The stigma of psychosis: lived experience, psychological consequences and strategies to overcome stigma

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Contents

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List of abbreviations

ACTION: Assessment of Cognitive Therapy Instead of Neuroleptics

ANCOVA: Analysis of Covariance

ARMS: At Risk Mental State

BDI-PC: Beck Depression Inventory – Primary Care

BLIPS: Brief Limited Intermittent Psychotic Symptoms

CAMI: Community Attitudes towards Mental Illness

CAARMS: Comprehensive Assessment of Mental Illness Scale

CAQ: Corrigan's Attribution Questionnaire

CI: Confidence Interval

CBT: Cognitive Behavioural Therapy

CFT: Compassion Focussed Therapy

CONSORT: Consolidated Standards of Reporting Trials

DH: Department of Health

DSM: Diagnostic Statistical Manual

DUP: Duration of Untreated Psychosis

EDIE: Early Detection and Intervention Evaluation

EIS: Early Intervention Service

EPD: Early Psychosis Declaration

IEPA: International Early Psychosis Association

ICD: International Classification of Disease

IPA: Interpretative Phenomenological Analysis

IS: Internalised Stereotypes

MDD: Major Depressive Disorder

NAE: Negative Appraisal of Experiences

NHS: National Health Service

NICE: National Institute for Clinical Excellence

NIHR: National Institute for Health Research

NHS: National Health Service

OPI: Opinion of Mental Illness

PANSS: Positive and Negative Syndrome Scale

PBEQ: Personal Beliefs about Experiences Questionnaire

PBIQ: Personal Beliefs about Illness Questionnaire

PCA: Principle Component Analysis

PPD: Post Psychotic Depression

PRU: Psychosis Research Unit

RCT: Randomised Controlled Trial

SAE: Social Acceptance of Experiences

SD: Standard Deviation

SIAS: Social Interaction Anxiety Scale

SSMI: Self Stigma of Mental Illness

SS: Self Stigma

SURG: Service User Reference Group

TAU: Treatment as Usual

WHO: World Health Organisation

WPA: World Psychiatric Association

Abstract

The University of Manchester
Candidate: Melissa Wardle
A thesis submitted to the University of Manchester for the degree of Doctor of
Philosophy in the Faculty of Medical and Human sciences in September 2013
Thesis title: The stigma of psychosis: lived experience, psychological consequences
and strategies to overcome stigma

This thesis explored how psychosis stigma affects the psychological wellbeing of
young people at risk of psychosis and people with psychosis. The efficacy of
psychosocial methods to reduce stigma in young people were explored. Multiple
methods were used including qualitative, cross sectional, longitudinal and a
randomsied controlled trial. Chapter 1 included a comprehensive review of the
literature on stigma. Chapter 2 provided a review of the methodology used
throughout the thesis. Study 1 (Chapter 3) examined the subjective experience of
psychosis using Interpretative Phenomenological Analysis. Three super ordinate
themes of judgment, disclosure and psychological distress were identified. Analysis
of the data suggested a directional relationship between the themes with societal
judgments, affecting issues of disclosure and judgment and disclosure issues
increasing psychological distress. Possible exits from distress were suggested. Study
2 (Chapter 4) explored relationships between internalised stereotypes (IS) of
psychosis and emotional dysfunction in people at risk of developing psychosis.
Correlational analyses indicated significant relationships between IS, depression,
social anxiety, and distress. Multiple regression analyses indicated that baseline IS
predicted depression at follow up. Results suggested that IS may increase
psychological distress and in particular depression in young people at risk of
psychosis. Study 3 (Chapter 5) explored relationships between IS and emotional
dysfunction in people with psychosis not taking antipsychotic medication. The
findings revealed significant positive relationships between IS, depression and social
anxiety. Multiple regression analysis suggested that baseline IS predicted depression
at follow-up but this did not remain significant when controlling for baseline
depression. These results replicate the findings of previous research carried out in
other psychosis populations. Study 4 (Chapter 6) explored differences in the level of
IS and the strength of relationship between IS and emotional dysfunction, between
those at risk of psychosis and those with psychosis. Results of the cross sectional
analysis indicated no significant differences between the groups on level of IS or on
the strength of correlation between IS and emotional dysfunction. This interesting
find suggests that young people at risk of psychosis may be internalising stereotypes
early and before official diagnostic labels are applied. Study 5 (Chapter 7) examined
the efficacy of internet based anti-stigma interventions for young people. Results
indicated a non-significant trend towards reduction in stigma, immediately post
intervention for the contact and psychosocial educational conditions, however
superiority over control was not demonstrated. Findings indicated that internet based
interventions for this group should be brief and ensure maximum engagement. This
thesis has demonstrated that stigma affects the wellbeing of people whose
experiences exist along the psychosis continuum. Research is required to better
understand the feasibility and efficacy of clinical and mass media interventions to
reduce the negative effects of stigma in people with psychosis and the public.

Declaration

Data

Data for Study 2 was collected as part of the Early Detection and Intervention Evaluation Trial (EDIE2) prior to the commencement of the current programme of work and were then subject to analysis by the author. Data for Study 3 was collected as part of the Assessment of Cognitive Therapy Instead of Neuroleptics Trial (ACTION) and the author was responsible for the management of the trial and contributed to data collection through management of recruitment strategy and supervision of research assistants. The author was independently responsible for the design, analysis and write up of Studies 2 and 3.

Published work

This thesis is submitted in alternative format (with five papers). Study 1 has been accepted at *Psychosis: Psychological, Social and Integrative Approaches*. Study 2 has been accepted at *Early Intervention in Psychosis*. Study 3 has received reviews from *Psychosis: Psychological, Social and Integrative Approaches* and revisions have been submitted. Study 4 is under review at *Psychiatry Research*. Study 5 is under review at *Stigma, Research and Action*. For the purpose of this thesis references and numberings are presented in a consistent manner. The thesis has been submitted in the author's maiden name of Wardle. However, the papers have been submitted to the above journals in the authors married name of Pyle.

Collaborators and authorship

Supervision regarding the development, analysis and conduct of the studies presented herein has been supervised by Professor Anthony P Morrison and therefore he is listed as an author on each paper. Studies 2 and 3 were conducted as

part of the EDIE 2 and ACTION trial and therefore researchers who were involved in the design and management of EDIE 2 and ACTION were included as co-authors on these papers,

Analysis and write up
The data analyses and writing required for each of the papers presented herein have been carried out by the candidate, under the supervision of Professor Anthony P Morrison.

No portion of the work referred to in the thesis has been submitted in support of an application for another degree or qualification of this or any other university of other institute.

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Acknowledgements

The Author

I started work in the National Health Service in 2005 delivering low intensity cognitive behaviour interventions to people with depression and anxiety. When an opportunity arose to work in the area of psychosis I was fortunate enough to acquire a position in 2006 as a research assistant on the Early Detection and Intervention Trial (EDIE 2). In 2009 I started a new position as trial manager for a randomised controlled trial (RCT) of Cognitive Behaviour Therapy (CBT) for people with psychosis not taking antipsychotic medication (ACTION), which I continued through the remainder of the PhD registration. I am now working as trial manager on a multi-site RCT of CBT for people whose symptoms of psychosis have shown little improvement on Clozapine (FOCUS).

Chapter 1: Literature review

Social psychologists, sociologists and clinical psychologists have researched stigma for decades; often the work of Goffman (1963) and Allport (1959) are seen as the founding research in this area. Researchers have asked questions about the social and psychological processes which drive stigma. They have defined attitudes towards numerous stigmatised conditions and explored the prevalence of stigma from the perspective of the stigmatiser and the stigmatised, and they have sought to investigate strategies to reduce stigma in the public.

The intention of this literature review is to firstly provide the reader with a comprehensive summary of the generic stigma literature, with a particular focus on defining stigma and the key psychological and social processes involved in stigma formation and maintenance. Secondly, as the focus of this thesis is stigma associated with psychosis, the current research in this area will be comprehensively reviewed. Specifically, attention will be paid to the phenomenon of internalised stigma and the consequences of internalised stigma for people across psychosis populations. Thirdly, the research into stigma reduction strategies with the public will be outlined and the methodologies used to reduce psychosis stigma will be critiqued.

Whilst the stigma literature is vast and it pertains to a wide range of stigmatised traits the focus herein will be stigma related to mental health problems and more specifically to psychosis. However, as conceptualisations of mental health stigma have been influenced by the stigma of other conditions, traits or difficulties, these will be considered where appropriate.

Finally, aims of this thesis, which have been generated from the review of the literature presented herein, will be detailed. Specific hypotheses for each of the studies detailed in this thesis will be presented within the individual chapters.

1.2 Defining key stigma concepts

As the literature on stigma has developed and expanded across disciplines, so too has the number of terms associated with it and also the number of definitions offered (Rose, Thornicroft, Pinfold, & Kassam., 2007). The purpose of this section is to provide the reader with an overview of the key terms and concepts used in the stigma literature to frame the work presented throughout this thesis.

1.2.1 Erving Goffman's Stigma Theory

Stigma involves both social and individual psychological processes and it is argued that stigma is specific to the societal structures in existence at any one time in history (Major & O'Brien, 2005). Erving Goffman (1963) was one of the earliest writers on the topic of stigma and his stigma theory is still frequently cited in the stigma literature (Byrne, 2001; Major & O'Brien, 2005). In his Stigma Theory Goffman (1963) postulates that stigma is the association of a negative attribute with a 'sign', which distinguishes a person and this could be their race, gender or religion (Goffman, 1963). This 'sign' may be visible on contact, for example a person's gender, or it may be less visible, for example a label of a physical or mental health problem (Phelan, Link, Stueve, & Pescosolido, 2000). Goffman's theory of stigma contends that when associations are made between a negative attribute and a sign the result is that the group becomes disqualified from society. Moreover, Goffman (1963) posits that the process of separating people into groups based on a sign is

reinforced by a set of beliefs, or a 'stigma theory' (Goffman, 1963). As noted above, in his stigma theory Goffman (1963) makes a distinction between visible and invisible stigmas and he refers to those with visual stigmas as being discredited because the stigma is instant due to the visual nature of the sign. However, if a sign is invisible this is described as a discreditable stigma because separation from society may not occur unless the stigmatised trait becomes exposed (Goffman, 1963).

Whilst frequently cited in the literature it has been argued by some that that language used in Goffman's (1963) stigma theory is suggestive that the responsibility of the stigma lies with the stigmatised rather than the stigmatiser (Link & Phelan, 2001). More recent conceptualisations of stigma have refined the terminology used in relation to stigma, as shall be discussed below.

1.2.2 The Social Cognitive Model of Stigma

Drawing on some of the concepts from Goffman's work, the social cognitive model of stigma provides an overarching framework to understand the individual psychological processes involved in stigma formation in context of wider social influences.

In their initial formulation, Link and Phelan (2001) outlined stigma as a system of three interrelated components representing cognitive and behavioural domains. In this model, stigma is conceptualised as labelling (cognitive domain), stereotyping (cognitive domain), separation (behavioural domain) and loss of status/ discrimination (behavioural domain). In a later edition of this model emotional reactions were added to the formulation of stigma (Link, Yang, Phelan, & Collins, 2004). In addition, Link and Phelan (2001) argue that social structures and institutions play a central role in allowing these psychological processes involved in

stigma to occur (Link & Phelan, 2001). Each component will be considered in more detail.

1.2.2.1 Labelling

Labels are conceived of as structures used by humans to distinguish one person from another and dominant social and cultural ideologies are considered to shape labels, defining which are important to humans at any given time in history (Link & Phelan, 2001; Link & Phelan, 1999). Whilst labelling is often a functional process required by humans to define and categorise information, labels can also denote derogatory information about another person (Link & Phelan, 1999). Here, we can see some similarities between the concept of a label and the concept of the 'sign' which Goffman (1963) proposed as a central component as his stigma theory. However, Link and Phelan (2001) argue that the distinction between a label and a sign proposed in Goffman's theory is that a label is applied to the stigmatised individual by others and is not an inherent part of them (Link & Phelan, 2001). Labelling theory (Scheff, 1974) and modified labelling theory (Link, Cullen, Struening, Shrout, & DHrewend, 1989), both address the consequences of mental health labels, and will be reviewed in more detail below in section 1.5.2.

1.2.2.2 Stereotyping

In their conceptualisation of stigma, Link and Phelan (2001) attest to the importance of the work carried out by Goffman in shaping the concept of stereotyping. Stereotypes are understood to be a set of often negative beliefs which are perceived to be true about a stigmatised group and as a consequence these are applied to all members of the group not taking into account idiosyncrasies (Biernat & Dovidio, 2003). Experimental research has indicated that stereotyping is an

automatic cognitive process, allowing for rapid categorisation of information about others. This information is then used to make decisions, preserving capacity for other tasks (Crandall, 2000; Fiske, 1993; Hamilton & Sherman, 1994). Research has indicated that stereotypes can often serve several functional roles for humans including social categorisation, justification for the treatment of out groups, maintenance of the status quo in a group and to avoid threat (Biernat and Dovidio, 2003), see section 1.3.1 for a full discussion.

In relation to mental health stigma, research has demonstrated that the public endorse many misunderstandings about mental health problems (Gaebel, Baumann, Witte, & Zaeske, 2002). Knowledge about mental health has been highlighted as a casual factor in stereotype formation. Thornicroft (2007) includes problems of knowledge in his three part definition of stigma (Thornicroft, 2007). An important debate in the literature in relation to knowledge and stereotypes exists in respect to the type of knowledge which contributes to stereotypes and which can dispel stereotypes (Read & Haslam, 2004). Often, knowledge has been associated with the term 'mental health literacy', with some research indicating that younger people and women have more accurate knowledge of mental health or better mental health 'literacy' (Jorm, Korten, Jacomb, Christensen, & Henderson, 1999; Lauber, Nordt, Sartorius, Falcato, & Rossler, 1999). However, it should be noted that the term 'mental health literacy' essential represents a biogenetic paradigm to mental health stigma reduction (Read & Haslam, 2004). This term was developed by Jorm et al (1999) to refer to the public's ability to recognise and classify symptoms of mental health problems into diagnostic categories. Furthermore, the term also refers to the public's ability to recognise causes of mental health problems and understanding of medicalised interventions. Jorm et al (1999) carried out research to identify the

extent to which the public could accurately classify symptoms of mental health problems and beliefs about appropriate interventions found that 23% of their sample of the general public rated antipsychotic medication as helpful for a person with symptoms of schizophrenia and interestingly, the sample rated non-clinical interventions as the most helpful. However, the conclusions drawn by the researchers from these findings were (1999) the public needed educating about diagnosis and the effectiveness of medications to 'improve' their knowledge (Jorm et al, 1999). As will be discussed in more detail in section 1.7.1 and 1.72, current research indicates that rather than being helpful in reducing stigma biogenetic perspectives which include classifying mental health problems and promoting the biological causal models of mental health problems can increase stigma (Kvaale, Haslam & Gottdiener, 2013).It has been argued by some, that stigmatisation can take place in the absence of stereotyping; for people whose stigma is idiosyncratic, for example a facial disfigurement, wider culturally accepted stereotypes are rare (Biernat & Dovidio, 2003).

1.2.2.3 Separation

The third component to stigma in the social cognitive model, which is highlighted by both Goffman (1963) and Link & Phelan (2001) is the separation of people in to 'us' (the stigmatiser) and 'them' (the stigmatised) groups based on the labels and stereotypes ascribed to them (Goffman, 1963). Separation of people into 'us' and 'them' groups is thought to make it easier to apply derogatory labels to the stigmatised group, because they are no longer part of the in-group's society (Link & Phelan, 2001). Goffman reflected on this separation, considering those who are targets of stigma to be the 'stigmatised' and those are not are considered to be 'normal' (Goffman, 1963). Thus, a separation of the human species can occur on the

basis of labels and stereotypes. Link and Phelan (2001) suggest that the language used to separate out stigmatised groups is very important; for example, people who have a condition that is not stigmatised are not defined by that condition, someone with cancer is not a 'canceric'. Those whose conditions are stigmatised are referred to as if that condition defines them; for example, in relation to mental health people with schizophrenia are often described as schizophrenics rather than a person with experience of schizophrenia. As noted, separation is very closely linked with the ideology about another person or group, which labelling and stereotypes can create and is closely related to the act of discrimination.

