the bi-phasic affective symptoms of manic-depression, yet had no experiences of psychosis (Jung, 1970). Today, Jung's distinction is referred to as 'bipolar I' (with possible psychosis) and 'bipolar II' (hypomania without psychosis), with a third type of 'cyclothymia' or sub-threshold bipolar disorder also added; the term "bipolar" only being coined in 1953, by another German psychiatrist, Karl Kleist (Angst & Marneros, 2001). 'Dementia praecox' was also renamed, but much earlier in 1911 by Eugene Bleuler who developed the term 'schizophrenia' from the Greek 'skhizein' meaning 'to split' and 'phren' meaning 'soul, spirit, mind', which he felt better described the core symptom of "breaking up or splitting of psychic functioning", or psychotic experiences (Fusar-Poli & Politi, 2008).

Despite name changes to Kraepelin's 'manic depressive psychosis' and 'dementia praecox', his core principles of definable diagnostic categories of mental illness, and biogenetic origins of disease have remained central to modern psychiatry (Ebert & Bär, 2010). Palm & Möller (2011) refer to a number of psychiatrists who criticised Kraepelin's theories. Much of the debate focused on the diagnosis of 'manic depressive psychosis', whereas 'dementia praecox' was more readily accepted, and viewed by some as a revolutionary step in psychiatry. Thalbitzer was one of many who criticised the over-simplicity of Kraepelin's distinction of two forms of severe mental illness, and suggested that the symptoms could present in infinitely different combinations. Similarly, others felt that the symptoms of 'manic depressive psychosis' were often also seen in patients diagnosed with 'dementia praecox', suggesting a greater overlap between the two than Kraepelin theorised. Further criticism focused on the delineation between periods of remission and less acute symptoms, and difficulties in cohesively classifying depression (or 'melancholia'). Whilst 'dementia praecox' was less scrutinized, one of Kraepelin's

disciples Oswald Bumke, felt that it was too readily falsely diagnosed in young people (Palm & Möller, 2011).

Kraepelin's work was also criticised at a methodological level. For example, Alfred Hoche, a psychiatrist noted for his writings on eugenics and euthanasia, and co-author of the Nazi party phrase "*Lebensunwertes Leben*" (life unworthy of life), criticised Kraepelin's work as diagnostically and prognostically unsatisfactory. Pioneer child psychiatrist August Homburger suggested that Kraepelin's system lacked causal links between onset, development and outcomes of mental illness. Yet many of these arguments were forgotten in the wake of the First World War, and Kraepelin's classification system of mental disorders became an accepted standard (Palm & Möller, 2011), which has substantially contributed to current classification systems such as the American Psychiatric Association's (APA) Diagnostic and Statistical Manual of Mental Disorders (DSM) (Ebert & Bär, 2010).

1.2. Biogenetic approaches to psychosis

Today, biomedical approaches to the origins of schizophrenia and bipolar disorder have remained the dominant view, and typically form the basis of treatment for mental disorders. These approaches suggest that experiences of psychosis are largely caused by genetic predispositions which cause abnormalities in brain chemistry or structure. Today two approaches are used to study the genetic determinants of mental illness. In classical or quantitative behavioural genetics, the extent to which characteristics are shared by family members is studied, with the aim of quantifying how inheritable a characteristic is. Newer molecular genetic methods focus on searching for specific gene sequences that are thought to be involved in the development of the inherited traits.

The basis of classical genetic research strategies is that we share alleles (gene variations) with other people according to how closely we are related to them. For example, half of our alleles are obtained from each parent, as with their own parents, meaning that we share half of our alleles with each our parents, and a quarter with each of our grandparents. Fraternal siblings and non-identical (dizygotic) twins share a random combination of alleles from each parent, so on average they will have half of the same alleles in common. Identical twins (monozygotic) are genetically identical, sharing all of their alleles, but may be differently affected by factors during development in the uterus.

The commonest method of examining genetic traits is the family study, in which cases of an illness such as schizophrenia are traced within large families. If the illness has a genetic basis, we expect to see it occur more frequently in family members who are closely related to the individual, than those who are distantly related. The risk of developing an illness as an inherited characteristic is compared to the risk seen in the general population, which for schizophrenia and bipolar disorder is estimated to be around 1-2% (Craddock & Jones, 1999; Kerner, 2014). Twin studies are also widely used to explore the heritability of mental illnesses. If genes are significant in the development of mental illness, we would expect to see a higher likelihood of an individual suffering from the same illness as their identical twin, and lower concordance for non-identical twins and fraternal siblings. As identical twins are likely to be brought up in the same environment, to control for environmental effects researchers also make use of adoption studies. The findings of these types of studies have been variable. Early studies examining the heritability of bipolar disorder have been criticised for not making sufficient distinction between bipolar disorder and unipolar depression (Craddock & Jones, 1999). Similarly, studies looking into the heritability of schizophrenia have been criticised for using unreliable diagnostic criteria (Bentall, 2009).

Nevertheless, the evidence from family, twin and adoption studies has led to the assumption that schizophrenia is between 64% and 85% heritable (Lichtenstein et al., 2009; Sullivan, Kendler, & Neale, 2003) and bipolar disorder is 40-70% heritable (Craddock & Jones, 1999). Under an additive model on heritability, the remaining variance is assumed to be due to environmental factors. However, Joseph (2004) discusses the methodological problem in using family, twin and adoption studies, suggesting that these types of research do not provide the conclusive evidence of genetic causation as is supposed. In a review of available data Joseph (2004) found concordance rates for schizophrenia to be 24% for identical twins, and 4.5% for non-identical twins, leading him to conclude that the heritability of the schizophrenia may be lower than has previously been suggested. Similarly Torrey, in a review of twin study evidence, estimated the pairwise concordance rate for schizophrenia to be 28% for identical twins and only 6% for non-identical twins. The findings for bipolar disorder were higher, suggesting 56% concordance for identical twins, and 14% for non-identical twins. Based on this evidence we might assume that around half of people who inherit genes for bipolar disorder actually develop it, and only one quarter of people who inherit genes for schizophrenia; suggesting that non-genetic factors must have a significant influence (Bentall, 2009).

Apart from the variance that cannot be explained by the genetics, classical genetic research methods suffer from a number of limitations. Families selected from specific hospital registers may not be representative of the population (Kendler et al., 1995), for example if diagnostic criteria differs from others in the reference population (Wray & Gottesman, 2012). Secondly, family samples tend to be small, resulting in large sampling variances, and have been criticised for being susceptible to over-reporting (Guo, 1998). These problems can be overcome by using national data (Kerner, 2014). For example, one Swedish study comprising over nine million individuals from over two million families represented all individuals born between 1932 and 2002 and all hospital records since 1973 (Lichtenstein et al., 2009), however this is not typical of the data normally available.

Due in part to these limitations, coupled with advances in the methods available, genetic scientists have moved towards searching for specific genes that cause schizophrenia and bipolar disorder. There have been no breakthrough discoveries (Joseph & Ratner, 2013), however some research has found particular genes related to risk of psychosis. For example, the neuregulin 1 gene (Georgieva et al., 2008; Stefansson et al., 2002), GRIN2B gene (Martucci et al., 2006) and the dysbindin gene (Papaleo & Weinberger, 2011). However the findings have often not been replicable (Okochi et al., 2009) and some researchers are now suggesting that multiple genes may be involved in risk for psychosis (not for a specific diagnosis), each contributing a very small effect (Owen, 2012). Whilst researchers suggest that identifying genes that contribute to psychosis risk will improve treatments (Xu et al., 2014), there are obvious concerns about the consequences of finding a genetic basis for mental illness. Historically we have seen arguments made for eugenics and euthanasia on the basis of lesser evidence, and the potential for anxiety, stigmatization, discrimination and the potential burden on family relationships should not be underestimated (Kerner, 2014).

Outside of genetics, psychosis has been considered to stem from abnormalities in the brain. Research has found both functional and structural differences found in individuals with a diagnosis of schizophrenia when compared to controls (Chua & McKenna, 1995; P. J. Harrison, 1999; Karlsgodt, Sun, & Cannon, 2010). For example, studies have found ventricular enlargement (Reveley, 1985), reduced volume of grey matter (Job et al., 2002) and reduced hippocampal volume (Nelson, Saykin, Flashman, & Riordan, 1998). Similarly, patients with bipolar disorder diagnosis have also been found to have reduced hippocampal volume (Frazier et al., 2005), as well as enlarged ventricles and reduced total cerebral volume (DelBello, Zimmerman, Mills, Getz, & Strakowski, 2004; Strakowski et al., 2002). These findings appear to suggest that schizophrenia and bipolar disorder are the result of functional and structural brain abnormalities. However similar abnormalities have been found in people with other diagnoses, and even within the general population. For example, Copolov and Crook (2000) found overlap

in ventricle enlargement between individuals with a schizophrenia diagnosis and the general population. Similarly, reduced hippocampal volume (Nemeroff et al., 2006) and reduced volume of anterior cingulate (Kitayama, Quinn, & Bremner, 2006) have been found in individuals with post-traumatic stress disorder.

Interpretation of these findings is complex. It is possible to argue that the structural abnormalities observed in psychosis patients precede the onset of any illness (Vita, De Peri, Silenzi, & Dieci, 2006), however there is also evidence to suggest that antipsychotic medications may be involved. The use of first generation antipsychotics has been associated with reductions in grey matter volume in the frontal cortex (Vita & De Peri, 2007). Similarly the enlargement in ventricles that has been observed in patients with diagnoses of schizophrenia and bipolar disorder has been associated with long-term antipsychotic medication use (Ho, Andreasen, Ziebell, Pierson, & Magnotta, 2011). An alternative explanation comes from the a traumagenic neurodevelopmental (TN) model approach to psychosis which suggests that the observed structural abnormalities could be the brain adapting in response to environmental stressors (Read, Perry, Moskowitz, & Connolly, 2001; Read, Fosse, Moskowitz, & Perry, 2014), in which case, abnormalities in the brains of people diagnosed with bipolar disorder or schizophrenia would not be congenital, and are unlikely to be the ultimate cause of associated symptoms. Research into the brain differences is impeded by the lack of contextual comparisons available. Ideally, we would need to see participants brains prior to the onset of any illness, or in the very least, prior to the use of antipsychotic medication to gain a clearer picture of any structural difference or change.

1.3. Psychosocial approaches to psychosis

The TN model of psychosis (see Read et al., 2001; Read et al., 2014) highlights the plausibility that environmental factors play a significant role in the development of psychosis. For example, research has shown that experiences of trauma, such as childhood sexual abuse (Hoy et al.,

2012) and maltreatment (De Bellis et al., 1999) can result in some of the observed structural brain changes outlined above. Research has found substantial evidence to support the role of childhood trauma in the development of psychosis. Studies into bipolar disorder have found child abuse and neglect to be linked to severity of mania, the number of manic episodes experienced, clinical course and, higher rates of suicide attempts (Garno, Goldberg, Ramirez, & Ritzler, 2005; Leverich et al., 2002; Read, Os, Morrison, & Ross, 2005). Childhood sexual abuse has also been repeatedly linked to specific psychotic symptoms, such as hallucinations, delusions and thought disorder (Hammersly et al., 2003; Janssen et al., 2004; Read, Agar, Argyle, & Aderhold, 2003; Read & Argyle, 1999).

There have been two meta-analyses examining the causal role of childhood trauma on subsequent psychotic disorders (Matheson, Shepherd, Pinchbeck, Laurens, & Carr, 2012; Varese et al., 2012). The Varese et al. (2012) meta-analysis pooled different studies (case-control, prospective, quasi-prospective, and cross-sectional) together and found that psychosis was 2.38 times more likely to develop if an individual had experienced sexual abuse, 2.95 times more likely with experiences of physical abuse, and 3.40 times more likely with experiences of emotional abuse. Furthermore, of the ten studies which looked for a dose-response relationship between trauma and psychosis, nine found one. The Matheson et al. (2012) study had similar findings, indicating that individuals with a schizophrenia diagnosis were 3.60 times more likely to have experienced childhood adversity (sexual abuse, neglect, physical abuse, or emotional abuse) than non-psychiatric controls. Researchers have speculated that if we assume causality, erasing the history of childhood trauma would reduce the number of individuals experiencing psychosis by 33%; suggesting that the impact of environment on the development of psychosis is substantial (Varese et al., 2012).

Further research into psychosocial factors has found a number of other risk factors which may be linked to the development of psychosis, even prior to childhood experiences; for example multiple risks have been associated with pregnancy and birth. A meta-analytic review of studies examining birth complications in relation to the development of psychosis found that pregnancy complications (e.g. pre-eclampsia, gestational diabetes, bleeding, rhesus incompatibility), abnormal foetal development (e.g. low birth weight, reduced head circumference, congenital malformations), and delivery complications (e.g. asphyxia, uterine atony, emergency caesarean section) have been indicated as increasing the risk of psychosis later in life (Leask, Done, & Crow, 2002; Messias, Chen, & Eaton, 2007). It has been theorised that psychosis as a result of birth complications may be due to foetal malnutrition (Susser & Lin, 1992), extreme prematurity, or inadequate oxygen or blood supply to the foetus (Byrne, Agerbo, Eaton, & Mortensen, 2004; Isohanni et al., 2000).

Less easily explained is the association between psychosis and season of birth. There have been numerous studies into this phenomenon, coming from researchers in both the Northern and Southern hemispheres (Berk et al., 1996; Davies, Welham, Chant, Torrey, & McGrath, 2003; McGrath & Welham, 1999). The majority of these studies have concluded that individuals who are given a diagnosis of schizophrenia are more likely to be born in winter, and a number of studies have reported similar findings for individuals diagnosed with bipolar disorder (Torrey, Miller, Rawlings, & Yolken, 1997). Whilst there is only a reported 5-10% increase in risk, the finding has been replicated repeatedly. One possible explanation is that the second trimester of pregnancy occurs in the height of the influenza season and that maternal infections during this period increases the risk for schizophrenia for the child (Brown et al., 2002, 2004; Munk-Jørgensen & Ewald, 2001). Aside from parental influenza, childhood illnesses have also been linked to psychosis, for example tuberculosis and meningitis (Messias et al., 2007; Torrey et al., 1997).

Multiple other factors have been identified as potential risk factors such as being the product of an unwanted pregnancy (Myhrman, Rantakallio, Isohanni, Jones, & Rartanen, 1996), separation from parents (Morgan & Fisher, 2007), insecure attachment relationships (Korver-Nieberg, Berry, Meijer, & De Haan, 2014; Read & Gumley, 2010), trauma in adulthood (Read et al., 2005; Scott, Chant, Andrews, Martin, & McGrath, 2007), minority ethnic status (Eaton & Harrison, 2000), cannabis use (Arseneault et al., 2002; van Os et al., 2002), relative poverty and social inequality (Burns, Tomita, & Kapadia, 2014; Kirkbride, Jones, Ullrich, & Coid, 2014; Wickham, Shryane, Lyons, Dickins, & Bentall, 2014) and living in urban environments (Vassos, Pedersen, Murray, Collier, & Lewis, 2012). This plethora of evidence has led researchers to argue that psychosocial risk factors likely play a key causal role in the development of psychosis (Bentall & Varese, 2012; Varese et al., 2012).

1.4. Reliability and validity of diagnosis

They called me mad, and I called them mad, and damn them, they outvoted me.

-Nathaniel Lee (n.d.)

By the end of the Second World War the American Psychiatric Association (APA) had formed a group to develop a formal diagnostic system that codified current clinical concepts, and the first Diagnostic and Statistical Manual of Mental Disorders was published in 1952. The diagnostic categories for both the DSM-I and the DSM-II were based on the consensus agreement of a panel of psychiatrists. Critics suggested that the system was inadequate due to the use of vague definitions and poor reliability (Beck, Ward, Mendelson, Mock, & Erbaugh, 1962). The third edition of the DSM provided a radical change of perspective, shifting from a psychodynamic framework to a biomedical model of mental illness, informed by greater reliance on empirical research, and providing more

distinct boundaries between diagnoses (Nemadé & Dombeck, 2009). The third edition also made the change from the term 'manic-depression' to 'bipolar disorder'. The DSM used a 'checklist' style of classification: in order to make a diagnosis using the DSM-III, the signs and symptoms listed had to be present in the patient. The authors of DSM-III, such as Robert Spitzer, claimed that this development of clearly defined symptoms made the system inherently reliable (Spitzer, 2001).

With the aim of improving and refining diagnostic classification, a revised version, DSM-III-R was released, narrowing the definition of schizophrenia, and broadening the definition of bipolar disorder to include a number of sub-types. Research suggests that the revised definition of schizophrenia did not lead to improvements in validity or homogeneity, and potentially excluded individuals who would previously been diagnosed under DSM-III, most notably because of the requirement that symptoms were present for 6 months (Fenton, McGlashan, & Heinsen, 1988; Isohanni et al., 1997). Subsequently, the DSM has undergone a number of revisions (DSM-IV & DSM-IV-TR) resulting in the inclusion of negative symptoms for schizophrenia (Tandon et al., 2013) and the differentiation of bipolar I and II. The most recent edition, DSM-V removed the schizophrenia sub-types (e.g. catatonic, paranoid) due to poor reliability and validity, and limited stability (Rodríguez-Testal, Senín-Calderón, & Perona-Garcelán, 2014), however with the existing criteria for schizophrenia in DSM-V there are a potential 12 different ways in which two individuals can meet the criteria for a schizophrenia diagnosis without having any symptoms in common, suggesting continuing difficulties with reliability and high heterogeneity within the diagnosis (Read & Dillon, 2013). This is commonly referred to as poor inter-rater reliability: the consistency in which two clinicians can deliver the same diagnosis if assessing the same person.

Reliability can be estimated through the use of the kappa coefficient statistic (Cicchetti, 1994). Cicchetti proposes that if the kappa coefficient is below 0.40, the level of clinical agreement is poor; 0.40-0.59 is fair, 0.60-0.74 is good, and above 0.75 indicates excellent levels of clinical agreement. In the DSM V field trials, clinicians diagnosing schizophrenia were said to be in "good agreement" yet

the reported kappa coefficient was only 0.46 (Freedman et al., 2013; Regier, 2007). The initial reliability trials for DSM-V also examined test-retest reliability: the likelihood of the same clinician arriving at the same diagnosis for the same patient at two separate time-points. The test-retest reliability findings ranged from 0.46 (Regier, Kuhl, & Kupfer, 2013) to 0.79 (Narrow et al., 2013) for psychosis, when assessed from 4 hours to 2 weeks apart. How these time-frames relate to real-world patient contact and experiences of diagnosis is unclear.

A second issue with the concept of diagnoses of mental illness is their validity. A diagnosis cannot be valid without first being reliable; and as the evidence for the reliability of psychosis diagnoses is persistently poor, some argue that investigating the validity of schizophrenia or bipolar disorder as a diagnosis is meaningless (Bentall, 2003; Kinderman et al., 2013; Read 2013a). Jim van Os further argues that if the diagnostic categories are not valid, they have drawn attention away from the true morbidity of psychotic disorders and hampered scientific progress in aetiology, treatment and prognosis for mental health issues (2009).

Predicative validity is the extent to which a diagnosis predicts a particular outcome; this is particularly important for the planning, design and implementation of clinical interventions. This is the most commonly used criteria to evaluate diagnostic criteria (Fenton, Mosher, & Matthews, 1981). The conventional view of psychotic disorders, particularly schizophrenia, is that there is a poor prognosis and recovery is unlikely; what Karon and Widener (1999) refer to as the “myth of incurability”. In reality studies have found wide heterogeneity in the very long-term (20+ years) outcome for schizophrenia, despite differences in the diagnostic criteria used (Harding & Zahniser, 1994; Harrison, Gunnell, Glazebrook, Page, & Kwiecinski, 2001). These studies have consistently found half to two thirds of patients show significant improvement or recovery, even in some very chronic cases. However, what constitutes improvement, recovery or a good measure of outcome in psychosis is highly debated (Bracken et al., 2012; Longden, 2010), making the ability of a diagnosis to meaningfully predict outcome difficult.

A further issue in the validity and reliability of diagnostic categories is comorbidity. Whilst diagnostic categories aim to cluster symptoms into distinct disorders, individuals with diagnoses of schizophrenia and bipolar disorder are often given multiple additional diagnoses to adequately explain their experiences such as panic disorder, posttraumatic stress disorder (PTSD), obsessive-compulsive disorder (OCD), generalized anxiety disorder, and social anxiety disorder, substance misuse, and depression (Buckley, Miller, Lehrer, & Castle, 2009; Forty et al., 2014). Alternatively, many service-users are classified as “not otherwise specified” (NOS) because they do not fit into the DSM diagnostic pigeon-holes (Potuzak, Ravichandran, Lewandowski, Ongür, & Cohen, 2012). Symptoms of schizophrenia and bipolar disorder have also been evident in other diagnoses. For example, individuals diagnosed with major depression have reported delusional and hallucinatory symptoms (Serretti, Lattuada, Catalano, & Smeraldi, 1999). This evidence suggests that mental health problems do not naturally fall into discrete categories, and Bentall (2014) argues that these issues with classification have impeded the progress of psychosis research

1.5. Current concepts of psychosis

The criticism of traditional psychiatric approaches and the use of diagnostic categories has led to the development of a number of alternative theories of psychosis which could be adopted in place of the Kraepelinian system. It has been increasingly suggested that psychosis exists in the general population as a continuous phenotype rather than as an all-or-none phenomenon; evidence indicates that psychotic experiences may lie on a spectrum which runs between non-clinical members of the general population and individuals experiencing the most acute forms of mental distress. For example, psychosis-related symptoms such as paranoid beliefs have been reported by as much as 12.6% of the general public (Poulton et al., 2000). Similarly, a large scale study conducted by van Os et al. (2000) found that 17.5% of their general population sample (n=7076) reported at least one positive psychotic symptom. Further evidence from van Os, Linscott, Myin-Germeys,

Delespaul, and Krabbendam (2009) supports the notion that psychotic experiences are measurable in non-clinical populations, may lie on a continuum.

This evidence has informed the shift away from diagnostic categories and criteria, and has led to the development of symptom-based dimensional models of psychosis. Liddle (1987) first reported 3 clusters of positive, negative, and cognitive disorganization symptoms, but more recent studies agree that 4 or 5 dimensions can describe the psychosis construct, with positive symptoms, negative symptoms, disorganization, and affective symptoms most frequently reported (Potuzak et al., 2012). One such model has been developed by van Os and Kapur (2009), who have argued that psychotic disorders such as schizophrenia, schizo-affective disorder and bipolar disorder can be explained by a framework of five dimensions: psychosis symptoms (e.g. delusions, hallucinations), negative symptoms (e.g. blunted affect, emotional withdrawal); cognitive impairment (e.g. sustained attention); mania (e.g. hyperactivity); and depression. It remains to be determined whether other less frequently reported dimensions can be considered useful in a dimensional approach to psychosis, such as substance abuse, lack of insight, anxiety, cognitive functioning, hostility, and behavioural disturbance (Potuzak et al., 2012). Nevertheless, Borsboom & Cramer (2013) suggest that a dimensional approach to psychosis may allow for greater observation and study of how different symptoms interact, and how these interactions may impact on prognosis and treatment. Studying psychosis in this way may also allow further investigation into the risk factors and psychological mechanisms underpinning psychotic symptoms (Bentall, 2014).

1.6. Recovery in psychosis

The need to determine prognosis and outcomes are typically cited as arguments for the classification of psychotic experiences, but concepts of 'recovery' vary widely, lack clear definition and are notoriously difficult to quantify (Beck et al., 2012; Brown, Rempfer, & Hamera, 2008). The universal criteria for recovery have been defined as someone who is not currently exhibiting any

signs or symptoms of any mental illness and not currently taking any medications; someone who is working, relating well to family and friends, integrated into their community, and behaving in such a way as to not be detected as having ever been hospitalized for psychiatric problems (Harding & Zahniser, 1994). Yet, recovery has been described as a personal journey defined by the individual (Anthony, 1993). As such, it has been suggested that there is little relationship between clinical, research, and service-user definitions of recovery, with typical outcome measures excluding aspects of recovery that are meaningful for consumers. Clinical definitions of recovery focus on remission of symptoms, medication compliance, current functioning, reduced admissions and reduced relapse (Lam et al., 2011; National Institute for Health and Care Excellence, 2009); whereas service-user definitions are often much more humanistic, encompassing functionality, autonomy, wellbeing, personal growth and the re-establishment of personal and social identity (Andresen, Oades, & Caputi, 2003; Lam et al., 2011; Pitt, Kilbride, Nothard, Welford, & Morrison, 2007).

Dillon (2012) discusses the unique experience of recovery and the importance of subjectivity, suggesting that it cannot be captured by symptom reduction or measured functioning alone, but instead needs to value personal experience and the individual's perceived quality of life. Studies exploring more patient-centred concepts of recovery have highlighted psychosocial factors, self-esteem, the therapeutic alliance, a sense of control, feeling supported, and reduced stigma as key factors enabling a positive outcome (Ciompi, 1984; Harrison, Hopper, et al., 2001; Law & Morrison, 2014; Morrison et al., 2013; Read, Haslam, Sayce, & Davies, 2006). Moreover, research has found that people experiencing psychosis often use a spiritual or psychosocial framework to understand their experiences; emphasising the importance of traumatic life experiences and stress (Carter, Read, Pyle, & Morrison, 2016; Dudley, Siitarinen, James, & Dodgson, 2009). These findings have led The Schizophrenia Commission (2012) to advocate more patient-centred, empathic and non-judgemental approaches to mental health care provision, and a focus on the individual's understanding of their illness and experiences.

A systematic review of 97, predominantly qualitative, research papers which focused on service-user concepts of recovery led to the development of a conceptual framework consisting of 13 characteristics of the recovery journey and five recovery processes (the 'CHIME' model of recovery) (Leamy, Bird, Le Boutillier, Williams, & Slade, 2011). The characteristics of the recovery journey included the idea of recovery as an active process, a journey, a life-changing experience, a trial and error process, and something that is unique to the individual. They also included the notion that recovery is different from a 'cure', can occur without professional intervention and is aided by a supportive and healing environment. The CHIME model comprises of connectedness; hope and optimism about the future; identity; meaning in life; and empowerment. Connectedness refers to social aspects of recovery such as peer support, relationships and community. Hope and optimism about the future encapsulates the belief in the possibility of recovery, motivation to change, aspirations and positive thinking. The role of identity in the CHIME model refers to redefining positive identities during recovery and overcoming stigma. Meaning in life refers to developing meaningful roles and goals, quality of life and spirituality. Lastly, empowerment focuses on personal responsibility, control over life, and focusing on one's strengths. This model of recovery is firmly rooted in service-user concepts of recovery, yet drastically differs from the typical notions of recovery presented in the biomedical model.

Studies examining comparing clinician-rated recovery to service-users' recovery perceptions found that these ratings correlated poorly (Morrison et al., 2013); and in response measures designed to assess the subjective experience of recovery in psychosis have been developed (Beck et al., 2012; Neil et al., 2009). The discrepancy between clinician and consumer concepts of recovery is also thought to particularly cause conflict in terms of available treatments and interventions for psychosis; for example, the clinical notion that rehabilitation can only occur after stabilization. Messias et al. (2007) argue that the focus on symptoms in clinical services means that typical treatment consists of assessment, diagnosis and medication; while rehabilitation and other support are considered secondary. They go on to suggest that stabilization through the sole use of

medication leads to 'maintenance' as opposed to recovery. As such, it has been suggested that biomedical models and measures of recovery, and the use of diagnostic categories, are unhelpful and may hinder recovery rather than promote it (Beresford, 2013; Longden, 2010; Read et al., 2006). In support of this idea, research has indicated that around a third of individuals with psychotic experiences disengage from mental health services and treatment (Kreyenbuhl, Nossel, & Dixon, 2009).

One barrier to mental health care provision and recovery from psychosis that has been identified is the significant stigma associated with mental health problems (Sartorius, 2007), especially psychosis. Internalised stigma in particular has been identified as an obstacle to help-seeking and accessing support (Sartorius, 2007); as such the focus of this thesis will be the roles of stigma and internalised stigma in recovery from psychosis, which will be reviewed in Chapter 2.

1.7. References

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Chapter 2:

The impact of stigma and self-stigma on identity and recovery.

2.1. Abstract

A wide body of research has provided evidence for the existence of mental illness stigma and its effects on the individuals who experience it. The aim of this review is to synthesise some of the key findings in the literature on how stigma affects individuals with psychosis with a particular focus on identity and recovery. This review will examine the common stigmatising attitudes pertaining to psychosis, the impact of the internalisation of stigma, how stigma is interpreted by the individual, how stigma influences personal and social identities, and influential factors in responses to stigma such as age, intersectionality, and causal attributions of illness.

2.2. Stigma concepts

Stigma is a widely researched concept, with public stigma, courtesy stigma and self-stigma (or internalised stigma) frequently cited as issues for those experiencing mental health issues. Goffman (1963) described stigma as a negative evaluation of an individual as 'tainted' because of attributes such as mental disorder, disability, or ethnicity. Goffman's 1963 book *Stigma: Notes on the Management of Spoiled Identity* is generally considered to be the genesis of stigma research, and forms the basis of many modern definitions of stigma (Dovidio, Gaertner, Niemann, & Snider, 2001; Wahl, 1999). However, there have been a number of useful multi-factor models of stigma developed over the years, with the elements of labelling, stereotyping, social isolation, prejudice and discrimination recurring throughout (Corrigan & Kleinlein, 2005; Corrigan & Rusch, 2002).

One of the most frequently cited models of stigma is that of Link and Phelan (2001). Link and Phelan's model of stigma identifies five components which when brought together, create stigma. Put simply these components are labelling, stereotyping, separation, discrimination, and power. Labelling refers to a process of identifying and labelling of human differences, whereupon these labels can be linked with negative associations creating a stereotype. Separation refers to placing labelled, stereotyped people into a category that distances and isolates them from the majority, and in some cases also puts them in opposition. Discrimination encapsulates the active response to the labelled individuals which typically manifests itself through the loss of opportunities, coercion in decision-making because the person is believed to be incapable, and segregation (Corrigan, Larson, & Rüscher, 2009). This model is applicable to stigma of all kinds but is particularly relevant to stigma in relation to mental illness as a major advantage of the model is its acknowledgement of the power of labelling, which is relevant to the use of diagnostic labels within the mental health sector.

The concepts of discrimination and stigma, although often used interchangeably, can be viewed differently. Some suggest that in essence, internalised stigma can be viewed as self-directed negative attitudes and thoughts regarding one's mental health issues. Whereas self-discrimination is

how these thoughts and feelings are put into practice. For example, in a social scenario, a person might think that no-one wants to socialise with someone who has mental health issues; this would be self-stigma. Consequently, they engage in self-discrimination by avoiding engaging in social activities because of their negative self-beliefs. Nevertheless, other researchers such as Link, Yang, Phelan and Collins (2004) suggest that the term 'discrimination' should be used as opposed to 'stigma' which has connotations of blame on the victim. This is a position which is becoming more prominent, particularly in the mental health activism movement, because of the view that the word 'stigma' can now in itself be stigmatising (Maio, 2004).