1.2.2.4 Discrimination

Link and Phelan (2001) consider the results of labelling, stereotyping and separation to be a loss of status within society and discrimination, which ultimately can lead to a downward drift through social hierarchy. In relation to gender and race stigma, experimental research has demonstrated that both gender and race shape social hierarchy in a group when people are unfamiliar with each other (Mullen, Rozell, & Johnson, 1996; Mullen, Salas, & Driskell, 1989). However, discrimination (the active behavioural component resulting from stigma), does not always occur when labels and stereotypes are applied to another group (Crocker, Major, & Steele, 1998). As outlined in more detail below, discrimination has been demonstrated to affect numerous aspects of life including getting and keeping a job (Stanley & Maxwell., 2004), obtaining insurance (Thornicroft, 2007), and within health care (González-Torres, Oraa, Arístegui, Fernández-Rivas, & Guimon, 2007). Traditionally discrimination has been considered to refer to the active behavioural component of stigma (Corrigan, Markowitz, Watson, Rowan & Kubiak., 2003; Link & Phelan., 2001). However, more recently the term has been used to refer to the

cognitive, emotional and behavioural aspects of stigma (Campbell, Byrne & Morrison., 2013), as it has been argued that the term stigma places an emphasis on the person who is the target of stigma and individualising a social problem (Campbell et al., 2013). Of note, the term stigma has been adopted in this thesis, in order to provide some cross referencing with the existing literature. The author however, states that their perspective of stigma is not one which individualises the problem of stigma; rather, the author considers stigma to derive from social processes and misinterpretations instead of as a result of the individual or group who is the target of stigma.

1.2.2.5 Emotional reactions

As noted above, emotional reactions were not an original component of Link and Phelan's (2001) conceptualisation of stigma. Added later, emotional reactions are considered to be experienced by both the stigmatiser and the stigmatised (Link et al., 2004). Research suggests that type of discrimination is related to the emotion associated with the attitude. Emotions of anger are known to lead to aggression (Weiner, 1995) and fear is known to lead to increased social distance (Corrigan, Kerr & Knudsen., 2005). A common emotional reaction experienced by both those who stigmatise and those who are stigmatised is fear, which occurs as an innate reaction to threat felt from another individual or group (Stangor & Crandall, 2000). Research has highlighted that shame is also a common reaction to stigma (Dinos, Steven, Serfaty, 2004) and people report feelings of shame or embarrassment because of the stigma which a trait, condition or experience carries. As a common reaction to the stigma of mental health problems, shame and issues of social rank will be explored in more detail in the proceeding section.

1.2.2.6 Shame, social rank theory and stigma

Shame has been described as external when an individual is concerned about how others perceive them in regards to their social status and attractiveness (Gilbert, 2000). Internal when the individual appraises themselves to be socially undesirable, bad or flawed in some way (Gilbert, 2000). Social rank theory postulates that social hierarchy revolves around a desire to gain and maintain an attractive status within the social world and when individuals or groups are perceived to have traits which are not considered attractive the result is that they become lower in social rank (Gilbert, 2000). Emotional reactions to lowered social rank include external and internal shame, and emotional dysfunction. Moreover, shame and emotional dysfunction have been shown to occur as a response to major life events that are 'depressogenic' because they result in a loss of social rank (Gilbert, 1992; Rooke & Birchwood, 1998). There are some similar distinctions which can be made between social rank theory and the social cognitive model of stigma; in particular the negative appraisal of a group, resulting in a split from society and the development of emotions such as shame, fear and embarrassment. However, social rank theory further explores the origin of these processes framing them an evolutionary paradigm, which will be further explored in section 1.3.2.

1.2.3 Summarising key stigma terms and concepts

The terminology used in the social cognitive model of stigma is frequently used in the stigma literature. However, it should be noted that the term prejudice is also frequently used and this may lead the reader to wonder what differences exist between the term prejudice and other terms used in Goffman's (1963) Stigma Theory and Link and Phelan's (2001) Social Cognitive Model of Stigma. First proposed by

Allport (1959) in his work on racial stigma, prejudice is also considered to be a cognitive and emotional process. Allport (1954) defines prejudice as emotions of antipathy based on faulty information (Allport, 1954). Similarly to Goffman (1963) and Link & Phelan (2001), Allport (1954) also suggests that the basis of negative emotions to another group is based on faulty or inaccurate information. However, separate literatures have developed around the terms stigma and prejudice and it has been suggested that in part, this may be the reason why the term stigma has evaded a clear definition (Phelan, Link, & Dovidio, 2008; Rose et al., 2007). More recently the terms stigma, prejudice and discrimination have been used together in the same literature and research texts (Heatherton, Kleck, Hebl, & Hull, 2000; Phelan, et al., 2008). Whilst the use of different terms in the literature may be confusing, an interesting study which reviewed similarities in 18 key models of stigma and prejudice found that the term stigma and prejudice have much in common and that they essentially represent the same concept (Phelan et al., 2008).

More recently, it has been argued that stigma is best seen as an umbrella term encompassing three problems reflecting cognitive, affective and behavioural domains of the social cognitive models of stigma (Thornicroft, 2007). These are defined as problems of knowledge including stereotypes, problems of attitude including prejudice and problems of behaviour including discrimination (Thornicroft, 2007)

Whilst it is clear that there are a number of terms relating to stigma and that many of these overlap, the central concepts which will be considered in this thesis are stereotyping and the emotional consequences of stigma. The social cognitive model of stigma is therefore relevant theory upon which much of this thesis is based.

1.3 Causes of stigma

1.3.1 Social constructs, norms and social institutions

The models outlined above describe the cognitive, behavioural and emotional processes involved in stigma. These theories also acknowledge the social and cultural factors that shape labels and stereotypes applied by members of society to certain groups. However, these models do not outline why certain groups are at any one time appraised negatively and, therefore, why negative emotions and behaviours towards them are displayed. In order to better understand what causes these processes to occur, several key models are outlined and reviewed in this section.

Social psychologists agree that stigma is a social construct (Arboleda-Florez, 2005; Major & O'Brien, 2005). Interestingly, in relation to mental health problems, there is across cultural variety in what is considered to be indicative of a mental health problem (Bentall, 2003) and experiences which are defined in western society as a sign of a mental health problem are considered in some cultures to be part of the normal range of experiences (Bentall, 1993; 2003). Moreover, some experiences such as hearing a voice is, in some cultures, considered to be positive and may be used in ritual practice or to connect to ancestors (Bentall, 1993). However, whilst cultures apply stigmas to mental health problems in varying ways, research indicates that in general mental health problems are stigmatised to some extent across the globe (Thornicroft, 2007), with stereotypes of mental health problems varying from lacking in will power (Alem, Jacobsson, Araya, Kebede, & Kullgren, 1999; Dietrich, Heider, Matschinger, & Angermeyer., 2004; Ozmen, Ogel, Aker, Sagduyu, Tamar & Baratau., 2004) to demon possession (Cheetham & Cheetham, 1976; Kirmayer, Fletcher, & Boothroyd, 1997). In the west particulalrly common stigmas of

psychosis, include dangerousness and unpredictability (Angermeyer, Dietrich, Pott, & Matschinger, 2005).

Anthropologists have argued that understanding the social norms and cultural values that shape stigma is essential to developing a full understanding of stigma (Kleinman & Hall-Clifford, 2009). Indeed, Goffman (1963) notes that a central feature of stigma is a shared social consensus or a 'stigma ideology' (Goffman, 1963), which justifies a stigma. In relation to mental health, Scheff (1974) has argued that social norms are an important factor in determined who is part of a stigmatised group. Social norms, which can be defined as what we think others would approve of and what others would do (Norman, Sorrentino, Windell, & Manchanda, 2008), have been shown to be related to stigma in a number of contexts. Social norms and conformity to these norms have been demonstrated to be associated with stigma in relation to mental health (Norman et al., 2008; Terry & Hogg., 1996). In research carried out with a student population, Crandall, Eshleman & O'Brien (2000) found that perceived norms regarding the acceptability of expressing negative attitudes towards a group were highly correlated with actual expression of stigma, suggesting that we are more likely to stigmatise groups of people for whom it is socially the norm to treat negatively. There is a relationship between social norms and intended behaviours towards a stigmatised group with research demonstrating that social norms mediate the relationship between attitudes and intended behaviours (Terry & Hogg., 1996). More specifically, in relation to mental health problems it has been demonstrated that social norms are related to social distance from people with depression and schizophrenia in particular (Norman et al., 2008). Endorsing the belief that schziophrenia is socially inappropriate and that it is the norm to desire social distance from people with a diagnosis of

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schizophrenia was found to significant predict social distance (Norman et al., 2008). The research on norms suggests that, in part, stigma is made acceptable by the shared social consensus that it is acceptable and appropriate to behave in a discriminatory fashion towards certain groups. Stigma has been considered to be a form of norm enforcement (Phelan et al., 2008).

Stigma is therefore considered to be influenced by social, political and economic conditions that drive society and social norms (Terry & Hogg., 1996). Institutional and structural models of stigma provide an overview of the social structures which promote social acceptance of stigma. Institutional stigma refers to forces within society that intend to cause stigma and structural refers to those which unintentionally result in stigma (Corrigan, Watson, Gracia, Slopen, Rasinski & Hall., 2005). Structural stigma can be hard to define and is often more subtle than institutional stigma; for example, the placing of mental health hospitals in isolated areas away from society has been argued to be a form of structural stigma (Link & Phelan, 2006). However, the portrayal of those with mental health problems in the media is one of the clearest examples of structural stigma (Corrigan, Watson, et al., 2005). Mass media is a body of information that contributes to how we perceive and understand the world including our perceptions of mental health problems (Anderson, 1997). Although the media may not intend to contribute to the stigma of mental health problems, they inadvertently do through the negative images that they promote (Corrigan, Watson, et al., 2005).

The media has been referred to as one of the most potent forms of structural discrimination (Thornicroft, 2007) and there is consistent evidence from studies conducted across the world that the images of mental health portrayed in the media, including newspapers, films and television programmes, are often negative

(Thornicroft, 2007). Those with mental health problems, in particular those with psychosis, are often stereotyped in the media as dangerous (Corrigan, Watson, et al., 2005; Coverdale, Nairn, & Claasen, 2002). An evaluation of 600 media stories relating to mental health in New Zealand newspapers found that over half stereotyped people with mental health problems as dangerous to others (Coverdale, et al., 2002). Additionally, themes of criminality, unpredictability and danger to self were also identified (Coverdale, et al., 2002). A UK study that looked at the attitudes of the public towards people with a diagnosis of psychosis, following a real incident of a violent crime carried out by a person with a diagnosis of psychosis found that selective reporting of this incident had impacted upon the publics' endorsement of stereotypes of danger and criminality (Appleby & Wessely, 1988).

Another form of mass media that has been investigated in relation to stigma, and in particular mental health stigma, is television. A cross sectional study of the German public, found significant positive relationships between television consumption and negative attitudes towards people with psychosis (Angermeyer, et al., 2005). Although the results of this study cannot indicate causality, findings do suggest a strong relationship between the two factors (Angermeyer, et al., 2005). The depiction of people with mental health problems as violent has been found to be the same on television as in newspapers; that is around half to three quarters are related to violence (Thornicroft, 2007). In summary, evidence suggests that negative images of people with mental health problems are persistent in the media (Angermeyer, et al., 2005; Angermeyer & Matschinger, 1996b; Lawrie, 2000) and that it is an important source of information on which we base our attitudes and emotions (Yankelovich, 1990), contributing significantly to structural stigma and discrimination.

The internet is a readily available media source for many people, with estimates of more than 90% of young people in American using the internet (Burns, Durkin, Nicholas, 2009). More specifically in relation to people who experience mental health problems, findings from a UK study indicated that 31.5% were accessing the internet specifically for information on mental health (Powell & Clarke, 2006). Whilst the internet is an important and accessible source of information in modern society there is a risk that some information hosted on websites about psychosis could increase stigma. Given there is clear association between biogenetic causal modes of psychosis and stigma, a key issue for stigma research is the effect of this type of information on both public and internalised stigma. There is currently limited research evaluating the content of websites of the effects of this information on the public and people with lived experience of psychosis. However, a study carried out by Read (2008) which evaluated the content of 66 websites, which were identified through search term 'schizophrenia' in two search engines (Google and Yahoo) found that 58% of the websites were funded through drug companies. Those websites which were funded by drug companies promoted biogenetic causes, medical interventions, statements about psychosis being debilitating, devastating or chronic and associations between non-compliance and violence significantly more than websites which were not funded through drug companies (Read, 2008). More recently, a meta-analysis of drug company funded mental health websites found that 42% of mental health websites were funded by, or received funding from drug companies and that the drug company funded websites were biased towards biogenetic causes of mental health problems (Read & Cain, 2013). The results of this meta-analysis replicate the findings of Read (2008). Clearly, the research carried out by Read (2008) indicates that there is an influence

of funding source on the information offered by websites on the internet. More concerning, is the potential effects of the biogenetic causal models offered on these websites on stigma considering the evidence that a biogenetic perspective increases stigma and discrimination (Magilanon, Read, Sagliocchi, Patalano, Oliverio, 2013). Conversely however, there is a signal that normalising, psychosocial information on the internet may reduce negative appraisals of psychosis (French et al., 2010)

Whilst social norms, structural and institutional models of stigma contribute to our understanding of what causes and maintains stigma, they are unable to provide an explanation for the reasons why one group is stigmatised over another. This will be explored in more detail in the following section.

1.3.2 Functional and motivational models of stigma: threat management and system justification

It has been suggested that as humans have evolved to group living, so too has the functionality of stigma (Neuberg, Dylan, Smith & Asher., 2000). Functional and motivational models examining this assumption will be summarised.

An evolutionary perspective of stigma has been proposed by several researchers (Birchwood et al., 2006; Iqbal et al., 2000; Rooke & Birchwood., 1998; Neuberg et al., 2000; Stangor & Crandall., 2000). Humans exist in groups, and living in groups has been advantageous to us as a species (Neuberg et al., 2000). However, it has been proposed that whilst group living is functional, it can also result in interpretations or misinterpretations that others are threatening to group cohesion in some way (Neuberg et al., 2000). Perceptions of threat seem central to many stigmas and, as discussed above; emotional reactions are a prominent feature of stigma (Link et al., 2004). It has been proposed by Stangor & Crandall (2003) that, at a basic

level, stigma occurs because of a perception of threat to the status quo of a group. In their theory of stigma aetiology, Stangor & Crandall (2003) categorise threats as either tangible, that is threats to health, resources or social positions, or symbolic threats to values, beliefs or ideologies (Stangor & Crandall., 2003). Furthermore, it has been argued that those considered to be different or unusual within society have different values and moral standing (Wilder, 1985). Social rank theory suggests that as part of group living human beings have developed a social hierarchy upon which the acquisition of resources revolves around perceived social attractiveness (Gilbert, 2000). The social attractiveness of an individual can be based on their perceived suitability for providing resources as a sexual partner for reproduction and an alliance. Also, social rank theorists propose that the ranking of people within social structure is based on appraisals of threat and behaviours which manage this threat; for example, exclusion (Fournier, Moskowitz & Zuroff., 2002). Therefore, the social exclusion of a group according to social rank theory is based on threat, acquisition of resources and perceived social attractiveness (Gilbert, 2000). Researchers in the field of psychosis have applied a social rank perspective to understanding the development of depression in people with experience of psychosis. Loss of social role, appraisals of entrapment, perception of oneself as being in a lower social role and humiliation have been associated with depression (Iqbal et al., 2000; Rooke & Birchwood., 2005).

System justification theory suggests that the motivation behind stigma lies in the need to confirm the social system in which we exist (Jost & Banaji, 1994; Jost, Kruglanski, & Simon, 1999; Stangor & Jost, 1997). Stereotypes serve to support the social systems at that time in history and can evolve over time in response to economic and social pressures (Watson, et al., 2003). Those with mental health

problems have often been removed from society being placed in prisons and asylums (Porter, 2002). It has been proposed that this pattern of exclusion leads to the development of stereotypes that people with mental health problems are dangerous, unpredictable and need to be paternalised in order to justify how we provide for those experiencing mental health problems (Corrigan, 2000). System-justification theory accounts for the similarities in the stereotypes of mental health problems that are seen across populations that cannot be accounted for by individual or specific group motivations (Watson, et al., 2003). There is some empirical evidence to support this theory (Hoffman & Hurst, 1990; Jost & Burgess, 2000) however, it has been criticised for being unable to account for the original system motivation that instigated the stigma (Watson, et al., 2003). However, it could be argued that social rank theory may account for the original source of stigma. It is widely accepted that applying a set of characteristics to a group of people allows for easy classification within a social structure (Biernat & Dovidio, 2003) and research has demonstrated that the use of stereotyping in social classification serves to preserve attention resources (Sherman, Macrae, & Bodenhausen, 2000).

1.4 Psychosis and the stigma of psychosis

The stigma of mental health problems is recognised as a prominent problem in society (Arboleda-Florez, 2005; Sayce, 2000; Thornicroft, 2007; Jorm & Wright., 2008; Thornicroft, Brohan, Rose, Sartorius, & Leese., 2009). In the United Kingdom, recent government policy 'No Health without mental health', has identified stigma as one of 6 priorities for the National Health Service (DH., 2011)

In particular, research indicates that psychosis is one of the most stigmatised mental health problems (Angermeyer, Buyantugs, Kenzine, & Matschinger, 2004; Arboleda-Florez, 2005; Thompson, Stuart, Bland, Arboleda-Florez, Warner, &

Dickson., 2002). Results from a recent national survey conducted in Australia of 3746 young people and 2005 parents indicated that those with psychosis and/ or substance abuse are stereotyped as dangerous/unpredictable and elicited the greatest desire for social distance (Jorm & Wright, 2008). The research regarding the stigma of psychosis will be reviewed comprehensively; however, in order to set the context for the research carried out in this thesis, the literature regarding the phenomenology and explanatory models of psychosis are discussed.

1.4.1 Overview of Psychosis

There have been attempts to define the phenomenology of psychosis for over 100 years, with Emil Kraeplin being the first to classify the experiences of hallucinations and delusions into a diagnosable 'disorder' called dementia praecox (Bentall, 2009). The term schizophrenia, however, was first introduced by Eugen Bleuler in 1911 to replace the term 'dementia praecox' with the word schizophrenia meaning a 'split mind'. The notion of splitting was central to the definition introduced by Bleuler and whilst this has been confused with split personality the intention of Bleuler was to capture the splitting of psychic functions which included affect and dissociation (Moskowitz & Heim, 2013). Today, psychiatric classification systems are often used to classify and diagnoses symptoms into a specific psychotic 'disorder'. In Europe the ICD-10 includes a number of psychotic disorders including schizophrenia, schizoaffective disorder and delusion disorder.

It is typically agreed that psychosis is characterised by both positive and negative symptoms. Positive symptoms are so called because historically they have been considered not to be found in the 'normal population' and so these are an 'addition'. The debate over whether positive symptoms are found in the general population is discussed in more detail below. Negative symptoms, which were

introduced as a concept by Crow in England in 1980 and Andreasen in the United States of America in 1982, are considered to represent the absence of features found in the 'normal' population and, therefore, called negative (Andreasen, 1982). What is particularly interesting about psychosis is the heterogeneity of symptoms. Positive symptoms, are conceived of as either unusual perceptual experiences, commonly referred to as hallucinations; unusual beliefs which are often referred to as delusions (Johns & van Os, 2001); or, thought disorder, which can be defined as abornalities in written or spoken communication. Hallucinations may be changes to auditory, visual, olfactory, gustatory or tactile senses and often auditory hallucinations are described as 'a voice' that another person cannot hear. This experience of hearing a voice when someone else is not present is a common experience in psychosis (Bentall, 1993). Delusions are beliefs which are considered to be 'unusual' as they are considered to be removed from a shared reality with society; these may include beliefs regarding persecution, thought insertion or ideas of grandeur (Bentall, 1993). The positive symptoms of psychosis are often those which lead a person to seek help and be brought to the attention of mental health services (Andreasen, 1995). Negative symptoms include blunted affect, anhedonia, alogia and avolition (Andreasen, 1995).

Psychosis typically occurs in young adults and the age of onset appears to be higher for women, with the mean age estimated at 37 years of age for women and 29 years of age for men (Davies & Drummond, 1994). Prevalence rates for psychosis vary in the UK between 4.8 – 22.6 per 100,000 and the variation in incidence rates are likely to reflect variation across geographical regions with incidence rates of schizophrenia differing between parts of the UK (Goldner, Hsu, Waraich, & Somers, 2002). Psychosis has been associated with significant personal, social and economic

costs and accounting for a large proportion of the NHS budget in the UK (Mangalore & Knapp, 2007). Therefore, treating psychosis has been identified as a national and international priority. A consensus statement from the International Early Psychosis Association (IEPA), endorsed by the World Health Organisation (WHO) sets standards and goals for the early intervention, detection and treatment of psychosis (Bertolote & McGorry, 2005). The objectives of the Early Psychosis Declaration (EPD) were to challenge stigma of psychosis, promote recovery orientated approaches, and raise awareness about the importance of early detection and intervention and to include a wide range of agencies in the area of health, social and education to contribute and support people with experiences of psychosis (Bertolote & McGorry, 2005). As noted, a primary focus of the EPD was to reduce stigma and discrimination associated with psychosis and it was suggested that this could be achieved by targeting young people with educational campaigns and programmes to raise awareness about psychosis (Bertolote & McGorry, 2005).

As noted above, psychotic 'disorders' have typically been identified using classification systems; however, there has been debate regarding the validity and reliability of these systems and it has been demonstrated that often different operational criteria do not diagnose the same patients with schizophrenia (Bentall, 1993). Moreover, it has been argued that research is still needed to test the conceptual and construct validity of psychosis (Jansson & Parnas, 2007). Some have suggested that the approach to classification of psychosis should be dimensional rather than categorical to account for the evidence that psychotic experiences exist within non-clinical samples (Bentall, 1993).

There is some debate in the literature regarding psychosis as a dichotomous entity versus one that exists along a continuum (Johns, et al., 2004; Johns & van Os,

2001; Verdoux & van Os, 2002). One approach in relation to this debate is to consider the cause and distribution of psychosis in the population (Johns & van Os, 2001). It has been put forward that in order for a disorder to be dichotomous, a person would be required to either have the disorder or not (John and van Os, 2001), and it is therefore difficult to apply this concept to psychosis as there are arguably an infinite number of vulnerabilities and stressful life events that may interact to result in a psychotic episode (van Os., 2003). Johns and van Os (2001) propose that the varying degrees and interactions of stressors and vulnerabilities that can cause psychosis would result in different distributions of psychosis traits, with the distribution of psychosis lying somewhere between a truly dichotomous curve and a continuum (Johns and van Os, 2001; van Os, 2003).

A commonly accepted model of psychosis is the vulnerability-stress diathesis model (Zubin & Spring, 1977). According to Zubin & Spring (1977) there may be numerous vulnerabilities, which may be environmental (abuse/ trauma), social/psychological (deprivation) as well as biological that predispose a person to experiencing a psychotic episode and stressful life factors (such as abuse and deprivation) are considered to be factors which can precipitate the onset of a psychotic (Zubin & Spring, 1977).

Further evidence to indicate that psychotic experiences lie along a continuum is incidence of psychotic experiences, not associated with the presence of a psychotic disorder, in the general population (Johns and van Os, 2001; Van Os, 2003; van Os, Hanssen, Bijl, & Ravelli, 2000). In the UK, a survey found that 5.5% of respondents to a National Survey of Psychiatric Morbidity reported one or more psychotic symptoms on a psychosis screening questionnaire (Johns, Cannon, Singleton, Murray et al., 2004). Studies conducted with college student samples have indicated

higher prevalence rates of psychotic experiences in the population with one study reporting 30 – 40% of the sample experiencing hearing a voice (Barrett & Etheridge, 1992). In relation to delusions, Peters, Joseph, Day and Garety (2004) conducted a study investigating the presence of delusions in both healthy controls and psychotic inpatients and found that that the range of scores were similar in both groups suggesting some overlap between psychotic experiences in clinical samples and the normal population (Peters et al., 1996). Furthermore, it is interesting to consider experiences and beliefs reported by new religious movements (NRM) such as spiritualists, Hare Krishna's and Druids. These groups often report beliefs that may be considered to match the definition of a delusion and people who are members of NRM have been shown to score similar to inpatients experiencing psychosis on measures of delusions, however they differed on the level of distress these experiences cause (Peters, Day, McKenna, & Orbach, 1999). It should also be noted that some cultures and societies value hallucinatory experiences and hallucinatory experiences such as hearing a voice exist within these cultures without being viewed as part of psychopathology (Bentall, 1993).

1.4.4 Summary of the biomedical model of psychosis

The biomedical model of psychosis was primarily founded in the nineteenth century by psychiatry and has a complex history. Early emphasis was placed on identifying brain abnormalities in people with psychosis and classification of disorders. In the later decades of the 20th century and into the 21st century, advances in technology and science have been considered to have contributed to the growth of biomedical research making what are considered new advancements possible. Bentall (2009), in the book 'Doctoring the Mind', offers a comprehensive account of psychiatry and

the medical model of psychosis. A summary of the research will be provided here to allow a full discussion of the approaches to psychosis.

A purely biomedical model of psychosis assumes that psychosis (and indeed all mental health problems) arises from biological causes including brain and biochemical abnormalities. Moreover, the purely biological perspective does not account for social and psychological factors in the etiology of psychosis (Engel, 1977).The biomedical approach is also concerned with diagnosing 'disorders' and postulates that mental health problems are dichotomous entities as discussed above i.e. a person either has the 'disorder' or they do not. Typically, on reading papers on biomedical perspectives of psychosis one will find the language of medicine to described people who experience psychosis i.e. their experiences are referred to as a disease, a disorder or an illness.

In particular, the use of drugs to treat mental health problems has significantly contributed to the theoretical basis for psychosis as a biological condition (Bentall, 2009). As antipsychotic drugs act upon specific neurotransmitters in the body and as certain drugs such as amphetamines can result in psychotic experiences, it is therefore argued that the neurotransmitters upon which these drugs interact must play a role in the development of psychosis (Wong & Van Tol., 2003). In particular, as these drugs affect the neurotransmitter dopamine, it has been hypothesised that dopamine plays a role in the etiology of psychosis (Wong & Van Tol., 2003). Whilst there is some evidence that dopamine transmission is higher in people with psychosis in comparison to those without, it has also been argued that this may be a result of treatment with antipsychotic medication and the evidence for the dopamine theory is inconclusive (Wong & van Tol., 2003). In addition to dopamine, other neurotransmitters including Serotonin and Glutamate have been

implicated in development psychosis; again the evidence for both is not conclusive (Wong & van Tol., 2003). Although the action of antipsychotics on neurotransmitters has been an instigator in neuro-chemical explanations of psychosis, recent research has drawn into question the benefits of antipsychotic medication (Morrison, Hutton, Shiers & Turkington., 2012). One Cochrane review found that the antipsychotic Risperidone was only marginally better than placebo (Rattenhalli, Jayarami & Smith., 2010) and meta analyses have indicated that atypical antipsychotics demonstrate only moderate effect over placebo (Leucht, Arbter, Engel, Kissling & David., 2009). In addition, the percentage of missing data in the trials is often high, limiting the conclusions which can be drawn (Leucht et al., 2009).

The biomedical approach to psychosis has sought from its infancy to identify differences in the brains of people with and without psychosis and this has underpinned the hypothesis that psychosis is a degenerative brain disease (Bentall, 2009). A great deal of research time and money has been given to studies analysing brain differences between people with and without a diagnosis of psychosis. For example, one meta-analysis included 58 studies with a total of 1588 people with a diagnosis of schizophrenia. The authors of this meta-analysis concluded that there are global brain differences between people with and without a diagnosis of schizophrenia, in particular lower cerebral and higher ventricular volume (Wright, Rabe-Hesketh, Woodruff, David, Murray & Bullmore., 2000). However, in a recent systematic review carried out by Moncrieffe & Leo (2010) which looked at longitudinal studies of the effects of antipsychotics on global brain structure found that 14 out of 26 studies identified a decline in global or grey matter volume over the course of treatment with antipsychotic medication. The authors concluded that some

of the brain abnormalities which have been identified in psychosis, which the biomedical model has attributed to structural differences caused by the 'disorder', may be a result of treatment with antipsychotics (Moncrieff & Leo., 2010). Morrison, Hutton, Shiers and Turkington (2012), in a recent editorial, argue that the emerging evidence from meta-analyses and systematic reviews on the efficacy and adverse effects of antipsychotics raises the question whether antipsychotics should always be the first line treatment for people with psychosis.

Another avenue of study in the biomedical model of psychosis has been the influence of genes on the development of psychosis, with studies using data from family, twin and adoption studies (Tsuang, 2000; Bentall, 2009). The basic aim of a genetic approach is to determine the extent to which it is caused by our genes and therefore its heritability (Bentall, 2009). In order to identify heritability, genetic research has traditionally used twins to identify concordance rates of psychosis in the pairs; monozygotic twins are genetically identical therefore, one would hypothesise that if a disorder was a result purely of genetics then the trait would be observable in both in 100% of cases and as di-zygotic twins share around 50% of their genetics then you would expect concordance rates to be about 50% (Tsuang, 2000). Research indicates that the concordance rates for monozygotic twins are between 50-70% and between 9-18% for di-zygotic twins (Tandon, Keshavan & Nasrallah., 2008). Data from concordance studies has been used to determine the percentage of variation in psychosis that can be attributable to genes and the heritability of psychosis has been calculated to be around 80% (Tandon et al., 2008). However, as Bentall (2009) notes the statistical calculation used to determine heritability has very important limitations, which results in an over emphasis of the role of genes and an under-emphasis of the important of environmental and gene by environmental factors

(Bentall, 2009). Whilst the heritability of psychosis is often emphasised by the biomedical approach as evidence of the biological roots of psychosis, research has been unable to identify a single gene locus for psychosis and no one gene appears to be necessary for the development of psychosis (Tandon et al., 2008).

1.4.3 Overview of Cognitive Models of Psychosis

A number of cognitive models of psychosis have been proposed and central to these models is the role of psychological processes such as appraisals , attributions and attention in the development and maintenance of hallucinations and delusions (Bentall, Corcoran, Howard, Blackwood, & Kinderman, 2001; Garety, Kuipers, Fowler, Freeman, & Bebbington, 2001; Morrison, 2001).

Bentall, Kinderman & Kaney (1994) have argued that the study of psychopathology can learn from the study of 'normal' psychological processes in people not experiencing mental health problems and in relation to psychosis, research can benefit from focussing on individual symptoms such as delusions of persecution, given the limited validity of schizophrenia (Bentall et al, 1994). In a series of studies and reviews, Bentall et al (1994; 2001) have proposed an integrated model of persecutory delusions with attention biases, external causal attributions of negative events and the resulting influence on self-representations as central to the development and maintenance of persecutory delusions (Bentall, et al, 2001). In two experimental studies Bentall & Kaney (1989) and Kaney, Wolfenden, Dewey & Bentall (1992) demonstrated that participants with persecutory delusions had greater attentional bias towards threat related stimuli than participants with depression or non-clinical controls. In the first study, an emotional stroop test which included threat-related, depression-related, neutral and meaningless strings or words was

completed by participants who had either persecutory delusions, depression or were healthy controls. It was found that the participants with persecutory delusions had a slower response time to naming the threat-related words in comparison to the other groups, indicating an attentional bias to threat related information (Bentall & Kaney, 1994). This has since been replicated in another group of participants who experienced persecutory delusions (Fear, Sharp & Healy, 1996). In a later study conducted by Kaney, et al. (1992) the ability of participants to recall social stories with and without threatening themes was compared across participants with persecutory delusions and participants with depression. It was found that participants who experienced persecutory delusions recalled more of the stories with persecutory themes than controls suggesting an attentional bias to threat related information.