The issue of mental health and stigma is an important one because severe and enduring mental illness in particular appears to engender stigmatising responses in others, with labels such as "unattractive", "unreliable" and "dangerous" being associated with people with mental health problems (Corrigan, Watson, & Ottati, 2003; Crisp, Gelder, Rix, Meltzer, & Rowlands, 2000; Martin, Pescosolido, & Tuch, 2000; Pescosolido, Monahan, Link, Stueve, & Kikuzawa, 1999). It has been suggested that people who experience psychosis are one of the most stigmatised minority groups in society (Wood, Burke, et al., 2014; Wood, Birtel, Alsawy, Pyle, & Morrison, 2014) with the Schizophrenia Commission (2012) recently reporting that 87% of individuals with a schizophrenia diagnosis had experienced public stigma and discrimination. Stigma within the psychosis spectrum also varies, for example, in a survey of a thousand people on their attitudes towards people with mental illness; it was found that 69% of individuals would engage in social-distancing from individuals with schizophrenia, and 29% for bipolar disorder. In comparison only 7% would make efforts to avoid a person with autism. The primary reason given for this discrepancy was a belief that individuals with schizophrenia are highly dangerous (Durand-Zaleski, Scott, Rouillon, & Leboyer, 2012); and unpredictable (Crisp et al., 2000; Stuart, Arboldea-Florez, & Sartorius, 2012; Walker & Read, 2002). Further research by Corrigan and Kleinlein (2005) found that individuals with severe mental health problems are again considered dangerous, but also incompetent and to blame for their illness. Stolzman (1994) suggests that these kinds of stigmatising attitudes create a vicious

circle of disability and disadvantage through diminishing quality of life, preventing early engagement with mental health services and treatment, inhibiting social roles and hindering social integration. It is also possible that the discrepancies between the stigmatising attitudes towards schizophrenia and bipolar disorder may well be reflected in the self-perception of individuals who have been given those diagnoses.

2.3. Internalising stigma

Although research on stigma in mental health and its consequences is abundant, the majority of research in the area is concerned with 'courtesy stigma' or stigma-by association (Goffman, 1963). This focuses on the experiences of the family of a person with mental health problems, or how the general public perceive people with mental health problems. Particularly in the latter, it is the stigmatising majority that are researched as opposed to the victims of stigma (Oyserman & Swim, 2001). Speaking to the long-term effects of stigma, several authors have suggested that beyond having an immediately distressing impact, stigma may be internalized (Ritsher & Phelan, 2004), and impede a person's chances of establishing identities unrelated to mental illness (Corrigan & Watson, 2002). Very little research is directed towards the experiences of the individual with mental illness and how they respond to stigma (Bagley & King, 2005; B Schulze & Angermeyer, 2003) and consequently there has been little research into self-stigma (Tang & Wu, 2012; Yen et al., 2005). In the past this has been attributed to most researchers having not personally experienced mental health problems, making them less aware of the issue of internalised stigma. Internalised stigma only really began to be seen as a valid area of research during the late eighties and early nineties (see Herman, 1993; Link, 1987; Link, Cullen, Struening, Shrout, & Dohrenwend, 1989; Mansouri & Dowell, 1989). Even these early studies found that individuals with mental health problems expect to suffer ill-treatment from others, experience reduced life satisfaction because of stigma, feel demoralised and rejected, and encounter discrimination.

Internalized stigma occurs when individuals that belong to groups (such as 'mentally ill') which are typically stigmatized against accept the relevant negative stereotypes as a true reflection of their own self-concept (Corrigan, Rafacz, & Rüsche, 2011). It is associated with significant behavioural and emotional consequences, such as reduced self-esteem and diminished self-efficacy (Carter et al., 2016). Internalised stigma is an important issue because it inhibits individuals from engaging more fully in various aspects of their lives. In a time where there are noticeable shifts in thinking from a medical model of mental health to a recovery model; where regaining a sense of quality of life is championed (Frese, Stanley, Kress, & Vogel-Scibilia, 2001), it is all the more important that this often overlooked but common experience is examined in more depth. Self-stigma in essence refers to internalised feelings of inferiority, guilt, shame and a wish for secrecy experienced by individuals with mental health problems (Goffman, 1963). It is also a term used to define the negative thoughts, feelings and emotions that a person has about themselves and the fact that they have a mental illness. Corrigan et al. (2009) suggest that this process occurs when people who are conscious of the stereotypes about mental illness expect and internalize devaluing and discriminatory attitudes. This devaluation occurs in three hierarchical steps which lead someone to experience self-stigma. A person needs to be initially aware of the stereotypes associated with mental illness, agree with those stereotypes, and subsequently apply them to themselves.

Research into self-stigma suggests that prior to diagnosis, people have internalised cultural stereotypes about mental health problems (Link, 1987; Link et al., 1989) when they themselves are labelled as having mental health problems, they apply the now relevant stereotypes to themselves. Corrigan and Kleinlein (2005) created a model of stigma that includes self-stigma alongside public stigma. In this model, stigma and self-stigma have three components: stereotypes, prejudice, and discrimination. The stereotypes are explained as negative beliefs held by the majority of members of a group about a minority. Prejudice is considered to be agreement with the negative stereotypes, which motivates discrimination – negative behaviours toward those in the minority. In self-stigma, the individual will hold the same beliefs as the majority about the minority (i.e. people with mental

illness) despite being a member of the minority, and agree with those beliefs. They will then turn these negative attitudes inwards which may lead to negative emotional reactions such as lowered self-esteem or diminished self-efficacy (Corrigan, 2004; Fung, Tsang, Corrigan, Lam, & Cheung, 2007; Yang, 2007) or self-discrimination, perhaps by withdrawing from relationships or not applying for a job which they desire, because of the negative beliefs they hold about people with mental illness and therefore themselves.

The end result is that self-stigma can diminish self-efficacy and willingness to fully engage in life opportunities (Corrigan et al., 2009; Corrigan & Kleinlein, 2005; Ritscher, Otilingam, & Grajales, 2003; Rosenfield, 1997). Moreover research suggests that experiences of stigma have a strong negative impact on self-esteem (Link, Struening, Neese-Todd, Asmussen, & Phelan, 2001), and further findings report that experiences of stigma can also result in a decreased sense of mastery (Wright, Gronfein, & Owens, 2000). Corrigan (2004) further stipulates that the interaction between public stigma and self-stigma can cause a vicious cycle of stigmatization which can negatively impact on recovery. For example, self-stigma might prevent someone for applying for a job, but the view from others might be that the individual is incompetent, work-shy or lazy; the awareness and internalisation of these views in turn further inhibits the individual from seeking work.

This dual model for stigma and self-stigma has been criticised by Peterson, Barnes and Duncan (2008) for its linear approach and failure to provide suggestions for breaking the process of self-stigma. Moreover, Peterson et al. suggest that the model is flawed as it makes no explicit link between public stigma and self-stigma. However, although self-stigma can be as a result of public stigma, it can also occur without any direct experience of stigma from others. More importantly, Corrigan and Kleinlein's theory provides an explanatory model of experienced stigma and internalised stigma, in which all three stages (awareness, application and agreement) are applicable to both forms of stigma; which reflects the important idea that they come from the same processes.

2.4. Insight, identity and internalised stigma

It is evident that the concept of insight in mental health is also intrinsic to the discussion of self-stigma and its impact, as both address a person's awareness of mental illness and how they react to this awareness. Definitions of insight typically revolve around the awareness and acknowledgement of illness and symptoms. Additionally concepts of being aware of the need for treatment, the idea that illness is on-going, and the overall awareness of the consequences that these factors will have are considered. It is thought that 30% to 50% of people with schizophrenia lack insight, and are unable to develop an awareness of their illness despite interventions from their healthcare providers (Lincoln, Lüllmann, & Rief, 2007). Similarly it has been suggested that around 50% of patients with a bipolar disorder diagnosis have moderate to severe impairment of insight during acute episodes (Ghaemi, Stoll, & Pope, 1995). In support of these figures, Engh et al. (2007) found no significant difference between levels of insight, self-reflectiveness and self-certainty in patients with diagnoses of schizophrenia and bipolar disorder.

Primarily due to concerns around non-adherence to treatment, the development of insight and acceptance of one's diagnosis is typically considered to be a turning point and a positive step towards good mental health. However, the negative consequence of taking this step is rarely considered. The implications of accepting a typically negative identity such as 'mentally ill' or 'psychotic' and trying to assimilate that as part of one's self-concept can be extremely challenging. Indeed, lack of insight can be viewed as a form of coping strategy in this sense, which may be supported by the fact that we still see self-stigma in individuals who lack insight (Lincoln et al., 2007). This suggests that perhaps on some level people are aware that they are ill, even if this awareness is not explicit. In these cases it is possible that individuals unconsciously deny an awareness of mental illness because acknowledgement and conscious acceptance would result in such severe changes to one's identity and what they believe about themselves at their core, in addition to the more global life changes that one might encounter as a result of mental illness.

Yanos, Roeb and Lysaker (2010) further explore the relationship between insight, identity and self-stigma with their concept of “illness identity”, which they define as the roles and attitudes a person has developed in relation to their understanding of having a mental illness. Yanos et al. suggest that the process of accepting the label of mental illness and its affiliated stereotypes of incompetence and inadequacy impacts on an individual’s sense of hope and self-esteem. This in turn affects vocational functioning, social interaction, symptom severity, coping and suicide risk. However, Watson et al. (2007) suggest that the internalisation of stigma and consequential loss of self-esteem are not inevitable, but in fact vary from person to person dependent on several factors. Yanos et al. suggest that the potential impact of insight into mental illness is seemingly moderated by how the person conceptualises their illness and what they infer from those beliefs. Once a person moves beyond the question of whether or not they are ill, they are faced by the difficulty of what this might mean for them, such as whether mental illness means that they are weak; whether it puts paid to their aspirations; or whether it is an unexpected hurdle which they will be able to overcome.

Whatever the process, the concept of insight into one’s state of mental health introduces the idea that one’s identity can be changed through acquiring new labels, awareness of their associated stereotypes and self-stigma. The impact of receiving a mental illness diagnosis on one’s identity has long been acknowledged (Goffman 1963), and identity and sense of self are recognised as important areas of focus in a world where therapeutic approaches increasingly view recovery with a patient-centred, subjective, self-defined approach (Bellack, 2006; Yanos, Roe et al., 2010). The sociological definition of identity focuses on the roles and social categories that a person attributes to themselves, in addition to those used by others to describe them. These may relate to any sphere of life, for example: relationships (“father”, “wife”, “friend”); work (“boss”, “baker”, “unemployed”), or life experience (“victim”, “patient”, “survivor”).

2.5. Positive effects of internalised stigma

In line with Yanos et al.'s theories on 'illness identity' (2010), there is evidence to suggest that rather than having a negative impact on one's identity or roles, self-stigma might have a positive effect for some people. Indeed this is described as the paradox of stigma and mental illness: some individuals sense of self is harmed by stigmatising attitudes, some appear indifferent, yet others react with righteous anger and are motivated and energized by the injustice they experience (Corrigan & Watson, 2002). Peterson, Barnes and Duncan (2008) found evidence to suggest that self-stigma can motivate a desire to challenge negative stereotypes and encourage positive action. Particularly, participants in the study's focus groups spoke of moving beyond a focus on 'recovery' to being 'out and proud' about their mental illness. In this sense, the self-stigma experienced by individuals serves to highlight the positive aspects of their self and adopt a more 'strengths-focused' attitude towards themselves. This positive attitude to their negative self-beliefs led to a number of benefits such as increased tolerance of difference, increased acceptance of others, and improvements in relationships with others. Another effect of changing one's perspective on self-stigma seems to be the encouragement of taking on new, positive roles that relate to mental illness, for example, peer support roles or mental health advocacy. The adoption and incorporation of such roles into one's identity reflects some desire to help others in similar situations, and a more positive, empowering relationship with mental ill-health, being defined by it in ways other than those projected by negative stereotypes.

This idea was supported by Onken and Slaten (2000) who conducted qualitative research on the effects of participating in the mental health consumer movement through advocacy groups and self-help services, and found that through self-disclosure and advocacy, participants were encouraged to not see themselves as "mental patients", but rather as "consumer advocates". This reconstruction of the concept of mental illness into something less negative makes it more acceptable, and in some cases a mark of social advantage (Yanos, Lysaker, & Roe, 2010). This

suggests that replacing negative identities that are marked with self-stigma with more positive, empowering identities is beneficial to recovering quality of life. Corrigan et al. (2009) suggest that as well as community activism, righteous anger about experiencing discrimination due to disagreement with the conventional stereotypes may also influence positive responses to stigma. This highlights the important role of empowerment as a mediator between self-stigma and its potential negative effects, particularly goal-attainment (Corrigan et al., 2009). People who are able to accept mental health problems as part of their identity on some level rather than feeling like someone who is 'wrong' (Peterson, Barnes & Duncan, 2008) and needs to be fixed, appear to suffer less from the ill effects of self-stigma.

2.6. Negative effects of self-stigma

However, where some people feel energised and empowered in response to stigma (Corrigan, Faber, Rashid, & Leary, 1999) the majority experience diminished self-esteem and self-efficacy. For the majority we see a negative impact from stigma and internalised stigma, particularly through the alteration of roles and identity.

The media representations of people with illnesses such as schizophrenia in particular are likely to have a negative impact on a person's identity and social roles. The media repeatedly presents people with schizophrenia as high-risk, dangerous, violent and unpredictable (Coverdale, Nairn, & Claasen, 2002; Owen, 2012). Similarly, Philo et al. (1994) found that two thirds of news and current affairs coverage of mental illness drew links between mental health issues and violence, despite evidence to the contrary. This kind of coverage and the perpetuation of misinformation about mental illness are strongly linked to stigma. It has been found that increased media consumption is associated with increased intolerance and desire for social distance from people with mental illness (Angermeyer, Dietrich, Pott, & Matschinger, 2005; Angermeyer & Schulze, 2001; Granello & Pauley, 2000). Moreover, individuals report feeling hurt and offended by media representations of mental illness (Wahl, 1999).

In fact, it has been suggested that mental health patients are more likely to be victims of crime than perpetrators (KM Research & Consultancy, 2009), highlighting the issue of access to justice for people with a mental health diagnosis. People with mental health problems are typically not considered to be credible witnesses to crime by the Crime Prosecution Service and the police (Sayce, 1998). Watson, Corrigan and Ottati (2004) found that police officers were less likely to take action based on information provided by victims and witnesses who had a history of mental illness. The internalisation of these stigmatising attitudes or invalidity and unreliability means that individuals are less likely to report a crime and pursue justice for fear of not being believed or supported if they do. Individuals may also diminish the significance of what happened to them as a victim of crime, attribute blame to themselves and question their own certainty about events (Read & Baker, 1996).

As well as issues with access to justice, individuals with mental health problems are often also subject to 'structural discrimination' whereby societal infrastructure and regulations systematically disadvantage those with severe mental health problems (Rüsch, Zlati, Black, & Thornicroft, 2014). For example, comparatively low funding for mental health services and research, when compared to other areas of health, can result in reduced access to services, fewer options for treatment, and poor quality of care. Similarly it is well documented that individuals with severe mental health issues have difficulty in accessing adequate housing, education, suitable employment, loans and insurance (Rüsch et al., 2014; Sayce, 2000; Read & Baker, 1996; Thornicroft, Brohan, Rose, Sartorius, & Leese, 2009). This increased disadvantage coupled with the intersectionality between the stigma of mental illness and the added stigma of homelessness, unemployment, ethnicity, gender and/or education level creates a downwards spiral and compounds the impact of both experienced and anticipated discrimination, often leading to increased avoidance and withdrawal (Farrelly et al., 2014; Haarmans, Vass, & Bentall, 2016; Livingston, Rossiter, & Verdun-Jones, 2011; Perlick et al., 2001; Rosenfield, 2012). This all has a potential impact on recovery in terms of regaining a sense of quality of life and wellbeing, so that individuals report reduced self-esteem

(Corrigan, Watson, & Barr, 2006), and feeling pessimistic about recovery and lacking hope for the future (González-Torres, Oraa, Arístegui, Fernández-Rivas, & Guimon, 2007).

2.7. Attributional causes of illness and stigma

As discussed in Chapter 1, there are a number of theories as to how psychosis develops. Lay persons' and service-users' casual attributions of illness are similarly heterogeneous and form the basis for how psychosis is understood and reacted to. Attributions about the cause and controllability of an individual's mental health problems lead to inferences about their responsibility. These in turn lead to emotional responses such as disgust, anger or pity, and consequently affect the likelihood of punitive or helpful behaviours from others (Corrigan, Markowitz, Watson, Rowan, & Kubiak, 2003; Read, Haslam, Sayce, & Davies, 2006). In terms of how the individual processes theories of mental illness, attribution of responsibility has been found to positively correlate with self-stigma. Service users who assumed personal responsibility for their mental illness were more likely to experience self-blame, worthlessness and feel disabled (Mak & Wu, 2006)

For a long time the assumption was held that bio-genetic explanations of severe mental illness would reduce perceived responsibility and blame, and promote more positive attitudes and compassion towards patients, referred to as the 'mental illness is an illness like any other' approach (Read et al., 2006a). In fact, the opposite appears to be true: theories of schizophrenia which focus on genetics or neurology actually appear to increase the level of stigma directed at service-users (Angermeyer, Holzinger, Carta, & Schomerus, 2011; Bennett, Thirlaway, & Murray, 2008; Read, Haslam, Sayce, & Davies, 2006b). Moreover, service-users who endorse biogenetic explanations may experience higher levels of internalised stigma and hold more stigmatizing attitudes towards others experiencing psychosis (Carter et al., 2016).

Biogenetic explanations are thought to tie-in with the stereotypes of unpredictability and dangerousness, as well as a perception of inability to recover (i.e. one might change their

environment but they cannot change their biology). It is possible that the public reaction to biogenetic explanations may be self-protective, creating a definite distinction between 'us' and 'them' to distract from the possibility that mental health problems may be something they could one day experience too (Read & Haslam, 2004). In contrast, psycho-social explanations of illness which frame mental health as an understandable psychological or emotional responses to life events reduce desire for social distance, fear and discrimination (Read et al., 2006b). The adoption of these explanations may also create a distance from the stigma associated with biogenetic explanations of psychosis for service-users, reducing experienced and internalised stigma (Carter et al., 2016).

2.8. Self-stigma and identity change

Davidson and colleagues explored the process of changing identity and constructing new concepts of self as part of recovery from mental illness through a series of qualitative (Davidson, Sells, Songster, & O'Connell, 2005; Davidson & Strauss, 1992) and found that constructing a new identity after diagnosis is essential to recovery. This was specifically linked to re-developing a sense of purpose through day to day activities. Similar findings were evident in Roe's longitudinal qualitative study (2001), which found that over a period of one year, patients who showed improved functioning shifted from the identity of 'patient' to 'person' in their narratives. Fulfilling activity of any sort is thought to be beneficial, and forms an integral part of identity through making connections as to what the activity means about them as a person ('I am creative'; 'I am a hard-worker'; 'I am sociable' etc.), and creating a sense of belonging through positive identification with others (Laliberte-Rudman, Yu, Scott, & Pajouhandeh, 2000). Evidence also suggests that engaging in activities helps to improve a lot of the aspects of self which self-stigma diminishes, such as self-esteem, self-confidence, self-mastery, sense-of-self and developing a positive self-identity (Fidler & Fidler, 1978; Gee, Pearce, & Jackson, 2003; Laliberte-Rudman et al., 2000; Mayers, 2000; E. E. Michalak, Yatham, Maxwell, Hale, & Lam, 2007). However, through avoidance and withdrawal

coping strategies, people experiencing self-stigma often do not engage in a whole range of interests which they once found enjoyable, and often feel inhibited from trying new activities.

Engaging in work also appears to have benefits beyond social interaction and fulfilment for people with mental health problems; Perkins, Raines, Tschopp and Warner (2009) found that gainful employment reduces stigma around individuals who are recovering from schizophrenia. Priebe, Warner, Hubschmid and Eckle (1998) found that people with schizophrenia who were employed had significantly fewer symptoms than those who were unemployed. Similarly Bond et al. (2001) found that severe mental illness patients who engaged in competitive work showed greater improvement of symptoms over time compared to those who were unemployed. This suggests that working has the potential to alleviate both negative experiences of stigma and even symptoms. However, in the United Kingdom, only 9% of people with a “probable psychotic disorder”, including most people with a severe mental health issues, are working full-time, with a further 19% employed in part-time work (Meltzer et al., 2002). The Schizophrenia Commission reported that only around 8% of people with schizophrenia are employed in the UK, against a national rate of 71% employment. Self-stigma is thought to be one of the main reasons for this, as the fear of having job applications rejected on the basis of having mental illness is inhibitory to seeking employment. This is in key with the idea that secrecy and withdrawal are the most common coping strategies for people experiencing self-stigma (Penn & Martin, 1998).

2.9. Self-stigma, identity & family relationships

Self-stigma can also cause serious disruptions in family relationships (Link et al., 2001). Family life and parenthood is particularly significant to many people’s constructs of identity and the roles they take within the family can be integral to their sense of self and who they are. Yet, in Read and Baker’s study, 62% of the 778 survey respondents felt that they had been treated unfairly by family or friends; and for those with children, 26% of men and 48% of women believed their parenting skills has been questioned. For example, one respondent stated “Friends avoided me and

would not let their children play with my children any more". Internalising external attitudes that one might not be a good parent, and is impacting on their children through association with them can cause feelings of guilt (Ueno & Kamibeppu, 2008) and can lead to alterations in behaviour. For example, Montgomery, Tompkins, Forchuk and French (2006) described women's attempts to appear as normal as possible for their children's sake. Similarly, Dolman, Jones and Howard (2013) found that several papers in their systematic review referred to women not wanting their children to see them when their illness was affecting them, and Venkataraman and Ackerson (2008) found that women with bipolar disorder were concerned about their children learning bad habits from them when manic, such as over-spending or gambling. Self-stigmatising fears about the impact of their illness on their children can cause parents to feel as though they are unsuitable as parents or should lessen contact with their children at times, particularly as many express concerns over being a burden to their children (Khalifeh, Murgatroyd, Freeman, Johnson, & Killaspy, 2009).

Wilson and Crowe (2009) found that the stigma associated with a mental health diagnosis was reinforced by being a parent. Davies and Allen (2007) suggest that women who are mothers and have a psychiatric diagnosis face strong challenges to their identity because of the intrinsic tension and discrepancy between societal ideals of what constitutes a good mother, and the negative conceptions surrounding mental health patients. Again, this is particularly an issue when these conflicting stereotypes are internalised. In a small qualitative study examining women's feelings about stigma during the postnatal period, Edwards and Timmons (2005) found that all of their respondents had experienced self-stigma and saw themselves as bad mothers who were failing and could not meet the societal expectations of the perfect mother. These expressions of self-stigma can lead people to withdraw from the parental role which is often very important to them. Meiser et al. (2007) found that individuals with a diagnosis or significant family history of bipolar disorder who felt that they had experienced high levels of stigma were significantly less willing to start their own family and have children. However, for some women the notion that they will be bad mothers because of their mental illness is viewed as motivation to make sure they always try hard and do a

good job, and in this sense their self-stigma impacts positively on them. Moreover, through taking on the new role of becoming a parent was seen by some as a way to normalise themselves in the eyes of society, and allow them to take on a new more positive identity; rather than being defined primarily as mentally ill, being defined as a mother (Edwards & Timmons, 2005).

2.10. Internalized stigma and age of onset

It is possible that age of onset of psychotic illness may also influence the extent of self-stigma and how much it impacts on one's identity. It has been suggested that during prodromal and early psychosis in young people, individuals and their families often recognise cognitive and behavioural changes yet tend not to identify these as signs of psychosis. Instead, both individuals and family members tend to attribute these changes to "a passing phase", a stage of development or less stigmatising syndromes (Judge, Estroff, Perkins, & Penn, 2008).

Adolescence is often cited as a period of identity consolidation and increasing autonomy (Feldman & Elliott, 1990). It has been suggested that self-stigma may be particularly influential when mental illness is diagnosed in late adolescence or early adulthood, because this is often viewed as a time of establishing one's identity and choosing a path in life, the impact of self-stigma can greatly affect a person's judgement and decision-making. At this stage in life, people often make the transition to independent living, serious relationships, parenthood, higher education, and progression into the world of work. Rüsç et al. (2006) suggest that individuals with a diagnosis of borderline personality disorder, for example, may experience greater levels of stigma (and potentially greater levels of self-stigma) due to the onset of the disorder in early adulthood, the chronic course of the illness, experience of multiple hospitalizations, and visible scarring from self-injury.

Similarly, the typically early onset of schizophrenia at the cusp of adulthood is thought to be particularly problematic for individuals in terms of stigma and self-stigma (Weich et al., 2011). As schizophrenia onset is commonly associated with early adulthood, the impact of receiving a

diagnosis may have serious implications such as damaged relationships, social isolation, academic failure, unemployment, imprisonment and homelessness (National Alliance on Mental Illness, 2008). The impact of internalised stigma is likely to heavily impact on individuals during the transition from adolescence to adulthood because of the associated turmoil at this age; the difficulties of having to incorporate mental illness as part of one's identity and the difficult feelings that surround that concept may have an effect on the rest of their adult lives.

Children may also suffer from greater levels of internalising stigma, as they have great tendencies towards forming in-groups and out-groups (Hinshaw, 2006), and a strong sense of group identity, favouritism and inclusion. There is evidence to suggest that these tendencies have already developed in children during their preschool years with regard to racial identity (Aboud, 2003). Even at this age, the language children use to describe mental illness have particularly negative connotations (i.e. "crazy", "nuts", "insane", "psycho"), to the extent that Wahl (2002) suggests that these terms need to be used when investigating the attitudes of children because they don't recognise terms such as "mental illness". This might suggest that children who are given psychiatric diagnoses, which is increasingly common, may exhibit high levels of self-stigma because their association with mental illness is so negative, and differentiation from the in-group of "normality" is unfavourable.

However, Spitzer and Cameron (Spitzer & Cameron, 1995) found that children find mental health problems much more difficult to recognise in vignettes of children and adolescents than they do in recognizing adults with mental health problems. Hinshaw (2005) suggests that this finding might reflect the notion that children have difficulty comprehending the concept of mental illness before they reach adolescence, which is supported by Wahl's (2002) findings that mental health knowledge increases through childhood to adolescence. However, in a longitudinal study examining children's attitudes to mentally ill people Weiss (1994) found that desire for social distancing from people with mental illness actually increased during late childhood to the point where at around age

13 to 14, young adolescents expressed more negative attitudes to mental health patients than to convicts. This would suggest that experiencing mental health problems at this stage, on the threshold of adolescence again could be very problematic in terms of self-stigma and impact on identity. However, Hinshaw (2005) suggests that the abject lack of research into the effects of stigma on children makes it difficult to draw any conclusions as to the potential developmental impact. Nevertheless, it is clear that stigma influences identity construction and personality development through multiple processes and in all stages of life. The influence of experienced, anticipated and internalised stigma for individuals experiencing psychosis is consequential, and appears to particularly impact on aspects of life which are pertinent to recovery. As such, the relationship between stigma, internalised stigma and recovery from psychosis will be the subject of this thesis.

2.11. Aims and outline of the present thesis

It has been long held that all forms of stigma can have an adverse impact on an individual's quality of life, but it is clear that at a deeper level self-stigma can erode at a person's identity. Internalised stigma seems to make the process of reclaiming identity, re-establishing identities unrelated to mental illness, and recovering one's roles in society much more difficult (Michalak et al., 2011; Corrigan & Watson, 2002). The damage to self-esteem and self-concept (Corrigan et al., 2009) can conceivably be ingrained and difficult to reverse, particularly at certain stages in life when people are at their most vulnerable. This undoubtedly has consequences for outcomes in psychosis which need to be explored in more depth. With this in mind, this thesis expands on previous research which suggests that stigma affects outcomes in psychosis. It addresses two areas lacking in sufficient research within the stigma literature: clarity in the relationship between experiences of stigma and internalised stigma; and both the concurrent and long-term effects of stigma on outcomes in psychosis. In particular it examines the relationship between stigma and internalised stigma with two diagnoses on the psychosis spectrum: schizophrenia and bipolar disorder. Whilst these diagnostic groups share many characteristics and patients report similar psychotic symptoms, it

is clear that the public perception of each diagnosis is different. A key point of this thesis is to explore whether these perceptions translate into stigma experiences and self-stigma, and whether this differs for each diagnostic group, or is similar for both. Overall, it elucidates the relationship between mental illness stigma and its effects on recovery for individuals with psychosis. This is achieved primarily by identifying key factors, processes and mechanisms involved in the relationship between stigma and outcomes. Lastly, it focuses on targets for psychological interventions and the therapeutic need to focus on helping service-users develop resilience against stigma and maintain an integral sense of their own identity, in order to create a truly patient-centred approach to treatment and rehabilitation.

The following chapters are comprised of published papers (Chapter 5), papers under review (Chapter 6) and recently submitted manuscripts (Chapters 3 & 4).

The study reported in Chapters 3 and 4, was a qualitative investigation based on interviews with 19 individuals who had received a diagnosis of either schizophrenia or bipolar disorder. The objective of the investigation was to explore how individuals processed receiving a diagnosis of schizophrenia or bipolar disorder, and how perceived, experienced and internalised stigma influenced that participants' self-perception, interactions and recovery feelings (Chapter 3). An unexpected aspect of these interviews was the participants' focus on the role of mental health services and experiences of treatment, particularly antipsychotic medication. As this is clearly an important aspect of the participants' experiences of living with psychosis, this was written up separately, forming Chapter 4.

The study presented in Chapter 5, used an epidemiological, longitudinal dataset (n=80) that formed part of independent research commissioned by the National Institute for Health Research (NIHR) under its Programme Grants for Applied Research scheme (RP-PG-0606-1086). This study aimed to examine how stigma impacts on symptomatic and subjective recovery from psychosis, both

concurrently and longitudinally. We also aimed to investigate whether self-esteem and hopelessness mediated the observed associations between stigma and outcomes.

The study reported in Chapter 6 utilised a clinical sample of 59 service-users with a diagnosis of either schizophrenia or bipolar disorder. The objectives of the study were to assess the impact of stigma on subjective recovery from psychosis, and whether self-esteem and internalised stigma mediates the observed associations between stigmatizing experiences and outcome, thus clarifying the relationship between stigma, self-stigma and recovery.

Chapter 7 presents an integrative summary of the findings, and considers the overall limitations and clinical implications, before providing suggestions of avenues for future research.

2.12. Co-author roles

The co-authors are identified with a footnote in each Chapter. Dr. Andrew Boardman was a co-author in Chapters 3 and 4. During a particularly difficult period of recruitment Dr. Boardman was invaluable in engaging participants for the qualitative study. Professor Anthony Morrison, Dr. Heather Law, James Dudley and Pamela Taylor are co-authors in Chapter 5 as, with my supervisor Professor Richard Bentall, they were part of the original NIHR grant under which the data was collected. Professor Morrison and Dr. Law both aided in the write up of the study by proof-reading prior to publication. Dr. Katarzyna Sitko was a co-author in Chapter 6 as she assisted in the design and measures used in the study and contributed to the interpretation of the findings. Sophie West was included as co-author on Chapter 6 as she was vital in gaining access to a mental health service within Lancashire Care NHS Trust, and aided in recruitment.

All data collection and analysis were completed by the candidate under the supervision of Professor Richard Bentall and Dr. Kate Bennett, who also provided guidance with the manuscript write-up.

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Chapter 3:

“It’s quite a lonely illness”: Service-users’ experiences of stigma and self-stigma in bipolar disorder and schizophrenia.¹

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3.1. Abstract

Experiences of psychosis, particularly those associated with a diagnosis of schizophrenia or bipolar disorder are highly stigmatising. Limited qualitative research has explored service-users' experience of stigma and the internalisation of stigma after receiving a diagnosis. This study used data from 19 semi-structured interviews with participants who had received a diagnosis of either schizophrenia or bipolar disorder within the past 5 years. Three overarching themes were identified in relation to stigma: reactions and responses; relationships; and recovery. Stigma is a significant concern for service-users with diagnoses of bipolar disorder and schizophrenia. There is a need for clinical services to work in a stigma-informed way in an effort to reduce the impact of stigma post-diagnosis, as well as the development of interventions aimed at preventing stigma from being internalised.