Another central tenent to Bentall et al's (2001) model is attribution processes and the influence of abnormal attributions on persecutory delusions. In a study comparing participants with persecutory delusions to participants with depression, Kaney & Bentall (1989) found that those with depression and those with persecutory delusions both reported excessive stable and global attributions for positive and negative events. However, participants with persecutory delusions differed in the attribution of positive events to internal causes i.e. resulting from the self and attribution of negative events to external causes i.e. others. Bentall et al (1994) suggest that attribution of negative events to external causes may serve as a defensive mechanism to protect self-esteem by minimising the discrepancies between actual-self and ideal-self perceptions (Bentall et al, 1994; Bentall et al, 2001).

The Cognitive Model proposed by Garety et al (2001) integrates research on the continuum of psychotic experiences and bio-psychosocial vulnerabilities to

suggest that the positive symptoms of psychosis arise because of the appraisals which a person attributes to their experiences. Moreover, this model considers psychosis to develop via two routes, the first is via cognitive and affective changes and the second route is through affective changes alone. However, Garety et al. (2001) suggest that processing disruptions and change in affect occur in both routes.

Morrison's (2001) cognitive model of hallucinations and delusions draws on the cognitive model of anxiety disorders, conceptualising delusions and hallucinations as intrusions into awareness that act in a manner similar to intrusions found in anxiety. This model suggests that intrusions into awareness can result in misinterpretations based on faulty social knowledge and self-beliefs. As noted, research indicates that people without a psychiatric history report beliefs that are unusual or delusional in content (Peters, et al., 1999) and describe hearing voices (Barrett & Etheridge, 1992). Morrison (2001) has argued this indicates that psychotic symptoms are essentially normal human experiences that intrude in awareness (Morrison, 2001). Further, the cognitive model of delusions and hallucinations proposes that the difference between psychotic and non-clinical populations is the cultural acceptability of the appraisal or misinterpretation (Morrison, 2001). Unlike psychosis, interpretations made by those who experience anxiety disorders, such as 'I am having a heart attack', are considered culturally acceptable interpretations. In contrast, interpretations reported by people who experience psychosis, such as belief in alien control, persecution from government forces or demonic possession are not considered to be culturally acceptable in western society and are therefore classed as delusional (Morrison, 2001). These interpretations or misinterpretations can then result in distress. In turn intrusions and interpretations are maintained by mood, physiology, cognitive and behavioural responses (Morrison, 2001).

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Morrison (2001) suggests that stigma and the social meanings attached to experiences in psychosis may contribute to the development and maintenance of misinterpretations. There are a number of features in this model which highlight stigma as a factor that can exacerbate distress Social norms of society define what type of belief is considered to be removed from reality and therefore delusional and it is noted by Morrison (2001) that the interpretations made by people who are diagnosed as psychotic are considered 'culturally unacceptable'. Delusions in this sense are a deviation from the social norm of what is an acceptable belief system. In support of this Major & O'Brien (2005) argue that those who are stigmatised are viewed to deviate in some way from the social norm (Major & O'Brien, 2005). Moreover, research indicates that stigma occurs when members of society reject people whose values do not reflect their own (Neuberg et al., 2000). Therefore, the very nature of the interpretations/ beliefs or experiences found in psychosis may place those with psychosis at higher risk of being stigmatised. Morrison (2001) also suggests that individuals experiencing hallucinations or delusions ascribe social meanings such as 'I am going mad' or 'I am going to be locked up' to these experiences. Such beliefs may place an individual with psychosis at risk of internalising social stereotypes attached to the label of psychosis. Morrison's (2001) cognitive model also proposes that limited social relationships may contribute to faulty self and social knowledge, maintaining the culturally 'unacceptable' interpretations of intrusions. As detailed below, stigma can lead to isolation and social exclusion (Thornicroft, 2007) and this may contribute to an absence or decrease in supportive social relations which could challenge faulty self and social knowledge. Therefore, stigma and the absence of social support may exacerbate existing problems in people who experience psychosis. Finally, Morrison (2001)

advocates the benefits of altering public perceptions of psychosis to improve social acceptability, in particular it is suggested that the media is a key target to altering public perceptions (Morrison, 2001).

Both Morrison (2001) and Garety et al. (2001) in their cognitive models of psychosis emphasise emotional processes which can result as a consequence of hallucinations and delusions and contribute to the maintenance of these experiences. Depression and self-esteem are associated with severity and content of hallucinations and distress experienced (Birchwood, Iqbal, & Upthegrove, 2005; Smith, Fowler, Freeman, Bebbington, Basford, Garety, et al., 2006). Research carried out by Birchwood et al (2005) found that appraisals regarding the perceived power of voices and perceived threat from persecutory delusions are associated with depression in psychosis (Birchwood, et al., 2005). In addition, emotional dysfunction experienced by people with psychosis has also been demonstrated to occur in response to factors other than interpretations of delusions and hallucinations including stereotyped cultural beliefs about psychosis (Birchwood, et al., 2005; Birchwood, Mason, MacMillan, & Healy, 1993) and health status or illness appraisals (Lobban, Barrowclough, & Jones, 2004). In particular, research has indicated that beliefs about health status or illness appraisals contribute to depression, anxiety and self-esteem cross-sectionally and over time in people with psychosis (Lobban, et al., 2004). This indicates that emotional difficulties experienced by people with psychosis may in part occur because of illness and stereotyped appraisals of psychosis, furthering the case for better understanding stigma in the area of psychosis and the role stigma may play in exacerbating distress. The research on the stigma of psychosis will be reviewed below, with a closer

inspection of the ways in which stigma can affect the lives of people with psychosis and in particular, playing attention to the impact on emotional dysfunction.

1.4.4 Research into the stigma of psychosis.

As discussed, research indicates that psychosis is one of the most stigmatised mental health problems (Angermeyer & Matschinger, 2003; Arboleda-Florez, 2005; Barney, Griffiths, Jorm, & Christensen, 2006; Gaebel, et al., 2002; Jorm & Wright, 2008). People with psychosis are often stereotyped as dangerous or unpredictable. Of concern, research indicates that the public express desire for social distance from people with psychosis (Angermeyer & Matschinger, 2003; Read & Harré, 2001; Read & Law, 1999). A large survey conducted in Australia with young people and their parents (N = 3746) found that psychosis was rated higher on dimensions of dangerousness, unpredictability and social distance than depression and social anxiety (Jorm & Wright, 2008). In Germany, Gaebel et al (2002) conducted another large telephone survey of the public attitudes towards psychosis (N = 7246) and they also found that the desire for social distance from people with psychosis by the public was high. Interestingly, this study also provided insight into specific dimensions of social distance, finding that the public expressed they would not support the notion of someone with psychosis living in their community, that they would reject a person with psychosis if they offered to look after their child, and that most people would pass over a job application of a person who had experienced psychosis (Gaebel et al., 2002).

The extent to which psychosis is stigmatised has been recognised globally and in 1996, the World Health Organisation launched the global programme against stigma and discrimination because of schizophrenia. In the UK the NICE Guidelines for Schizophrenia (NICE, 2009) prioritise the reduction of stigma and discrimination

and recent government policy in the UK 'No Health Without Mental Health' prioritised stigma as one of six priorities for healthcare in the UK (DH, 2011). Stigma is therefore a national and international concern.

As discussed above, public surveys indicate stigma towards those who experience psychosis. However, there is also evidence that health professionals can stigmatise and discriminate (González-Torres, Oraa, Arístegui, Fernández-Rivas, & Guimon, 2007; Mukherjee, Fialho, Wijetunge, Checinski, & Surgenor, 2002). In a survey study conducted in a London medical teaching hospital, psychosis was one of the most stigmatised mental health problems. Those with experience of psychosis were stereotyped as being dangerous and unpredictable by 50% of the respondents (Mukherjee et al, 2002). Service users who have experience of psychosis have also reported that stigma and discrimination from health professionals is problematic. In one study service users reported that health professionals were the most important group in need of reform (Pinfold, Byrne, & Toulmin, 2005). In a qualitative study (Gonzalez-Torres et al, 2007), the accounts of participants demonstrated direct and indirect stigma from health professionals. In particular, the participants expressed they did not feel they were believed and that they were neglected in relation to physical health problems because of their diagnosis of psychosis (Gonzales-Torres, et al, 2007). Whilst it is apparent that stigma and discrimination towards psychosis exists within the health profession, the extent and context in which it occurs appears to be a complex picture; to conclude that all health professionals stigmatise would be a generalisation that would be an injustice to those who are dedicated to improving the lives of people with psychosis. However, the NICE Guidelines for the treatment of schizophrenia has highlighted the importance of health professionals remaining aware of the stigma of psychosis and the potential role they may play either directly

or indirectly (NICE, 2009). A recent consensus study of experts in the field of cognitive behavioural therapy (CBT) for psychosis indicated agreement that therapists assumptions should be normalising and de-stigmatising and that therapists should believe symptoms of psychosis are common in the population (Morrison & Barratt., 2010).

1.5 Measuring public and personal stigma

The concept of stigma is multifaceted with various social and psychological aspects of stigma in relation to both public stigma and the experiences of those targeted by stigma. A review of the measures will be outlined below, before moving on to discuss the implications of, and interventions for, stigma. In a review of stigma measures, Link, Yang, Phelan and Collins (2004) suggested that researcher should consider four questions before deciding on a measure. The first is whether the measure is based on the research question. The second is whether the measure is suitable for the population. The third is whether the measure is reliable and valid and the fourth is whether using the measure is feasible (Link, et al., 2004).

1.5.1 Measures of public stigma

A great deal of attention has been paid to researching the attitude, emotions and behaviours of the general population towards people with mental health problems (Wahl, 1999). Link et al (2004) provide a detailed review of most of the major studies that have measured mental illness stigma up to 2003. In total, they review 109 empirical studies and 14 literature reviews which included participants from the general public, professionals groups, family members and young people. Studies investigating the stigma and discrimination of mental health problems have generally adopted either a survey, experimental or qualitative design (Link & Phelan, 2004).

Two of the most frequently cited opinion surveys used by researchers to measure the public's attitudes towards people with mental health problems are the Opinions about Mental Illness Scale (OMI) and the Community Attitude Towards the Mentally Ill (CAMI 11). The OMI was developed in by Cohen and Stuening (1962; 1963) from the responses of 1194 psychiatric hospital staff and comprises 70 items. Factor analysis revealed five factors; these are (1) authoritarianism, (2) benevolence, (3) mental hygiene ideology (mental illness as any other illness), (4) social restrictiveness and (5) interpersonal ideology (mental illness arises from interpersonal experiences). A later revision of the measure saw the subscale of mental hygiene ideology dropped from the measure due to insufficient reliability, reducing the number of items to 51. The remaining four factors demonstrated adequate internal consistency reliability (Link et al, 2004). Although developed some decades ago, the OMI has been reported regularly in mental illness stigma studies (Link et al, 2004; Holmes, Corrigan, Williams, Canar, Kubiak, 1999; Corrigan,

Edwards, Green, Diwan & Penn, 2001). The OMI covers a wide range of stigma and discrimination issues that are comparable to models of mental illness stigma (Link et al, 2004). In addition, the OMI has been used for decades and therefore allows the opportunity to assess attitudes over time (Link et al, 2004). However, the OMI was developed during a period in which hospitalisation was the standard treatment for mental health problems. Since this time, deinstitutionalisation has occurred and therefore it is possible that this measure may not be entirely representative of today's community based treatment approach to mental health problems (Link et al, 2004). Furthermore, this measure was developed in consultation with mental health professionals from psychiatric hospitals; as such it may be more representative of the attitudes of psychiatric hospital staff rather than the general public.

In order to develop a measure more reflective of the public's attitudes, Taylor and Dear (1981) developed the CAMI 11, which is a 40 item measure. Factor analysis revealed four factors that relate to mental illness stigma, (1) authoritarianism, (2) benevolence, (3) social restrictiveness and, (4) community mental health ideology. All four factors showed good internal consistency reliability with Cronbach's alpha ranging from 0.68 to 0.88. Further analysis provided strong support for the external validity of the measure (Taylor and Dear, 1981). The CAMI 111, although developed some time ago, has been used recently in mental illness stigma and discrimination research. Pinfold, Toulmin, Thornicroft, Huxley, Farmer & Graham (2003) used a reduced item version in an intervention study aimed at investigating the effects of a psychosocial intervention on police attitudes towards people with mental health problems. In this study the authors selected 12 items from the CAMI 111 that were considered to represent beliefs about interaction, attitude to treatment and view of mental illness (Pinfold et al, 2003). Whilst the CAMI 111 has

demonstrated good psychometric properties and is utilised in current research, it is a measure of attitude towards people with mental health problems and is unable to capture actual behaviour of the respondents towards people with mental health problems, therefore, relationships between attitudes and discrimination are unable to be evaluated. This limitation is not exclusive to the CAMI 111, but is also a limitation of other attitude measures.

Another method to measure mental illness stigma by the public is the use of attribution questionnaires. Corrigan, et al (2003) developed the Corrigan's Attribution Questionnaire (CAQ) to measure aspects of their attribution model of public discrimination towards people with mental health problems. The key concepts measured were controllability and perceived dangerousness of a mental health problem; these concepts were investigated in relation to personal beliefs about people with mental health problems, emotional responses and discriminatory/ helping behaviours (Corrigan et al, 2003). In the main body of the questionnaire there are 21-items rated on a nine-point Likert scale (1=not at all, 9=very much). There are eight factors including responsibility attributions, dangerousness attributions, feeling of pity, fear and anger and behaviours including help, avoidance, and coercion/segregation. All of the subscales (except the dangerousness subscale and avoidance subscale which were not examined in Corrigan et al's 2003 paper) have been found to have high levels of internal consistency (responsibility = 0.70, pity = 0.74, anger = 0.89, fear = 0.96, helping = 0.88, coercion/segregation = 0.89). Unlike the public surveys discussed above (CAMI 111 and OMI), attribution questionnaires are carried out in association with a vignette regarding a man who experiences schizophrenia. There are four versions of this vignette which vary in the degree to which they indicate dangerousness and controllability of psychosis and

participants are allocated one of the four vignettes to read prior to completing the CAQ. However, it should be noted that whilst vignettes are useful tools for investigating the effect of beliefs about causality on mental health stigma and discrimination, they are hypothetical pieces of information and may not represent real world examples of mental health problems.

Social distance is defined as "a willingness to interact with a target person in different types of relationships" (Link et al, 2004). Social distance, and therefore social isolation, can have detrimental psychological, social and relationship consequences for the person experiencing it (Howard, Leese & Thornicroft, 2000). In relation to psychosis, studies indicate that the desire for social distance is high (Gaebel et al, 2002; Jorm & Wright, 2008). Consequently, this aspect of stigma and discrimination is important to measure and as such individual scales have been developed (Link et al, 2004). The earliest measure of social distance was developed in relation to racial/ ethnic stigma and discrimination by Bogardus (1925). This measure was developed over 8 decades ago and a measure of social distance more commonly used today is an adapted version of this scale developed by Link, Cullen, Frank & Wozniak (1987). This scale contains seven items relating to social relationships, including having a person with a mental health problem as a tenant, a co-worker, a neighbour, a member of the same social circle, a person one would recommend for a job, an in-law and a child carer (Link et al, 1987). These seven items are rated on a 5 point Likert scale from 'in any case' to 'in no case at all' in relation to the degree to which they would accept the person presented to them in a vignette. This measure has been used in recent stigma research by Angermeyer & Matschinger (2005) in a trend analysis study conducted in Germany, which investigated the relationship between the public's causal explanations for

schizophrenia and social distance. Other versions of the social distance scale are available. In later research by Link, Phelan, Bresnahan, Stueve & Pescosolido (1999), the social distance scale was reduced to five items; again participants are asked to rate their willingness to, (1) move next door to the person in the vignette, (2) spend an evening socialising with the person, (3) make friends with the person, (4) work closely in a job with the person and (5) have the person marry into the family. This version of the measure has been used in stigma research. For example Jorm & Griffiths (2008) utilised the scale in a survey study conducted in Australia which investigated whether stigmatising attitudes are increased by the use of psychiatric labels and biogenetic causal explanations of mental health problems. In this article Jorm and Griffiths reported good internal consistency reliability of the scale, Cronbach's alpha for the scale as 0.87 (Jorm & Griffiths, 2008). The social distance scale has also been modified for use with young people and their parents. The five original items on the scale were reworded to make them more applicable to young people. The items were changed to, (1) spending time together, (2) going out together at the weekend, (3) working on a project, (4) inviting them to your house and developing a close friendship (Jorm & Grifiths, 2008).

As noted, the above measures have been developed to be used in conjunction with case vignettes and as such can be applied to research investigating social distance from any mental health problem. More specific measures have been developed that measure social distance in the absence of a vignette, for example, in relation to desire for social distance from people with a diagnosis of schizophrenia. Schulze, Richter-Werling, Matschinger and Angermeyer (2003) developed an instrument to measure desire for social distance from a person with a diagnosis of schizophrenia, specifically for use with young people. This scale was developed

from qualitative data obtained from 60 young people who participated in a focus group aimed at identifying the social relationships of young people. In total, the questionnaire has 12 items pertaining to various aspects of social relationships which are rated on a 3 point scale of 'agree', 'disagree' and 'unsure'. Cronbach's alpha demonstrated good reliability for the scale at each time point that the measure was administered (range 0.80 − 0.85) (Schulze et al, 2003). Whilst measures of social distance show good reliability (Jorm & Griffiths, 2008; Schulze et al, 2003; Link et al, 2004), there are some limitations to using social distance scales. Measures of social distance are limited by social desirability bias from the participants. Participants may under report their desire for social distance in order to avoid appearing un-caring towards those with mental health problems (Link et al, 2004). Furthermore, it is difficult to infer actual behaviours of social distance from social distances scales and it is possible that actual behaviour may be affected by other key factors not measured on social distance scales (Link & Phelan, 2004).

A criticism of psychometric measurement of stigma is that it is likely to be confounded by social desirability effects. Therefore, some stigma researchers have also utilised approaches to measure implicit attitudes towards people with mental health problems (Lincoln, Arens, Berger & Reif., 2008). Greenwald and Banaji (1995) describe implicit attitudes as being ones which are not under conscious control and therefore, measuring these are likely to identify attitudes which a person does not want to reveal due to social desirability (Greenwalk, McGhee & Schwartz., 1998). The Implicit Associations Test (IAT) has been developed to measure implicit attitudes. It is delivered via a computer and it involves four stimuli, two of which are classed as target concepts and two as attribute concepts (De Houwer., 2002). For example, if one wanted to explore attitudes towards people with and without

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psychosis the two target concepts would be 'psychotic' and 'not psychotic' and the attribute concepts maybe dangerous and safe. The IAT test is used to measure how fast the concepts are sorted and the theory is that sorting of categories will be faster when the two concepts are implicitly associated by the participant (Greenwald et al., 1998). In regards to stigma, IAT has been employed in a study of biogenetic vs. psychosocial anti-stigma interventions (Lincoln et al., 2008). There are however limitations to using this methodology. In particular it has been argued that IAT is not a measure of beliefs, rather it is a measure of associations and as De Houwer (2002) notes, beliefs are often comprised of many associations (De Houwer., 2002). Furthermore, there is debate regarding whether IAT accurately reflects personal associations or whether it is influenced by societal associations (De Houwer., 2002).

1.5.2 Measures of internalised stigma

In a recent review of the measures used in studies of stigma which included people with personal experience of mental health problems 57 studies were reviewed and the authors identified 14 questionnaires which measured perceived, experienced and internalised stigma (Brohan, Slade, Clement, Thornicroft., 2010).

As outlined below in section 1.6, a key concern of this thesis is the internalisation of stigma which has been defined as awareness of the labels associated with a given mental health problem and identifying with the stereotypes (Link et al., 2004). Internalised stigma has also been defined as the internalisation of shame, blame, hopelessness, guilt and fear associated with mental health problems (Corrigan & Watson., 2002). The focus of this section will be the measurement of internalised stigma. The review carried out by Brohan and colleagues (2010) identified five measures of internalised stigma which measured other aspects of

personal stigma including experienced and perceived, one was specific to depression only (Brohan, Slade, et al., 2010). The Internalised Stigma of Mental Illness Scale (ISMIS) measures three concepts of experienced and self-stigma (alienation/ stereotype endorsement/ social withdrawal) and stigma resistance (Ritsher, Otilingam, & Grajales., 2003). The Self-stigma of Mental Illness Scale (SSMIS) is a measure of perceived stigma and self-stigma, which covers dimensions of stereotype agreement, stereotype self-concurrence and self-esteem decrement (Corrigan, Watson, & Barr, 2006). The Stigma Scale (SS) is a measure of experienced, self-stigma (disclosure) and positive aspects of stigma (King, Dinos, Shaw, Watson, Stevens, Passetti, et al., 2007). The fourth measure identified was the Inventory of Stigmatising Experiences (ISE), with subscales for perceived stigma, experienced stigma, social withdrawal and impact of stigma (Stuart, Milev, & Koller, 2005). The ISMIS and the SS are most commonly used in research investigating internalised stigma (Livingston & Boyd, 2010) both of which reported content validity, construct validity, internal consistency and test re-test reliability (Brohan, Slade, et al., 2010). These measures reflect three components of internalised stigma including stereotype awareness, secrecy and social withdrawal (Brohan, Slade, et al., 2010). Stereotype awareness, endorsement and application to self have been demonstrated to be a key feature of internalised stigma (Corrigan, Rafacz, Rusch., 2011). Whilst the ISMI and the SSMIS both contain subscales relating to stereotypes, neither scales were developed specifically for use with either psychosis or at risk of psychosis populations.

The Personal Beliefs about Illness Questionnaire (PBIQ) was developed by Birchwood, Mason, MacMillan & Healy (1993) specifically for use in psychosis populations and is a measure of the extent to which a person with psychosis

endorsed the cultural stereotypes of psychosis to be true of them. The original version of this measure evaluated social containment, stigma, expectations and control over illness and demonstrated good reliability (Birchwood et al., 1993). As outlined below in section 1.6 the measure has been used on a number of occasions exploring the relationships between dimensions of internalised stigma such as entrapment, loss and shame with emotional dysfunction in psychosis (Birchwood et al., 1993; Birchwood., 2003; Birchwood et al.,2005; Karatzias, Gumley, Power, O'Grady., 2007; Rooke & Birchwood., 1998).

1.5.3 Qualitative research

Within health and clinical psychology there has been an increase in the use of qualitative methods to investigate how people make sense of their experiences. It has been argued that the study of human experience requires qualitative and quantitative approaches in order to fully capture the range of human experience (Lieberman, 1989; Nicolson, 1995). Research into subjective experience creates an opportunity to understand how people make sense of their experiences and it can provide additional breadth and depth to quantitative research (Lewis, 1995). Research into the subjective experience of psychosis through the use of qualitative methodologies has been relatively neglected in comparison to objective research and it has been posited that the neglect of subjective experience limits conceptualisations of psychosis (Geekie & Read., 2009).

Early first person accounts, such as that of Gallo's account of internalised stigma (Gallo, 1994), which was featured in the Schizophrenia Bulletin first person's account series, pathed a way for further exploration of subjective accounts of stigma experienced and anticipated by people with psychosis. There are however, relatively

few qualitative studies looking at the stigma of psychosis and a recent systematic review of the qualitative literature indicates eight studies which have explored the stigma experiences of people with psychosis (Wood, Burke, Chapman, Pyle, Morrison, 2013). Some have included the experiences of family members (González-Torres et al., 2007; Schulze and Angermeyer, 2003) and health professionals who work with people with psychosis (Schulze and Angermeyer, 2003). It could be argued that quantitative research measures the concepts that the researcher defines as important in relation to stigma; qualitative research puts the concerns of the person with psychosis at the heart of the results.

To date the qualitative literature has highlighted concerns that stigma: affects relationships and leads to infantilization by others (Gonzalez-Torres et al., 2007); results in emotions of fear, guilt, isolation and worry on the part of the stigmatised individual (Dinos et al., 2004); affects interpersonal interactions with friends and family (Schulze and Angermeyer, 2003); can result in avoidance, secrecy and isolation (Knight, Wykes, Hayward., 2003). Qualitative research in the area has also hinted that some people with psychosis personally express positivity about having a diagnosis or mental health problem and are less concerned by stigma (Dinos et al., 2004).

A review of the qualitative literature indicated only one study with the specific aim of investigating stigma from an Interpretative Phenomenological Analysis (IPA) approach. Conducted over a decade ago, Knight et al (2003) indicated three themes of judgement, comparison and personal understanding of the issue; stigma was both interpersonal and intrapersonal (Knight et al., 2003). Participants reported a strong sense of being stigmatised as 'different'. Each theme presented a wealth of information. Judgement was both actual and anticipated and

came from a wide range of sources with consequences for the participant's self-concept, every day experiences and personal feelings of responsibility for their mental health problems. The theme comparison related to a process of reflecting on current self with the past and future self and concepts and normality and difference were identified by the participants as important issues in relation to how they understood their past, present and future self. . Personal understanding of the issue related to how the person understands their life situation including being ill, coping via avoiding, withdrawing or secrecy from others and educating others sometimes via modified information (Knight et al., 2003).

As an approach to understanding stigma, although underrepresented in the literature, qualitative approaches have provided a rich, detailed account of stigma from the perspective of those with psychosis.

1.6 The Consequences of Stigma and Discrimination

So far, this literature review has considered the psychological and social components of stigma and provided an overview of the current theories of what causes and maintains stigma. In particular, attention has been paid to the stigma of psychosis including the prevalence of public stigma and the methods used to research stigma from a public and personal perspective. This section will consider the consequences of stigma for people with psychosis. Key models which have been proposed to formulate processes that occur and to the stigmatised individual will be considered before reviewing the literature regarding social isolation and exclusion and internalised stigma.

1.6.1 Identity threat

Stigma is a threat to self-identity (Major and O'Brien, 2005). Drawing from an extensive review of the stigma literature, Major and O'Brien (2005) have proposed a model of stigma-induced identity, accounting for the impact of stigma on identity. A graphical representation of the model can be seen below in Figure 1. The stigma induced identity threat model outlines processes and interactions which are thought to occur in an individual who is stigmatised. Identity threat is considered to arise from personal knowledge about societal representations of a stigmatised trait, situational cues observed from the environment and from personal characteristics such as stigma consciousness (Major & O'Brien, 2005). A number of voluntary and involuntary consequences occur in response to identity threat, which include secrecy, withdrawal and physical responses such as increases in blood pressure and cardiovascular responses. These voluntary and involuntary responses can have a negative effect on health and self-esteem.

Figure 1: A Model of Stigma-Induced Identity Threat

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┌─────────────────────┐                              ┌─────────────────────┐
│ Collective          │                              │ Involuntary responses│
│ representations such │                              │                     │
│ as stereotypes      │──┐                           └─────────────────────┘
└─────────────────────┘  │                                      ↑
                         ↓                                      │      ┌─────────────────┐
┌─────────────────────┐  ┌──────────────┐                     │      │ Outcomes        │
│ Situational cues such│ │ Identity     │─────────────────────┘      │ Health          │
│ as being exposed to  │ │ threat       │                            │ Self esteem     │
│ media representations,│→│ appraisals   │                            └─────────────────┘
│ being in a group of  │ │ "Who am      │                                   ↑
│ non mental health    │ │ I?"          │─────┐                             │
│ patients             │ └──────────────┘     │      ┌─────────────────────┐│
└─────────────────────┘        ↑              └─────→│ Voluntary responses or││
                               │                     │ coping mechanisms    ││
┌─────────────────────┐        │                     └─────────────────────┘│
│ Personal characteristics     │                                            │
│ such as stigma      │────────┘                                            │
│ consciousness and    │                                                     │
│ group identification │                                                     │
└─────────────────────┘                                                      │
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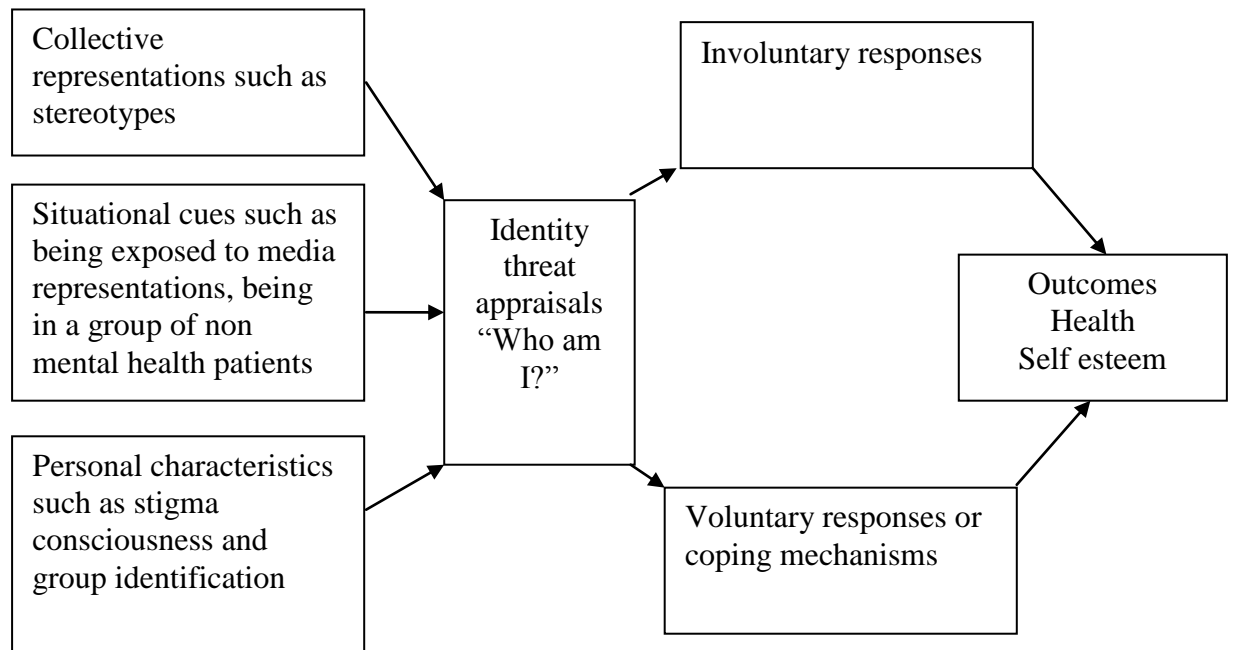
1.6.2 Labelling and modified labelling theory

The identity threat model was developed as a generic model of stigma and is not specific to mental health problems or psychosis. Scheff (1974) proposed that the labels and stereotypes that are ascribed to those who experience mental health problems result in a vicious cycle or self-fulfilling prophecy for the person labelled as mentally ill. This process is referred to in the model as 'sealing' chronic illness (Scheff., 1974). It has been argued that the behaviours associated with mental health problems occur frequently in society but are not often considered to be indicative of a mental health problem unless the behaviour deviates from accepted social norms (Scheff., 1974)..

Scheff's (1974) theory has been adapted by Link et al (1989) and re-named as Modified Labelling theory (Link, et al., 1989). Although adopting many of the features of labelling theory, the emphasis of modified labelling theory is less

definitive in regard to the outcome of labelling on people with mental health problems and suggests that there is variability in the public's perceptions and the labelled person's perceptions of how they will be viewed and treated by others (Link, et al., 1989; Link & Phelan, 1999). A central part of this model is that labelling occurs through accessing treatment centres and through receipt of a mental health diagnosis, following which the person is at risk of becoming devalued and discriminated against, internalising stigma, adopting behavioural strategies such as secrecy and withdrawal to prevent devaluation and discrimination and increased psychological problems such as reduced self-esteem (Link, et al., 1989). Testing this model, people who were not in clinical services that scored on measures of psychopathology were compared to those with a diagnosed mental health problem who had repeated contact with services. It was found that those who scored on the measure of psychopathology but were not in contact with services reported awareness of labels but did not engage in strategies of secrecy and withdrawal, unlike those with repeated contact with treatment centres (Link, et al., 1989). This suggests that it is the label of a mental health problem, which triggers internalisation processes and result in harm.