3.2. Introduction

Of the research into mental illness stigma, much has focused on the experiences of people diagnosed with schizophrenia (Brohan, Elgie, Sartorius, & Thornicroft, 2010), but relatively little has explored the experiences of people with bipolar disorder or how this compares to the experiences of others on the psychosis spectrum. Individuals on the psychosis-spectrum are widely considered to be one of the most stigmatised minority groups in society (Wood, Burke, et al., 2014). A cross-sectional study (n=202) investigating stigma in major depression, bipolar disorder and schizophrenia spectrum diagnoses found that 87.5% of service-users reported experiences of discrimination, and 92.6% anticipated discrimination in at least one area of their lives (Farrelly et al., 2014). Similar findings were reported by a large scale study (n=3579) conducted by Corker et al. (2013) who found that 72% of participants anticipated stigma and felt that they had to conceal their mental health status to some extent.

The greatest stigma appears to be attached to the schizophrenia diagnosis; in a survey of one thousand French citizens, 69% said they would engage in social-distancing from individuals diagnosed with schizophrenia, compared to 29% for people diagnosed with bipolar disorder (Durand-Zaleski et al., 2012), despite both diagnoses falling on the psychosis spectrum. This may in part be due to media representations of each diagnosis. Whilst it has been repeatedly shown that the media perpetuates negative stereotypes about mental illness through selective reporting and misinformation (Angermeyer, Dietrich, Pott, & Matschinger, 2005; Byrne, 2000) there is a particular focus on schizophrenia in forensic news reporting, and horror films (Angermeyer & Schulze, 2001; Goodwin, 2014). It has also been found that increased media consumption is associated with increased intolerance and desire for social distance from people with mental illness (Angermeyer et al., 2005; Angermeyer & Schulze, 2001; Granello & Pauley, 2000). In contrast, there have been a number of popular media figures who have publicly disclosed a bipolar disorder diagnosis, and celebrities such as Stephen Fry and Ruby Wax act as public ambassadors for the UK anti-stigma

campaign Time to Change. These different associations may contribute to these different public perceptions of bipolar disorder versus schizophrenia.

On an individual level, one study found that most service-users felt hurt and offended by media representations of mental illness (Wahl, 1999). Common stigmatising attitudes include beliefs that mental illness is a sign of weakness, personal deficits, low intelligence, incompetency, unreliability, unpredictability, and a propensity for violence (Crisp et al., 2000; Harrison & Gill, 2010; Putman, 2008). These attitudes are not limited to individuals who are mentally healthy, but are often internalised by those experiencing mental health issues (Sartorius et al., 2010).

Internalised stigma (or self-stigma) is the personal response to perceived and experienced mental illness stigma (Brohan, Gauci, Sartorius, & Thornicroft, 2011; Corrigan & Watson, 2002). When this occurs a persons' sense of self is altered as they incorporate the 'mentally ill' identity, adopt a stigmatised and devalued view of themselves, and lose previously held positive identities (Livingston & Boyd, 2010; Yanos, Roe, Markus, & Lysaker, 2008). This typically leads to feelings of inferiority, guilt, shame, a desire for secrecy (Goffman, 1986) and demoralisation (Cavelti, Kvrjic, Beck, Rüsich, & Vauth, 2012), that reduces self-esteem, and hinders both symptomatic and subjective recovery (B Schulze & Angermeyer, 2003; Vass et al., 2015).

The effects of internalized stigma when added to stigma experiences and perceived or anticipated stigma create a vicious circle of disability and disadvantage through preventing help-seeking and engagement with services (Thornicroft, Rose, & Kassam, 2007) inhibiting social roles, increasing social exclusion, isolation, and hindering social integration (Link et al., 2001; Thornicroft et al., 2007). Individuals also experience reduced life, work and education opportunities (Thornicroft et al., 2009) feelings of powerlessness (Burke, Wood, Zabel, Clark, & Morrison, 2016), and questioning their value as a member of society (Jenkins & Carpenter-Song, 2009). Ultimately, stigma prevents individuals regaining a sense of quality of life and wellbeing, leaving individuals feeling pessimistic about recovery and lacking hope for the future (Burke et al., 2016; González-Torres et al., 2007).

This study aims to (1) explore the effects of stigma and internalised stigma for individuals who have been given a diagnosis of schizophrenia or bipolar disorder; (2) the extent to which these experiences bear similarity between the two diagnoses. To the best of our knowledge, a qualitative comparison of stigma experiences in schizophrenia and bipolar disorder has not been previously done.

3.3. Method

3.3.1. Sample

Participants were eligible if they were aged between 16 and 65, and had been told they had a diagnosis of Bipolar Disorder or Schizophrenia within the past 5 years. Diagnosis was self-reported by participants and confirmed by their clinician. 19 service-users (11 male, 8 female, mean age = 36.89, SD = 12.60) were recruited, exceeding the minimum theme saturation threshold of twelve interviews set forward by Guest, Bunce and Johnson (2006). Thirteen participants (7 male, 6 female) reported that they had been given a diagnosis of bipolar affective disorder (BPD) and 6 (4 male, 2 female) reported that they had been given a diagnosis of schizophrenia (SZ). The demographics of the sample are presented in Table 1.

Table 1: Participant demographics.

Ppt. ID	Gender	Age	Ethnicity	Employment status	Diagnosis	Interview length (minutes:seconds)
A	Male	44	White	Unemployed	BPD	61:03
B	Female	54	White	Unemployed	BPD	133:26
C	Female	33	White	Unemployed	BPD	36:27
D	Female	44	White	Unemployed	BPD	43:43
E	Female	54	White	Employed	BPD	46:41
F	Female	32	White	Employed	BPD	43:58
G	Male	44	White	Unemployed	BPD	53:41
H	Male	55	White	Employed	BPD	56:35
I	Male	27	White	Unemployed	BPD	55:32
J	Female	37	White	Unemployed	BPD	54:14
K	Male	19	White	Unemployed	BPD	22:06
L	Male	25	White	Unemployed	BPD	33:41
M	Male	25	White	Unemployed	BPD	72:53
N	Male	60	White	Unemployed	SZ	32:00
O	Male	25	White	Unemployed	SZ	31:04
P	Female	35	White	Unemployed	SZ	23:32
Q	Male	19	White	Unemployed	SZ	36:48
R	Female	39	White	Unemployed	SZ	52:42
S	Male	30	White	Employed	SZ	48:28

Note: BPD = bipolar disorder; SZ = schizophrenia

3.3.2. Interview

A semi-structured interview method was used to enable consistency in questioning between participants, whilst still allowing individual participants to focus on areas of particular importance to them. The interview began with factual questions to collect some demographic information (Section a). We used an open chronological retrospective approach which allowed participants to work through their experiences since being diagnosed to the present. Section B explored the participants' life prior to diagnosis, the onset of illness, and the experience of entering services and being diagnosed e.g. before your mental health diagnosis what was life like?). Section C concerned the immediate aftermath of engaging with mental health services, how the participants' processed their newly acquired diagnosis, and any initial changes they felt had occurred (e.g. did you think differently about yourself than before?). Section D explored the present, reflections on the impact of receiving a diagnosis, and participants' thoughts about the future (e.g. thinking about your roles and responsibilities in the family, did they change at all after your diagnosis?). Section E inquired about perceived causes and explanations of illness and sources of information used to learn about their diagnosis (e.g. what do you understand Bipolar Disorder/Schizophrenia to be?). The interviews were concluded with an opportunity for participants to consider what advice they might give to others in a similar situation to themselves. The full interview schedule is found in Appendix A.

It is important to note that there were no explicit questions in the schedule regarding stigma, as it was felt this might be leading. However, if the topic of stigma was raised by the participant it was explored further.

Participants were interviewed alone and in person by the first author. Interviews took place either in the participant's home (n=13) or at a local health service (n=6). The interview was introduced to participants as a means of exploring the experience of receiving a diagnosis of BPD or SZ. The study has received ethical approval from the National Health Service Research Ethics Committee.

3.3.3. Analysis

Data analysis was carried out by the first author. The primary method of analysis was adapted from the grounded theory approach outlined by Bennett and Vidal-Hall (2000), and Charmaz (2006). Rooted in a symbolic-interactionist theoretical perspective, this entailed a greater focus on interpretivism/constructivism than traditional Grounded Theory. The symbolic interactionist perspective assumes that people act toward things based on the meaning those things have for them, and these meanings are derived from social interaction and modified through interpretation. The latter stages of analysis departed from classic grounded theory to focus on the emerging themes in the context of mental health stigma.

(1) Each transcript was read in its entirety to allow the researcher to become familiar with the narrative and gain a contextualised understanding of each participant's experience.

(2) Interviews were re-read and coded line by line, allowing the development of initial codes. During this stage, initial impressions and interpretations were recorded separately in a reflective diary. This process was reflexive, meaning that each new emerging code led to re-coding of earlier parts of the transcript.

(3) Once all transcripts were initially coded, the transcripts were re-read and similar themes between participants' initial codes were grouped into a number of broader categories, or sub-themes, which were then further refined into the final themes, which are presented in Table 2.

Due to the wealth of information in the interviews, here we focus on inter- and intrapersonal experiences of stigma and diagnosis. Other themes, such as service-users experiences of mental health services and medication will be published at a later date.

3.4. Findings

Table 2: Thematic structure.

Final theme	3.4.1. Reactions & Responses	3.4.2. Relationships	3.4.3. Recovery
Sub-themes	<ul style="list-style-type: none"> ▪ Processing diagnosis ▪ Loss ▪ Illness & identity ▪ Worthlessness and reduced self-esteem 	<ul style="list-style-type: none"> ▪ Disclosure ▪ Perceived stigma ▪ Burdensomeness ▪ Treated differently ▪ Stigma experiences ▪ Need for understanding ▪ Differentiation from others 	<ul style="list-style-type: none"> ▪ Reduced functioning ▪ Adapting & adjusting ▪ Growth through experience ▪ Future thinking

Three superordinate themes were identified in the analysis: “reactions and responses”, “relationships” and “recovery”. Each comprised of a number of sub-themes which are presented in Table 2.

3.4.1. Reactions and responses

This theme explores participants’ thoughts and feelings when they were initially diagnosed; the perceived and experienced impacts of living with a diagnosis; and how they processed the diagnosis over time in relation to their identity and sense of self.

Processing the diagnosis

Participants initial impressions and responses to their diagnosis were varied. Some felt “worried” (Participant O, SZ), or “fear” (Participant I, BPD), and found it “frightening” (Participant S, SZ) and “confusing” (Participant D, BPD) when they were told. This was attributed to having difficulty understanding what they were being told “didn’t fully understand it, still don’t fully understand it” (Participant A, BPD); and considering the implications of living with a mental health diagnosis “It was just a shock really. After so many years. Someone told me, you know. You’ve got bipolar. And you’ll be on medication for the rest of your life.” (Participant D, BPD).

Perhaps unexpectedly, all participants expressed a sense of “huge relief” (Participant A, BPD) at receiving a diagnosis as they knew what they were “dealing with” (Participant C, BPD).

Something being wrong, being told that I was ill. It was relief that it wasn’t the fact that my personality and that I wasn’t just a generic prick because that’s how I came across. I was just an absolute arsehole. Um, and so when they started using the bipolar term it was like, right, okay, something may actually be wrong, I might be ill here. Uh, it was a fear but a relief at the same time, I think it was fear of the unknown and what was going to happen but relief that I wasn’t on my own... (Participant I, BPD)

Participants felt their diagnosis provided an explanation for their experiences and helped them to reduce self-blame for past behaviours. Many expressed that they found it reassuring to know there was not something inherently wrong with their personality, but rather that this was something treatable.

Loss

Despite feeling relieved, all of the participants expressed a process of re-evaluating their past in light of receiving a diagnosis; and the loss of life opportunities they felt had occurred which they could now pinpoint as being a result of their illness experiences:

You go through pain. You have pain of oh that's why I couldn't do that marry thing, that's why I couldn't cope with maybe being responsible for children, or you know I couldn't touch that, oh ok so that's what it was about. (Participant B, BPD)

These particularly focused on potential personal relationships, work and education. Participants also made reference to actual experienced losses, "I've lost a career, I've lost a bloody good job and a marriage and I've lost a lot" (Participant G, BPD), "I've lost a lot of friends to it" (Participant H, BPD), that had occurred during the course of their illness and since their diagnosis. As well as a retrospective sense of loss, participants felt a loss for aspects of the person they one day hoped to be:

How would the new [girlfriend] react, knowing my past, my violent history and mental illness. How would she - or how would a person react. Erm if I wanted to get a job, I can't join the Army. I can't join the police force. I can't go to America. All the stuff like that. Just stuff that could happen in the future, but it's not going to happen now because I've got that diagnosis. (Participant Q, SZ)

The young men interviewed notably talked about expected marginalisation and the loss of future career opportunities due to the stigma of mental illness. The prospect of future romantic relationships, as with the participant above, also frequently arose for participants as something that was unlikely to happen: "Nobody wants to live with a ticking time-bomb, do they?" (Participant H, BPD), which overall gave a sense that their expectations for future life opportunities should be reduced to fit with their diagnoses.

Worthlessness and reduced self-esteem

The reduced ambition and expectations expressed by participants was coupled with reduced confidence and strongly reflected internalised messages of worthlessness which are common in mental health stigma; as Participant B explained, "You devalue yourself, because no one is valuing you". Participants had a wealth of negative self-perceptions relating to their diagnosis, such as

feeling “faulty” (Participant M, BPD), “damaged” (Participant H, BPD), “ashamed” (Participant E, D), “odd” (Participant D, BPD), “like a nothing” (Participant B, BPD), “like I’ve failed” (Participant P, SZ) and “on the rubbish heap” (Participant N, SZ). The distressing sense of abnormality and difference expressed here was frequently contextualised by the desire to “be like a normal person” (Participant S, SZ).

Illness and identity

The negative self-evaluations participants made in light of their diagnosis made participants feel conflicted about how they could distinguish themselves and their sense of identity from their illness:

I’m just mum. But once you put that on that they know I’m mentally ill. Even that sounds terrible.

Mentally ill. You know, it makes me sound like a nutcase and I’m not. But I am mentally ill, so that’s why I find it really hard. Feel like I’ve lost my identity somewhere along the way with all this.

(Participant E, BPD)

Participant S explained: “That’s what I find distressing as well, I’ve got no control over it. It’s inside, part of me. It won’t go away.” This desire to be rid of this aspect of themselves and “take it off” (Participant E, BPD) was commonly reported. However, participants also felt that the long history of symptoms they had experienced “does shape your development into adulthood, it does shape your perspective” (Participant M, BPD), and meant that their personality had to some extent been affected by their mental health issues:

It must have changed my, like what I experienced, how I acted, so it would’ve changed my personality related to how I experienced things, you know what I mean? Yeah, yeah, so it must be part of me isn’t it, it must be. (Participant K, BPD)

This perspective generally led participants to feel that accepting mental health issues as “innate...part of your whole being, your, the essence of you” (Participant B, BPD), part of their life experiences and incorporating it into their identity was “easier” (Participant L, BPD). Participants felt that this allowed for a greater sense of control over their mental health issues, “it’s not a case of

something that can attack you, it's your own thoughts and you can deal with them when they happen" (Participant O, SZ) through working with their experiences rather than against them.

3.4.2. Social interaction

This theme describes social consequences of psychotic experiences and receiving a diagnosis, in terms of how existing and potential relationships may be affected, changes in relationship dynamics, and experiences of stigma and discrimination.

Disclosure

Participants has shared their diagnosis with a very limited number of others, usually only family and close friends. Participant Q reflected: "If they need to know, they need to know. If they don't, then they don't. You know what I mean?" This autonomy with disclosure was of significance to participants, particularly as some had expressed discomfort or reported negative experiences as a result of their diagnosis being disclosed to others second-hand. The potential damage to status and relationships from disclosing illness was a key concern, and participants worried about being viewed differently, even by those close to them:

Embarrassment. As I say ashamed. I haven't even told my son. My daughter knows because she's studying psychology at the moment... But I couldn't tell my son, because he's not, I just don't think he'd understand. I just find it embarrassing to say, "Yeah, you know, I'm not the perfect mother" like.
(Participant E, BPD)

Disclosure to friends and acquaintances outside of their immediate circle were not just viewed as unnecessary but also as potentially stigmatising "I'm afraid that people would discriminate against me and treat me differently" (Participant S, SZ); "They'd shun me. They wouldn't accept me" (Participant D, BPD) and were avoided. Regardless of their diagnosis, all of the participants preferred to discuss their mental health experiences with others in terms of symptoms rather than using the diagnostic term because, as Participant R explained, "when you say it people will have expectations".

By explaining their symptoms, participants felt that they had the chance to explain their experiences to others without preconceptions.

Perceived stigma

The discomfort around disclosing mental illness was inherently tied in with the participants perceived and anticipated stigma. Their awareness of existing negative stereotypes was at times internalised, and meant that participants often expected others to desire social distance and discriminate against them, even when they had not experienced this directly:

I feel as though they may be reluctant to engage with me and have some sort of relationship with me, because they may think I'm dangerous because of the diagnosis, because I believe that people with paranoid schizophrenia are labelled as dangerous, and, because there have unfortunately been incidents where paranoid schizophrenics attack people and kill people, but in my case I'm not really like that at all, no. I'm quite safe person, I'm on medication. I'm safe. (Participant S, SZ)

The bottom line is I'm not ashamed but I understand and I'm very aware of the mental health stigma that surrounds everything especially bipolar and schizophrenia. Um, and believe...I don't want to put myself into a situation where I'm treated differently and so I don't want to give the people the option...to treat me differently (Participant I, BPD)

This often resulted in avoidant behaviours, particularly where stigma was expected. In some cases this appeared to be self-protective, and participants would withdraw from social situations or not engage in interactions to pre-emptively avoid the possibility of rejection.

Burdensomeness

Within their close circle, participants often felt that they were a burden to their family and friends in a number of ways. In a purely pragmatic sense participants felt dependent on others to assist them with day-to-day activities "I became very reliant upon her. She cooked for me, did washing for me" (Participant S, SZ). This was often expressed with a great sense of shame and a reduced sense of self-worth which suggested that they struggled with their dependence on others. In some respects

this seemed to be due to the ‘invisible’ nature of mental health issues, but also through participants’ unwillingness to discuss the true extent of their symptoms, particularly the effects of low mood on their ability to function:

You don’t want to sound as if you’re moaning to people, you know? You don’t want to be sitting in the pub with your mate saying, “Oh yeah, I’m really down at the moment I can’t walk”, carry on, you know, but really, what I’m trying to say is I can’t walk, I can’t move...my heart is breaking. (Participant G, BPD)

To a greater extent, participants were concerned about the emotional encumbrance for their loved ones, and similarly used this as a reason to avoid disclosing details about the extent of symptoms or negative emotions:

I’m sure there’s lots of things that I have negated telling my mother because I don’t want her to worry. So you always talk to your parents with a filter on... But I, I just don’t really, genuinely, want people to worry. (Participant L, BPD)

For the unemployed men in the sample, the intersectionality between the stigma of mental illness and the stigma of unemployment was a particular concern which frequently arose: “They think I’m a bit of a lay-about...” (Participant O, SZ). The conflict between the notion that people with mental health problems are not valued by society and have difficulty gaining employment coupled with the masculine stereotype of the breadwinner led participants to feel weak and vulnerable, and intrinsically tied in with their sense of worth and value both within the family setting and in wider society:

...and I’d like to pay my taxes, I like the feeling...’Ah, at last I am part of this society! I’m working and paying my taxes and hopefully everybody won’t attack me all the time!’ - well directly or indirectly. (Participant M, BPD)

Lastly, participants expressed a sense of being a burden in social situations as company for others, for fear of causing others to feel awkward or the need to edit behaviour:

I thought I'll go to [a voluntary service] for my Christmas dinner 'cause I don't have family as such, and your friends, you don't want to be in their family environment, because you know you're different. (Participant B, BPD)

This sense of being a burden led participants to express feelings of alienation and otherness, and led to increased social isolation through withdrawal, the rejection of certain relationships, and active avoidance of social gatherings.

Treated differently

Outside of their concerns about how they affected their friends and family, participants considered how their interactions and relationships had changed since they had been diagnosed, and the challenges this brought to their interactions, "because you can't ignore the fact that I've got a diagnosis, I understand that. But I don't want to be treated any differently... But then sometimes I need to be treated differently." (Participant I, BPD) Participants expressed a resignation that changes were predictable and a result of others expressing care for them, however they weren't welcomed and often made individuals feel uncomfortable:

I feel like, I feel like my, everything I do I feel like my judgement is questioned through the channel of "is this a bipolar moment?" (Participant A, BPD)

I just get the impression that I wouldn't be trusted with the kind of level that, I don't know. I don't really get given roles or responsibilities... (Participant L, BPD)

Sometimes, I do feel that people aren't entirely comfortable for me to, like, look after the children for a bit or something you know, like I feel, sometimes I feel a bit upset about that because it is like well there's – I'm perfectly capable of you know, being responsible for the, you know, erm children, so sometimes that is bit of an upset (Participant J, BPD)

Participants felt hurt and invalidated by familial over-involvement and monitoring, and did not feel like they had an equal voice in the family setting. Moreover, participants felt that their

actions and emotions were often judged through the lens of their diagnosis and subsequently discredited rather than being taken seriously.

Stigma experiences

Participants also shared explicit experiences of maltreatment in relation to their diagnosis. For instance, participants reported negative social interactions, particularly feeling “abused” (Participant N, SZ), “bullied and coerced” (Participant A, BPD); and verbal abuse, with participants reporting being called “a divvy and a nutter” (Participant D, BPD), “insane” (Participant N, SZ) and “mad” (Participant H, BPD). Participants also recounted others accusing them of malingering and pressuring them to engage more fully and be well:

They keep on telling me, “You need to get yourself a job.” Like I’m playing around being disabled, like I’m playing around at disability. (Participant G, BPD)

I think I struggled to- having the symptoms still and I think, you know especially the pressure from home to be fixed, you know, and to be sorted. (Participant J, BPD)

Participants felt “hurt” (Participant M, BPD) by these discriminatory experiences, and typically attributed them to poor awareness of mental health issues in the wider public.

Need for understanding

Participants felt the general public had a negative attitude and limited understanding of bipolar disorder and schizophrenia, and were uncomfortable with the diagnoses: “I think they realize that they don’t understand it and maybe that’s scary to some people” (Participant O, SZ). Participants felt that most people’s sources of information were the media. For the bipolar group this was framed more positively with reference to celebrities “like Stephen Fry...and people like that in television”(Participant G, BPD) and helpful portrayals in film. For the schizophrenia group all but one participant referenced violent stereotypes spread through the media; “Cause they see things on the

telly about people with mental illnesses, killing people and that, there's a stigma about it"

(Participant Q, SZ).

The lack of awareness coupled with the fears around disclosure and others' reactions meant participants felt a keen sense of isolation, "It's hard because it is a very lonely world, you know"

(Participant D, BPD), difficulty coping and a need to share their experiences and be understood by others:

Really lonely, it makes me feel like no one really gets me. Because I don't tell them and if I do tell them anything they sort of take a backwards step and think "she's mad her". So I say nothing. It's quite a lonely... I mean it's quite a lonely illness. (Participant E, BPD)

Participants expressed feeling that genuine understanding and sympathy was only available from others experiencing mental health problems, and often remarked on this with humour: "my girlfriend's a bit...mental and all (laughs) so like, um yeah she understands and that, I help her and she helps me" (Participant K, BPD). This often suggested a sense of absurdity in only feeling 'normal' amongst others who would typically be viewed as 'abnormal'. Others expressed a fathomable sense of relief at being able to share experiences with someone who could empathise with them:

Ahh, our experience has been different. But I do feel comfortable going to [the wellbeing centre]...I think because you know everyone around you has got mental health problems...I am more chatty with them there. And er we can share if we had a bad week we can share, you know, what's happened...(Participant D, BPD)

In contrast, despite finding friends and family well-meaning and supportive on the whole; expressions of sympathy and understanding from people without a history of mental health problems were often viewed as a cause of great frustration. These were perceived as diminishing the gravity of the participants' experiences, patronising, and at times, inflammatory:

...they don't know what to say and when, and so one time they could say something that would absolutely touch, you know, hit a nerve – I mean my brother and my dad said something to me out in front of the house once and they said that it was normal what I was going through. And everybody goes through it. And I flipped out and I was about to beat the shit out of them and I was like, "You've got no idea what I'm going through." (Participant I, BPD)

In response to this perceived lack of understanding participants confessed to editing their behaviour and hiding their symptoms and genuine emotions: "I will have a mask of how I feel constantly" (Participant I, BPD), as a means of avoiding potentially difficult social interactions, or making other people feel uncomfortable.

Differentiation from others

Despite finding others with mental health problems to be a source of comfort and support, participants often made a point of distinguishing both their level of symptoms and functioning from others who shared their diagnosis:

...I don't want to say the type of people I'd only ever seen going into the pharmacy room before but they weren't me, you know? And erm I suppose I was only ever in there at the wrong times seeing the wrong people going in but I thought to myself, this is heavy stuff you know... (Participant A, BPD)

I have a mental disability but I think if anyone ever notices I'd be surprised, whereas on the other hand if I go to [voluntary service] and there's lots of people who visually, physically, mannerisms-wise, it's so obvious that they have a mental health condition...I speak to them with the same respect... (Participant B, BPD)

When this was explored further, it seemed that participants struggled to integrate their pre-existing ideas of mental illness and awareness of negative stereotypes with their own experiences:

Well, I had perceived before I had my diagnosis was a schizophrenic as a dangerous person and unreliable person. Somebody you wouldn't really want to know because it will be difficult. Sort of all over the place, but obviously it isn't that...well it isn't that in my situation. (Participant R, SZ)

On the surface these disclosures appeared to reflect a lack of compassion for others experiencing mental health issues, but on further exploration it seemed that participants made efforts to distinguish themselves from others with mental health issues in order to distance themselves from the negative mental health stereotypes. This self-protection through distancing seemed to help participants maintain links with their identity prior to diagnosis, and focus on positive aspects of their functioning rather than experienced deficits.

3.4.3. Recovery

This theme describes participants' feelings about recovery in terms of current feelings, and hopes for the future.

Reduced functioning

Participants reported feeling incapable of fully engaging in life and work opportunities, unable to function in variety of ways, and conflicted between their own needs and other's expectations of them:

I was promised from the psychiatrist that I would lead a normal life and go to work and I'm not doing any of them things you know, I've lost all my confidence, paranoia's raging and I'm not in a place where I can go back to work, but everyone's telling me I need to go back to work. (Participant A, BPD)

I feel as though I can never really achieve everything that I want to do. I feel as though because of the diagnosis it's made me feel as though I should step back a bit and not really go for high achievements anymore. (Participant S, SZ)

Whereas for some this was linked with symptoms, for others the repeatedly reported avoidance and withdrawal was clearly a response to anticipated and internalised stigma. Participants often described this as a conscious process of withdrawing as a means of maintaining autonomy and feeling in control of the events surrounding them. By reducing external interactions and influences, participants reported feeling "safe" (Participant B, BPD) and more contained.

Adapting and adjusting

As with the reduction of functioning, participants reported making active changes to their lifestyle and activities in order to adapt to their diagnosis, and much of this again appeared to be focused on moderating their expectations “It’s thrown a major spanner into the what I’d like to achieve category” (Participant L, BPD).

However, participants also reported being particularly dedicated to self-monitoring “I’m starting to learn the illness” (Participant G, BPD); and finding patterns or cycles in their symptoms which could aid in their self-care “I can go forward in my life now. I just need to learn these little waves and then I’ll get to it.” (Participant C, BPD). Many of these adaptations were aimed at creating stability and consistency in the hopes of reducing flare-ups of psychotic experiences, “I’m living a kind of half-life. But it’s a safer, safer life for me to live” (Participant H, BPD), and minimising stress as a coping strategy to avoid triggering the onset of more acute symptomology:

I understand that if I drink a load of coffee and a load of alcohol and don’t sleep and take drugs and things like that, then it’ll affect my moods but if I am sober and getting enough sleep and exercise and things like that, then the mood swings will be contained by drugs, you know, prescription drugs. I’ll be contained. (Participant I, BPD)

For most of the participants these adjustments weren’t seen as ideal, but necessary, and part of “looking after yourself” (Participant B, BPD). Despite not feeling fully engaged in life, participants felt safer and more in control of their experiences, and more self-compassionate.

Growth through experience

Participants felt that aside from increased self-control and self-compassion, they had grown as people through their experiences with mental illness. A major aspect of this was feeling more open-minded and accepting of others:

Yeah, the insight on life. It’s a bit weird. Like, you take your blinkers off and get your widescreens on. You just see a bigger picture of everything. (Participant C, BPD)

Participants also felt more accepting of themselves, and expressed feeling “proud” (Participant E, BPD) about carrying on with day-to-day life and overcoming adversity. Participants felt that their experiences made them more sensitive and aware of other’s suffering and some had engaged in voluntary activities with service-users, such as mentoring and work within recovery colleges: “The people on the course need people like me in their life, positive people” (Participant P, SZ). These roles were particularly empowering and appeared to counteract some of the negative self-appraisals participants had expressed in relation to their diagnosis:

I don’t, I don’t need to hide who I am. It’s better for me if I talk about it and it’s better for other people and it’s better for future people because it’s again I say again it’s getting rid of the stigma. (Participant F, BPD)

The idea of reducing the stigma surrounding mental health problems and supporting others with similar experiences was seen as particularly positive, and these voluntary roles were often seen as a step towards gainful employment in the future.

Future thinking

Participants referred to the long-term and chronic nature of their illness as something they would have to manage for the rest of their lives: “I’m realistic - it’s never, ever gonna go away. I’ll try and manage it the best I can but it’s a very difficult thing to manage, you know? You managing what you can’t see, you’re fighting shadows.” (Participant G, BPD).

However, participants made a strong distinction between coping with symptoms “it’s a total battle all the time” (Participant A, BPD), their perceived inability to live life symptom-free “It can be quite distressing if you think about it - to think I’m going to be for the rest of my life...reliant upon medication to remain in an acceptable level of wellbeing” (Participant S, SZ); and their desire to recover in terms of improving wellbeing and engaging with life opportunities: “I think the things that you’re concerned about can still be achieved and that’s the most important thing.” (Participant O, SZ). Of particular importance was the re-establishment of a sense of independence and self-reliance:

Um, positive to the fact that my life is in order, my finances are in order, we're in control of where we are, who we are, who we want to be, where we want to go, and it's about becoming self-reliant. And that is, the biggest thing for us is being independent. And we're still on that border of crossing into total self-reliance and that's about dropping the things that have happened in the past and forgetting about them and moving on. And it's just a couple of things that there's just a couple of things that um, hold me back very slightly. (Participant I, BPD)

Overall, whilst the participants acknowledged that recovery was a long process, and had concerns about the possibility of relapses and reoccurrence of symptoms, they expressed a great deal of positivity and hope for the future. Participants felt able to move forward "getting through each day as it comes" (Participant D, BPD) whilst continuing to learn, and develop the skills to manage their illness. Participants weren't focused on 'getting better' but "doing better" (Participant A, BPD), with independence, autonomy and wellbeing at the heart of their goals.