Some critics of labelling theory argued that those with mental health problems were not subject to, or affected by stigma because of the labels ascribed to them, but that stigma was a result of the so called 'bizarre' behaviour people with mental health problems demonstrate (Crocetti, Spiro, & Siassi, 1971; Gove & Fain, 1973). Extensive research carried out since indicates this not to be the case, and it has been strongly argued that stigma experienced by those with mental health problems is not a consequence of the behaviours they may display (Angermeyer, et al., 2004; Angermeyer & Matschinger, 1996; Arboleda-Florez, 2005).

Recent research has demonstrated the extent to which stigma and discrimination is experienced, anticipated and internalised (Brohan, Elgie, Sartorius, & Thornicroft, 2010; Thornicroft et al., 2009). In a cross sectional study which included 27 countries and over 700 participants with psychosis, discrimination from a range of sources including work and personal relationships was experienced by just under half of the participants (Thornicroft, et al., 2009). Unsurprisingly, the level of anticipated discrimination was reasonably high, with 55% and 64% of participants for relationships and work respectively, and 72% reported that the felt they needed to conceal their diagnosis (Thornicroft, et al., 2009). Internalised stigma or 'self' stigma has also been shown to be a relatively frequent problem for people with psychosis. In another large cross sectional study carried out in 14 countries with over 1000 participants, almost half of the participants reported moderate to high levels of internalised stigma (Brohan, Elgie, et al., 2010). Qualitative accounts of stigma from those with mental health problems have suggested that stigma can be more disabling than the mental health problem itself resulting in a 'second 'illness' (Schulze & Angermeyer, 2003). As indicated in the identity threat model (Major & O'Brien, 2005), labelling theory (Scheff, 1974) and modified labelling theory (Link, et al., 1989), whether stigma is experienced, anticipated or internalised, there are often negative psychological and social consequences for the person who is the target of this stigma (Cavelti, Kvrgic, Beck, Rüsch, & Vauth, 2012; Corrigan, Rafacz, & Rüsch, 2011; Karidi, Stefanis, Theleritis, Tzedaki, Rabavilas, & Stefanis., 2010; Livingston & Boyd, 2010; Muñoz, Sanz, Pérez-Santos, & Quiroga, 2011; Vauth, Kleim, Wirtz, & Corrigan, 2007). The consequences of stigma will be discussed in more detail below with a particular emphasis on the consequences of internalised stigma.

1.6.3 Social Distance and Isolation

Social distance is defined as a willingness to engage in relationships with a person (Lauber, Nordt, Sartorius, Falcato & Rossler., 1999). The public's endorsement of stereotypes, such as danger and unpredictability, is associated with negative emotions towards the stigmatised individual and as a result an increased desire for social distance (Lauber, et al., 1999). This can impact on social relationships, and research indicates that people with psychosis often have smaller social networks (Howard et al, 2000) and more often comprise of other people with mental health problems and mental health staff (Howard et al., 2000). In addition to social distance because of the public's perceptions of those with mental health problems, the fear of rejection can lead to strategies to avoid discrimination such as avoidance of friends and family, which further increases isolation and reduces social networks (González-Torres, et al., 2007).

Research demonstrates that being in employment can promote good mental health (Warr, 1987); employment provides practical benefits of security and money, but it can also provide interpersonal contact and the sense of being valued (Warr, 1987). Unemployment can, therefore, result in the opposite, causing practical, social and emotional problems (Thornicroft, 2007) and research clearly indicates that employment opportunities for people with mental health problems are significantly less than for those with physical health problems and the general population (Read & Baker, 1996; Thornicroft, Tansella, Becker, Knapp, Leese, Scherer., 2004). There are variations in the proportion of unemployed people with mental health problems and this variation can differ from country to country (Thornicroft, et al., 2004). In one study, rates of employment for people with psychosis was found to be 20% in Spain and 23% in Italy; the percentage in England was 5% (Thornicroft et al., 2004).

In stark contrast to these findings, research has indicated that people with mental health problems have a high desire to work; a UK study conducted with people with mental health problems reported that this group had the highest want to work rate compared to any other group (Stanley & Maxwell, 2004). Loss of, or inability to sustain, employment has both practical ramifications such as loss of income, and can compound feelings of isolation and hopelessness.

Fear of such discrimination can leave the stigmatised individual with a dilemma of whether to disclose diagnosis to family, friends and employers and those with psychosis are most likely to edit the information about their diagnosis to avoid stigma (Dinos et al., 2004). Keeping psychiatric history a secret has been identified as a stressor that can increase the chance of relapse (Birchwood, Spencer, & McGovern, 2000). Furthermore, research indicates that those with mental health problems who are fearful of stigma and discrimination are less likely to seek support for their problem in the early stages (Freidl, Lang, & Scherer, 2003; Kessler, Demler, Frank, Olfsen, Pincus, Walters et al., 2005; Rost, Smith, & Taylor, 1993). As discussed, ppsychosis is one of the most stigmatised mental health problems (Angermeyer, et al., 2004), and delays in recognition and treatment have been found to typically be between 1-2 years (Johannessen, 2004). In relation to psychosis, delay in help seeking results in longer periods of untreated psychosis (DUP), which is significantly related to poor prognosis in terms of response to treatment, recovery and long term outcomes. Considering the effect of longer DUPs on prognosis, the potential impact of stigma on delays in help seeking is concerning.

Alongside stereotype awareness, avoidant coping styles such as withdrawal and secrecy have been shown to contribute to the variance in anticipated stigma (Vauth, et al., 2007)

1.6.4 Internalised Stigma

As noted, the stereotypes and emotions about psychosis can become internalised by the individual who is experiencing psychosis, and research demonstrates that around 50% of people with psychosis report moderate to high levels of internalised stigma (Brohan, Elgie, et al., 2010). Sometimes referred to in the literature as 'felt' or 'self' stigma, internalised stigma is a process whereby people who are stigmatised move from being aware of the social stereotypes, to agreeing with them and applying these stereotypes into their own self-concept (Corrigan, et al., 2011). Throughout this thesis, the term internalised stigma will be adopted as the author argues that the term self-stigma indicates that the root of stigma is from the 'self' placing the problem with the individual rather than with society.

Not all people with psychosis report internalised stigma, and factors such as low perceived legitimacy of stigma and low perception of stigma may act as protective factors for internalised stigma (Rusch, Lieb, Bohus, & Corrigan, 2006). However, the research detailed above by Brohan and colleagues (2010) clearly indicates that internalised stigma is a problem for a significant number of people with psychosis. Furthermore, research indicates that internalised stigma may be particularly damaging, even in the absence of direct stigma or discrimination from others (Ritsher, Otilingam, & Grajales, 2003). Interestingly, recent research suggests stigma experienced from close social networks, such as family and friends has a greater impact than when it is from wider social networks (Muñoz, Sanz, Perez-Santos, Quiroga., 2011). As with public stigma, internalised stigma is comprised of cognitive, emotional and behavioural components including feeling ashamed, devalued and engaging in behaviours such as withdrawal and concealment (Cavelti,

et al., 2012). Ritsher, Otilingam & Grajales (2003) empirically derived a five factor model of internalised stigma, which suggested five central concepts of internalised stigma including alienation, stereotype endorsement, discrimination experience, social withdrawal and stigma resistance. However, conceptions of internalised stigma have been criticised for being static rather than fluid, and in response to this Corrigan et al. (2011) have proposed a progressive model of internalised stigma, which outlines the processes involved in the internalisation of stigma. As with labelling (Scheff, 1974) and modified labelling theory (Link, et al., 1989), the progressive model of self-stigma suggests that people are socialised to the stereotypes of psychosis throughout child and adulthood and it is when a person is labelled with a mental health problem that a series of events may occur in the internalisation process (Corrigan et al., 2011). These events include agreement with stereotypes, application of stereotypes to self-concept and psychological harm arising from the application of stereotypes (Corrigan, et al., 2011). Longitudinal research has suggested some support for the progressive model of self-stigma indicating that internalisation occurs in two phases; the first is awareness and agreement with stereotypes, and the second is application of stereotypes into the self-concept and the resulting psychological harm (Corrigan, et al., 2011).

Structural equation modelling has been used to demonstrate relationships between social, cognitive and behavioural factors of internalised stigma in people with 'severe mental health problems' include psychosis (Muñoz, et al., 2011). In this study 108 participants completed a range of measures relating to social (discrimination), cognitive (stigma, self-stigma and recovery) and behavioural components (psychosocial functioning and autonomy) of stigma; results indicated key interactions between social, cognitive and behavioural components of stigma.

Firstly, significant positive relationships were found between level of personal awareness of stigma and level of internalised stigma and greater levels of internalised stigma are associated with poorer social functioning and expressed lowered recovery expectations (Muñoz, et al., 2011). The research carried out by Corrigan et al. (2011) and Muñoz, et al. (2011) both indicate the negative outcomes that internalised stigma can have on the psychological wellbeing of the person who is stigmatised. This will be explored in more detail in the next section with a focus on emotional dysfunction.

1.6.5 Internalised stereotypes of psychosis and emotional dysfunction in people with psychosis

Research demonstrates that internalised stigma can have an impact on emotion and be a risk factor for emotional difficulties (Lysaker, Roe, & Yanos, 2007), in particular depression (Vauth, et al., 2007). Recent meta-analyses found that high levels of internalised stigma were associated with reduced hope and self-esteem (Livingston & Boyd, 2010). An interesting paper that adopted qualitative methodology to investigate the effects of stigma found that participants identified reduced self-esteem as a consequence of internalised or self-stigma (Knight, Wykes, & Hayward, 2003). Investigating how dimensions of self-esteem linked to domains of stigma, Lysaker, Tsai, Yanos & Roe (2008) found that people who internalised stereotypes had lower self-esteem, and in particular they viewed themselves as less competent and had less self-approval (Lysaker et al., 2008). Furthermore, it was also demonstrated that the more a person experienced social distance, the less lovable the participant felt (Lysaker et al., 2008).

Depression in psychosis may occur as a response to psychotic symptoms (Morrison, 2001). This may be due to appraisals that voices are powerful or because

of the threat of persecution (Birchwood, et al., 2005); it may also occur as a developmental anomaly or trauma (Birchwood, 2003). In relation to psychosis and treatment with antipsychotic medication, depression may occur as a side effect of antipsychotics (Mullholland & Cooper, 2000). However, research has also indicated that depression in psychois may occur as a negative reaction to becoming psychotic (Birchwood., 1993; Birchwood, 2003; Birchwood et al., 2005; Rooke & Birchwood., 1998). Birchwood et al. (2005) have argued becoming psychotic may for some be a depressogenic life event because of stigma and the consequential loss of roles, shame, embarrassment and enforced lowered social rank which can result of being diagnosed with a stigmatised mental health problem (Rooke & Birchwood, 1998).

In the first of a number of studies by Birchwood and colleagues exploring the area, participants who experienced psychosis with and without depression were compared on a measured developed for the purpose of that study entitled the Personal Beliefs about Illness Questionnaire (Birchwood, et al., 1993). The study indicated that those with depression reported greater internalisation of stereotypes of psychosis and less perceived controllability over experiences in comparison to those without depression (Birchwood, et al., 1993). Since this study, further studies have demonstrated that those with depression report greater levels of shame, humiliation, loss and entrapment because of psychosis than those without depression (Birchwood, 2003; Karidi, et al., 2010).

Internalising stereotypes of psychosis has also been associated with social anxiety, a co-morbid difficulty that a number of people with psychosis experience (Pallanti, Quercioli, & Hollander, 2004). Proposing a stigma model of social anxiety in psychosis, Birchwood et al. (2006) suggest that having an awareness of the stereotypes of psychosis prior to the onset of a psychotic episode can result in the

person appraising themselves as socially unattractive and of low personal worth. This heightened sense of being socially unattractive may then result in increases in threat monitoring and social anxiety (Birchwood, et al., 2006). In a study of psychosis and social anxiety, it was found that participants with psychosis and social anxiety disorder attached greater shame to their diagnosis, felt more marginalised and of lower social status than those with experienced psychosis alone (Birchwood, et al., 2006). Gumley, O'Grady, Power and Schwannauer (2004) also demonstrated that those who experienced psychosis with social anxiety disorder reported a greater level of shame, self-blame and entrapment in comparison to those with psychosis who did not experience social anxiety disorder (Gumley et al., 2004). There is, therefore, growing evidence to indicate that internalising stereotypes of psychosis can play a role in emotional dysfunction experienced by people with psychosis; both in relation to depression and social anxiety.

The research carried out to date focuses on those with established psychosis and cannot account for the impact of stigma and internalised stereotypes before a person makes a transition to a first episode of psychosis. It is unclear whether awareness of these stereotypes may impact in the prodromal phase. There is debate in the literature regarding the possibly stigmatising effect of early detection and intervention for young people at risk of psychosis and the possible implications for stigma as will be reviewed below in the next section.

1.6.6 Psychosis stigma and early detection, and intervention with people at risk of psychosis: an ethical debate on the effects of stigma

Over the past decade there has been a focus on early detection and intervention for people at risk of developing psychosis (Addington, Epstein, Liu, French, Boydell & Zipursky., 2011; McGorry, Yung, Phillips, Yuen, Francey,

Cosgrave, et al., 2002; Morrison, et al., 2003; Phillips, Yung, & McGorry, 2000; Yung, Nelson, Stanford, Simmons, Cosgrave, Killackey et al., 2008; Yung, Phillips, Yuen, Francey, McFarlane, Hallgren, et al., 2003; Yung, et al., 2006; Yung, Yuen, McGorry, Phillips, Kelly, Dell'Olio, et al., 2005). In particular research efforts have focussed on the development of criteria to identify those at risk of developing psychosis. The Comprehensive Assessment of At Risk Mental States (CAARMS) is the most commonly used measure for identification of people meeting criteria for an at risk mental state (Parker & Lewis, 2006). Three subgroups are identified via the CAARMS, the first two relate to state factors and include attenuated psychotic symptoms or brief limited intermittent psychotic symptoms (BLIPS). The third subgroup relates to state plus trait factors, which include a reduction in functioning plus a first degree relative with psychosis or pre-existing schizotypal personality disorder (Phillips, et al., 2000).

As discussed, there are now criteria for the identification of people at risk of developing psychosis and a number of services in the UK, Australia and elsewhere are in existence, which offer treatment to young people at risk of psychosis. A pioneering service in Australia called the PACE clinic has been providing services to young people at risk of psychosis since 1994. Less is known about the potential stigma and discrimination that young people at risk of psychosis may face. There is debate in the literature regarding the 'risks' associated with being at risk of psychosis, one of which is stigma and discrimination (Yang, Wonpat-Borja, Opler, Corcoran, 2010). When identifying people at risk of psychosis, there is a proportion that will be false positives and the predictive ability of any measure used to identify persons meeting ARMS criteria is variable depending on the base rate of illness, which results in a relatively high false positive rate (Warner 2005). Therefore, some

have argued that the rationale for early detection and intervention, either pharmacological or psychological, is questionable (Warner 2005). Whilst the public's perceptions of those at risk of psychosis are unknown, it is clear that psychosis is one of the most stigmatised mental health problems. Therefore, it could be argued that the public's perceptions and stereotypes of psychosis may be applied to those who meet criteria for ARMS. This in turn may lead to stigma, discrimination and consequences for personal identity (Corcoran, Malaspina, & Hercher., 2005; Yang, Wonpat-Borja et al. 2010; Yung, Nelson et al. 2010).

Currently a diagnosis for this group does not exist in either the Diagnostic and Statistical Manual V or International Classification of Disease 10 (ICD-10). However, the proposal for a risk syndrome in the DSM V resulted in much debate regarding the potential risks of stigma for this group, if a formal psychiatric diagnosis were to be applied; this was of particular concern given the high false positive rate (Corcoran, First, & Cornblatt, 2010; Morrison, Byrne, & Bentall, 2010; Yang, Wonpat-Borja, Opler, & Corcoran, 2010).

There is an indication from qualitative research that young people at risk of psychosis are concerned about being stigmatised (Byrne & Morrison, 2010). Combined with the debate within the literature regarding the risks of being at risk and concerns over formal diagnoses of psychosis risk, this is an area of stigma research which requires further attention.

1.7 Interventions to reduce the stigma of psychosis

As outlined above, stigmatising beliefs and discriminatory behaviour by the public towards those with psychosis results in a wide range of social, economic and psychological problems (Thornicroft, 2007), and, therefore, stigma can be a major

barrier to recovery (Sayce, 2000). Tackling the problem of stigma and reducing stigma in the public is on the agenda of both international and national policies.

Internationally, The World Health Organisation (WHO, 2001) and The World Psychiatric Association (WPA, 2000) both called for campaigns to reduce stigma and discrimination about mental health (Pinfold, Toumlin, Thornicroft, Huxley, Farmer, & Graham., 2003). In response to this need the WPA launched the 'Programme to reduce stigma and discrimination because of schizophrenia' (WPA, 2001) which has been active in 20 countries across the globe (WPA, 2001). In the UK reducing stigma of psychosis was a priority of the Mental Health Policy Implementation Guide (DH, 2001) and the National Institute for Clinical Excellence (NICE) guidelines for the treatment of schizophrenia (NICE, 2010). The most recent mental health policy from the UK government 'No Health Without Mental Health' lists stigma as one of six priorities for health services (DH, 2011).

In October 2007 the 'Time to Change campaign to end the stigma and discrimination of mental health was launched. Funded by the Big Lottery Fund and Comic Relief the Time to Change campaign has over 35 programmes aimed at achieving change in mental health attitudes in adults in the UK (Pinfold, 2008).

The need for change is clearly identifiable and recognised by leading organisations. The problems of how to reduce the stigma and discrimination of mental health with a specific focus on psychosis is discussed below. Both biogenetic and psychosocial approaches will be considered. Future directions for research are also considered.

1.7.1 Mental illness is an illness like any other': Biogenetic frameworks

The biogenetic approach to reducing stigma adopts an 'illness ideology' that applies the same biological and medical assumptions of physical illness to mental health

problems (Read, 2007). In essence, this a medical approach to understanding and treating mental health problems and behaviour is seen as the result of chemicals, organic brain impairments or genetics (Read, 2007). In this respect, psychosis is viewed as a 'mental illness as any other illness' (Read, Haslam, Sayce, & Davies, 2006; Read & Law, 1999). This is evident in the terminology adopted by campaigners in their anti-stigma campaigns; for example, mental health problems are often referred to as illnesses (Read, 2007). This approach assumes that a biogenetic perspective on the causes of mental health problems will reduce the potential for the public to blame individuals for their mental health problem as the causes are controlled by the individual's biology (Angermeyer & Matschinger, 2005).

The biogenetic framework also postulates that stigma is a result of the public's mental health illiteracy. The term 'mental health literacy' was developed from general health literacy by Jorm, Korten, Jacomb, Christensen, Rodger, & Pollitt (1997) to refer to knowledge and beliefs about mental disorders which aid recognition, management or prevention (Jorm, et al., 1997) and those who adopt the 'mental health literacy' and 'mental illness as any other illness' approach equate knowledge of mental health problems with knowledge of the illness paradigm (Read, 2007). This approach is also concerned with teaching the public how recognise mental health problems and how to apply diagnostic labels to symptoms (Jorm, 2000). Advocates of this approach argue that members of the public are not able to correctly recognise 'disorders' or understand what psychiatric terminology means, which can result in psychiatric problems being misdiagnosed at a primary care level and result in stigma (Jorm, 2000). This standpoint is very much associated with the biogenetic approach to understanding the causes of mental health problems. Research has demonstrated that when the psychiatric label 'schizophrenia' was

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applied to a vignette, participants increased the degree to which they endorsed biogenetic factors as causal in the development of schizophrenia (Angermeyer & Matschinger, 1996). Jorm (2000) considered this form of education i.e. identification of biogenetic causal factors by applying diagnostic labels, to be the key benefit of the mental literacy approach. Whilst some have promoted the mental health literacy approach to stigma reduction, others have called this approach into question (Read, Haslam, Sayce & Davies, 2006). A systematic review of twenty-one studies of causal models and attitudes towards mental health problems, which were carried out between the years of 1970 and 2005, found nineteen studies which evaluated the effect of biogenetic causal models on attitudes (Read et al, 2006). Of these nineteen studies, only one found associations between biogenetic perspectives and positive attitudes towards mental health problems (Read et al, 2006).

The biogenetic approach has been adopted as the framework for many anti-stigma campaigns (Angermeyer & Matschinger, 2005). However, when empirically tested it was found that as the public's endorsement of the biological causes of psychosis increased so did the desire for social distance (Angermeyer, et al., 2005). More specifically, a detailed analysis of the data indicated that respondents who endorsed the biological causes of psychosis also endorsed that people with psychosis were lacking in self-control, unpredictable and dangerous. The authors concluded that the biogenetic approach to stigma reduction can lead to more instead of less rejection (Angermeyer and Matschinger, 2005).

The biogenetic approach to reducing the stigma of mental health, and in particular psychosis, has been criticised for several reasons, . Firstly, service users and family members have also expressed concern over the medical model of psychosis (Read, 2007; Read, et al., 2006). Furthermore, the medical approach to

anti-stigma campaigns encourages the listener to adopt a diagnostic or labelling approach to mental health problems (Read, 2007). Although there can be positive outcomes from diagnosis for the service user, it has also been found that this can have negative effects such as disempowerment and can be a cause of social exclusion (Pitt, Kilbride, Welford, Nothard, & Morrison, 2009). Promoting biogenetic causes for psychosis in anti-stigma campaigns may cause more harm than good for the service users and family members who consolidate this message. Research into the public's views about the causes and treatments for psychosis and the views of service users indicates that the biogenetic approach is not favoured by either (Read et al., 2006; Read., 2007).

It has been argued that the biogenetic perspective of biological psychiatry is underpinned by a form of essentialist thinking about human difference (Haslam, 2000). Essentialist thinking, when applied to human difference suggests that the differences observed between groups are of a 'natural kind' (Haslam, 2000). In this sense, difference is considered to be defined by a distinct and underlying property (such as a genetic marker), which binds those with the difference together (everyone has this genetic marker), that this underlying property results in the attributes that are different (such as a symptom) and the underlying property is measurable and can be identified(Haslam, 2000). Essentialist thinking therefore can increase the divide between groups by increasing the perception in the in-group that there is something fundamentally different with the out-group. Essentialist thinking has been shown to be associated with stigma and discrimination (Bastian & Haslam, 2006; Haslam, Rothschild & Ernst, 2002). Recent research from a meta-analytic review analysing the effect of biogenetic explanations on stigma has demonstrated that biogenetic

explanations promote pessimism and reinforce the stereotype that people with mental health problems are dangerous (Kvaale, Haslam & Gottdiener, 2013).

Secondly, although some campaigners adopt the biogenetic viewpoint to psychosis, the literature implies that the public does not, in general, endorse this view (Read, 2007; Read, et al., 2006). A recent review of this approach, which included 39 studies that investigated the public's preference for biogenetic or psychosocial causal explanations for mental health problems, found that 35 of 39 studies demonstrated a significant preference for psychosocial causal explanations (Read, 2007). Furthermore, the studies that indicated a preference for biogenetic causes had adopted a medicalised diagnostic approach to the case vignette by providing the vignette with a diagnostic label of 'schizophrenia'. A review of these studies highlights that although many anti-stigma campaigns have adopted a biogenetic causal explanation of psychosis, the public have continued to demonstrate a preference for psychosocial explanations (Read, 2007). It is an empirical question, therefore, why the public remain resilient to the illness ideology and why it is pursued by some campaigners.

It is also important to ask whether there is an evidence base for this approach as a method to reduce stigma (Read, et al, 2006; Read, 2007). Most studies that have investigated the relationship between causal explanations (either biogenetic or psychosocial) of mental health problems and stereotypes have found that there is a positive significant relationship between endorsing biogenetic causes and negative stereotypes of people with mental health problems (in particular, stereotypes of dangerousness and unpredictability (Read & Harre, 2001; Read & Law, 1999). An experimental study that assigned participants to either a biogenetic or psychosocial causal explanation of psychosis following the same video footage found that those

who received the biogenetic explanation reported significantly increased perceptions of people with psychosis as dangerous and unpredictable (Walker & Read, 2002). In a recent review of twelve studies, Read et al (2006) examined the effect of causal beliefs and attitudes towards mental illness. Of these twelve studies, eleven found that biogenetic beliefs were related to negative perceptions of people with mental health problems (Read, et al., 2006).

Angermeyer & Matschinger (2005) carried out a trend analysis in Germany to evaluate how the public's causal explanations of psychosis and their desire for social distance changed over the period between 1990 and 2001. Their findings indicated that as belief in the biogenetic causal explanations of schizophrenia increased so did the public's desire for social distance. Increased endorsement of biogenetic causal explanations (in particular psychosis as a brain disease) was associated with increased belief in stereotypes of lacking self-control, unpredictability and dangerousness. Angermeyer and Matschinger (2005) conclude that "educating people about the biological causes of schizophrenia may not improve their attitude towards people with schizophrenia" (Angermeyer & Matschinger, 2005 Page 334). More recently, Angermeyer, Matschinger & Schomerus (2013) published the results of a further population survey carried out in 2011 and reported on changes in attitudes towards mental health problems including schizophrenia, depression and alcohol dependence. The authors found that over two decades the biological perspective that schizophrenia is a brain disease had increased and that attitudes towards schizophrenia had worsened; this trend was not observed for depression or drug dependency (Angermeyer, Matschinger, & Schomerus., 2013). Results of this study provide further evidence for a targeted approach to anti-stigma interventions, suggesting interventions should address attitudes towards specific diagnoses and, in

particular, the findings from the survey are evidence that attention should be paid specifically to improving beliefs about psychosis.

Whilst many campaigners promote the idea that education about biological causes of psychosis is an effective method to reduce stigma, the evidence base is limited and most studies indicate that biogenetic causal explanations can increase fear and social distance (Angermeyer & Matschinger, 2005)

To summarise, whilst the intention of many biogenetic anti-stigma campaigns are well intended, research suggests that this approach is not endorsed by the public, it is does not fit with what service users deem appropriate, there is a limited evidence base of its effectiveness, and there is an ever increasing evidence base to indicate that it may cause more harm than good, increasing fear and prejudice towards people with psychosis.

1.7.2 The psychosocial model to reducing stigma.

The psychosocial approach to reducing stigma and discrimination associated with psychosis adopts the principals of the psychosocial approach to understanding psychosis. Essentially, the psychosocial approach assumes that the experiences associated with psychosis are understandable reactions to adverse events (Read, 2007; Read & Harré, 2001; Read, et al., 2006). Typically, the stress vulnerability model is used as a causal model of psychosis (Zubin & Spring, 1977). The psychosocial approach promotes the message that recovery from psychosis is possible and that psychosis develops as an understandable reaction to social and environmental factors (Read, et al., 2006). This approach aims to normalise mental health problems by removing the distance between 'them' and 'us' (Pinfold, et al., 2003), and there is research to suggest that the psychosocial approach is successful in reducing stigma associated with psychosis, in particular fear and social distance

(Campbell, Shryane, Byrne, & Morrison, 2010; Chan, Mak, & Law, 2009; Pinfold, et al., 2003; Read & Harré, 2001; Read & Law, 1999; Walker & Read, 2002). The campaigns that have been conducted have comprised of psychosocial education which adopts the features of psychosocial education outlined above, contact with service users and have targeted specific audiences (Pinfold et al, 2003). Each shall be discussed in turn.

1.7.2.1 Psychosocial Education

The problems associated with misunderstanding psychosis have been highlighted by Thornicroft (2007) in his three part definition of stigma, viewing stigma in part as a problem of knowledge, including stereotyping (Thornicroft, 2007). Delivering information that dispels inaccuracies is considered to be an important aspect of psychosocial anti stigma campaigns (Pinfold, et al., 2003). Often the strategy adopted is to dispel common myths of psychosis with accurate evidence based information (Corrigan & Watson, 2007). Service users have emphasised the importance of education about mental health problems for the public throughout all levels of society (Pinfold, Byrne, et al., 2005). There is some evidence to suggest that education is effective in producing short term improvements in attitudes towards psychosis (Corrigan,Rowan, Green, Lundin, River, Uphoff-Wasowski, et al., 2002; Holmes, et al., 1999). However, research clearly indicates that education which is focused on promoting biogenetic perspectives and teaching the public to recognise and label mental health problems increases stereotypes of dangerousness (Angermeryer & Matschinger, 2005; Angermeyer, Matschinger & Schomerus, 2013; Kvaale, Haslam & Gottdiener, 2013; Read, Haslam, Sayce & Davies, 2006). A recent consensus study of experts in the field of stigma intervention revealed that important psychosocial messages to use in population level campaigns are recovery

and 'see the person' messages (Clement, Jarrett, Henderson & Thornicroft., 2010). Other messages which the authors suggested for further consideration were social inclusion, human rights and the high prevalence of mental health problems (Clement et al., 2010).

Limitations to psychosocial education approaches to stigma reduction include the lack of longitudinal research demonstrating the effects of intervention, the absence of random allocation of participants to intervention groups at the individual level and the absence of a control group. Furthermore, findings from a recent study investigating the active ingredients in anti-stigma programmes in mental health indicated that it is contact with service users that yields the greatest significance (Pinfold, Thornicroft, Huxley, & Farmer, 2005).

1.7.2.2 Contact with people who have experience of psychosis

The benefits of contact with a stigmatised group have been well recognised for decades. The principles have been applied to the stigma of mental health (Couture & Penn, 2003). Contact with someone who experiences, or has experienced, psychosis allows for an effective combination of information/education and direct contact, providing personal experience that is inconsistent with the stereotypes one may have of psychosis (Couture & Penn, 2003). The involvement of service users at all levels of development and delivery in anti-stigma interventions has benefits for the service user other than the direct reduction of stigma. Involvement with anti-stigma programmes can be empowering and promote recovery (Pinfold et al, 2003).

Findings from across the world, both from retrospective self-report and experimental studies, have consistently indicated the significant beneficial effect that contact has on negative attitudes and emotions towards people with psychosis in particular the desire for social distance (Chung, Chen, & Liu, 2001; Ingamells,

Goodwin, & John, 1996; Read & Harré, 2001; Vezzoli, Archiati, Buizza, Pasqualetti, Rossi, Pioli., 2001). Findings from a meta-analysis of over 200 studies has provided support for the effectiveness of this approach in reducing prejudice and suggests that the effects of contact are strongest when they involve direct face-face contact, equal status for the groups involved, shared goals for the programme, a tone of collaboration rather than competition and senior managerial support for the programme (Pettigrew & Troop, 2000). Corrigan & Watson (2007) have added a fifth element to these optimal conditions, the contact with the service user has to moderately disconfirm the stereotype (Corrigan & Watson, 2007). Previous personal contact with someone with a mental health problem has been shown important in reducing stigma (Pinfold, et al., 2003).

Contact has been repeatedly demonstrated as an effective method in increasing positive attitudes and emotional change towards mental illness per se, and in particular psychosis (Corrigan & Penn, 2003). Furthermore, it effectively combines education & evidence to disconfirm stereotypes with service user empowerment, thus providing a duality of benefits (Pinfold et al, 2003). However, studies that have included contact have often neglected to include a control group for comparison, weakening the findings of these studies, and future experimental studies should consider including control groups for comparison (Chan, et al., 2009; Pinfold, Thornicroft, et al., 2005; Pinfold, et al., 2003).