3.5. Conclusions

The findings contribute to the existing qualitative evidence base and supports previous research recognising stigma as a serious concern for people with experiences of psychosis, particularly those diagnosed with bipolar disorder and schizophrenia. Whilst we expected to find substantial differences between the effects of stigma for each diagnosis, we actually found individuals' experiences to be very similar. Although, all but one of the participants with a schizophrenia diagnosis made specific reference to negative schizophrenia stereotypes perpetuated in the media; whereas participants with a BPD diagnosis made reference to positive celebrity role models, and viewed the media as informational. This discrepancy, whilst interesting and congruent with the literature, did not result in significantly different participant accounts of experiences of stigma. Participants in both groups expressed some desire to conceal their diagnosis from others, experiences of ill or different treatment, and an altered sense of identity after receiving their

diagnosis. Moreover, both groups of participants felt that there was a lack of understanding about their illness in the general population, which is supportive of previous research (Burke et al., 2016).

There are similarities between the themes described in this study and in other qualitative studies exploring experiences of stigma and psychosis (Burke et al., 2016; Pyle & Morrison, 2013; B Schulze & Angermeyer, 2003; Wood, Burke, et al., 2014) which indicates that the issues described here are common to the experience of psychosis. In terms of the wider literature we also found many parallels, such as reduced functioning and avoidance (Burke et al., 2016), a sense of reduced life, work and education opportunities (Thornicroft et al., 2009) and not feeling like a valuable member of society (Jenkins & Carpenter-Song, 2009). The findings relating to internalised stigma are particularly important given the relatively limited research in this area (Yen et al., 2005). The internalisation of stigma was displayed through a number of means such as reference to unwillingness to engage and social withdrawal, anticipation of stigma, and self-protective reasoning and humour. This led to a heightened sense of burdensomeness and vigilance in social interactions. Participants struggled to cohesively incorporate their illness with their previous self-image, and were often keen to differentiate themselves from others with the same diagnosis. Moreover, there was a pervasive sense of worthlessness, devaluation and shame associated with the diagnoses.

In terms of recovery feelings, the findings were more complex. Participants did not appear positive about a remission of symptoms, stating that it was “a total battle all of the time” (Participant A, BPD) and referenced the chronicity and ‘lifelong’ nature of their illness, as in the existing research (González-Torres et al., 2007). Indeed, participants felt that their illness was often an inherent, inextricable part of them. Yet contrary to expectations, participants spoke hopefully about recovery in terms of recovering independence, stability, relationships and employment in the future. Moreover, many spoke positively about how they had grown as an individual through their experiences, at times feeling empowered through their ability to help others in similar situations, and a sense of pride and strength from overcoming adversity.

3.5.1. Limitations

The interview did not specifically contain questions regarding stigma to avoid leading participants. On the one hand, this may be seen as a positive as participants divulged the information spontaneously; however it is also possible that due to the absence of direct questioning some stigma experiences may not have been disclosed to the interviewer. The sample was entirely white and biased towards individuals with a bipolar disorder diagnosis, which may have skewed the findings. More research with these individuals and those in black and minority ethnic communities is needed and this should be an avenue for future research. It is worth highlighting that the study findings were not returned to the participants for validation, and whilst the relevant excerpts were analysed in the wider context of the interviews, the analysis may have benefitted from further participant collaboration, for example in clarifying ambiguous statements.

3.5.2. Clinical Implications

In line with the existing findings, stigma was identified as a significant barrier to recovery. Moreover, it was evident that participants struggled to cohesively incorporate mental illness with their previous sense of self, causing emotional turmoil and a sense of loss for the life they felt they would have had. Avoidance, withdrawal and reduction in functioning were also key issues. As such mental health services need to routinely assess for stigma (Burke et al., 2016) consider the impact of receiving a diagnosis, and ensure that service-users have access to adequate support and counselling to help them adjust during this period of personal identity change. The wealth of information disclosed about stigma without the use of direct questioning indicates that this is a subject of great significance to service-users. Clinicians should be aware of the different means by which difficulties with stigma are expressed conversationally, and make efforts to enquire about stigma and discrimination. Growth through experience and the ability to help others experiencing psychosis was a positive theme which empowered individuals and could be taken forward as a social

intervention through the implementation of mentoring schemes, recovery colleges, and service-user led self-help groups to help individuals begin to re-establish positive identities.

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Chapter 4:

The role of medication and mental health services in recovery from psychosis: service user's perspectives.²

² The findings presented in this chapter were not expected but arose during the interviews and analysis. They have been included in the thesis as they were considered to be an important aspect of participant's feelings about the process of recovery from psychosis.

4.1. Abstract

Experiences of psychosis, particularly those associated with a diagnosis of schizophrenia or bipolar disorder often result in lengthy engagement with mental health services and the extended use of psychiatric medication. Limited qualitative research has explored service-users' experiences of mental health services and drug-based therapy, and how these impact on subjective recovery perceptions. This study used data from 19 semi-structured interviews with participants who had received a diagnosis of either schizophrenia or bipolar disorder within the past 5 years. Five overarching themes were identified: living with medication; reinforcing stigma; involvement in care; unmet needs; and positive aspects of care. Service-users made positive reports of aspects of both medication and clinical services. However, participants had extensive concerns about the use of medication, and felt limited in their choice of alternatives. Moreover, service-users felt they lacked autonomy, were not involved in care decisions, and thought their contact with services could be invalidating and frustrating. There is a need for clinical services to reduce behaviours that reinforce stigma, and work collaboratively and transparently with service-users, ensuring that goals for treatment correspond between clinicians and consumers.

4.2. Introduction

Despite advances in psychological therapies for psychosis, medication remains the backbone of treatment for people with schizophrenia-spectrum disorders and bipolar disorder. There are a number of recognised issues with the prescription of antipsychotic medications, such as 'polypharmacy' or the concurrent use of multiple drugs, inappropriately high dosages, risk of toxicity, and risk of substantial side effects (Buckley & McManus, 1998; Ciranni, Kearney, & Olson, 2009; Harrington, 2002; Lelliott et al., 2002). Rates of non-adherence to psychiatric medication reportedly average between 41.0% and 49.5% (Lacro et al., 2002). Long-term rates decrease even further, with one study finding only 11.6% of 2655 service-users completed 12 months of uninterrupted use of antipsychotic medication (McCombs, Nichol, Stimmel, Shi, & Smith, 1999). There has been a large amount of quantitative research into medication adherence in people with experiences of psychosis (Seale, Chaplin, Lelliott, & Quirk, 2006), and this has led to the identification of over 200 contributing factors, such as perceived treatment tolerability and negative attitudes towards medication (Hardeman, Harding, & Narasimhan, 2010; Lacro et al., 2002; Tranulis, Goff, Henderson, & Freudenreich, 2011). In contrast qualitative research into patient experiences of medication are notably scarce (Rogers, Day, Randall, & Bentall, 2003; Tranulis et al., 2011).

An increased focus on patient-centred approaches to psychiatric care in recent years has led to increased criticism of traditional treatments, and greater appreciation of the role of the therapeutic alliance (Bentall et al., 2002; Seale et al., 2006). Further examination of the relationship between clinician and client has also identified a number of discrepancies in their perceptions. For example, the degree to which psychiatrists and service-users estimate the extent of adverse effects from antipsychotic medication differ substantially (Day, Kinderman, & Bentall, 1998; Rettenbacher, Burns, Kemmler, & Fleischhacker, 2004). Similarly, clinician-rated recovery and service-users' recovery perceptions have been found to correlate poorly (Morrison et al., 2013). Clinical definitions of recovery typically focus on remission of symptoms, medication compliance, current functioning,

reduced admissions and reduced relapse (Lam et al., 2011; National Institute for Health and Care Excellence, 2009). In contrast service-user definitions of recovery are often much more holistic encompassing functionality, autonomy, wellbeing, personal growth and the re-establishment of personal and social identity (Andresen, Oades, & Caputi, 2003; Lam et al., 2011; Pitt et al., 2007). The discrepancy between clinician and consumer concepts of recovery is also thought to cause conflict in terms of available treatments and interventions for psychosis; for example, the clinical notion that rehabilitation can only occur after stabilization. Messias et al. (2007) argue that the focus on symptoms in clinical services means that typical treatment consists of assessment, diagnosis and medication, while rehabilitation and other support are considered secondary, despite being viewed as more important by service-users. Similarly, qualitative studies have highlighted the importance of a sense of autonomy and self-management for service-users when taking antipsychotic medication (Rogers et al., 1998).

User-defined perspectives and evaluations of anti-psychotic medication and interactions with mental health services are limited in the current literature. As such, this study aims to explore these experiences, and how they influence service-users' feelings about recovery.

4.2. Method

4.2.1. Sample

Participants were eligible if they were aged between 16 and 65, and had been told they had a diagnosis of Bipolar Disorder or Schizophrenia within the past 5 years. Diagnosis was self-reported by participants and confirmed by their clinician. 19 service-users (11 male, 8 female, mean age = 36.89, SD = 12.60) were recruited, exceeding the minimum theme saturation threshold of twelve interviews proposed by Guest, Bunce and Johnson (2006). Thirteen participants (7 male, 6 female) reported that they had been given a diagnosis of bipolar affective disorder (BPD) and 6 (4 male, 2 female) reported that they had been given a diagnosis of schizophrenia (SZ). The demographics of the sample are presented in Table 3.

Table 3: Participant demographics and specified medications.

Ppt. ID	Gender	Age	Ethnicity	Employment status	Diagnosis	Interview length (minutes:seconds)	Medications specified*
A	Male	44	White	Unemployed	BPD	61:03	Lithium, Seroquel
B	Female	54	White	Unemployed	BPD	133:26	None specified
C	Female	33	White	Unemployed	BPD	36:27	Fluoxetine, Citalopram, Quetiapine
D	Female	44	White	Unemployed	BPD	43:43	Lithium, Haloperidol, unspecified diazepam
E	Female	54	White	Employed	BPD	46:41	Olanzapine, Lithium, Venlafaxine
F	Female	32	White	Employed	BPD	43:58	Duloxetine, Lithium
G	Male	44	White	Unemployed	BPD	53.41	Lithium, Venlafaxine, Risperidone
H	Male	55	White	Employed	BPD	56.35	Lithium, Aripiprazole
I	Male	27	White	Unemployed	BPD	55.32	Divalproex Sodium, Citalopram, Olanzapine
J	Female	37	White	Unemployed	BPD	54:14	Lithium, Quetiapine
K	Male	19	White	Unemployed	BPD	22.06	Amisulpride
L	Male	25	White	Unemployed	BPD	33:41	Unspecified antidepressant and mood stabiliser
M	Male	25	White	Unemployed	BPD	72:53	Sertraline, Venlafaxine, Quetiapine, Lorazepam, Divalproex Sodium
N	Male	60	White	Unemployed	SZ	32:00	None specified
O	Male	25	White	Unemployed	SZ	31:04	Olanzapine
P	Female	35	White	Unemployed	SZ	23:32	Clozapine, Olanzapine, Quetiapine, unspecified beta-blockers
Q	Male	19	White	Unemployed	SZ	36:48	Aripiprazole, Risperidone, Procyclidine
R	Female	39	White	Unemployed	SZ	52:42	Aripiprazole, Risperidone
S	Male	30	White	Employed	SZ	48:28	None specified

Note: BPD = bipolar disorder; SZ = schizophrenia. *Refers to both historical and medications mentioned by participants.

4.2.2. Interview

Participants were interviewed alone and in person by the first author. Interviews took place either in the participant's home (n=13) or at a local health service (n=6). The interview was introduced to participants as a means of exploring the experience of receiving a diagnosis of BPD or SZ. The study has received ethical approval from the National Health Service Research Ethics Committee.

A semi-structured interview method was used to enable consistency in questioning between participants, whilst still allowing individual participants to focus on areas of particular importance to them. The interview began with factual questions to collect some demographic information (Section a). We used an open chronological retrospective approach which allowed participants to work through their experiences since being diagnosed to the present. Section B explored the participants' life prior to diagnosis, the onset of illness, and the experience of entering services and being diagnosed (e.g. before your mental health diagnosis what was life like?). Section C concerned the immediate aftermath of engaging with mental health services, how the participants' processed their newly acquired diagnosis, and any initial changes they felt had occurred (e.g. did you think differently about yourself than before?). Section D explored the present, reflections on the impact of receiving a diagnosis, and participants' thoughts about the future (e.g. thinking about your roles and responsibilities in the family, did they change at all after your diagnosis?). Section E enquired about perceived causes and explanations of illness and sources of information used to learn about their diagnosis (e.g. what do you understand Bipolar Disorder/Schizophrenia to be?). The interviews concluded with an opportunity for participants to consider what advice they might give to others in a similar situation to themselves. The full interview schedule is found in Appendix A.

It is important to note that there were no explicit questions in the schedule regarding experiences of medication or mental health services, but if the topics were raised by the participant they were explored further.

4.2.3. Analysis

Data analysis was carried out by the first author. The primary method of analysis was adapted from the grounded theory approach outlined by Bennett and Vidal-Hall (2000). The latter stages of analysis departed from classic grounded theory to focus on the emerging themes in the context of mental health stigma.

(1) Each transcript was read in its entirety to allow the researcher to become familiar with the narrative and gain a contextualised understanding of each participant's experience.

(2) Interviews were re-read and coded line by line, allowing the development of initial codes. During this stage, initial impressions and interpretations were recorded separately in a reflective diary. This process was reflexive, meaning that each new emerging code led to re-coding of earlier parts of the transcript.

(3) Once all transcripts were initially coded, the transcripts were re-read and similar themes between participants' initial codes were grouped into a number of broader categories, or sub-themes, which were then further refined into the final themes, which are presented in Table 4.

Table 4: Table of final themes for service-user’s perspectives on medication and mental health services

Final themes	4.3.1. Living with medication	4.3.2. Reinforcing stigma	4.3.3. Involvement in care	4.3.4. Unmet needs	4.3.5. Positive aspects of care
Sub-themes	<ul style="list-style-type: none"> ▪ Reservations ▪ Expectations ▪ Frustrations ▪ Lifestyle change 	<ul style="list-style-type: none"> ▪ Perceived stigma ▪ Recovery prospects ▪ Invalidation 	<ul style="list-style-type: none"> ▪ Lack of control ▪ Lack of information & transparency ▪ Collaborative care 	<ul style="list-style-type: none"> ▪ Access and barriers to treatment ▪ Access to alternatives 	<ul style="list-style-type: none"> ▪ Voluntary services ▪ Helpful ▪ Supportive

4.3. Findings

4.3.1 Living with medication

All of the participants were currently undergoing treatment with psychiatric medication, and had past experience with drug-based interventions. Some participants had also elected to come off their medication at various points in the past. This theme explores the challenges of living on psychiatric medication. In particular it focuses on participant's impressions and experiences of drug-based interventions, and how the participant's felt medication had impacted day-to-day life and their prospects for recovery.

Reservations

Participants expressed initial concerns about taking medication: "my major concerns for the future initially...was plans for the medication" (Participant L, BPD). These anxieties predominantly revolved around reduced functioning "concerned they're gonna rob me of my impetus" (Participant L, BPD), and the common psychiatric medication stereotype of being "zombified out" (Participant J, BPD):

I was scared I was going to be on all kinds of crazy tablets. I'd heard rumours that it would take your personality away, or take your libido away. It will, you know, steal your soul. You'll be this lithium zombie, you know, all those kinds of things. And I was going to do it by eating hazelnuts and eating lots of oily fish, you know, and not have a stressful life... (Participant G, BPD)

As Participant G suggested, participants were also worried about the toxicity of psychiatric drugs, with many of them indicating they "don't necessarily feel comfortable about taking medication generally" (Participant J, BPD). This made participants feel conflicted between their beliefs about their physical and mental health, and the need to engage in treatment. At times, these conflicts led to non-adherence:

Health. I don't want to pump myself full of drugs. The fear of passing on any effect that that may have onto future children, so if we were to have more children, I wouldn't want to have the drugs in

my body. But I've got a very holistic approach...I believe in a higher power, not like God and things like that, but I believe in spirits and doing it myself with meditation and things like that and that's the route I wanna go down and seriously controlling my mood and my mental state. And so, um, I'd prefer to do that instead of drugs. And so two weeks ago, I got it into my head, I needed, about 3 weeks ago, that I needed to come off, I don't need to take - it was only a short period like four or five days but it was long enough to have a quick effect on me. (Participant I, BPD)

The need to "feel you're in control" (Participant E, BPD) as opposed to being dependent on the medication was not uncommon, with participants reporting that they "didn't want to rely on them" (Participant P, SZ). Similarly, despite disliking their medication, participants were worried about mental and physical dependency on medication, and were frightened about the possibility of the effects of withdrawal if they come off medication

Just fed up with it but sort of accepting that that's how it is now. I just feel like that and I've been tempted to stop taking the tablets quite often, but I don't know what the withdrawal symptoms would be like and I'm a coward. (Participant E, BPD)

In contrast, many of the participants with a bipolar disorder diagnosis also cited a second reason for considering stopping their medication:

Even though the Lithium is doing a wonderful thing for me - but it's not because I no longer have them great highs which really were fantastic, despite the mistakes you made with them. I am still predominantly low you know. (Participant A, BPD)

For these participants, the benefits of taking medication were not always clear, as they valued part of their psychotic experiences, and did not necessarily find that the medication dealt with the symptoms that they found most problematic. For others, the issue wasn't whether or not take medication, but rather the quantity of medication prescribed:

And, going onto the medication has been very high. It's been... I mean, the psychiatrist says is been very high - what they put you on in hospital, and he's taken it down, but I think all that medication and all the stresses I have it's made me, made me a bit depressed. (Participant R, SZ)

Concerns about dosages being too high made participants hesitant to engage with psychiatric drug treatments from the outset, particularly when their first experiences of medication were enforced during sectioning. Instead, the participants felt that medication should ameliorate symptoms, but not at the expense of functioning.

Frustrations

Participant's concerns around over-medication were not limited to dosages, but also related to the cumulative prescriptions of multiple medications, "they add on" (Participant G, BPD); "first thing that doctor did when I moved over here was introduce two more drugs" (Participant A, BPD). This led participants to express confusion and frustration over what factors influenced their clinician's decision-making and willingness to prescribe further medication:

I'd go in like dead low and they'd given me Prozac and I'd be like 'What are you giving me that for?' And then I'd go in a couple of weeks later and I'd say I'm having anxiety and panic attacks and I'm dead high. I need something to bring me down, and he gives me Citalopram. So I was like, how the hell are you stabilizing my mood? (Participant C, BPD)

They left my Risperidone for a long time and, and it's only been recently they put me on Aripiprazole only because the Trust wouldn't pay for it, it's hard in this area. (Participant R, SZ)

Participants repeatedly expressed their understanding that prescription wasn't straightforward and was a gradual process of trial and error "it's a lot of tweaking and trying different things you know, to get you sound" (Participant E, BPD). However, some felt as though by not responding well to their prescribed medications and repeatedly requesting alternatives, they were a burden to their clinicians. This often meant participants felt pressured to stick with treatments that weren't right: "really he needed to see whether it was gonna- *the drug or a drug*

was gonna..." (Participant A, BPD). Participants not only felt like a burden to their clinicians, but that medication could be a burden to them:

It has definitely changed my life since I've been on medication, having to remember to take two dots of tablets a day. It is a bit irritating having to take eight tablets a day, like four in the morning and four in the evening. (Participant S, SZ)

Participants also found their medication to be particularly burdensome in terms of side-effects which one participant described as "absolutely horrendous" (Participant A, BPD). Participants reported numerous side-effects from medication such as: "I see things" (Participant A, BPD), "shakes" (Participant D, BPD), "sleepiness" (Participant J, BPD), "drowsiness" (Participant S, SZ), "flat feeling" (Participant E, BPD), "blurred vision and wooly-headed" (Participant L, BPD), "incapacitated" (Participant O, SZ) and "restless legs and my tongue gets restless which is really annoying" (Participant Q, SZ). Of these, the emotional dulling and sedative and effects of psychiatric medication were frequently reported as being particularly bothersome and impinging on day-to-day life:

Um, it's more sedating, not a lot, but, but is more sedating. And... so, I tend to sleep longer. And it's a bit dulling. What might make sparks for me or I might think I will read this or I'll go there - I don't so much want to do those things quite so much. A bit dull really. The good side of it is that it's not as sedating as Risperidone [laughing] It's a funny name! Which I had before. And that really affected the quality of my life. I wasn't really awake till eleven. Even then I had a load of coffee. And, and then the afternoon when I was really awake at night times. I was just too tired to have a social life. So it did affect me a lot. (Participant R, SZ)

Participants felt these effects were a barrier to engaging in aspects of life, stating that medication "does cut down some of your drive" (Participant H, BPD) and "takes away the motivation" (Participant E, BPD). Participants also felt that the side-effects had "caused problems at home" (Participant J, BPD) and would be problematic for future employment:

And not being particularly confident because of the drowsiness and the medication. I think I'd have to take it before I left for work so that I was really tired when I got home and so I could get the rest of long hours rest I need before the next day. (Participant O, SZ)

Some side-effects prevented engagement in life opportunities because they made participants feel embarrassed or less confident. For some this was because of the visible nature of the side-effect, such as Participant D, here talking about her Parkinsonian symptoms: "In a restaurant, if I want coffee. Because I can't physically pick up the cup at times. So I just sort of blank people off that I'm using the straw to drink coffee". Many also found the weight gain associated with psychiatric medication to be particularly difficult to live with, "I'm 2 stone heavier -I don't really fancy going into town cause I don't feel good." and felt this had majorly impacted their self-esteem and confidence to engage:

I put on two and half stone ...in about three weeks and it absolutely rocketed and I've not been able to shift it since and that's had a massive knock-on effect on me in terms of my personal opinion of myself and so, my self-esteem has fallen massively and I literally do not like myself or my body, um, even though people are telling me like, "You're not actually fat." But it's the fact that I'm not as healthy or as trim as I used to be. (Participant I, BPD)

Lifestyle change

Participants social interactions were further impacted by the medication by leading to changes in lifestyle:

And I was bit angry actually because she said to me I couldn't drink, and a whole other part of my life was at the weekend when I'm not at work, was to go out and get absolutely bladdered. I absolutely loved it. I loved doing it. I'd still love to do it if I could but I can 'cause the meds won't let me. But, you know and they were telling me I couldn't drink, and I couldn't do this. And I was quite annoyed really, because I thought just leave me alone, I'm fine as I am. (Participant E, BPD)

And I can't drink like a fish anymore, not on lithium and all the things I'm on. And sometimes you've got to make lifestyle choices. I mean, I'm making these choices to stay well. And if it means if I've got fewer friends, that's what I'll do. (Participant H, BPD)

Whilst participants accepted that abstinence from alcohol was encouraged by services in order to reduce drug-alcohol interactions, they expressed great frustration and a sense of isolation from not being able to participate in social drinking, and felt this had impacted on their relationships. Similarly Participant F felt that her interest in sports and exercise had been impacted through medication: "I can't take any anti-inflammatories for it and it sets me back so much and that's my biggest issue with the medication." "Practical issues" (Participant O, SZ) were a further concern, as some participants were no longer able to drive "I had my licence taken off me" (Participant I, BPD). Many expressed the sense that there was a great need for "routine" (Participant Q, SZ) and that life had to revolve around the medication "anybody who takes the medication has to curb to suit the medication" (Participant H, BPD). Overall, this conveyed difficulty in continuing with life as before engaging with treatment.

Expectations

Despite these difficulties with the medication, on the whole participants believed that the drugs were beneficial and would ultimately help them if they could "get it perfectly right" (Participant G, BPD):

"I know drugs isn't the answer to it all but I reckon it's got a bigger part to play than it's playing"
(Participant A, BPD)

"They think it's a cure, it's not the cure. But I still got hope of the medication." (Participant G, BPD)

These assertions whilst optimistic, retained a sense of uncertainty and hesitancy, suggesting that it was still "early days" (Participant E, BPD) and things might improve. However, when explored further, it was not symptoms that participants were focused on improving, but rather their functioning and independence:

I feel all right about it really as long as it helps me maintain a good functioning level and stuff (Participant J, BPD)

And I can live with being on medication, ideally I want to move more to independence as time goes on and maybe not rely on them as much. (Participant M, BPD)

If it works and it makes my life normal, I'm happy to take two tablets at night for the rest of my life if need be. (Participant F, BPD)

Whilst participants spoke of hopefully reducing medication in the future, most expected the use of medication to be "pretty much life-long" (Participant J, BPD) and were resigned to the idea that "I'm going to be taking that for the rest of my life, and that's a fact of life." (Participant H, BPD).

4.3.2 Reinforcing stigma

This theme explores participant's perceptions of stigma in relation to their treatment and interaction with mental health services.

Prognosis

The stereotypical notions of people with psychosis being unlikely to ever recover (e.g. Crisp et al. 2000) and the life-long nature of illness were particularly reinforced by discussions with about prognosis and outcome in services:

"...saying that he thinks I've possibly being ill since for a lot longer before I was brought to their attention. And because of that he thinks it's less likely I would recover from it, he gave some facts."
(Participant R, SZ)

"They've given you a diagnosis, they're telling you how much care you need and it's a, you know a serious mental condition you're going to have for the rest of your life and they've no, you can't see the care, you can't see a very fundamental word erm, nurturing. Every person with mental health needs nurturing." (Participant B, BPD)

Participant's conveyed this as a "shock" (Participant D, BPD) when they were initially told, but generally accepted it as fact, having come from a professional: "I mean I can only trust them and what they're telling me, and I hope that it does get better" (Participant E, BPD). Few participants reported that they had been told they may recover, however those that did were more optimistic about the future:

As far as the experience itself was trying to keep things above the water line and I think knowing statistics about psychosis and schizophrenia and how many people recover as well as they do recover from it was very helpful. People are saying there's a great chance you'd be absolutely fine in however long and ... it might seem ... It seems a heck of a lot worse now wouldn't it ... in the future and that was very important because I felt like I wasn't in a sinking ship anymore, you know? (Participant O, SZ)

The notion of no longer being a "sinking ship" suggested that positive encouragement from services about recovery prospects reduced self-stigmatising around psychosis as an incurable illness.

Perceived stigma

Participants were not only concerned with their prognosis and quality of their interactions with mental health services, but also how engaging with services reflected on them. Participants were concerned about the stigma of being involved with mental health services and at times expressed reluctance at being seen by others at mental health clinics "Mostly I just come on me own. So I don't tell people because I'm embarrassed by it" (Participant E, BPD). Others reported concern about exposure through home-visits by members of their care-team, drawing unwanted attention to them:

"...especially you know people kind of being nose-y and what have you, thinking who's that, you know, it's obviously a, you know, a professional of the nursing kind with the classic diaries that they carry every day and stuff and you're thinking what's going on there, you know. Is everything ok?"

(Participant J, BPD)

Participants also perceived stigma around needing or taking psychiatric medication and what others might infer about them: “It’s an anti-psychotic. Well, I’m not anti-psychotic” (Participant H, BPD). At times, the anticipated stigma as a reaction to their medication was a cause for anxiety:

I feel as if I met someone, should I tell them or not, or should I keep it from them, should I tell them that I’m on medication and how well on medication, because I’m well, is it necessary to tell them I’m on medication or just keep the medication secret and not tell them; so those sorts of thoughts go through my mind. (Participant S, SZ)

And a lot of people involved in this and the community don't really have an understanding of mental health. And medication. Yeah. It's just, I just don't like it at all. (Participant R, SZ)

Ultimately participants responded to these concerns of exposure with a desire for concealment “I’d probably have to hide my tablets” (Participant P, SZ), “probably take it in secret” (Participant S, SZ) in order to avoid the anticipated difficult interactions.

Invalidation

Difficult interactions with services were a great source of frustration for the participants, and were a recurrent theme throughout the interviews. Many of these interactions led to participants feeling invalidated, and internalising feelings of worthlessness: “I felt gutted, I felt massively... wounded, let down and offended. I felt like a nothing, like you don’t matter and no one cares anyway” (Participant B, BPD)

Participants particularly spoke about not feeling heard or being taken seriously, and receiving poor responses to help seeking:

“You’re left – you are left thinking are you taking me seriously? Do I have to – what do I have to do? Come in with an arm full of marks ‘cause I’ve hurt myself? Or do I need to have had a near fatal car accident or...?” (Participant A, BPD)

Some participants responded to this by “trying to get someone to come with me” (Participant B, BPD) or engaging advocates in meetings with services to avoid feeling unheard or discredited; “the advocate can sometimes acknowledge things or witness things” (Participant R, SZ). Participants also felt undermined when family members were asked for information or were involved in decision-making when they were not. For example, Participant R said “I do become unwell at times and it doesn't mean that, you know, I can't speak for myself”, and “it makes me angry. It makes me angry that they don't bother to ask me.” These experiences ultimately led participants to “devalue yourself... because no one is valuing you.” (Participant B, BPD) and internalise these stigmatising attitudes.

4.3.3. Lack of involvement in care

This theme continues from invalidation experiences and deals with wider issues in the service-user's interactions with mental health services, focusing particularly on our participant's involvement in making decisions about their care.

Lack of control

Some of the most distressing experiences conveyed by participants were concentrated on their contact with services as hospital in-patients sectioned under the Mental Health Act (1983 & 2007). These were entirely described as negative experiences, with Participant D saying “I didn't want to be there”, and Participant I asserting it was “something that I will avoid at all costs again.” On the whole, hospitalisation was described as “stressful” (Participant Q, SZ), “pretty scary” (Participant I, BPD), and “pretty frightening” (Participant N, SZ). Participants understandably felt like they had little power over their situation and likened hospital to a prison situation, as opposed to a care setting:

And I bought myself an orange jump suit, a fluorescent orange jump suit which I wore around the wards, and I used to say to people ‘Well, if you're gonna treat me like a prisoner I'll dress like one’ (Participant H, BPD).

In particular, participants felt that they had no control over the treatments they were given, and felt uninformed about care decisions:

And it's really One Flew Over The Cuckoo's Nest. You go to the pharmacy at 9'O clock on the ward and they give you your drugs for the night. No-one explains what those drugs are or you're going to be on this drug for the rest of your life. Do you know what I mean? (Participant H, BPD)

I had 27 electric shock treatments...Well, the men's ward was pretty frightening. The electric shock treatment was pretty frightening (Participant N, SZ)

Fear was a recurrent feeling, not just in regards to experiences of hospitalisation, but also at the risk of being sent back. Participant Q, here talking about his concerns about his Community Treatment Order (CTO) says:

To be honest, I want to get off the CTO I'm scared of it... 'Cause if you relapse they can send you straight back. Whereas if I relapsed I wouldn't want to go straight back I would want help in the community. Rather than going back into hospital.

The desire for treatment in the community related to shame around hospitalisation as much as the unpleasantness of the hospital setting:

Um, it was a bit embarrassing, to be honest...Because all your friends, I don't know. All of them have normal lives and now I'm stuck in the hospital (Participant P, SZ)

Participants expressed an anticipated stigma around hospitalisation, feeling that others would use it to make evaluative judgements and perceive their illness as more severe as a result. When receiving treatment in the community, participants continued to express feelings of being judged and assessed:

Well it's letting somebody else basically judge you and analyse your life because obviously if you would go through a diagnostic.....diagnosis rather, to go through that process, you'll have to fill out lots of different personal questionnaires some of which feel pointless, get into lots of interviews with

people they will ask you lots and lots of personal questions you're not always comfortable with divulging, you do all the tests and everybody from different professions in different parts of your life will pick away and analyse your history, your personality and everything. (Participant M, BPD)

Participants found these interactions to be invasive and stressful, yet felt pressured to continue to engage

I mean it's not like they say we can visit you more because... if you want that. They are not merely asking you. They're saying you have to do this. I have to meet them. It is quite stressful. (Participant R, SZ)

Despite the pressure participants felt under to perform in assessments and give detailed personal information; they did not feel like there was a choice "obviously I have to" (Participant R, SZ) and that it was necessary to "go with the flow" (Participant M, BPD). In general, participants felt that they had no power over their engagement with services, saying "I don't feel I have much of a say" (Participant I, BPD) and "I do as I'm told" (Participant A, BPD).

Lack of information & transparency

Participants feelings of powerlessness were in part due to feeling uneducated and uninformed about mental health problems and mental health services; participants found this "confusing" (Participant D, BPD) and suggested that "there's an awful lot of presumption of knowledge" (Participant B, BPD). Participant's expressed frustration at being given a mental health diagnosis but not having it explained to them or being given any information to aid their understanding:

Well, if they just tell you you've got it, like and what it is, make sure you've got schizophrenia, that's a disorder of your mental health but they don't go into detail. Well that can worry people as well, 'cause they can say, "Well, why me? Why have I got it?" And they could explain it in depth. Then you could understand more clearly about how it happens rather than just, oh you've got it, you move on with your life. Do you know what I mean? (Participant Q, SZ)

I think they should help you when you get your diagnosis of giving you clearer insight to what someone's life is going to be like on the diagnosis and on the treatment. It's a bit sketchy. (Participant H, BPD)

This created anxiety around prognosis and treatment, but also meant that participants didn't feel they could direct their interactions with services to focus on aspects of their experience which were important to them:

We haven't really spoken about the other aspects of the future, just about medication and planning for that and stuff. (Participant L, BPD)

Collaborative care

It was felt that many of these issues could be addressed with more collaborative approaches to care provision and decision-making, as participants were keen to have an active hand in determining their treatment "but when I get the help, it's - a type of help you can govern yourself" (Participant B, BPD)

Participants struggled with decisions that had been made about them without their involvement "So, I don't know whether things have progressed and he's decided to change the diagnosis, but I don't know at what point that was made" (Participant R, SZ). In contrast, they valued changes made on the basis of their input and requirements "I told them I wanted to change it because I didn't like the side effects" (Participant Q, SZ)

Participants also desired collaboration on goals and future planning, as it felt like treatment was hampered because they and their clinicians weren't working to the same objectives:

So then I was wearing clothes that I didn't what to wear, in a size that I didn't want to be, but in terms of ticking a box for the doctors, my mental, my mental state was strong. But it wasn't actually strong. I didn't feel good. (Participant I, BPD)

The different objectives of care perceived by participants made them feel less trusting and engaged with their care-providers, and left them with a number of frustrations and unmet needs.

4.3.4. Unmet needs

Many participants discussed additional unmet needs and additional elements participant's desired from their care, as well as what issues they felt created barriers to more effective engagement with services.

Access and barriers to treatment

A major issue for the participants in terms of accessing services was the limited time clinicians had available:

I go there. I have been there for like four minutes when it goes, is everything alright? Yeah everything fine with your meds, yep results look fine. Yeah. Go on then. [Laughter] (Participant F, BPD)

Cause the NHS system is very, it's very short on psychiatry, the amount of time that's available.

They're like gold-dust. I think we've got 3 psychiatrists for the <region> area now, or something. I thought, in my head, psychiatry would be you sit there and you talk to somebody for an hour, but you've got 20 minutes. And that 20 minutes is always the same. It's 'Are you taking your medication? Are you eating? Are you working? Are you sleeping?' You know, this checklist. 'Are you drinking too much?' All valid, but it's just like a... you feel like a car in an MOT³, like you're having your oil changed. (Participant H, BPD)

Participants were very aware of the time pressures on staff and felt like they made it difficult to engage on a more personal and intimate level. Nevertheless, participants expressed wider awareness of the circumstances that influenced care-provision and acknowledged that deficits in care were not always easily addressed:

Or that my doctor's hands tied behind his back as well and with that I mean, financial budget.

Essentially, that's what it all comes down to. I understand the, you know, I understand the NHS, I understand the budget, I understand the mental health, um, you know, I read up about a lot of things.

I'm not saying that I'm an expert but I understand... (Participant I, BPD)

³A Ministry of Transport test (MOT) is a regular mandatory safety check for cars in the United Kingdom.

I can understand the reasons why rationing and too many health service users and budget cuts and stuff like that, I could understand why it's been that way (Participant M, BPD)

Nevertheless, the lack of quality contact with services left participant feeling under-supported and as though an important aspect of service-provision was missing: "someone you can talk to about – 'well what do you want to do' you know?" (Participant A, BPD). Similarly, the difficulty in accessing care and getting the desired support left participants feeling frustrated and at times desperate:

It literally has taken 2 overdoses in 2 years for me to see a psychologist. One overdose you get a psychiatrist, two overdoses you get a psychologist (laughs). (Participant B, BPD)

This quote from Participant B not only illustrates her impressions of her struggle in accessing services, but also highlights the lack of variety of care and interventions on offer for service-users like her.

Access to alternatives

Most of the participants had only experienced drug-based therapy during their time with services "it's basically been medication" (Participant O, SZ) and had not been offered alternatives such as the opportunity to engage in psychotherapeutic interventions, "I've not had no CBT and I've not had no counselling" (Participant A, BPD); yet suggested that these could be helpful if they were available "I think probably some therapy might help on that one" (Participant E, BPD).

Participants also expressed a keen desire to have greater access to alternative, complimentary therapies to provide a more holistic approach to health:

I believe in spirits and doing it myself with meditation and things like that and that's the route I wanna go down (Participant I, BPD)

It would be lovely to have holistic things, they are what, they make you well, like you know head massages, massages, reiki, all of that is so good for mental health cause it stills the body, the nerves, it just has a soothing effect. (Participant B, BPD)

I do go to... a day centre, I go there for massage and relaxation. (Participant D, BPD)

This again highlighted the discrepancy between what was offered and what was needed; and the contrast between the services focus reducing symptoms through medication, and the service-user's focus on increasing wellbeing by other means.

4.3.5 Positive aspects of care

This theme explores what our participants like about their treatment and care, and the positive experiences of services that they shared.

Helpful

Despite the participant's desires for alternatives to medication or supplementary interventions, many felt that their medication had benefitted them overall: "I think it helps a lot" (Participant D, BPD); "it's done its job pretty much" (Participant A, BPD). Participants felt that the effects of the medication had challenged their preconceptions and assuaged their concerns about psychiatric drugs "I'm hell of a lot better now and I actually understand now. That there was a need." (Participant E, BPD)

Participants reported a number of positive effects from taking medication:

And then since taking them I feel a lot more human again. You know, I feel like things are flowing. (Participant C, BPD)

Like a few years ago I'd never read a book but I've started reading. I got something yesterday and I'm already four chapters in. That's something I couldn't do a few years ago. (Participant Q, SZ)

These positive reports again seemed to focus on wellbeing and quality of life as opposed to symptom-reduction. Nevertheless, it was clear that improvements in functioning and ability to engage in life were a key motivator to continuing with drug-based therapy.

Supportive

Participants particularly valued positive experiences of care from their mental health teams and were keen to convey the importance of services as part of their support network. They described services and members of staff as “soothing” (Participant D, BPD), “reassuring” (Participants H & O), “wonderful” (Participant A, BPD), “brilliant” (Participant C, BPD), “helpful” (Participants J & O), “pretty good” (Participant K, BPD), and “full of people who wanted to be something good for everybody” (Participant B, BPD). Some participants felt that they had interacted with service staff on an emotional level in a way that was personally meaningful to them:

She was very sympathetic and she listened to me, for the first time someone had listened to me.

(Participant A, BPD)

She’s not just lovely, she’s just gets it. She gets me as well, she knows me, she gets me, she sussed me out, you know? She knows what I’m all about, pretty much, not that there’s much to get but you know. (Participant G, BPD)

Getting the psychologist a week or so ago, that was my first sense of care (Participant B, BPD)

It was clear that these types of interactions and being spoken to “on a human level” (Participant A, BPD) were beneficial to participants’ self-esteem and made them feel secure and confident about further help-seeking. These interactions also built participants’ confidence in their ability to cope with low-points in their illness, engage in treatment and work towards recovery:

I think I received such good help with it that I was made to feel very comfortable and I was able to deal with it. It was intense and it was problematic and it was stressful and unpleasant but I was able to deal with it perfectly well. (Participant O, SZ)

I've been offered quite a few, the team I have working with me are fantastic. They um, they really do provide quite a few opportunities for you to get out of the house. (Participant L, BPD)

On the other hand, support "on a practical level" (Participant H, BPD) was frequently mentioned and appreciated as a necessary step towards establishing independence and progressing towards recovery:

I just felt very down. Then social services got me a flat. After 6 months...Then I got a grant from the government for furniture. Then I moved into my flat. I've lived there ever since. I love my flat.

(Participant N, SZ)

When I first came out of hospital, um, they gave me this flat, and I did get quite a lot of support actually. People used to come round all the time and used to help me get furniture and everything together. Really supportive. (Participant P, SZ)

These types of affirmative contact with services counteracted their more frustrating experiences, and were key to participants feeling supported and their willingness to trust and engage with their mental health teams.

Voluntary services

Away from National Health Service mental health services, participants spoke positively about the role of voluntary sector mental health services in providing extra support to them, which Participant B described as "exceptionally useful". It was clear that these services were key to some participants increasing their social activities "so as not to isolate" (Participant B, BPD). Much of this support was about a mutual understanding and shared life experiences between the participants and other service-users:

If you'd walked through that door and said 'Oh hi, I'm your mentor. Never had anything, but you know, I'll mentor you' well how can you mentor me when you haven't been through it yourself? So it's just good that way (Participant C, BPD)

Participants further spoke about gaining opportunities in the voluntary sector to help others:

[They] gave me a chance to do voluntary work as an advisor....And you start, you start liking yourself a little bit more. (Participant N, SZ)

I do well, I mainly do like, activities and things like that with the services users....the people on the course need people like me in their life, positive people. (Participant P, SZ)

The voluntary work participants engaged in with other service-users were a clear source of pride and self-confidence, which boosted self-esteem and their sense of wellbeing. Moreover, acting as role-models through work as a “recovery mentor” (Participant C, BPD), for example, appeared to be affirming and encouraging for the participant’s own sense of progression in their recovery journey.

4.5. Conclusions

The findings contribute to the limited qualitative literature on user-defined perspectives and evaluations of anti-psychotic medication and mental health services. On the whole, participants expressed a belief in medication working and being beneficial to their functioning. However, as in the existing literature, participants conveyed numerous frustrations and dissatisfaction with polypharmacy and the side effects associated with antipsychotic medication (Buckley & McManus, 1998; Ciranni et al., 2009; Harrington, 2002; Lelliott et al., 2002). Participants also anticipated stigma in response to drug-based therapy, which led to a desire to conceal the use of medication from others. Concerns about stigma also arose from interactions with services. On the one hand, participants didn’t want to be observed engaging with mental health services for fear of public identification as ‘mentally ill’ and negative stereotyping. On the other hand, many of the participants’ experiences with mental health services appeared to reinforce feelings of internalised stigma and shame. In particular, this occurred through feelings of powerlessness, worthlessness and

invalidation as a result of not being taken seriously by clinicians and not being involved in care decisions. Similarly, the use of coercive care, such as when under section, was understandably associated with feeling fearful and a lack of control.

Participants perceived a number of unmet needs and barriers to full engagement with services. Most notably, participants found clinical interactions to be mechanical, cold and lacking in the human touch. This noticeably damaged the therapeutic relationship and made service-users feel disconnected and less trusting of decisions made by their clinicians. Moreover, the financial and time pressures for clinicians were recognised as obstacles and key factors which affected the treatment received. When decisions were made on the basis of financial and time constraints, participants felt that their needs were low priority. In contrast, when participants did have quality interactions, they were particularly valued and appreciated, and were associated with increased self-esteem and confidence. Moreover, positive interactions with care-providers led to optimistic evaluations of future prospects and recovery. Above all, service-users wanted to have greater control and involvement in care decisions. Collaboration between client and clinician was particularly desired, but it was important that this did not just focus on treatments but on cooperatively planning for the individual's future.

4.5.1. Limitations

The interviews analysed were part of a study examining the consequences of receiving a diagnosis of bipolar disorder or schizophrenia, in terms of stigma and self-stigma. As such, the interview did not specifically contain questions regarding medication and mental health services; these topics arose organically as key parts of service-users experiences of living with psychosis. The lack of direct questioning on these topics may mean that further detail and exploration of these issues was missed. Additionally the sample was entirely white and biased towards individuals with a bipolar disorder diagnosis, which may have skewed the findings. Similarly, the participants were all from the North-West of England, and it is possible that service-users in other areas may have

differing experiences within their local services. More directed research into the experiences of consumers using different types of mental health services (e.g. early intervention, community mental health teams, acute psychiatric care) and at different stages of recovery is needed, and this should be an avenue for future research. It is worth highlighting that the study findings were not returned to the participants for validation, and future research may benefit from a more collaborative, dynamic approach to analysis with greater participant involvement.

4.5.2. Clinical implications

Participants often felt frustrated in their interactions with mental health services, and wanted greater transparency and involvement in decision-making about interventions and future-planning. Concordance models of mental health care are increasingly advocated (Bissell, May, & Noyce, 2004) as a means of recognising the expertise and rationality of service-users. Such approaches use a framework of mutual respect, reciprocal understanding and collaboration, with shared decision-making being key (Murray, Charles, & Gafni, 2006; Seale et al., 2006). The endorsement of concordance models in mental health services may improve service-users experiences of healthcare through improved understanding, engagement and autonomy. Moreover, the therapeutic alliance has been found to have a causal relationship with outcomes in psychosis (Goldsmith et al., 2015); and evidence suggesting that these kinds of improvements to the relationship between clinicians and service-users are likely to lead to better outcomes in the treatment of psychosis (Howgego, Yellowlees, Owen, Meldrum, & Dark, 2003; McCabe & Priebe, 2004). Similarly, benefits to overall wellbeing were expressed by service-users who were engaged with voluntary mental health services, as they led to the establishment of positive identities, increased self-esteem, and feelings of empowerment. Such involvement could be encouraged by clinical services and taken forward as a social intervention by establishing mentoring schemes and service-user led self-help groups.

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Chapter 5:

How stigma impacts on people with psychosis: The mediating effect of self-esteem and hopelessness on subjective recovery and psychotic experiences.⁴

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5.1. Abstract

This study aimed to examine how stigma impacts on symptomatic and subjective recovery from psychosis, both concurrently and longitudinally. We also aimed to investigate whether self-esteem and hopelessness mediated the observed associations between stigma and outcomes. 80 service-users with psychosis completed symptom (Positive and Negative Syndrome Scale) and subjective recovery measures (Process of Recovery Questionnaire) at baseline and 6-months later, and also completed the King Stigma Scale, the Self-Esteem Rating Scale and the Beck Hopelessness Scale at baseline. In cross sectional regression and multiple mediation analyses of the baseline data, we found that stigma predicted both symptomatic and subjective recovery, and the effects of stigma on these outcomes were mediated by hopelessness and self-esteem. When the follow-up data were examined, stigma at baseline continued to predict recovery judgements and symptoms. However, self-esteem only mediated the effect of stigma on PANSS passive social withdrawal. Self-esteem and hopelessness should be considered in interventions to reduce the effects of stigma. Interventions that address the current and long-term effects of stigma may positively affect outcome for people being treated for psychosis.

5.2. Introduction

Stigma is a widely researched concept, with public stigma and self-stigma frequently cited as problems by those experiencing mental health issues (Corrigan, Kerr, & Knudsen, 2005). Goffman (1986) described stigma as a negative evaluation of an individual as 'tainted' because of attributes such as mental disorder, disability, or ethnicity. Public stigma is typically described as a process of prejudice, stereotypes and discrimination towards the stigmatised group or individual, and self-stigma is the internalisation of these negative attitudes, beliefs and behaviour. This internalisation is a relatively under-researched topic (Tang & Wu, 2012; Yen et al., 2005) with only a small amount of the stigma research focusing on the experiences of the individual and how they personally respond to stigma (Bagley & King, 2005; B Schulze & Angermeyer, 2003). Nevertheless, the internalisation of stigma, the processes and mechanisms which underlie it, and the impact that it has is an important issue. Early studies found that people with mental health problems expect to experience discrimination and receive ill-treatment from others, have less life satisfaction because of stigma, and feel demoralised and rejected by others (Herman, 1993; Link, 1987; Link et al., 1989; Mansouri & Dowell, 1989). Later work has suggested that self-stigma results in reduced self-esteem, increases depression and anxiety and hinders recovery (B Schulze & Angermeyer, 2003).

It has been suggested that people who experience psychosis are one of the most stigmatised minority groups in society (Wood, Burke, et al., 2014; Wood, Birtel, et al., 2014) with the Schizophrenia Commission (2012) recently reporting that 87% of individuals with a schizophrenia diagnosis had experienced public stigma and discrimination. Research has repeatedly shown that the majority of the general public hold negative beliefs about people experiencing psychosis; and particularly those diagnosed with schizophrenia. For example, in a survey of a thousand French citizens on their attitudes towards people with mental illness, it was found that 69% of individuals would engage in social-distancing from individuals with schizophrenia, compared to 29% for bipolar disorder and 7% with autism ($p < 0.001$) (Durand-Zaleski et al., 2012). The primary reason given for

this discrepancy was a belief that individuals with schizophrenia are highly dangerous. Other studies not only support this observation that people diagnosed with schizophrenia are considered dangerous, but also that they are considered unpredictable (Crisp et al., 2000; Stuart et al., 2012; Walker & Read, 2002), incompetent, to blame for their illness (Corrigan & Kleinlein, 2005) and unlikely to ever recover (Crisp et al., 2000).

These kinds of stigmatising attitudes create a vicious circle of disability and disadvantage through diminishing quality of life (Stolzman, 1994), preventing help-seeking and engagement with mental health services and treatment (Thornicroft et al., 2007), inhibiting social roles, increasing social exclusion and hindering social integration (Link et al., 2001; Link, Struening, Rahav, Phelan, & Nuttbrock, 1997; Thornicroft et al., 2007). Individuals also experience reduced life, work and education opportunities (Thornicroft et al., 2009) leaving people feeling ashamed and unwilling to disclose their illness for fear of the repercussions, and questioning their value as a member of society (Jenkins & Carpenter-Song, 2009). This all has a potential impact on recovery in terms of regaining a sense of quality of life and wellbeing, so that individuals report feeling pessimistic about recovery and lacking hope for the future (González-Torres et al., 2007).

It is evident that the impact of public stigma and self-stigma are far-reaching. However, researchers have so far neglected the possibility that both types of stigma, as well as contributing to poor quality of life and poor adjustment, may have an impact on the course and outcome of psychotic illness. This could happen if they impact on psychological mechanisms which in turn affect either symptoms, or subjective recovery or both. Two likely mechanisms which may play this role, which are investigated in the current study, are self-esteem and hopelessness, which have both previously been identified as responses to public stigma (González-Torres et al., 2007; Link et al., 2001) and which are often important elements of psychotic patients' pessimism about their own illness (Pitt et al., 2007).

For self-esteem and hopelessness to play the mediating role hypothesized here, they would have to affect symptoms and subjective recovery, and there is evidence that this may be the case. Low self-esteem has been identified as a risk factor for psychosis (Janssen et al. 2003) and modern cognitive accounts of positive symptoms, particularly paranoid delusions, emphasize the important role of self-esteem in driving symptoms, especially paranoia (Bentall, Corcoran, Howard, Blackwood, & Kinderman, 2001; Freeman, Garety, Kuipers, Fowler, & Bebbington, 2002). Indeed, a recent longitudinal study found evidence that negative beliefs about the self and others predicted paranoid symptoms prospectively (Fowler et al 2013). Another recent study found that self-esteem and negative emotion were major determinants of subjective recovery, and that the impact of positive symptoms on subjective recovery was largely mediated through these variables (Morrison et al. 2013). The role of hopelessness in driving suicidal thinking is well documented (Heilä et al., 1997; King, Baldwin, Sinclair, & Campbell, 2001; Nordentoft et al., 2002) and a recent systematic review identified hopelessness as a major barrier to recovery (Soundy et al. 2015). Hence it seems reasonable to hypothesize that one pathway through which stigma might affect both objective and subjective outcomes would be through self-esteem and hopelessness.

The aim of the present study is therefore to test the predictions that: (a) perceptions of stigma will predict both objective and subjective outcome of psychosis; we also attempted to assess whether any such effects are short term (immediate) or long-term (6-months); (b) that observed relationships between perceived stigma and outcome will be mediated by self-esteem or hopelessness.

5.3. Methods

5.3.1. Participants and design

Eighty service-users (49 male, 31 female, mean age = 39.15, SD = 11.56) with experiences of psychosis were recruited from psychiatric services in 5 NHS trusts in the North-West UK. Two had only completed primary education, 34 had completed secondary education, 28 had been in receipt of vocational training and 15 had been educated at university (data missing from one patient). Six patients had never had an inpatient admission, 7 had one admission and the others had multiple admissions (data missing for 10 patients). All met the ICD criteria for a schizophrenia spectrum diagnosis as determined by their responsible clinicians, and their symptoms were confirmed with a researcher-conducted PANSS interview (PANSS; Kay et al., 1987, 1989). 78 were in receipt of antipsychotic medication; 13 were in receipt of psychological therapies and 46 reported ever having received psychological therapy (data missing from 10 patients). All participants had a sufficient level of English literacy to complete the measures and capacity to provide informed consent. The majority were White British (75%). Participants were recruited from early intervention services (n=12), community mental health teams (n=61), assertive outreach teams (n=3) and other mental health services (n=4). Data for all measures were collected at baseline, and the outcome measures were administered a second time six months later.

5.3.2. Measures

All research measures were administered by graduate psychologists who had received specific training in the relevant assessments. For the present analyses we focused on data pertaining to the key concepts of perceived stigma and recovery, with the influence of hopelessness and self-esteem considered as mediators. Other measures which will be reported in later papers are not discussed here.

5.3.2.1. Independent variables

Stigma

The King et al. Stigma Scale (KSS; 2007) is a 28-item self-report questionnaire measure of perceived stigma with items rated on a scale of 0 (strongly disagree) to 4 (strongly agree). There are three sub-scales: Discrimination (12 items), Disclosure (11 items), and Potential Positive Aspects of mental illness (5 items). King et al. (2007) found all items to have a test-retest reliability kappa coefficient of 0.4 or greater. Cronbach's α for Discrimination was reported to be 0.87, for Disclosure 0.85, and for Positive Aspects 0.64. Alpha coefficients for all scales in the current sample are given in Table 5. It can be seen that, whereas the coefficients for Discrimination and Disclosure in this study were acceptable, that for Positive Aspects was not; therefore this subscale (which was short and, in any case, of less theoretical interest than the others) was not employed in subsequent analyses.

5.3.2.2. Mediator variables

Hopelessness

The Beck Hopelessness Scale (BHS; Beck et al., 1974) is a 20 item self-report measure which measures three aspects of hopelessness: feelings about the future, loss of motivation, and negative expectations. Participants rate each statement as true or false for their attitudes over the last week. The psychometric properties of the BHS have been examined in a number of studies and it has demonstrated good validity and reliability (Dyce, 1996; Nunn, Lewin, Walton, & Carr, 1996; Young, Davila, & Scher, 1993).

Self-esteem

The Self Esteem Rating Scale—short form (SERS; Lecomte et al., 2006) is a 20-item self-report measure assessing positive and negative beliefs about the self. Items are rated on a 7 point Likert scale ranging from “never” to “always”. The scale has demonstrated good reliability and adequate validity. As the positive and negative totals for the self-esteem rating scale are so highly

correlated ($r=-0.65$, $p<0.01$) for the purpose of the regression and mediation analyses we extracted the principle component of the two subscales to yield a single scale score.

5.3.2.3. Outcome variables

Subjective recovery

The Questionnaire about the Process of Recovery (QPR; Neil et al., 2009) is a 22-item self-report measure developed in collaboration with service-users and clinicians. Items are rated on a five point Likert scale ranging from “strongly disagree” to “strongly agree”. Higher scores on the measure are indicative of greater sense of recovery. In this study we used total scores, which had excellent reliability.

Symptomatic recovery

The Positive and Negative Syndrome Scale (PANSS; Kay et al., 1987, 1989) is a 30 item semi-structured clinical interview and rating scale which includes 7 items to evaluate positive symptoms (e.g. delusions), 7 items to evaluate negative symptoms (e.g. blunted affect) and 16 items to assess global psychopathology (e.g. anxiety). Symptoms are rated by the interviewer from 1 (not present) to 7 (severe). The PANSS has been used in many studies and has been shown to have good reliability and validity.

We tested whether the stigma variables predicted PANSS subscale (positive, negative and general) at baseline and follow-up. However, we also hypothesized that stigma would relate to particular PANSS items. Items 1 (delusions) and 6 (suspiciousness/persecution), from the PANSS positive subscale were expected to relate to stigma as past research has found that experiences of discrimination predicted the later development of paranoid symptoms (Janssen et al., 2003). As guilt and shame are often described as part of the process of experiencing and internalising stigma (Link et al., 2004; Scheff, 2013), item 3 (guilt feelings) from the PANSS general subscale was considered

individually in relation to stigma. Similarly, as stigma is often linked to a withdrawal from social interaction (Yanos et al., 2008) item 16 (active social avoidance) from the general PANSS subscale, and item 4 (social withdrawal) from the negative PANSS subscale were examined.

5.3.4. Procedure

The study was approved by an NHS Research Ethics Committee, and was designed with the advice of a service-user reference group. Participants were recruited through posters, advertisements and referrals from health professionals. Mental health services and voluntary sector agencies across the North West were approached for suitable referrals to ensure diversity in experience of psychosis and service provision. All participants gave informed consent. To reduce participant burden, participants were given the option to complete some or all of the measures.

5.3.5. Statistical analyses

We hypothesised that perceived stigma would negatively affect recovery beliefs. That is, the more stigma experienced, the less recovered a person would feel. We also hypothesised that the variables self-esteem and hopelessness would mediate this relationship. In terms of symptoms, we hypothesised that the individual symptoms of interest from the PANSS would be predicted by perceived stigma at baseline and longitudinally at six months.

All analyses were conducted using SPSS (version 21). We examined bivariate relationships between the variables (including the KSS subscales) and Cronbach's alpha coefficient was used to estimate the reliability of the measures. In subsequent linear regression models, only KSS total scores were considered in the light of the high correlations between total scores and subscale scores, and also in order to reduce the risk of type-1 error proliferation.

If it was found that the potential mediators appeared to have an effect in the multiple regressions, mediational models were tested with the KSS discrimination and disclosure subscales using the PROCESS macro on SPSS 21 (Hayes, 2013). For this purpose, the direct effects (c paths)

between stigma and the dependent variables (QPR or PANSS scores at baseline and at six months) were firstly estimated. The mediating variables (self-esteem and hopelessness) were then introduced, generating models with direct effects between the independent variables and the mediators (*a* paths), direct effects between the mediators and dependent variables (*b* paths), and direct effects between the independent and dependent variables whilst controlling for the mediators (*c'* paths). The six-month follow-up models controlled for the baseline recovery beliefs or PANSS data as appropriate. Similarly, each stigma sub-scale mediation model controlled for the other sub-scale to account for its influence. This allowed us to look at the influence of each sub-scale individually whilst acknowledging them as part of the overall experience of stigma. The models were estimated using maximum likelihood (ML) estimators. As mediation models are sensitive to parametric assumptions and we had a relatively modest sample size, the statistical significance of mediating and indirect effects was examined with bootstrapped bias-corrected percentile-based confidence intervals of 1,000 bootstrap draws. In cases where zero did not fall within the 95 per cent intervals of the bootstrapped samples, the mediating effect was considered to be significant (MacKinnon, Fairchild, & Fritz, 2007; MacKinnon, Lockwood, & Williams, 2004; Preacher & Hayes, 2008).

5.4. Results

5.4.1. Correlation analysis

There were no effects of age or gender on the stigma scores. Table 5 shows the correlation matrix between stigma, self-esteem, hopelessness and the recovery measures (QPR and PANSS scales). Unsurprisingly, there were significant associations between the subjective recovery measure (QPR) and the symptom-based recovery measures (PANSS subscales).

As expected both total stigma and the sub-scales, discrimination and disclosure, correlated highly with the QPR at baseline and at six months.

Total stigma correlated with PANSS positive and general subscales scores at baseline, but only with the PANSS general subscale score at follow-up. The discrimination sub-scale correlated with PANSS general at both time points but only the PANSS positive subscale at 6 months follow-up. The disclosure subscale correlated only with the PANSS general scores at baseline.

Self-esteem and hopelessness all displayed significant associations with the positive, negative and general PANSS scores at baseline. At six months these relationships remained for positive and general PANSS scores, but became non-significant for negative PANSS scores. Hopelessness and self-esteem also correlated with QPR scores at both time-points.

Table 5: Mean, reliabilities and Pearson's inter-correlations for all variables in the multiple mediation models of the effects of stigma on recovery.

Measure	<i>n</i>	α	1	2	3	4	5	6	7	8	9	10	11	12	13	14
1. Total Stigma	73	0.86	-													
2. Discrimination	73	0.79	0.80**	-												
3. Disclosure	73	0.84	0.86**	0.40**	-											
4. Positive Aspects	73	0.34	0.58**	0.26*	0.48**	-										
5. Hopelessness	74	0.92	0.54**	0.47**	0.40**	0.40**	-									
6. Negative Self Esteem	74	0.91	0.53**	0.49**	0.37**	0.40**	0.70**	-								
7. Positive Self Esteem	74	0.89	-0.45**	-0.42**	-0.30**	-0.38**	-0.56**	-0.58**	-							
8. QPR Baseline	78	0.90	-0.41**	-0.23*	-0.40**	-0.38**	-0.62**	-0.60**	0.53**	-						
9. QPR 6 Months	52	0.87	-0.43**	-0.41**	-0.30*	-0.34*	-0.59**	-0.49**	0.58**	0.65**	-					
10. PANSS Positive Baseline	79	0.59	0.24*	0.23	0.19	0.07	0.46**	0.39**	-0.40**	-0.52**	-0.52**	-				
11. PANSS Positive 6 Months	54	0.67	0.21	0.27*	0.12	0.02	0.49**	0.44**	-0.36**	-0.55**	-0.63**	0.71**	-			
12. PANSS Negative Baseline	79	0.74	0.23	0.20	0.16	0.20	0.34**	0.34**	-0.43**	-0.39**	-0.38**	0.46**	0.46**	-		
13. PANSS Negative 6 Months	54	0.74	0.15	0.05	0.16	0.24	0.25	0.10	-0.38**	-0.24	-0.30*	0.29*	0.43**	0.65**	-	
14. PANSS General Baseline	80	0.69	0.46**	0.44**	0.34**	0.22	0.64**	0.58**	-0.51**	-0.57**	-0.55**	0.64**	0.50**	0.63**	0.40**	-
15. PANSS General 6 Months	54	0.80	0.35**	0.37**	0.22	0.23	0.57**	0.52**	-0.41**	-0.55**	-0.70**	0.51**	0.77**	0.53**	0.49**	0.68**

Notes: Total Stigma = KSS Total score, Discrimination = KSS discrimination sub-scale, Disclosure = KSS disclosure sub-scale, Positive Aspects = KSS positive aspects of stigma sub-scale, Hopelessness = BHS, Negative Self Esteem = Negative sub-scale of SERS, Positive Self Esteem = Positive sub-scale of SERS. * $p \leq 0.05$; ** $p \leq 0.01$, α = Cronbach's alpha coefficient.

5.4.2. Linear regression analyses

5.4.2.1. Subjective recovery at baseline

The upper portion of Table 6 shows the results for regression models calculated with total stigma as a predictor of baseline subjective recovery (QPR). The stigma variable was entered first and then the self-esteem and hopelessness measures were entered afterwards. Stigma predicted subjective recovery at baseline, $F[1,70] = 14.31, p < 0.001$, adjusted $R^2 = 0.16$, but, when self-esteem and hopelessness were entered into the model, the model improved, $F[2,68]_{\text{change}} = 18.98, p < 0.001$, leading to a final significant model, $F[3,68] = 19.88, p < 0.001$, adjusted $R^2 = 0.44$. In this final model, both self-esteem and hopelessness became significant predictors but the effect for stigma was no longer significant. The fact that stigma was no longer significant after the addition of self-esteem and hopelessness suggests that the latter two variables may be mediators of the relationship between stigma and subjective recovery that was significant at the earlier stage.

5.4.2.2. Subjective recovery at follow-up

The lower portion of Table 6 shows similar models calculated for subjective recovery scores at the six-month follow-up. In the case of these data, predictors were entered in three stages: first, the baseline recovery scores, then stigma, and finally the hypothesised mediators. The second stage in these models therefore indicates whether stigma predicts subjective recovery at six months even when baseline subjective recovery is controlled for. The addition of KSS total scores led to a significantly better model than the baseline scores alone, $F[1,48]_{\text{change}} = 4.41, p < 0.04$, leading to a significant model, $F[2,48] = 21.41, p < 0.001$, adjusted $R^2 = 0.45$, in which stigma was a significant predictor. However, adding self-esteem and hopelessness did not lead to a further improvement in the model.

Overall, these findings indicate that perceived stigma strongly predicts current subjective recovery judgements, with self-esteem and hopelessness as potential mediators of this association. However, the evidence that perceived stigma affects future recovery judgements is less clear; in the case of KSS total scores there is some evidence that this may be the case but there was no evidence of mediation by self-esteem and hopelessness.

Table 6: Multiple regressions for subjective recovery at baseline and 6-month follow-up.

Variable	Subjective Recovery at Baseline Model 1			Subjective Recovery at Baseline Model 2			Subjective Recovery at 6 Months Model 1			Subjective Recovery at 6 Months Model 2			Subjective Recovery at 6 Months Model 3		
	<i>B</i>	<i>Std. Error</i>	<i>β</i>	<i>B</i>	<i>Std. Error</i>	<i>β</i>	<i>B</i>	<i>Std. Error</i>	<i>β</i>	<i>B</i>	<i>Std. Error</i>	<i>β</i>	<i>B</i>	<i>Std. Error</i>	<i>β</i>
Total Stigma	-0.27	0.07	-0.41***	0.01	0.07	0.02	0.72	0.12	0.65***	-0.18	0.09	-0.24*	-0.10	0.09	-0.13
Self-Esteem				3.89	1.21	0.42**							2.12	1.69	0.20
Hopelessness				-0.58	0.22	-0.34**							-0.30	0.30	-0.16
Discrimination	-0.29	0.14	-0.23*	0.29	0.13	0.23*	0.72	0.12	0.65***	-0.41	0.15	-0.29**	-0.24	0.19	-0.17
Self-Esteem				4.64	1.17	0.50***							1.66	1.80	0.15
Hopelessness				-0.66	0.21	-0.39**							-0.25	0.31	-0.13
Disclosure	-0.46	0.13	-0.40***	-0.15	0.11	-0.13	0.72	0.12	0.65***	-0.13	0.16	-0.09	-0.11	0.15	-0.08
Self-Esteem				3.59	1.15	0.39**							2.62	1.63	0.24
Hopelessness				-0.50	0.21	-0.30*							-0.35	0.30	-0.18

5.4.2.3. PANSS symptoms at baseline

Table 7 shows the results of the multiple regressions for PANSS subscales and items at baseline. As with the subjective recovery analyses, the stigma variable was entered first and then the self-esteem and hopelessness measures were entered afterwards. Stigma predicted PANSS Positive subscale scores, $F[1,71] = 4.36, p < 0.05$, adjusted $R^2 = 0.05$, but, when self-esteem and hopelessness were entered into the model, the model improved, $F[2,69]_{\text{change}} = 8.37, p < 0.01$, leading to a final significant model, $F[3,69] = 7.33, p < 0.001$, adjusted $R^2 = 0.24$. Self-esteem and hopelessness both became significant predictors and effect of stigma was no longer significant, indicating possible mediation.

Stigma further predicted PANSS item P6 (suspiciousness/persecution), $F[1,71]=10.96, p < 0.01$, adjusted $R^2 = 0.12$. However, when self-esteem and hopelessness were added to the model, the model improved, $F[2,69]_{\text{change}} = 9.36, p < 0.001$, leading to a final significant model, $F[3,69]= 10.76, p < 0.001$, adjusted $R^2 = 0.29$, where self-esteem and hopelessness both became significant predictors of suspiciousness/persecution, and stigma no longer had a significant effect.

Similarly, stigma predicted PANSS item G16 (active social avoidance), $F[1,71]=7.75, p < 0.01$, adjusted $R^2 = 0.10$. When self-esteem and hopelessness were added, the model improved, $F[2,69]_{\text{change}}=12.99, p < 0.001$. This led to a final significant model, $F[3,69]=12.11, p < 0.001$, adjusted $R^2 = 0.32$, with self-esteem and hopelessness significantly predicting G16, and the effect of stigma becoming non-significant. However, stigma did not predict PANSS item N4 (passive social withdrawal) or G3 (guilt feelings).

Overall, these findings suggest that current experiences of stigma strongly predict positive symptoms, particularly suspiciousness and persecution; and active social avoidance. Moreover self-esteem and hopelessness may potentially mediate these relationships.

Table 7: Multiple regressions for PANSS sub-scale and items at baseline.

Note: Positive PANSS = PANSS Positive sub-scale, Suspiciousness/Persecution = PANSS item P6, Passive Social Withdrawal = PANSS item N4, Guilt Feelings = PANSS item G3, Active Social Avoidance = PANSS item G16, Total Stigma = KSS Total Score, Discrimination = KSS discrimination sub-scale, Disclosure = KSS disclosure sub-scale, Self-Esteem = SERS factor, Hopelessness = BHS. *p≤0.05, **p≤0.01, ***p≤0.001.

	Positive PANSS			Suspiciousness/Persecution			Passive Social Withdrawal			Guilt Feelings			Active Social Avoidance		
	<i>B</i>	<i>Std. Error</i>	<i>β</i>	<i>B</i>	<i>Std. Error</i>	<i>β</i>	<i>B</i>	<i>Std. Error</i>	<i>β</i>	<i>B</i>	<i>Std. Error</i>	<i>β</i>	<i>B</i>	<i>Std. Error</i>	<i>β</i>
Model 1															
Total Stigma	0.71	0.03	0.24*	0.04	0.01	0.37***	0.01	0.01	0.19	0.02	0.01	0.22	0.03	0.01	0.31**
Discrimination	0.13	0.07	0.23*	0.06	0.02	0.34**	0.04	0.02	0.26*	0.06	0.02	0.31**	0.04	0.02	0.24*
Disclosure	0.10	0.06	0.19	0.05	0.02	0.29**	0.07	0.02	0.06	0.03	0.021	0.14	0.04	0.02	0.27*
Model 2															
Total Stigma	-0.02	0.04	-0.08	0.01	0.01	0.05	-0.01	0.01	-0.14	0.01	0.01	0.03	-0.00	0.01	-0.05
Self-esteem	-1.07	0.65	-0.26	-0.48	0.20	-0.35*	-0.27	0.16	-0.26	-0.31	0.24	-0.22	-0.57	0.18	-0.47**
Hopelessness	0.24	0.12	0.32*	0.06	0.04	0.23	0.06	0.03	0.34*	0.03	0.04	0.13	0.04	0.03	0.19
Discrimination	-0.02	0.07	-0.04	0.01	0.02	0.06	0.00	0.02	0.01	0.03	0.03	0.18	-0.02	0.02	-0.10
Self-esteem	-1.02	0.65	-0.25	-0.47	0.20	-0.35*	-0.21	0.16	-1.33	-0.24	0.23	-0.17	-0.59	0.18	-0.48***
Hopelessness	0.23	0.12	0.31*	0.06	0.04	0.23	0.06	0.03	0.30*	0.03	0.04	0.10	0.04	0.03	0.19
Disclosure	-0.01	0.06	-0.02	0.01	0.02	0.07	-0.02	0.02	-0.18	-0.00	0.02	-0.01	0.01	0.02	0.04
Self-esteem	-0.97	0.63	-0.24	-0.48	0.19	-0.35*	-0.25	0.15	-1.63	-0.33	0.23	-0.23	-0.54	0.17	-0.44**
Hopelessness	0.23	0.12	0.30*	0.06	0.04	0.22	0.07	0.03	0.35*	0.04	0.04	0.14	0.04	0.03	0.16

5.4.2.4. PANSS symptoms at follow-up

For symptomatic recovery at 6 months follow-up we included baseline symptomatic recovery scores in the first stage in order to control for their effect. Stigma was added in the second stage, and self-esteem and hopelessness were added in at the third stage. Stigma did not predict PANSS positive subscale scores or P6 (suspiciousness) at 6 months but it did predict three of the individual PANSS items in ways that were consistent with our hypotheses.

Despite the lack of association between stigma and passive social withdrawal (N4) at baseline, N4 at 6 months was unexpectedly predicted by total stigma, $F [1,51] = 9.20, p < 0.005$, adjusted $R^2=0.18$, when baseline PANSS N4 data was controlled for. When self-esteem and hopelessness were added into the model, the model improved, $F [2,49]_{\text{change}} = 3.95, p < 0.05$, leading to a significant final model, $F[4,49]=5.73, p < 0.01$, adjusted $R^2=0.26$, in which self-esteem (but not hopelessness) became a significant predictor and the effect of stigma was no longer significant.

Active social avoidance (G16) was also significantly predicted by total stigma $F [1,51] = 4.03, p \leq 0.05$, adjusted $R^2=0.41$ after controlling for baseline scores. The addition of self-esteem and hopelessness did not improve the model. Similarly, guilt feelings (G3) was predicted by total stigma, $F[1,51] = 7.49, p < 0.01$, adjusted $R^2=0.33$, but the addition of self-esteem and hopelessness in the third stage did not improve the model.

In summary, there was evidence that stigma at baseline predicted passive social withdrawal, active social avoidance and guilt feelings at six month follow-up. The effect of stigma on passive social withdrawal may be mediated by self-esteem and hopelessness.

5.4.3. Multiple mediation analyses

5.4.3.1. Multiple mediation analyses at baseline

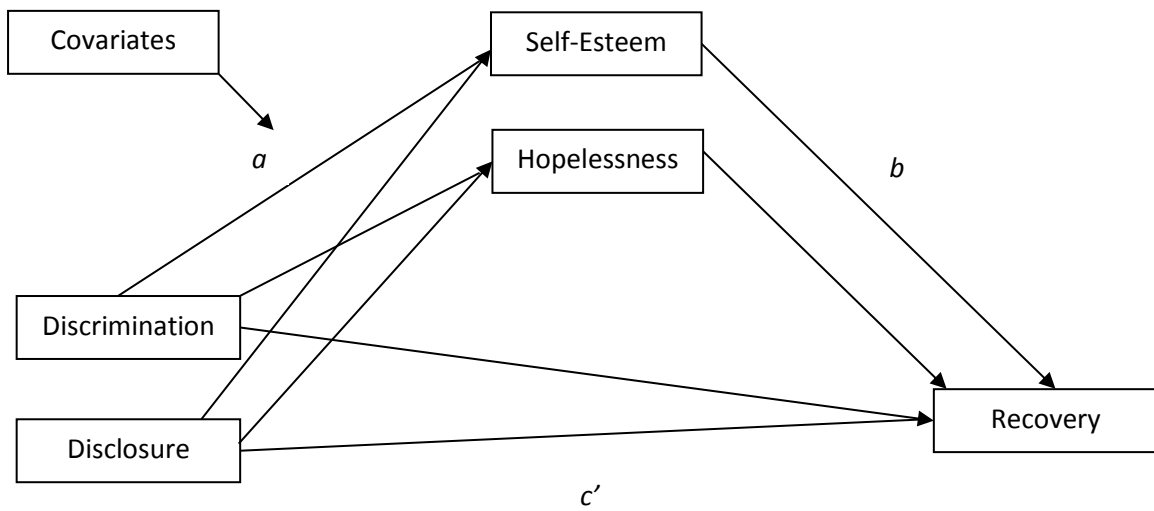
Multiple mediation analyses were carried out using the PROCESS macro for SPSS (Hayes, 2013) to further interrogate the data where the regression analyses indicated that they might be appropriate. In these analyses it was possible to consider the effects of the individual KSS subscales (discrimination and disclosure) together, in each case controlling for the remaining subscale. In the case of 6-month follow-up data, baseline scores on the appropriate recovery measure were also controlled for; see Figure 1. Detailed statistical results are available in supplementary tables in Appendix B (for baseline data) and Appendix C (6 month follow-up data).

At baseline, the effect of total KSS scores on subjective recovery was fully mediated by both low self-esteem (specific indirect effect $B = -0.16$, 95% CI = $-0.28 - -0.05$) and hopelessness ($B = -0.12$, 95% CI = $-0.25 - -0.04$). The effect on PANSS positive scores was fully mediated by hopelessness ($B = 0.05$, 95% CI = $0.00 - 0.10$) and not by self-esteem.

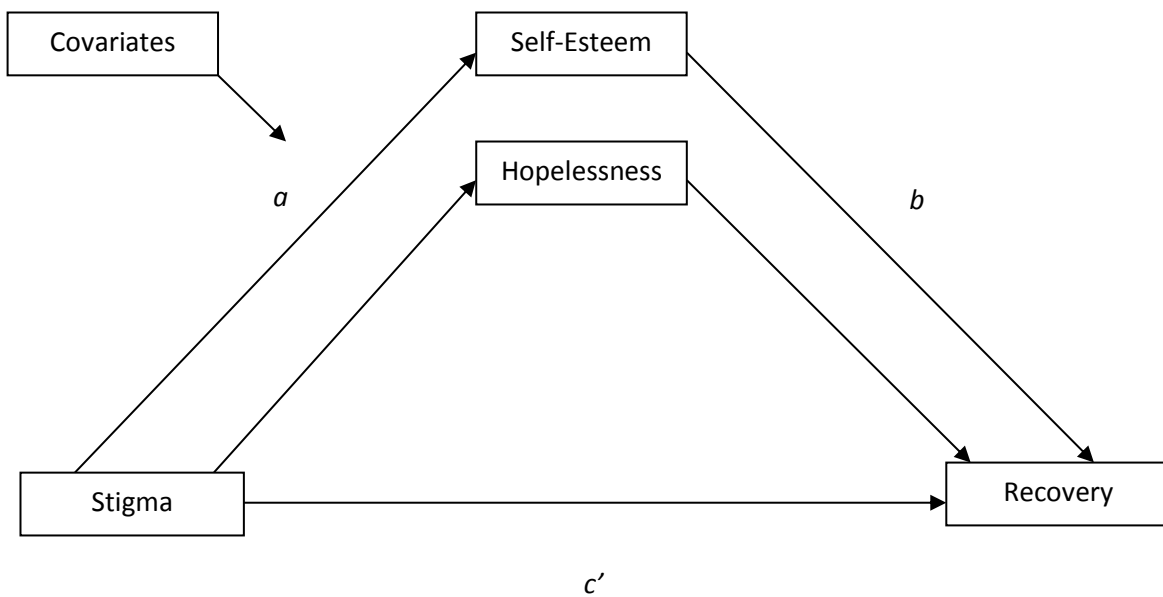
When individual PANSS items were examined, the effect on suspiciousness (P6) was fully mediated through self-esteem ($B = 0.02$, 95% CI = $0.01 - 0.03$) as was active G16 social avoidance ($B = 0.02$, 95% CI = $0.00 - 0.04$). The effect of total stigma on passive social withdrawal (N4) was fully mediated through hopelessness ($B = 0.01$, 95% CI = $0.00 - 0.03$).

When the KSS subscales discrimination and disclosure were entered together as predictors, substantially similar results were obtained with the exception of the analysis for the QPR, in which the effect of disclosure was only mediated through hopelessness, and the effect of discrimination was only partially mediated through both self-esteem and hopelessness (there was a residual direct effect of discrimination on QPR scores).

Figure 1: Illustration of mediation models 1 and 2



Note: Model 1 was run for PANSS and QPR at baseline and at 6 months. Self-Esteem = SERS factor, Hopelessness = BHS, Discrimination = KSS discrimination sub-scale, Disclosure = KSS disclosure sub-scale, Recovery = QPR, or PANSS subscale, or PANSS item at baseline or at 6 month follow-up.



Note: Model 2 was run for PANSS and QPR at baseline and at 6 months. Self-Esteem = SERS factor, Stigma = KSS total, Recovery = QPR, or PANSS subscale, or PANSS item at baseline or at 6 month follow-up.

5.4.3.2. Multiple mediation analyses at follow-up

For the 6-month follow-up data, only N4 passive social withdrawal showed evidence of mediation in our regression models and so only this outcome was considered in our multiple mediation analysis. In the case of total KSS scores, the association between stigma and outcome was fully mediated by self-esteem ($B = 0.01$, 95% CI = 0.00 – 0.04). When the individual KSS subscales were considered, the effect of discrimination was fully mediated by self-esteem ($B = 0.03$, 95% CI = 0.01 – 0.07) but there was no effect for disclosure.

5.5. Discussion

The primary aim of the study was to examine whether internalised stigma had a negative impact on subjective and symptomatic recovery. Previous research has suggested that this may be the case through a number of pathways, for example reduced help-seeking (Thornicroft et al., 2007), reduced social functioning and engagement (Link et al., 2001, 1997; Thornicroft et al., 2007) and reduced life opportunities (Thornicroft et al., 2009). However, whilst it is clear that internalised stigma affects a number of aspects of recovery, the underlying processes and the nature of these relationships requires further clarification.

The results of this study suggest that both subjective recovery judgments and symptoms may be affected. At baseline, experiences of internalised stigma strongly predicted poor subjective recovery judgements. Similarly, internalised stigma appeared to predict positive symptoms, particularly suspiciousness and persecution, and active social avoidance. At 6 month follow up, active social avoidance, guilt feelings and self-blame were predicted by internalised stigma. Passive social withdrawal was also longitudinally predicted by internalised stigma, and by discrimination. The effect of stigma and discrimination on passive social withdrawal at six months appeared to be mediated by self-esteem. The effect of internalised stigma on baseline recovery judgements appeared to be mediated through low self-esteem and hopelessness. However, neither self-esteem

nor hopelessness appeared to explain the persisting association between internalised stigma and long-term recovery judgements (as discussed below, this might be because there was a long gap between the measurement of these mediators and the six-month outcome).

Previous research has highlighted one aspect of the relationship between positive symptoms and internalised stigma, suggesting that more positive symptoms result in more experiences of internalised stigma (Lysaker, Davis, Warman, Strasburger, & Beattie, 2007). Our results suggest that the relationship might also work in the opposite direction, with internalised stigma experiences affecting later positive symptoms. Our results were consistent with previous work which has described feelings of guilt and shame as integral to the internalisation of stigma (Corrigan & Watson, 2002) as we found that guilt feelings and self-blame were predicted by stigma at 6 month follow-up in our regression analyses. However, it is difficult to determine to what extent the guilt feelings are related to the causes or the consequences of mental illness without examining the content of the feelings expressed. For example, research suggests that service users with psychosis are 2.72 times more likely to have been exposed to childhood adversity than the general population (Varese et al., 2012) and self-blame is well-documented in victims of trauma (Coffey, Leitenberg, Henning, Turner, & Bennett, 1996). Therefore, whilst we cannot assume that internalised stigma is the sole predictor of guilt and self-blame, it clearly has a significant effect on this experience in people with psychosis.

The negative effects of stigma on social interaction have often been observed (Link et al., 2001, 1997; Thornicroft et al., 2007), but it was interesting to find in our data that the effects of internalised stigma at baseline were still significant six months later. Active social avoidance is characterised by diminished social involvement consequent on unwarranted fear, hostility, or distrust. The long-term effects apparent in the data suggests that patients may be self-stigmatising and pre-emptively withdrawing from social interaction in the anticipation of experiencing negative reactions from others. This finding is consistent with previous findings from Yanos et al. (2008), who, in a cross-sectional study, found that internalised stigma increases avoidant coping and active social

avoidance. Yanos et al. further found hope and self-esteem to be influential in this relationship; however we only found self-esteem to have a mediating effect between experienced stigma and active social avoidance at baseline, whereas hopelessness mediated the effect on passive avoidance. Contrastingly, at 6 months the effect of stigma on passive (but not active) social withdrawal was mediated by low self-esteem. These discrepancies between the role of self-esteem and hopelessness at the different time points may be less important than they at first appear; the two variables were measured at the same time point at the beginning of the study and were moderately correlated; hence, it may have been difficult for our design to discriminate between these different facets of a pessimistic cognitive style.

Neither self-esteem nor hopelessness were able to explain the persisting association between internalised stigma and long-term recovery judgements. It is possible that this finding reflects a study limitation, as only the recovery measures and not the mediators were repeated at the six month follow up. Perhaps mediation would have been detected had self-esteem and hopelessness been assessed closer to the 6-month follow-up point. Previous research has shown that perceived discrimination and stigma strongly predict future self-esteem at 6 months and 24 months (Link et al., 2001, 2004), although no comparable data is available for hopelessness. It is also possible that the effects of perceived stigma are cumulative as an individual may have more discriminatory experiences over time; in which case the association between internalised stigma, self-esteem and hopelessness may have an even greater impact on recovery judgements long-term if six-month data were available for all measures.

Nevertheless, for both subjective recovery and symptoms at baseline, and for symptoms at six month follow-up, it is evident that hopelessness and low self-esteem play a key role in facilitating the effects of stigma. Overall, the findings are consistent with existing research which suggests that stigma causes loss of self-esteem (Link et al., 2001) and hope (González-Torres et al., 2007), and can impede recovery.

5.5.1. Limitations

There are several limitations of the present study that might be noted. First, the mediating psychological mechanisms were measured only at baseline and it would have been preferable to repeat them at follow-up, which might include several time points. Secondly, we deliberately invited a broad range of patients to take part in the hope of sampling a range of symptom profiles and recovery judgments but this may have obscured effects that are important at particular stages of illness course. Third, stigma is clearly a multi-faceted construct and there are aspects that we have not measured; for example there has recently been interest in implicit measures of stigma (Rüsch, Corrigan, Todd, & Bodenhausen, 2010; Teachman, Wilson, & Komarovskaya, 2006). Fourth, the KSS is time-nonspecific (items do not specify whether stigma is experienced in the present or the past); future studies which address the question of whether stigma fluctuates over time may be better able to address associations with self-esteem, hopelessness and symptoms which, undoubtedly, also fluctuate. Finally, of course, even the longitudinal approach we have adopted cannot eliminate unmeasured confounding and so it is not possible to exclude the possibility that an unmeasured predictor of internalised stigma predicts outcome, creating a spurious correlation between stigma and outcome. While we feel this is unlikely, in the absence of an experimental manipulation of stigma, it is extremely difficult to eliminate these kinds of effects, although new instrumental variable methods that are being applied to analyse mediators in trial data may have promise in this regard (Goldsmith, Dunn, Lewis & Bentall, 2015).

Given our finding that stigma may impact on future clinical outcomes, further research is vital to test this possibility. In the light of the limitations of the present study just listed, future studies should include mediator variables at later time points, should consider focusing on the first episode (or even during the prodromal period before first onset) to understand how stigma evolves across the course of illness, and the extent to which stigma impedes recovery, should also consider

the inclusion of implicit measures, and also consider more sophisticated ways of demonstrating that stigma has a causal effect on outcome.

5.5.2. Clinical implications

The limitations of the present study notwithstanding, our findings have some important clinical implications. Whilst there are numerous anti-stigma campaigns which target stigma on a societal level (Wood, Burke, et al., 2014) they have had varying success with some campaigns resulting in increased desire for social distance from individuals with mental health problems (Read, Haslam, & Magliano, 2013; Read et al., 2006b). However, it is important to target stigma not only on the population level, but also on an individual level with a view to ameliorating its injurious effects on self-perception and sense of recovery. Our results suggest that the mediators of self-esteem and hopelessness may be crucial targets in this respect.

NICE (National Institute for Health and Care Excellence, 2009) recommends Cognitive Behavioural Therapy (CBT) as the first line of psychological intervention for psychosis. Crucially, since their inception, CBT interventions for psychosis have included a normalizing rationale, with the aim of reducing the patient's perception of being different from others, and therefore internalized stigma (Kingdon & Turkington, 1991). Normalizing strategies include providing information about the widespread prevalence of psychotic experiences and of famous people who have been successful despite experiencing psychosis (Morrison, Renton, Dunn, Williams & Bentall, 2003). Research has shown that CBT shows promise in terms of improving self-esteem in clients with psychosis (Hall & Tarrrier, 2003) and it has been suggested that it would be the most appropriate approach to addressing issues such as feelings of hopelessness regarding recovery (Wood, Burke, et al., 2014; Yanos et al., 2008) Moreover, when CBT is utilised as a group therapy there is preliminary evidence from uncontrolled studies to suggest it may be successful at reducing internalised stigma, improving self-esteem, and advancing recovery (Knight, Wykes, & Hayward, 2003; Lucksted et al., 2011; MacInnes & Lewis, 2008), and a recent randomised controlled trial found that a cognitive

behavioural self-stigma reduction programme had significant benefits on self-esteem (Fung, Tsang, & Cheung, 2011). Other interventions that aim to promote optimism and improve self-esteem, such as peer support, may also be worth evaluating in terms of effects on internalised stigma (Pyle & Morrison, 2013).

Interventions may extend beyond conventional psychological therapies. A focus on how internalised stigma is handled, encouraging social participation and preventing isolation is important for wellbeing and symptomatic recovery in the long-run (Garety, Fowler, & Kuipers, 2000; Garety, Kuipers, Fowler, Freeman, & Bebbington, 2001; Pyle & Morrison, 2013; Wood, Birtel, et al., 2014). Hence, mental health services need to consider practical ways of minimising patients' social exclusion, for example by encouraging service-user led self-help groups and by employing service-user advisors, and by developing robust anti-stigma policies that apply to all staff.

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Chapter 6:

How stigma gets under the skin: the role of stigma and self-stigma in subjective recovery from psychosis.⁵

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6.1. Abstract

This study aimed to examine the impact of stigma on subjective recovery from psychosis, and whether self-esteem and internalised stigma (self-directed negative attitudes and thoughts regarding one's mental health issues) mediates the observed associations between stigmatizing experiences and outcome. 59 services-users with schizophrenia or bipolar affective disorder diagnoses completed symptom (Positive and Negative Syndrome Scale) and subjective recovery measures (Process of Recovery Questionnaire), and also a range of stigma measures (the King Stigma Scale, Internalised Stigma of Mental Illness Scale), and the Self-Esteem Rating Scale. Diagnosis was a persistently significant factor in all analyses, suggesting a negative effect of the term 'schizophrenia' on subjective recovery. In a multiple serial mediation analysis, experiences of stigma predicated subjective recovery and this effect was mediated through internalised stigma, which consequently impaired self-esteem. Internalised stigma is an important psychological mechanism in recovery. Interventions aimed at improving self-esteem and recovery feelings for psychosis-spectrum service-users may benefit from taking the role of internalised stigma into account.

6.2. Introduction

Stigma is a widely recognised issue for individuals living with mental health issues. People with psychosis-spectrum of diagnoses, in particular, are amongst the most stigmatised minority groups in society (Wood, Burke, et al., 2014; Wood, Birtel, et al., 2014). Public conceptions of individuals who experience psychosis are that they are dangerous (Durand-Zaleski et al., 2012), unpredictable (Crisp et al., 2000; Stuart et al., 2012; Walker & Read, 2002), incompetent, to blame for their illness (Corrigan & Kleinlein, 2005) and unlikely to recover (Crisp et al., 2000). It has been suggested that beyond its immediately distressing impact, stigma may be internalized (Ritsher & Phelan, 2004), and impede a person's chances of establishing identities unrelated to mental illness (Corrigan & Watson, 2002). Internalised stigma is a term used to define the negative thoughts and emotions that people have about themselves as a consequence of mental illness. Corrigan et al. (2009) suggest that this occurs when people who are conscious of negative stereotypes about mental illness adopt these devaluing and discriminatory attitudes and use them in self-evaluation. This typically leads to feelings of inferiority, guilt, shame, a desire for secrecy (Goffman, 1986) and demoralization (Cavelti et al., 2012) that reduces self-esteem, and hinders recovery (B Schulze & Angermeyer, 2003).

The greatest stigma has been attached to the schizophrenia diagnosis; in a survey of a thousand French citizens, 69% said they would engage in social-distancing from individuals diagnosed with schizophrenia, compared to 29% for people diagnosed with bipolar disorder (Durand-Zaleski et al., 2012). The internalisation of stigma is a relatively under-researched topic (Tang & Wu, 2012; Yen et al., 2005) with limited study of how individuals personally respond to stigma (Bagley & King, 2005; B Schulze & Angermeyer, 2003) and how it might affect recovery. However, given existing public perceptions it can be expected that greater levels of internalised stigma will be seen in individuals with a diagnosis of schizophrenia, when compared to those with a bipolar affective disorder diagnosis.

'Recovery' for people who experience psychosis currently lacks a clear definition (Beck et al., 2012; Brown et al., 2008). It has been suggested that there is little relationship between clinical and service-user definitions of recovery, with typical outcome measures excluding aspects of recovery that are meaningful for consumers. Bio-medical approaches to recovery focus on remission of symptoms, medication compliance, reduced admissions and reduced relapse (National Institute for Health & Clinical Excellence, 2010; Lam et al., 2011). Service-user definitions are often broader, encompassing functionality, autonomy, wellbeing, personal growth and re-establishment of identity (Andresen, Oades, Caputi, Welford, & Morrison, 2003; Lam et al., 2011; Pitt et al., 2007). In the light of this discrepancy, measures designed to assess the subjective experience of recovery in psychosis have been developed (Beck et al., 2012; Neil et al., 2009).

The relationship between symptoms, stigma and recovery is likely complex and bidirectional. It has been suggested that people with the most acute symptoms may attract more attention and experience worse stigma, particularly when associated with socially undesirable labels like schizophrenia, and that this may result in increased social distancing and self-stigmatizing beliefs (Lysaker, Davis, Warman, Strasburger, & Beattie, 2007). On the other hand, it has been suggested that symptoms may be exacerbated by stigma (Lysaker, Roe, & Yanos, 2007; Yanos, Roe, Markus, & Lysaker, 2008). Studies have shown that internalising stigma negatively impacts on self-esteem (Corrigan et al., 2006) which is known to be related to recovery (Lysaker, Ringer, Maxwell, McGuire, & Lecomte, 2010). Drapalski et al. (2013) have suggested that self-esteem may therefore play a mediating role between poor self-concept resulting from stigma, and symptoms.

Consistent with these findings, in a previous study we found that, both concurrently and longitudinally, the impact of stigma on symptoms is mediated by self-esteem (Vass et al., 2015). However, this study did not distinguish between the effects of experienced stigma and internalised stigma on subjective recovery judgements. In this study we therefore aimed to test a model in which experiences of stigma effect recovery judgements through a sequence of mediators: internalised

stigma and then self-esteem (experienced stigma → internalised stigma → self-esteem → subjective recovery).

6.3. Methods

6.3.1. Participants and design

59 service-users (37 male, 22 female, mean age = 48.69, SD = 9.36) with experiences of psychosis were recruited from psychiatric services in NHS trusts in the North-West UK. Thirty (15 male, 15 female) reported that they had been given a diagnosis of bipolar affective disorder (BPD) and 29 (22 male, 7 female) reported that they had been given a diagnosis of schizophrenia (SZ) by their clinicians. All clinicians used ICD-10 criteria when making these diagnoses.

Participants were recruited from early intervention services, community mental health teams, assertive outreach teams, acute inpatient services, and other mental health services. The majority identified as White British (91%, n=54), consistent with population estimates for the areas of recruitment (Office of National Statistics, 2011). All participants had a sufficient level of English literacy to complete the measures and capacity to provide informed consent.

6.3.2. Measures

All research measures were administered by graduate psychologists who had received specific training in the relevant assessments. For the present analyses we focused on data pertaining to the key concepts of self-esteem, stigma and recovery. Alpha coefficients for all scales in the current sample are given in Table 8.

6.3.2.1. Independent variables

Experienced Stigma

The King et al. Stigma Scale (KSS; 2007) is a 28-item self-report measure of experienced stigma (e.g. “People have insulted me because of my mental health problems”) with items rated on a scale of 0 (strongly disagree) to 4 (strongly agree). Items explore positive aspects of stigma as well as discrimination experiences and willingness to disclose mental illness to others.

6.3.2.2. Mediator variables

Self-esteem

The Self Esteem Rating Scale—short form (SERS; Lecomte et al., 2006) is a 20-item self-report measure assessing positive and negative beliefs about the self which has demonstrated good reliability and adequate validity. Positive and negative beliefs were highly correlated ($r=-0.65$, $p<0.01$) so, for the purpose of the regression and mediation analyses, we used the total scale score.

Internalised Stigma

The Internalised Stigma of Mental Illness Scale (ISMI; Boyd-Rishter, Otilingam & Grajales, 2003) is a 29-item self-report questionnaire aimed at exploring the subjective experience of stigma (e.g. “I am disappointed in myself for having a mental illness”), designed in collaboration with service users. Items are rated on a scale of 1 (strongly disagree) to 4 (strongly agree). The ISMI has been found to have high internal consistency and test-retest reliability (Boyd-Rishter, Otilingam & Grajales, 2003).

6.3.2.3. Outcome variables

Subjective recovery

The Questionnaire about the Process of Recovery (QPR; Neil et al., 2009) is a 22-item self-report measure developed in collaboration with service-users and clinicians. Items (e.g. “I am basically strongly motivated to get better”) are rated on a five point Likert scale ranging from

“strongly disagree” to “strongly agree”. Higher scores are indicative of greater sense of recovery. In this study we used total scores, which had excellent reliability.

6.3.2.4 Covariates

Demographics

Age, gender and diagnosis were considered as covariates in the multiple mediation analyses.

Psychotic Symptoms

The Positive and Negative Syndrome Scale (PANSS; Kay et al., 1987, 1989) is a 30 item semi-structured clinical interview and rating scale which includes 7 items to evaluate positive symptoms (e.g. delusions), 7 items to evaluate negative symptoms (e.g. blunted affect) and 16 items to assess global psychopathology (e.g. anxiety). Symptoms are rated by the interviewer from 1 (not present) to 7 (severe). The PANSS has been used in many studies and has been shown to have good reliability and validity. In this study, we chose to focus on the total score for symptoms, and the positive subscale, as these symptoms are most likely to impair self-esteem and recovery perceptions. The complex relationship between stigma and symptoms meant that in these analyses PANSS-measured symptoms were included as a covariate factor in all analyses to control for their effect.

6.3.4. Procedure

The study was approved by an NHS Research Ethics Committee. All participants gave informed consent. To reduce participant burden, participants were given the option to complete some or all of the measures.

6.3.5. Statistical analyses

All analyses were conducted using SPSS (version 21). We examined bivariate relationships between the variables and Cronbach’s alpha coefficient was used to estimate the reliability of the measures.

Mediational models were tested using the PROCESS macro on SPSS 21 (Hayes, 2013). For this purpose, the direct effects (*c* paths) between the independent and dependent were firstly estimated. The mediating variables were then introduced, generating models with direct effects between the independent variables and the mediators (*a* paths), direct effects between the mediators and dependent variables (*b* paths), and direct effects between the independent and dependent variables whilst controlling for the mediators (*c'* paths). We ran sequential or serial multiple mediator models (PROCESS model 6). In these models the causal influence of one mediator (M_1) on the another mediator (M_2) is explored by estimating a partial correlation between the two mediators after controlling for the independent variable. If the correlation remains it is reasonable to assume that the indirect effects occur in a causal sequence ($X \rightarrow M_1 \rightarrow M_2 \rightarrow Y$). All models controlled for age, gender and diagnosis. The models were estimated using maximum likelihood (ML) estimators. As mediation models are sensitive to parametric assumptions and we had a relatively modest sample size, the statistical significance of mediating and indirect effects was examined with bootstrapped bias-corrected percentile-based confidence intervals of 1,000 bootstrap draws. In cases where zero did not fall within the 95 per cent intervals of the bootstrapped samples, the mediating effect was considered to be significant (MacKinnon et al., 2007, 2004; Preacher & Hayes, 2008).

6.4. Results

6.4.1. Independent Samples T-test

An independent sample t-test was used to determine any differences between the diagnostic groups (schizophrenia and bipolar disorder) in relation to the study measures. There was a significant difference in the scores for participants diagnosed with schizophrenia ($M=51.31$, $SD=17.06$) and participants diagnosed with bipolar disorder ($M=64.53$, $SD=12.20$) for the measure of subjective recovery; $t(57)=3.43$, $p = 0.001$. Age (schizophrenia: $M=46.00$, $SD=8.02$; bipolar: $M=51.38$, $SD=9.96$; $t(56)=2.27$, $p=0.03$), gender (schizophrenia: $M=0.24$, $SD=0.44$; bipolar: $M=0.50$, $SD=0.51$;

t(57)=2.10, p=0.04) and ethnicity (schizophrenia: M=1.24, SD=0.58; bipolar: M=1.00, SD=0.00; t(57)-2.29, p=0.03) were also significantly different between the two groups. No other significant effects were apparent.

6.4.2 Correlation analysis

There were no effects of age or gender on the stigma scores. Age was associated with self-esteem, and diagnosis. Diagnosis was also associated with subjective recovery. Table 8 shows the correlation matrix between the stigma, self-esteem, symptoms, and recovery measures.

Unsurprisingly, there were significant associations between the subjective recovery measure (QPR) and all of the symptoms measures (PANSS scales). Similarly, all three stigma measures (experienced and internalised) correlated with subjective recovery; however, internalised stigma had the most significant association. The stigma measures also correlated with the PANSS total, positive and general scores, but not the negative subscale.

Experienced stigma and internalised stigma were strongly positively correlated, suggesting that high levels of experienced stigma are associated with high levels of internalisation. Self-esteem was significantly associated with subjective recovery; as well as symptom total scores and symptom subscale scores.

Table 8: Mean, reliabilities and Pearson's inter-correlations for all variables in the multiple mediation models of the effects of stigma on recovery.

Measure	<i>n</i>	α	1	2	3	4	5	6	7	8	9	10	11
1. Experienced Stigma	58	.87	-										
2. Internalised Stigma	58	.90	.62**	-									
3. Self Esteem	57	.92	.52**	.73**	-								
4. Subjective Recovery	59	.94	-.32*	-.61**	-.63**	-							
5. Total Symptoms	59	.88	.42**	.42**	.54**	-.47**	-						
6. Positive Symptoms	59	.76	.28*	.30*	.43**	-.36**	.85**	-					
7. Negative Symptoms	59	.45	.22	.23	.44**	-.42**	.66**	.40**	-				
8. General Symptoms	59	.82	.46**	.45*	.50**	-.41**	.95**	.71**	.49**	-			
9. Gender	59	-	-.03	-.25	-.19	.22	-.01	-.17	.03	.07	-		
10. Age	59	-	-.11	-.22	-.30*	.25	-.17	-.08	-.12	-.20	.13	-	
11. Diagnosis	59	-	.09	.21	.18	-.41**	.15	.24	.22	.02	-.27	-.29*	-

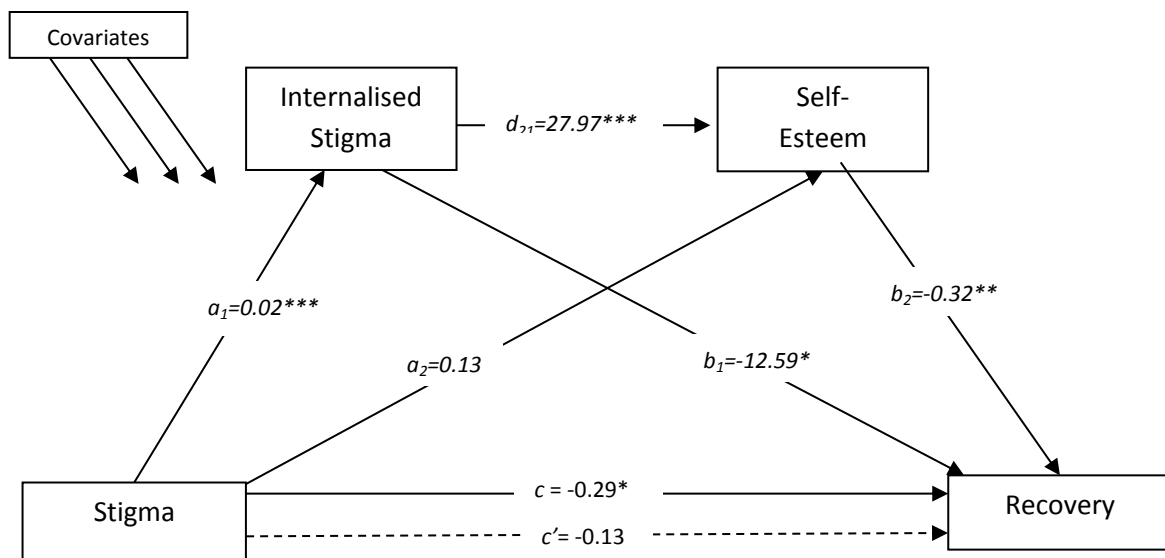
Notes: Experienced Stigma = KSS Total score, Internalised Stigma = ISMI total score, Self Esteem = SERS total score, Subjective Recovery = QPR total score, Total Symptoms = PANSS total score, Positive Symptoms = PANSS positive subscale, Negative Symptoms = PANSS negative subscale, General Symptoms = PANSS general subscale. * $p \leq 0.05$; ** $p \leq 0.01$, α = Cronbach's alpha coefficient.

6.4.3. Serial multiple mediation analyses

Detailed statistical results of the serial multiple mediation analysis are reported in Table 9.

The model tested is shown in Figure 2.

Figure 2: Illustration of serial multiple mediation model



Notes: Stigma = KSS Total score, Internalised Stigma = ISMI total score, Self-Esteem = SERS total score, Recovery = QPR total score, Covariates = PANSS Total Score, Gender, Age and Diagnosis.
* $p \leq .05$, ** $p \leq .01$, *** $p \leq .001$.

As predicted, the effect of experienced stigma (KSS) on subjective recovery (QPR) was fully mediated by internalised stigma and low self-esteem in turn (stigma \rightarrow internalised stigma \rightarrow self-esteem \rightarrow subjective recovery (total indirect effect $B = -0.29$, 95% CI = $-0.54 - -0.04$). There was also a substantial significant effect of diagnosis on outcome ($B = -10.08$, 95% CI = $-18.70 - -1.45$).

As can be seen in Figure 1, the total effect (path c) ($c = -0.29$, SE = 0.12 , $t = -2.34$, $p < .05$) of experienced stigma on subjective recovery was at significant. Similarly the direct effect of

experienced stigma on internalised stigma (path a_1) was highly significant ($B = 0.02$, $SE = 0.00$, $t = 5.63$, $p < .001$); however, the effect of experienced stigma on self-esteem (path a_2) was not significant ($B = 0.13$, $SE = 0.16$, $t = 0.83$, $p = 0.41$).

The direct effect of internalised stigma as the first mediating variable on the second mediating variable of self-esteem (path d_{12}) was significant ($B = 27.97$, $SE = 5.81$, $t = 4.81$, $p < .001$). The direct effects of the mediating variables on subjective recovery showed that these effects of internalised stigma (path b_1 ; $B = -12.59$, $SE = 5.61$, $t = -2.25$, $p < .05$) and self-esteem (path b_2 ; $B = -0.32$, $SE = 0.11$, $t = -2.82$, $p < .01$) were also significant.

When experienced stigma and both mediating variables were simultaneously entered into the model, the direct relationship between experienced stigma and subjective recovery was no longer significant ($c' = -0.08$, $SE = 0.31$, $t = -0.24$, $p = 0.81$). The model overall was significant ($F(4,49) = 4.54$, $p < .01$) and explained 27% of the total variance in subjective recovery. The comparison of indirect effects and specific effects of experienced stigma on subjective recovery perceptions through internalised stigma then self-esteem is shown in Table 9.

Table 9: Results from the serial multiple mediation analysis

Effect	B	95% Confidence Interval		
		Std. Error	Lower	Upper
Model 1 (n=55)				
Direct Effects (paths a₁, a₂)				
KSS → ISMI	0.02***	0.00	0.01	0.02
KSS → SERS	0.13	0.16	-0.19	0.46
Direct Effects (paths b₁, b₂)				
ISMI → QPR	-12.59*	5.61	-23.86	-1.31
SERS → QPR	-0.32**	0.11	-0.55	-0.09
Direct Effects (path c')				
KSS → QPR	0.13	0.13	-0.13	-0.38
Direct Effects (path d₁₂)				
ISMI → SERS	27.97***	5.81	16.28	39.66
Total Indirect Effects of Stigma (path c)				
KSS → QPR	-0.29*	0.12	-0.54	-0.04
Specific Indirect Effects of Stigma				
KSS → ISMI → QPR	-0.22	0.13	-0.50	0.01
KSS → ISMI → SERS → QPR	-0.16	0.07	-0.31	-0.04
KSS → SERS → QPR	-0.04	0.04	-0.17	0.02

Notes: *p≤.05, **p≤.01, ***p≤.001.

6.5. Discussion

The stigma of psychiatric disorder is associated with lowered social functioning and engagement (Link & Phelan, 2001b; Thornicroft et al., 2007), diminished life opportunities (Thornicroft et al., 2009) and reduced help-seeking (Thornicroft et al., 2007). This study aimed to test a model in which experiences of stigma affect recovery judgements through a sequence of mediators; internalised stigma and then self-esteem. The results are consistent with previous findings highlighting the role of self-esteem (Lysaker, Ringer, Maxwell, McGuire, & Lecomte, 2010; Vass et al., 2015) and support our proposed model. It is clear, therefore, that stigmatising experiences are, at least in part, internalized by individuals and consequently negatively affect self-concept (Drapalski et al., 2013). However, it is important to bear in mind that a person does not have to directly experience stigma to

experience its negative consequences (Brohan et al., 2010). Interestingly, across all of the analysis there was evidence that a diagnosis of 'schizophrenia' has a highly damaging effect on recovery perceptions, irrespective of actual symptoms. However, there was no evidence that this effect was via our mediation pathway (the diagnostic groups did not differ on internalized stigma or self-esteem).

6.5.1. Limitations

Our analyses could not clarify the nature of the relationship between experiences of stigma and psychotic symptoms; because there is good reason to believe that these can both lead to stigma and be exacerbated by stigma, they were considered only as a covariate. The sample population was relatively small, mostly male, and ethnically homogeneous. Our decision to include participants from a broad variety of mental health services in the hopes of capturing a wide variety of psychosis-spectrum symptoms, stigma experiences, and recovery progressions may have obscured effects related to particular stages of the illness course, for example first-episode psychosis. Nevertheless, to find such significant effects sizes in such a small sample suggests that the study is worth replicating with a larger, more diverse group.

The internalisation of stigma may be particularly influenced by specific kinds of stigma, which we did not consider in this study. For example, it has been suggested that discriminating experiences at work or home are more relevant to the internalisation of stigma than are discriminatory attitudes encountered in a broader social context (Wahl, 1999). Our data were cross-sectional and, in future studies, it will be useful to explore the evolution and interacting causal effects of symptoms, experienced stigma and internalized stigma longitudinally in prodromal patients developing the first symptoms of psychosis and in patients recovering from a first episode.

6.5.2. Clinical Implications

To date, the internalisation of stigma has received considerably less attention than discrimination experiences (Tang & Wu, 2012; Yen et al., 2005) and yet our findings suggest it may be an important psychological mechanism in the recovery process. The enduring, long-term effects of both experienced and internalised stigma on recovery perceptions (Vass et al., 2015) and emotional discomfort (Lysaker, Davis, Warman, Strasburger, & Beattie, 2007) found in previous research suggest that their impact on patients should not be overlooked. It is therefore important for clinicians to routinely assess the role of stigma for clients presenting with psychosis in order to better plan for provision of care (Burke et al., 2016).

The increasing recognition of the role of internalised stigma in psychosis has led to a number of pilot trials of targeted interventions, including cognitive therapy, psychoeducation, and cognitive behavioural therapy (CBT) (Burke et al., 2016; Knight, Wykes, & Hayward, 2006; Lucksted et al., 2011). CBT has also been found beneficial in improving self-esteem in clients with psychosis, so in terms of our model, may be a promising intervention to reduce the effects of stigma on recovery.

Beyond conventional psychological therapies, preventing isolation and encouraging social participation is imperative for wellbeing and symptomatic recovery in psychosis long-term (Garety et al., 2000, 2001; Pyle & Morrison, 2013; Wood, Birtel, et al., 2014). Hence, mental health services need to consider practical ways of minimising patients' social exclusion, for example by encouraging service-user led self-help groups and by employing service-user advisors, and by developing robust anti-stigma policies that apply to all staff (Vass et al., 2015).

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Chapter 7:

Discussion

7.1. Integrative summary and discussion

The four studies presented in this thesis address a number of important questions about the implications of stigma for recovery from psychosis. This chapter will attempt to integrate the findings from the empirical chapters, address overall limitations to the studies, consider clinical and social policy implications, and suggest potential avenues of future research.

The aim of this thesis was to examine the impact of stigma experiences and internalised stigma on recovery from psychosis. This was achieved by firstly exploring service-user's experiences of stigma and self-stigma, as well as their perceptions of medication and mental health services. Latterly, I built on these findings and examined the psychological processes underpinning the relationship between stigma and recovery; and attempted to clarify the interactive relationship between stigma, internalised stigma and recovery.

Chapter 3 described the findings from my qualitative study of the experience of living with bipolar disorder and schizophrenia and the associated mental health stigma. I expected to find that service-users with each of these diagnoses would have different experiential accounts of stigma. However, the participants' experiences were qualitatively similar, regardless of diagnosis. The only noted difference was the perception of the media: participants diagnosed with schizophrenia felt that media portrayals of their illness often misrepresented them or perpetuated negative

stereotypes. In contrast, participants diagnosed with bipolar disorder felt that there were a number of positive role models for bipolar disorder in the media.

Participants expressed relief at being able to put a name to their psychotic experiences when they were initially given a diagnosis, but also expressed some hesitancy and shock about the specific diagnosis given. These mixed reactions suggested that some individuals may have held some negative beliefs about the specific diagnoses of bipolar disorder and schizophrenia, prior to their own diagnosis. Participants subsequently explained a process of reevaluating past incidents in light of their diagnosis, which often led to sense of loss of the life they felt they may have had were it not for their illness. Similarly, the loss of identity was also conveyed, as individuals struggled to integrate the acquired diagnosis with their existing sense of self. Predominantly, the process of entering services and being diagnosed and awareness of associated severe mental illness stereotypes led to self-stigmatising, and consequent self-devaluation, loss of self-esteem and feelings of worthlessness.

Participants encountered different treatment and outright discrimination in their social relationships. The internalisation of these experiences led service-users to feel inhibited in disclosing their diagnosis to others, perceive themselves as a burden to others, and anticipate further stigma in future encounters. Social withdrawal and reduced interaction were common responses, and in some

cases, participants attempted to distance and differentiate themselves from others with mental health diagnoses.

In terms of recovery, participants' engagement with work and life opportunities was hampered by the expectation of stigma and discrimination. Internalised negative self-attributes meant that participants lacked the self-belief necessary to take chances, and led to a chronic avoidance of stressful situations or anything that might be potentially triggering. On the other hand, participants spoke positively about personal growth through their lived experiences, and consequently felt more compassionate towards others. Concepts of recovery were framed in a similar context, and focused on growth, wellbeing and improved functioning. Participants often did not consider or particularly value the reduction of symptoms in their hopes for recovery, but rather wanted to live well.

In Chapter 4, the discrepancies between service-users and clinicians views of recovery were further highlighted, as the focus on functioning and quality of life for service-users contrasted with services' emphasis on symptom-reduction. This study used the same data-set as Chapter 3, but focused solely on participants' perceptions of medication and mental health services. The findings reflected the idea that service-users did have some positive experiences of supportive staff and reduction in symptoms from the use of medication. However, the predominant picture was one of

frustration and feeling invalidated. Participants felt conflicted about taking medication, noting the possibility of reduced functioning, excessive dosages, polypharmacy, potential toxicity and side effects as dissuasive factors for medication adherence. Participants with a bipolar diagnosis also suggested that the medication didn't reduce their depressive feelings, but caused an absence of their 'highs' or mania, which they missed. At times, this prompted voluntary discontinuation of medication. Participants were uncomfortable with the lifestyle changes necessitated by taking medication, particularly abstinence from alcohol which was perceived to interfere with social activities. Moreover, there was anticipated stigma associated with medication, and with the use of mental health services. Participants especially worried that these were means by which others could identify them as 'mentally ill'.

Stigma was reinforced through the use of services by the often communicated prognosis of being unlikely to ever recover from psychosis – a common negative stereotype associated with psychosis (e.g. Crisp et al. 2000). This was further reinforced by the lack of patient involvement in care decisions and lack of collaboration between consumer and clinician. Rather, service-users typically felt discredited and invalidated through their interactions with clinicians, which led to further internalisation of stigma. Overall, participants felt limited in their options for treatment,

perceived a lack of information and transparency of process within services, and desired much more inclusive, patient-centred approaches to care.

Chapter 5 aimed to explore the psychological mechanisms underpinning the relationship between stigma and outcomes in psychosis, with findings suggesting that both symptomatic and subjective perceptions of recovery may be effected by stigma. Participants were assessed for stigma at baseline, and outcome measures were repeated again after 6 months. At baseline, experiences of internalised stigma strongly predicted poor subjective recovery judgements. Similarly, internalised stigma appeared to predict positive symptoms of psychosis, most notably suspiciousness and persecution, and active social avoidance. At 6 month follow up, active social avoidance, guilt feelings and self-blame were predicted by internalised stigma. Passive social withdrawal was also longitudinally predicted by baseline internalised stigma, and by discrimination. The effect of stigma and discrimination on passive social withdrawal at six months appeared to be mediated by self-esteem. The effect of internalised stigma on baseline recovery judgements appeared to be mediated through low self-esteem and hopelessness. However, neither self-esteem nor hopelessness appeared to explain the persisting association between internalised stigma and long-term recovery judgements. However, this discrepancy may have occurred due to the long gap between the measurement of these mediators and the six-month outcome. Nevertheless, to my knowledge,

there is no previous research which examines the long-term effects of stigma on psychosis; making this finding that stigma does indeed negatively impact both symptomatic and subjective outcomes of psychosis longitudinally one of the key findings of this thesis.

The study presented in chapter 6 aimed to clarify the relationship between stigma experiences, internalised stigma and recovery by testing a model in which experiences of stigma effect recovery judgements through a sequence of mediators; internalised stigma and then self-esteem. The results were consistent with previous findings highlighting the mediatory role of self-esteem (P. H. Lysaker et al., 2010; Vass et al., 2015) and supported the proposed model. Whilst it is not thought necessary to directly experience stigma to experience its negative consequences (Brohan et al., 2010): the findings suggested that stigmatising experiences are, at least in part, internalized by individuals which consequently diminishes self-esteem and ultimately reduces subjective perceptions of recovery. One of the most interesting findings from this study was the evidence that a diagnosis of 'schizophrenia' has a highly damaging effect on recovery perceptions, irrespective of actual symptoms. However, there was no evidence that this effect was via the mediation pathway (the diagnostic groups did not differ on internalized stigma or self-esteem). Nevertheless, it did speak to the damaging effects of 'schizophrenia' as a diagnostic label. Moreover, previous research has struggled to clarify the relationship between experienced stigma

and internalised stigma; the thesis findings suggest the relationship is causal, and greater experiences of stigma result in greater internalisation of stigma.

Taken together, the findings highlight the pervasive nature of stigma; service-users don't just experience stigma and discrimination, but are consumed by it, anticipating it at every turn and internalising the negative attributes associated with mental illness as devaluing aspects of the self. Stigma is continually reinforced through social interactions and interactions with mental health services. Moreover, mental illness stigma is re-traumatising. Individuals with experiences of psychosis are significantly more likely to have experienced childhood adversity and trauma (Read, van Os, Morrison, & Ross, 2005; Read, Fosse, Moskowitz, & Perry, 2014; Varese et al., 2012). Such experiences are commonly acknowledged as life-changing, effecting identity construction and often altering a person's sense of self. Moreover, trauma impairs feelings of autonomy (Brison, 2002), which I found to be true for stigma also. Similarly, many of the long-term effects of trauma such as hyper-vigilance, depression, and a lack of interest in activities (Brison, 2002) are often paralleled as typical responses to stigma and discrimination. These were particularly evident in the interviews with participants, when they spoke of their anticipation of stigma and social withdrawal:

The bottom line is I'm not ashamed but I understand and I'm very aware of the mental health stigma that surrounds everything especially bipolar and schizophrenia. Um, and believe...I don't want to put

myself into a situation where I'm treated differently and so I don't want to give the people the option...to treat me differently (Participant 1, SZ).

These parallels reflect a vicious cycle in which individuals that have experienced past trauma and are more likely to develop psychosis, and resultantly experience further trauma from stigma through discrimination and ill-treatment. Cumulatively, the findings suggest that stigma is not just a bad or unpleasant, yet minor, issue associated with mental illness. Rather, it is a ubiquitous poison evident in all areas of life and continually internalised, systematically breaking down individuals' self-esteem and ability to recover. In addition to the finding that stigma directly affects key psychological mechanisms in psychosis, namely self-esteem and hopelessness, it is evident that stigma is not just a passive side-effect of psychosis, but actually amplifies and worsens it.

7.2. Policy implications

The findings suggest that experiences of stigma and discrimination are internalised by individuals experiencing psychosis, lowering their self-esteem and ultimately reducing subjective perceptions of recovery. These findings suggest that reducing actual experiences of stigma on a societal level is instrumental in facilitating recovery from psychosis. Moreover, the systemic nature of mental health stigma reflected in the findings means that policy interventions are needed in a wide range of domains outside of clinical services. Corrigan and Penn (1999) suggest three approaches to promoting change in attitudes towards mental illness: protest, education and contact.

The findings suggested that the media was an influential factor in the perpetuation of mental illness stigma, particularly relating to schizophrenia. It is argued that protest sends messages to the media to stop reporting inaccurate depictions of mental illness, while simultaneously discrediting these representations to the general public (Corrigan & Watson, 2002).

Anecdotal evidence suggests that group protests against inaccurate and hostile representations of mental illness have been effective in getting stigmatizing images withdrawn (Corrigan & Watson, 2002). For example, a Twitter protest in 2013 involving thousands of people 'tweeting' their disapproval of a 'mental patient' Halloween costume being sold by a major UK supermarket chain resulted in mainstream media coverage, a public apology from the retailer, and the removal of the items from sale (Betton et al., 2015). During the same protest a #mentalpatient hashtag was created by people with lived experience of mental health issues, and used to caption photographs of themselves to satirise the Halloween costume. Similarly, a high-street retailer received backlash for their "Don't get mad, take Lithium" greetings cards and corresponding online commentary, which were seen to be stigmatising and highly offensive to people with bipolar disorder (Culzac, 2014). It has been suggested that these types of 'viral' responses to social media protests may create a sense of solidarity and normalise the experience of mental health problems by exhibiting it as the experience of many, not just one. Moreover, it increases the 'limited contact'

between members of the general public and service-users; this increased personal contact undermines prevailing stereotypes (Betton et al., 2015; Corrigan, Morris, Michaels, Rafacz, & Rüschi, 2012). Similarly, it has been suggested that the general public are encountering fewer media endorsed examples of negative mental illness stereotypes due to protest efforts (O. F. Wahl, 1997). Whilst anecdotal, the evidence suggests that online protests have the potential raise awareness of mental health stigma and alter retailer and media policies on materials relating to mental illness.

Another aspect of protest seen in relation to mental health issues is the emerging academic field of mad studies, and the mad-pride movement amongst service-users and psychiatric survivors. Whilst the qualitative interviews highlighted the benefits of positive group identities associated with mental health problems, and more empowering responses to stigma; mad-pride provides a somewhat more extreme activist approach. Mad-pride developed as a movement against the widespread stigma and discrimination of mental illness (Curtis, 1996) and aims to reclaim typically stigmatising language associated with mental health issues, such as "mad", "nutter", and "psycho". This is often likened to gay-rights activists reclaiming the word "queer" – changing it from being a term of abuse to a term which is positively used to describe the gay culture and community, and those who identify with it. Mad-pride activists seek to re-educate the general public on the misconceptions surrounding mental health issues, particularly through the use of mass media

campaigns and outreach activities. It also aims to shift traditional psychiatric perceptions of mental health problems through challenging the medicalization of mental distress and encouraging critical discourses around mental health services and psychiatric power. In recognition of mad-pride, the academic field of mad studies has been developing, which Castrodale (2015) describes as a “multi-voiced and interdisciplinary field of activism, theory, praxis and scholarship”. The aim of mad studies is to learn about mental health issues through those who are experts by experience (mental health consumers) as opposed to clinicians and academics.

Education is thought to be influential in targeting stigma on a societal level as it promotes more positive attitudes towards mental illness (Corrigan & Penn, 1999). Research has indicated that individuals who demonstrate a good understanding of mental illness are less likely to endorse mental health stigma and discrimination (Corrigan & Watson, 2002); suggesting that considered provision of educational material and information appears to lessen negative stereotypes. A study of 232 college students’ attitudes towards mental illness concluded that students already had well-established attitudes about mental illness despite minimal coverage of mental health issues in the curriculum (Boysen, Fredonia, & Vogel, 2008). Similarly, Schulze & Angermeyer (2005) found that secondary school students already knew that schizophrenia was a form of mental illness. Research suggests that children and adolescents with early established negative attitudes to mental illness are

less likely to reduce negative stigmatizing attitudes than their peers who hold generally neutral or positive attitudes (Boysen et al., 2008). This indicates that education about mental health issues is likely to be most effective in reducing prejudiced thinking if implemented early in a young person's education, and should be considered as part of education policy.

Moreover, the type of model used to understand mental health problems in education is critical to addressing stigma. Research indicates that the 'mental illness is an illness like any other' approach to de-stigmatisation has failed to improve the attitudes of lay people to individuals experiencing mental health difficulties (Walker & Read, 2002; Read & Harre, 2009). For example, Read and Harre (2009) replicated earlier findings that the public have a tendency to reject biological and genetic explanations of mental health problems in favour of psychosocial explanations which focus on negative life events, such as trauma. The research further indicated that biological and genetic causal beliefs are related to negative stereotypical attitudes, including perceptions that 'mental patients' are dangerous and unpredictable. In relation to schizophrenia, Dietrich, Matschinger and Angermeyer (2006) found that the more people endorsed brain disease as the cause of illness, the more dangerous they believed the person with schizophrenia to be. Perhaps surprisingly Walker & Read (2002) didn't find that education promoting psychosocial explanations of mental illness significantly improved attitudes. However, they did find that people who knew

service-users or had personal experiences of mental health difficulties had more positive attitudes, suggesting that increased contact with and exposure to individuals with experiences of mental health issues should be a key focus of de-stigmatisation efforts.

Stigma that is part of social and institutional policies and practices (structural stigma) is a further issue which may prevent help-seeking and create barriers to recovery. It has long been held that mental health issues lack parity with physical health issues in terms of recognition, resources and research funding (Corrigan, Druss, & Perlick, 2014). Individuals with severe mental illnesses, such as schizophrenia and bipolar disorder, die on average 15 to 20 years earlier than the general population (The King's Fund, 2015). Worldwide, psychiatric conditions constitute 13 per cent of the global disease burden, and a median of 2 per cent of health care budget expenditure is allocated to mental health treatment (WHO (World Health Organization), 2003). In the United Kingdom, mental health problems account for 23 per cent of the burden of disease, yet spending on mental health services consumes only 11 per cent of the National Health Service budget (The King's Fund, 2015).

People with mental health issues also lack parity with others in the legal system as they are typically not considered to be credible witnesses to crime by the Crime Prosecution Service and the police (Sayce, 1998). Watson, Corrigan, & Ottati, (2004) similarly found that police officers were less likely to act on information provided by victims and witnesses who had a history of mental illness.

These forms of invalidation may cause individuals to not report a crime and pursue justice for fear of not being believed or supported. Moreover, it may prompt individuals to diminish the significance of what happened to them as a victim of crime, attribute blame to themselves and question their own certainty about events (Read & Baker, 1996). This self-doubt, erosion of pride and lessened desire or ability to stand up for oneself can seriously impact on an individual's identity and sense of self-worth. As such, changes to policy and legislation to affect large-scale organisations such as the National Health Service and Crown Prosecution Service is needed to promote equality and reduce discriminatory treatment which reinforces stigma for individuals experiencing mental health difficulties.

7.3. Clinical implications

The thesis findings have fundamental implications for clinical work. Chapter 4 particularly focused on service-users' experiences of mental health services and drug-based interventions, which revealed a number of unmet needs. Participants cited the lack of transparency, lack of information and lack of involvement in making care-decisions to be sources of frustration and invalidation; reinforcing negative stereotypes of incapability, and encouraging them to internalise stigmatising attitudes of worthlessness and powerlessness. The reinforcement of stigma was a particularly concerning finding which highlights the necessity for mental health services make efforts to develop

robust anti-stigma policies, and ensure that all staff members are sufficiently trained to work in a stigma-informed way. The 'CHIME' model of recovery suggests that recovery is particularly aided by a supportive and healing environment (Leamy et al., 2011), suggesting that services where coercive, non-collaborative approaches are used may be detrimental to outcomes.

Findings from the National Comorbidity Survey Replication showed amongst respondents who indicated a perceived need to access services, a desire to handle the problem on one's own was the most common reason given both for not seeking treatment (72.6%) and for dropping out of care (42.2%) (Corrigan et al., 2014; Mojtabai et al., 2016). This finding highlights the need for autonomy and control felt by service-users when engaging with services, suggesting that a greater focus on provision of collaborative patient-centred approaches is needed to validate consumers and increase their sense of agency and control over their mental health. Concordance models of mental health care are increasingly advocated (Bissell, May, & Noyce, 2004) as a means of recognising the expertise and rationality of service-users. Such approaches endorse shared decision-making, and use a framework of mutual respect, reciprocal understanding and collaboration (Murray, Charles, & Gafni, 2006; Seale et al., 2006). The implementation of concordance-based models in mental health services may improve service-users experiences of healthcare through improved understanding, engagement and autonomy. The likely improved relationships between clinicians and service-users

are likely to lead to better outcomes in the treatment of psychosis, as the therapeutic alliance has been found to have a causal relationship with outcomes in psychosis (Goldsmith et al., 2015; Howgego, Yellowlees, Owen, Meldrum, & Dark, 2003; McCabe & Priebe, 2004).

The discrepancy between goals of treatment and recovery meanings for clinicians and service-users was another issue highlighted in the thesis. However, the mental health plan for England 2009–2019 promised an ‘expectation that services to treat and care for people with mental health problems will be... based on the best available evidence and focused on recovery, as defined in discussion with the service user’ (Leamy et al., 2011; Siva, 2009). Whilst this indicates a greater focus on service-user defined recovery, intention does not always lead to implementation.

Traditionally concepts of recovery have been criticised for their wide variation and lack clear definition, and the difficulty in quantifying them (Beck et al., 2012; Brown, Rempfer, & Hamera, 2008). However, a systematic review of 97 studies exploring the meaning of recovery for service-users led to the development of the ‘CHIME’ model (Leamy et al., 2011). The model comprises of connectedness; hope and optimism about the future; identity; meaning in life; and empowerment. Implementation of the ‘CHIME’ model could provide a practical framework for clinical services as a measure of recovery which is meaningful to consumers, not only supporting reflective practice, but

providing a means of evaluation of progress in recovery, and a method of identifying aspects of life which service-users may need further support in.

The 'CHIME' model also highlights the importance of redefining identities, developing meaningful roles and goals, and empowerment as key aspects of recovery. However, it has been previously suggested that internalised stigma makes the process of reclaiming identity, re-establishing identities unrelated to mental illness, and recovering one's roles in society much more difficult (Corrigan & Watson, 2002; Michalak et al., 2011). An important finding in the qualitative studies was the positive role of voluntary mental health services and networks in establishing positive roles and identities after diagnosis. A phenomenon noted by medical sociologists is the way in which many people create and join illness-based social movements, generate knowledge about their own medical conditions, and create new communities based on their illness-identities (Banks & Prior, 2001; Brown et al., 2004). This has most commonly been associated with cancer-survivors, who raise money for cancer research, create support networks, and maintain 'survivor' as a defining aspect of their identity during recovery (Brown et al., 2004). Similar reports of activities and involvement with voluntary sector mental health services were reported by the participants. These engagements were associated greater wellbeing, the establishment of positive identities, increased self-esteem, and feelings of empowerment. Personal growth through lived experience and the ability

to help and mentor others experiencing psychosis validated individuals and improved self-confidence. Such involvement could be encouraged by clinical services and taken forward as a social intervention by establishing recovery colleges, mentoring schemes and service-user led self-help groups. Moreover, encouraging social participation and preventing isolation is important for wellbeing and symptomatic recovery in the long-term (Garety et al., 2000, 2001; Pyle & Morrison, 2013; Wood, Burke, et al., 2014). It is important for mental health services to consider practical ways of minimising patients' social exclusion, and this could be achieved by encouraging voluntary network engagement, establishing service-based consumer led self-help groups and employing advisors who are 'experts by experience'.

It is clear from the thesis findings that there is a need for mental health services to routinely assess for stigma (Burke et al., 2016), consider the impact of receiving a diagnosis of schizophrenia or bipolar disorder, and ensure that service-users have access to adequate support and counselling to help them adjust during this period of personal identity change. The abundance of information disclosed about stigma without the use of direct questioning in the qualitative interviews indicates that this is a subject of great personal significance to service-users. As such, clinicians should be aware of the different means by which difficulties with stigma are expressed conversationally, and make efforts to enquire about stigma and discrimination. Moreover, greater consideration to the

use of diagnostic labels is needed. The study presented in Chapter 7 found a persistent negative effect of the label 'schizophrenia' on perceptions of recovery, even when symptoms were controlled for. This suggests that the term 'schizophrenia' is inherently damaging to individuals, and the internalisation of the stigma pertaining to it reduces feelings of recovery regardless of symptom-level. Japan was the first country to acknowledge the negative stereotypes associated with their equivalent term, "Seishin Bunretsu Byo" ("mind-split-disease"), and changed it into the new term of "Togo Shitcho Sho" ("integration disorder"), in 2002 (Sato, 2006). The renaming was well-received, and resulted in a shift from the Kraepelinian disease model to the vulnerability-stress model. Moreover, psychiatrists reported finding it more suitable to inform and explain to patients (Sato, 2006).

Critics have suggested that simply rebranding schizophrenia is not enough due to deep-rooted stigma associated with the illness (Bentall, 2013). However, Jim van Os has suggested that a similar change be made to 'schizophrenia', replacing it with the term 'Salience syndrome' (van Os, 2009). He proposes that evidence favours a syndromal system of classification, merging categorical and dimensional models of psychosis. Moreover, van Os proposes that the term 'salience' may help to normalise psychotic experiences and facilitate public understanding of psychosis as a universal human experience. Whilst these are changes which may benefit consumers in the future, at present

the continued use of the term 'schizophrenia' should be used carefully by clinicians, with particular awareness of the associated negative effects. Ultimately, rather than replacing diagnostic terminology which may eventually take on the same stigmatising qualities over time; a shift from traditional diagnostic concepts of mental illness to dimensional models is needed. As well as reducing both the public and internalised stigma that is associated with diagnostic labels, Borsboom & Cramer (2013) suggest that a dimensional approach to psychosis may allow for greater observation and study of how different symptoms interact, and how these interactions may impact on prognosis and treatment. This approach drastically differs from psychiatric approaches which allow the diagnosis to guide the treatment and access to services, as opposed to the experienced symptoms. Studying psychosis in this way may also allow further investigation into the risk factors and psychological mechanisms underpinning psychotic symptoms (Bentall, 2014)).

The finding of long-term effects of experienced stigma on recovery is particularly concerning, and highlights the need for targeted psycho-therapeutic interventions. These results suggest that the mediators of self-esteem and hopelessness may be crucial targets in this respect. Similarly, the increasing recognition of the role of internalised stigma in psychosis has led to a number of pilot trials of targeted interventions, including cognitive therapy, psychoeducation, and cognitive behavioural therapy (CBT) (Burke et al., 2016; Knight, Wykes, & Hayward, 2006; Lucksted

et al., 2011). NICE (National Institute for Health and Care Excellence, 2009) recommends CBT as the primary choice of psychological intervention for psychosis. CBT interventions for psychosis characteristically include a normalizing rationale, with the aim of reducing the patient's perception of being different from others, and therefore potentially reducing internalised stigma (Kingdon & Turkington, 1991). Normalizing strategies include providing information about the widespread prevalence of psychotic experiences and of famous people who have been successful despite experiencing psychosis (Morrison, Renton, Dunn, Williams & Bentall, 2003). Research has shown that CBT shows promise in terms of improving self-esteem in clients with psychosis (Hall and Tarrier, 2003) and it has been suggested that it would be the most appropriate approach to addressing issues such as feelings of hopelessness regarding recovery (Yanos et al., 2008; Wood et al., 2014b). As such, in terms of the models presented in the quantitative chapters, CBT may be a promising intervention to reduce the effects of stigma on recovery. Moreover, when CBT is utilised as a group therapy there is preliminary evidence from uncontrolled studies to suggest it may be successful at reducing internalised stigma, improving self-esteem, and advancing recovery (Knight, Wykes, & Hayward, 2003; Lucksted et al., 2011; MacInnes & Lewis, 2008). Similarly, a recent randomised controlled trial found that a cognitive behavioural internalised stigma reduction programme had significant benefits on self-esteem (Fung et al., 2011). Other interventions that aim to promote

optimism and improve self-esteem, such as peer support, may also be worth evaluating in terms of effects on internalised stigma (Pyle and Morrison, 2013).

7.4. Limitations

The studies presented in this thesis have a number of limitations. Overall, I struggled to recruit individuals from black and minority ethnic backgrounds. This was expected as the White British population in the areas of recruitment is thought to range from 91.86%-93.9% (Office of National Statistics, 2011). However, research indicates that individuals from black and minority ethnic (BME) communities experience 'dual-stigma' from the intersectionality between ethnicity and mental illness. Individuals already experience racial prejudice and discrimination on the basis of their ethnicity and culture, and subsequently experience further discrimination from mental health stigma (Gary, 2005; Leamy et al., 2011). Moreover, findings from a systematic review of recovery concepts suggest that black and minority ethnic perceptions of recovery contain extra elements which are not necessarily observed in others. For example, being part of a faith community and having a religious or spiritual affiliation is considered an important aspect of an individual's recovery. Culture-specific factors were also considered in concepts of recovery for BME individuals, such as faith-healing and traditional medicine (Leamy et al., 2011). These cultural nuances are missing from the thesis findings due to the high percentage of White British participants. Similarly, sexual orientation was not

considered in the studies, and it is evident from previous research that stigma associated with gender and sexuality can be an influential factor in individuals' experiences of psychosis (Haarmans et al., 2016).

The qualitative studies were also biased towards individuals who had been given a bipolar disorder diagnosis, which may have further skewed the findings. Difficulty in recruitment meant I struggled to get participants with a schizophrenia diagnosis referred to the study, meaning that twice as many people with a bipolar disorder diagnosis took part. A further limitation of the qualitative studies may be the lack of direct questioning on topics of interest. Whilst the two studies which came from the interviews focused on stigma and experiences of mental health services and medication, participants were not asked about these subjects deliberately to avoid leading or pressuring participants to disclose information. On the one hand this can be viewed as a key strength of the studies, as the information was not prompted but rather arose spontaneously as a major aspect of the participants' experience of living with psychosis. On the other hand, it is possible that the full extent of participants' experiences may not have been elicited, and information could have been missed. Similarly, as I did not expect such a wealth of information on experiences of drug-based interventions and interactions with mental health services, no attempt was made to rigorously gather details on types of medication taken and the type of service participants were

engaged with. These details would have provided a richer context and background for the participants' stories. Finally, the study findings were not returned to the participants for validation.

Qualitative research can benefit from participant input during the analysis stage, to corroborate researcher interpretations and clarify ambiguous statements. This was unfortunately not considered during the study design, and consequently further insights from the participants may have been missed.

In the quantitative studies I encountered some limitations in the methods. In the study presented in Chapter 5, the utilisation of secondary data meant that some measures, such as stigma, were only assessed at baseline. Whilst this led to a finding that stigma experienced in the past still effects recovery longitudinally (6 months later), measures taken at both time points would have been preferable. The study presented in Chapter 5 also differs from the others in the thesis in that it sampled a broad range of individuals on the schizophrenia-spectrum, as opposed to individuals with specific diagnoses of schizophrenia and bipolar disorder. Whilst I have found experiences of the participants with each diagnosis to be pointedly similar, and many modern concepts of psychosis consider schizophrenia, schizophrenia-spectrum disorders, and bipolar disorder to all be part of a larger symptom-based psychosis spectrum, one cannot necessarily generalise the findings of individuals on the schizophrenia-spectrum to individuals who have been given a diagnosis of bipolar

disorder. Moreover, whilst a broad range of service-users were deliberately invited to take part in the hope of sampling a range of symptom profiles and recovery judgments, this may have obscured effects that are important at particular stages of illness course, for example first-episode psychosis. Both of the quantitative studies would have benefitted from larger sample sizes, particularly the study presented in Chapter 6 (n=59). However, to find such significant effects sizes in such a small sample suggests that the study is worth replicating with a larger, more diverse group.

7.5. Avenues for future research

As the thesis limitations suggest, greater diversity is needed in future research. Replicating these studies with more ethnically diverse participant samples would be beneficial to gauging the difference in experience between white, black and minority ethnic populations. Similarly, more diverse sampling of sexual orientation and gender may provide greater insight into the intersectionality between the multiple stigmas experienced by individuals with mental health issues. More directed research into the experiences of consumers using different types of mental health services (e.g. early intervention, community mental health teams, acute psychiatric care) and at different stages of illness and recovery is needed, and this should be an avenue for future research. A key avenue of future research should be to consider focusing on the first episode (or even during

the prodromal period before first onset) to understand how stigma evolves across the course of illness, and the extent to which stigma impedes recovery. Specifically, I would like to replicate the key finding in this thesis that psychosis outcomes are longitudinally affected by stigma, and investigate the relationship between the different forms of stigma, psychological mechanisms and types of recovery longitudinally, by following the process of recovery for service-users from first-episode over a period of several years.

Some of the measures used in the studies presented in the thesis, such as the King Stigma Scale (M. King et al., 2007) were time-nonspecific (items do not specify whether stigma is experienced in the present or the past); future studies which address the question of whether stigma fluctuates over time may be better able to address associations with self-esteem, hopelessness and symptoms which, undoubtedly, also fluctuate. Future studies should include mediator variables at later time points, and should also consider more sophisticated ways of demonstrating that stigma has a causal effect on outcome. Given the finding that stigma may impact on future clinical outcomes, further research is vital to test this possibility.

The findings and the literature regarding mental health services provision and the therapeutic alliance indicate that poor interactions with service-users are damaging to recovery from psychosis. The findings also suggest that the use of voluntary mental health services was beneficial

to participants, as was more collaborative and inclusive approaches to mental health care. Research to examine the efficacy of these as interventions for preventing and remedying internalised stigma should be considered. Moreover testing concordance models, and exploring the use of service-user informed frameworks of recovery such as the 'CHIME' model as an outcome measure and a means of improving the therapeutic alliance should be considered in future research.

7.6. References

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Appendix A

Chapters 3 & 4: Qualitative Interview Schedule.

Interview Schedule

Reactions and Responses to Diagnoses of Schizophrenia and Bipolar Disorder: A Qualitative Study in Patient Experience

Thank you for agreeing to talk about your experience of mental health diagnosis. I'm interested in your own personal experience which may be different from other people's, so please tell me what it has been like for you. The interview will probably last between one and one and a half-hours, and with your permission I would like to tape-record the conversation. We will be able to arrange an opportunity for you to hear the tape if you would like. Should you wish to stop the interview at any time, or take a break, please let me know. You're under no obligation to answer any questions that you feel uncomfortable with, so if you don't want to answer a particular question just let me know. As the topic of our discussions is sensitive I can assure you that the interview will remain entirely confidential, and no information will be passed on to your care-team.

I would like first of all to ask you a few factual questions, and then ask you some more open questions about the experience of being diagnosed with Schizophrenia or Bipolar Disorder and how this has made an impact on you and your life.

Section A

1. How old are you? Where were you born? What is your ethnicity?
- 2a. What diagnosis have you been given?
- 2b. And how long have you had that diagnosis? When were you first diagnosed with...?

Section B

I would now like to ask you a little bit about yourself before your diagnosis

3a. Before your mental health diagnosis what was life like?

Prompts: How would you have described yourself to me if I'd met you then?

Did you suspect something was wrong?

3b. Prior to your diagnosis what did you think of people with Bipolar Disorder/Schizophrenia? Has that changed at all now?

4. Was there a particular incident that led you to seek help/resulted in you being diagnosed with..?

4b. Did you have any ideas about what might be the problem, did you give a name to it yourself at all?

4c. How long did it take for you to get a diagnosis?

Prompts: what was it like waiting to be diagnosed?

did you feel included in what was going on?

did you feel like you had control of the situation?

did you understand what was happening?

5. What did you feel about being diagnosed?

Prompts: what was it like?

how were you told?

did you accept what you were being told?

did you disagree?

did you understand it?

did it feel good to put a name to it?

did you have any concerns?

5b. What did it feel like to be told that you had Bipolar Disorder/Schizophrenia?

Prompts: what did it feel like in that first instance that you were told?

what were your first thoughts when you were told?

if you could pick maybe 3 or 4 words that described how you felt what would they be?

5c. **How would you describe yourself to me if I had met you just after you had been diagnosed with...?**

5d. (if they struggled with the diagnosis) **How did being unhappy with your diagnosis affect you?**
Do you think it was easy to have treatment when you didn't agree with the diagnosis?

Section C

I would now like to ask you to think about the weeks after you were diagnosed with...

6a. **What did you do?**

Prompts: did you carry on as normal?

what did you do during the days following your diagnosis?

did you feel that you were coping with the news?

6b. **Did you tell anyone? Who did you tell?**

family support?

other social support?

how long did it take you to tell someone?

6c. **How did you feel?**

Prompts: how were you?

what was your mood like?

what happened as the days passed?

how were you with other people?

did you tell people?

did you talk about it with anyone?

how were your thoughts?

did you think differently about yourself than before?

6d. How would you have described yourself to me if I'd met you then?

6e. How would your close friends have described you?

Section D (longer term)

I would now like to ask you to think about what it was like a year or so later/now?

7. How did you feel after some time had passed?

Prompts: how were you?
 what was your mood like?
 did you feel good or bad?
 how were your thoughts?

7b. How were you with other people?

Prompts: who did you surround yourself with?
 had your social life changed?
 who would you have turned to for someone to talk to?
 can you tell me why?
 do you feel like you have enough support?

7c. How has being diagnosed with Bipolar Disorder/Schizophrenia impacted on your life - has it changed anything?

7d. Thinking about your roles and responsibilities in the family, did they change at all after your diagnosis?

Think about:

Around the home

Family/childcare

Finance

Prompts: were there any changes to your circumstances? How did they effect you?

how did you feel about those changes?

7e. How do you feel about it now? Do you think that will change in the future?

8. Do you think that receiving a diagnosis of Bipolar Disorder/Schizophrenia has changed the way you see yourself or think about yourself?

8b.. Overall how would you say your identity has changed, if at all; from before your mental health diagnosis up to now?

8c. Do you believe that your public/social identity has changed during this time as well?

Prompt: how do you think society/others see you now compared to when you weren't diagnosed with...?

Prompts: is it something that you tell new people that you meet (potential friends/colleagues/partners)?
if not why not, has anyone ever reacted badly?

Section E

In this last section I'd like to know a little more about what you think about Bipolar Disorder/Schizophrenia. There are no right or wrong answers, this is just to gain some understanding of what you think.

9. What do you understand Bipolar Disorder/Schizophrenia to be?

Prompt: if you had to explain it to someone else what would you say?

9b. What do you think the causes of Bipolar Disorder/Schizophrenia are?

Prompt: Some people think genetics, or environment or a bad incident in the past etc., what do you think?

9c. What sources of information do you use to find out more about your condition?

Prompt: Where would you look to find out more?

Internet, forums, self-help groups, books, care teams etc.

Finally....

10. What advice would you give someone in the same situation as yourself?

Appendix B

Chapter 5: Supplementary table for mediation analysis with baseline data.

Effect	<i>B</i>	95% Confidence Interval		
		<i>Std. Error</i>	<i>Lower</i>	<i>Upper</i>
Baseline Model 1				
Direct Effects (path a)				
KSSTotal → SERS	-0.04***	0.01	-0.05	-0.03
KSSTotal → BHS	0.22***	0.04	0.14	0.29
Direct Effects (path b)				
SERS → QPR	3.89**	1.21	1.47	6.31
BHS → QPR	-0.58**	0.22	-1.01	-0.14
SERS → PANSS+	-1.07	0.65	-2.36	0.22
BHS → PANSS+	0.24*	0.12	0.01	0.48
SERS → P6	-0.48*	0.20	-0.88	-0.08
BHS → P6	0.06	0.04	-0.02	0.13
SERS → G16	-0.57**	0.18	-0.92	-0.22
BHS → G16	0.04	0.03	-0.02	0.11
SERS → N4	-0.26	0.16	-0.58	0.05
BHS → N4	0.06*	0.03	-0.03	0.01
Direct Effects (path c')				
KSSTotal → QPR	0.01	0.07	-0.13	0.16
KSSTotal → PANSS+	-0.02	0.39	-0.11	0.05
KSSTotal → P6	0.01	0.01	-0.02	0.03
KSSTotal → G16	-0.00	0.01	-0.03	0.02
KSSTotal → N4	-0.01	0.01	-0.03	0.01
Specific Indirect Effects of Stigma				
KSSTotal → SERS → QPR	-0.16*	0.06	-0.28	-0.05
KSSTotal → BHS → QPR	-0.12*	0.05	-0.25	-0.04
KSSTotal → SERS → PANSS+	0.04	0.03	-0.01	0.10
KSSTotal → BHS → PANSS+	0.05*	0.02	0.00	0.10
KSSTotal → SERS → P6	0.02*	0.01	0.01	0.03
KSSTotal → BHS → P6	0.01	0.01	-0.01	0.03
KSSTotal → SERS → G16	0.02*	0.01	0.00	0.04
KSSTotal → BHS → G16	0.01	0.01	-0.01	0.03
KSSTotal → SERS → N4	0.01	0.01	-0.01	0.03
KSSTotal → BHS → N4	0.01*	0.01	0.00	0.03
Baseline Model 2				
Direct Effects (path a)				
Discrimination → SERS	-0.06***	0.01	-0.09	-0.33
Discrimination → BHS	0.29**	0.08	0.13	0.45
Disclosure → SERS	-0.02	0.01	-0.05	0.00
Disclosure → BHS	0.17*	0.07	0.02	0.32
Direct Effects (path b)				
SERS → QPR	4.46***	1.15	2.16	6.76

BHS → QPR	-0.59**	0.21	-1.00	-0.18
SERS → PANSS+	-1.03	0.65	-2.33	0.28
BHS → PANSS+	0.23*	0.12	-0.00	0.47
SERS → P6	-0.47*	0.20	-0.87	-0.06
BHS → P6	0.05	0.04	-0.02	0.13
SERS → G16	-.58***	0.18	-0.94	-0.23
BHS → G16	0.04	0.03	-0.02	0.10
SERS → N4	-0.23	0.16	-0.55	0.09
BHS → N4	0.06*	0.03	0.01	0.12
Direct Effects (path c')				
Discrimination → QPR	0.34**	0.13	0.08	0.59
Disclosure → QPR	-0.20	0.11	-0.42	0.01
Discrimination → PANSS+	-0.02	0.07	-0.17	0.12
Disclosure → PANSS+	-0.01	0.06	-0.13	0.12
Discrimination → P6	0.01	0.02	-0.04	0.05
Disclosure → P6	0.01	0.02	-0.03	0.05
Discrimination → G16	-0.02	0.02	-0.06	0.02
Disclosure → G16	0.01	0.02	-0.02	0.04
Discrimination → N4	0.01	0.02	-0.03	0.04
Disclosure → N4	-0.02	0.02	-0.05	0.01
Specific Indirect Effects of Stigma				
Discrimination → SERS → QPR	-0.28*	0.10	-0.52	-0.11
Discrimination → BHS → QPR	-0.17*	0.07	-0.36	-0.06
Disclosure → SERS → QPR	-0.11*	0.06	-0.27	-0.01
Disclosure → BHS → QPR	-0.11*	0.06	-0.26	-0.02
Discrimination → SERS → PANSS+	0.06	0.04	-0.02	0.16
Discrimination → BHS → PANSS+	0.06*	0.03	0.01	0.15
Disclosure → SERS → PANSS+	0.03	0.02	-0.00	0.10
Disclosure → BHS → PANSS+	0.04*	0.02	0.01	0.10
Discrimination → SERS → P6	0.03*	0.01	0.01	0.06
Discrimination → BHS → P6	0.01	0.01	-0.00	0.04
Disclosure → SERS → P6	0.01*	0.01	0.00	0.04
Disclosure → BHS → P6	0.01	0.01	-0.00	0.03
Discrimination → SERS → G16	0.03*	0.02	0.01	0.08
Discrimination → BHS → G16	0.01	0.01	0.01	0.04
Disclosure → SERS → G16	0.02*	0.01	0.01	0.04
Disclosure → BHS → G16	0.01	0.01	-0.01	0.04
Discrimination → SERS → N4	0.01	0.01	-0.01	0.04
Discrimination → BHS → N4	0.02*	0.01	0.00	0.05
Disclosure → SERS → N4	0.01	0.01	-0.00	0.03
Disclosure → BHS → N4	0.01*	0.01	0.00	0.03

Note: PANSS+ = PANSS Positive sub-scale, P6 = PANSS item for suspiciousness/persecution, N4 = PANSS item for Passive Social Withdrawal, G16 = PANSS item for Active Social Avoidance, QPR = Subjective recovery (at baseline), KSS Total = Total stigma score, Discrimination = KSS discrimination sub-scale, Disclosure = KSS disclosure sub-scale, SERS = Self-esteem, BHS = Hopelessness. *p≤.05, **p≤.01, ***p≤.001.

Appendix C

Chapter 5: Supplementary table for the mediation analyses for 6 month follow-up data.

Effect	<i>B</i>	95% Confidence Interval		
		<i>Std. Error</i>	<i>Lower</i>	<i>Upper</i>
6 Month Model 1				
Direct Effects (path a)				
KSSTotal → SERS	-0.03***	0.01	-0.05	-0.02
KSSTotal → BHS	0.17**	0.05	0.06	0.27
Direct Effects (path b)				
SERS → QPR	3.42*	1.65	0.11	6.74
BHS → QPR	-0.56	0.29	-1.15	0.04
SERS → N4	-0.42*	0.19	-0.79	-0.04
BHS → N4	0.02	0.03	-0.05	0.08
Direct Effects (path c')				
KSSTotal → QPR	-0.12	0.09	-0.30	0.07
KSSTotal → N4	0.01	0.01	-0.01	0.03
Specific Indirect Effects of Stigma				
KSSTotal → SERS → QPR	-0.12	0.09	-0.36	0.01
KSSTotal → BHS → QPR	-0.09	0.06	-0.23	0.00
KSSTotal → SERS → N4	0.01*	0.01	0.00	0.04
KSSTotal → BHS → N4	0.00	0.01	-0.01	0.02
6 Month Model 2				
Direct Effects (path a)				
Discrimination → SERS	-0.07***	0.02	-0.11	-0.04
Discrimination → BHS	0.34**	0.11	0.13	0.56
Disclosure → SERS	0.00	0.02	-0.03	0.04
Disclosure → BHS	0.02	0.10	-0.19	0.23
Direct Effects (path b)				
SERS → QPR	3.70*	1.69	0.30	7.11
BHS → QPR	-0.56	0.30	-1.16	0.04
SERS → N4	-0.47*	0.19	-0.85	-0.09
BHS → N4	0.02	0.03	-0.05	0.04
Direct Effects (path c')				
Discrimination → QPR	-0.04	0.20	-0.44	0.37
Disclosure → QPR	-0.19	0.17	-0.53	0.16
Discrimination → N4	-0.01	0.02	-0.05	0.04
Disclosure → N4	0.03	0.01	-0.01	0.07
Specific Indirect Effects of Stigma				
Discrimination → SERS → QPR	-0.27	0.17	-0.73	-0.03
Discrimination → BHS → QPR	-0.19	0.13	-0.51	0.03
Disclosure → SERS → QPR	0.01	0.06	-0.12	0.14
Disclosure → BHS → QPR	-0.01	0.07	-0.17	0.12
Discrimination → SERS → N4	0.03*	0.01	0.01	0.07

Discrimination → BHS → N4	0.01	0.01	-0.02	0.03
Disclosure → SERS → N4	-0.00	0.01	-0.01	0.02
Disclosure → BHS → N4	0.00	0.00	-0.01	0.02

Note: QPR = Subjective recovery (at six month follow-up), KSSTotal = Total stigma score, Discrimination = KSS discrimination sub-scale, Disclosure = KSS disclosure sub-scale, SERS = Self-esteem, BHS = Hopelessness. *p≤.05, **p≤.01, ***p≤.001.