1.7.2.3 Targeting specific groups

Targeting specific groups, most often children/ young people, police, health professionals and employers, has become a trend in recent years (Thornicroft, 2007). There is growing interest in the effectiveness of psychosocial interventions in reducing stigma and discrimination about psychosis by young people (Campbell, et

al., 2010; Chan, et al., 2009; Pinfold, Stuart, Thornicroft, & Arboleda-Florez, 2005; Pinfold, et al., 2003; Schulze, et al., 2003). Young people have been identified as a priority by international and national agencies and institutions; The Early Psychosis Declaration an international statement issued by the World Health Organisation and the International Early Psychosis Association pledged to combat the stigma of psychosis by educating young people and their teachers (Bertolote & McGorry, 2005).

There are several reasons why targeting young people in anti-stigma intervention campaigns are important. Firstly, although research indicates that children and young people have an awareness of the stereotypes of mental problems they do not fully endorse these with prejudice and discrimination till later in adolescents and adulthood (Flavell, Miller, & Miller, 2001). Targeting this group with anti-stigma interventions is thought to be an effective way of challenging stereotypes, prejudice and discrimination before it becomes entrenched.

Secondly, young people are the next generation and as the next generation of health professional, journalists, television and film producers, doctors etc., it is crucial that the stereotypes and negative affect associated with these stereotypes are reduced to help prevent the perpetuation of stigma (Pinfold et al., 2003).

Thirdly, young people may be the next generation of service users and the normalising message of the psychosocial approach may encourage help seeking by those young people who may be in the early stages of mental health problems. Recent research has provided evidence for the importance of early detection of mental health problems (French & Morrison, 2004) and anti-stigma campaigns aimed at young people may not only serve the primary aim of reducing the stigma of mental health problems, but may also serve an important function of increasing help-

seeking in young people at risk of developing a psychosis (Pinfold et al, 2005; Chan et al., 2009).

1.7.2.4 Targeting young people

Anti-stigma interventions with young people aimed at reducing stigma and discrimination about psychosis have typically combined education and contact together in their programmes (Schulze et al., 2003; Pinfold et al, 2003; Pinfold et al, 2005)

Schulze et al (2003) implemented a controlled experimental study of an anti-stigma project in German schools. The intervention was specifically aimed at the reduction of psychosis stigma in people aged 14-18 year olds. The programme was a week in duration and involved both education and contact components with an emphasis on similarities rather than differences between the students and the service user with psychosis. Results from the study indicated a significant reduction in stereotypes of psychosis and a positive trend was observed for social distance, suggesting that anti-stigma projects carried out within schools are a promising approach to improving attitudes and reducing stereotypes (Schulze et al, 2003).

In the UK, Pinfold et al (2003) also conducted an anti-stigma programme in schools which combined education and contact. This study was extensive, successfully recruiting and following up 472 students. The intervention was delivered in two phases. Phase one comprised of a mental health awareness workshop aimed at improving understanding of mental health problems and challenging stereotypes. Phase two involved contact with a service user. Positive attitudes towards people with mental health problems were found to have small but significant increases, at both one week and six month follow up. The authors concluded that educational workshops can produce positive changes in young

people's reported attitudes towards people with mental health problems. However this study was limited by the lack of a controlled comparison group (Pinfold, et al., 2003).

In Canada and the UK, Pinfold et al. (2005) conducted a large scale study to evaluate the effectiveness of a school based intervention for raising awareness of mental health and reducing stigma and discrimination. The intervention was aimed at 14-16 year olds and as with Schulze et al, (2003) and Pinfold et al (2003) contained both educational and contact components. The emphasis of the intervention differed slightly in each country. In the UK the programme placed an emphasis on mental health problems in general whereas in Canada the emphasis was on psychosis. In Canada, two schools were recruited (N = 1501), and in the UK, five schools were recruited (N = 635). Both programmes were found to have significant effects on positive scores on accurate factual recall about mental health. Both programmes showed a significant positive impact on desire for social distance. In Canada this was found on all four items relating to social distance, however, in the UK significant improvement was found on social distance items that related to talking to and being in the same class as someone with mental health problems but not on being friend someone with mental health problems and disclosing family mental health problems to friends. The findings of this study further suggest the effectiveness of psychosocial anti-stigma programmes in reducing stigma and discrimination. As with Pinfold et al (2003), this study did not have a controlled comparison group which may weaken the findings. The authors also suggest that note that this and other studies (Schulze et al, 2003, Pinfold et al, 2003) have relatively short follow up and are, therefore, unable to indicate the long term effects of psychosocial anti stigma programmes.

A recent study in China has also yielded results to indicate the effectiveness of psychosocial interventions (Chan, et al., 2009). This study adopted a mass media approach to delivering an anti-stigma programme in the form of a video. In addition to the effectiveness of the intervention in reducing stigmatising attitudes and social distance, the study was also designed to evaluate the effects of ordering of education and contact i.e. contact followed by education or education followed by contact. They hypothesised that presenting an entertainment experience in the form of video contact would facilitate information processing in the educational component. The study adopted a demythologizing, recovery approach and aimed to highlight similarities rather than differences between the students and people with psychosis. Three conditions were compared, education, education followed by video contact and video contact followed by education. A significant reduction in stigmatising attitudes, social distance and knowledge about psychosis was found in all three conditions with small effect sizes for stigmatising attitudes and knowledge and a medium effect size for social distance. The hypothesis that contact followed by education would have the greatest effect was not supported, interestingly the education followed by contact was found to have the greatest and more lasting effects than education alone and contact followed by education. The authors conclude that a brief intervention using education-video approach should be a building block to a curriculum that covers issues relating to mental health (Chan, et al., 2009). This study replicates the findings of other psychosocial approaches to reducing stigma and continues to highlight the importance of service user involvement in the success of such approaches (Pinfold et al., 2003; Schulze et al., 2003, Pinfold et al., 2005) and the need for mental health education as a part of the national curriculum.

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1.7.2.5 A critique of the psychosocial approach to reducing psychosis stigma

Results from the studies discussed above are promising and provide empirical evidence for a psychosocial approach to reducing the stigma and discrimination of mental health problems; however, there are some limitations.

The majority of the studies above have been uncontrolled interventions. The lack of a controlled comparison group is limiting as it weakens the findings of the study (Pinfold et al, 2003). Without the presence of a control group the changes in attitude, social distance and knowledge may only be inferred (Pinfold, et al 2003). Schulze et al (2003) did have a control comparison group however allocation to control or experimental group was not randomised. Participants in the control group were pupils who had chosen a school project that was not related to mental health (Schulze et al, 2003). Pupils in the control group, having chosen not to do a mental health related project may represent a group that were less likely to change their attitudes towards mental health due to the lack of interest in the area. The absence of a randomisation procedure may have produced bias in the results. There are similar difficulties with the design adopted by Chan et al (2009), whilst this study was randomised, the randomisation was done at class rather than individual level; it is acknowledged that cluster randomised trials are less powerful than classical randomised controlled trials (Chan et al., 2009).

Reduction in stigma about psychosis in respect to attitudes, social distance and knowledge has been observed in studies examining its effectiveness (Schulze et al, 2003; Pinfold et al, 2003; Pinfold et al, 2005; Chan et al, 2009; Campbell 2009). Effect sizes range between small (Chan et al, 2009) to medium (Pinfold et al 2003, Campbell 2009) and the effects of the intervention are often time limited (Schulze, 2003; Pinfold et al 2003; Pinfold et al 2005; Campbell et al., 2010). Researchers

have, therefore, continually highlighted the need for these interventions to become a regular feature of the curriculum in order to have long term effects (Schulze et al, 2003).

Whilst there is strong evidence to indicate the importance of contact and education in psychosocial educational interventions (Schulze et al, 2003; Pinfold et al, 2003; Pinfold et al 2005, Campbell et al., 2010; Pettigrew & Troop, 2000; Chan et al, 2009; Corrigan et al, 2007), there is little understanding about the active ingredient that affects the most change and studies to date have primarily evaluated contact or education alone or have combined the two psychosocial approaches together. In a review of the findings from the Mental Health Awareness Action (MHAA) programme in England, Pinfold et al. (2005) reports that the key active ingredient identified by all the groups involved in the programme (police officers, young people and mental health professionals) was the contact and testimonies from service users (Pinfold et al., 2005). The recent consensus study carried out by Clement et al. (2010) suggests that in addition to contact 'recovery' and 'see the person' orientated messages should be used in anti-stigma interventions. Whilst the research to date has provided opinion from experts in the field and participants of anti-stigma programmes, there is a gap in the literature for a randomised and controlled experimental study to evaluate the active ingredients of psychosocial anti-stigma interventions.

Whilst targeting particular groups is a common method to reduce the stigma and discrimination of psychosis, Link & Phelan (2001) suggest that for efforts to be most effective they need to be multifaceted and multilevel. Therefore anti stigma action also needs to address structural discrimination and be targeted at a national

level in relation to the media, law, insurance and welfare benefits and also at the international level in terms of human rights (Thornicroft, 2007).

1.8 Summary of the literature

Psychosis is one of the most stigmatised mental health problems with far reaching personal, social and economic costs. Associated with social isolation, reduced opportunities, shame, fear and the development of other psychological difficulties stigma and in particular internalised stigma, can act as a barrier to recovery. The recent UK government policy 'No Health without Mental Health' lists stigma as one of six priorities for health care and internationally the Early Psychosis Declaration calls for the reduction of stigma about psychosis in young people. Research into the stigma of psychosis from the perspective of the person with psychosis has generally utilised quantitative methodology and measurement. Qualitative research in the area is limited with only eight studies utilising qualitative methodology to explore the subjective experiences of people with psychosis. For people with psychosis research indicates that internalised stigma is associated with emotional dysfunction however current research has not investigated this association in people with established psychosis who are free from the possible confounds of antipsychotic medication or those at risk of psychosis.

In relation to stigma reduction in the public research has clearly demonstrated that a biogenetic approach to reducing stigma can inadvertently increase the public's fear of psychosis and desire for social distance. Alternatively, there is emerging evidence for the effectiveness of psychosocial anti stigma programmes that comprise of both education and contact with service users. (Schulze et al, 2003; Pinfold et al, 2003; Pinfold et al, 2005; Chan et al, 2009). However this research has methodological flaws including lack of a controlled experimental

condition and the absence of random allocation of participants (Pinfold et al, 2003; Pinfold et al, 2005). Whilst contact appears to be the most successful form of psychosocial intervention (Pettigrew & Troop, 2000) there is no known randomised control study designed to investigate the active ingredients of psychosocial interventions to reduce stigma and discrimination of psychosis.

1.9 Broad aims of this thesis

The overarching aim of this thesis is to understand how stigma affects the lives of people who report experiences which are considered to exist on the psychosis continuum, and to contribute to the current literature on psychosocial stigma interventions with the public. In order to achieve this, four broad aims were set:

The first aim was to develop a broad understand of the lived and subjective experience of stigma and discrimination by placing services users as experts on the experience of stigma.

The second aim was to investigate the relationship between internalised stereotypes of psychosis and emotional dysfunction with a focus on internalised stereotypes in two previously under researched groups of people along the psychosis continuum, namely young people at high risk of developing psychosis and those with established psychosis who have chosen not to take antipsychotic medication.

The third aim was to explore possible differences in internalised stereotypes between those at risk of developing psychosis and those with established psychosis.

The fourth aim was to survey young people's attitudes and intended behaviours towards people with psychosis and to examine the effectiveness of internet based psychosocial interventions aimed at reducing the stigma and discrimination of psychosis in young people.

Chapter 2 Methodology employed across the thesis

Chapter One of this thesis provided the reader with an overview of the relevant stigma and psychosis literature in order to provide a clear rationale for the aims of this thesis. This chapter intends to build on Chapter One by outlining the methodologies used to address these aims, the rationale for the approaches used and the strengths and limitations of these approaches. This is particularly important as the studies presented in the thesis are in the format for peer-reviewed academic journals and, therefore, there is insufficient space to adequately discuss the methods employed within each chapter due to the limited word count of journal articles.

2.1 Summary of research aims and the studies which address these aims

The aims and objectives of this these are detailed in Chapter One, however these will be briefly repeated. In order to allow the reader to identify which studies are associated with the four aims each study will be numbered and referred to in the text by this number.

1. The first aim was to develop a broad understand of the lived and subjective experience of stigma and discrimination by positioning services users as experts on the experience of stigma. This aim was addressed using qualitative methodology in Study 1 entitled, "It's just a very taboo and secretive kind of thing really': making sense of what it is like to live with stigma and discrimination from the accounts of nine people with experience of psychosis".

2. The second aim was to investigate the relationship between internalised stereotypes of psychosis and emotional dysfunction with a focus on internalised

stereotypes in two previously under researched groups of people along the psychosis continuum, namely young people at high risk of developing psychosis and those with established psychosis who have chosen not to take antipsychotic medication. This aim was be addressed by Study 2 entitled "Internalised stigma, emotional dysfunction and unusual experiences in young people at risk of psychosis". It will also be addressed by Study 3 entitled "Associations between internalised stereotypes of psychosis and emotional dysfunction in people with psychosis not taking antipsychotic medication".

3. The third aim was to explore possible differences in internalised stereotypes between those at risk of developing psychosis and those with established psychosis. This was addressed by the Study 4 entitled "Internalised stereotypes of psychosis across ultra-high risk and psychosis populations".

4. The fourth aim was to survey young people's attitudes and intended behaviours towards people with psychosis and to examine the effectiveness of internet based psychosocial interventions aimed at reducing the stigma and discrimination of psychosis in young people. This aim was addressed by Study 5 entitled "Efficacy of internet based psychosocial interventions for psychosis stigma reduction".

2.2 Overview of approaches: qualitative and quantitative methods

Within the context of this thesis, both qualitative and quantitative methods have been used to address the research aims. Historically social scientists have often opted for either qualitative or quantitative approaches to research, but there is a growing trend for researchers to utilise both approaches (Murray Thomas., 2003). There is also an argument in the literature that researchers should be pragmatic, selecting methodologies that are guided by the research question being asked (Onwuegbuzie & Leech., 2005). In relation to this thesis, the most appropriate methodologies were

selected for the research questions, and, therefore, both empirical/ hypothesis driven and phenomenological paradigms were adopted. These will be discussed in greater detail.

2.3 Qualitative methodology

2.3.1 Overview of qualitative methodologies

The first research aim of this thesis was concerned with the subjective experience of stigma and therefore Study 1 which addressed this aim was not hypothesis driven, but was concerned with service user's experiences and priorities in relation to stigma. Therefore, a qualitative approach was most appropriate to address this aim.

As with quantitative research, a number of methodological approaches can be taken when carrying out qualitative research. Typically the methodological approaches taken to qualitative research include, Interpretative Phenomenological Analysis, Grounded Theory, Thematic Analysis and Discourse Analysis. Each will be briefly reviewed before outlining the rationale for the methodology used in Study 1.

Thematic Analysis

Thematic Analysis (TA) is considered to be a process for identifying patterns in an qualitative dataset, which are referred to as 'themes' (Braun & Clark, 2006). Themes are therefore considered to be seen as something important in the data which interprets or relates to the research question (Boyatzis, 1998). Unlike other qualitative approaches TA does not assume a specific epistemological stance and it has been argued that this flexibility is an advantage to TA (Braun & Clark, 2006).

Although, TA is a flexible approach Braun & Clark (2006) have developed a 6-stage process to guide and define the analysis process involved in a thematic analysis. The 6-phase procedure involves becoming familiar with the data through transcription, repeated reading of transcripts, and note-taking. Data-driven coding is then performed and all meaningful responses to the research questions are noted. Once the coded data has been organised, emerging themes are noted and refined and collated into a 'thematic map'. Review and refinement of suggested themes then involves naming, re-naming, collapsing or expanding specific themes until there is confidence that candidate themes, sub-themes and codes form coherent patterns and are accurate representations of the data set as whole.Given TA does not require the researcher to assume a particular epistemological stance and as it is relatively easy to learn it is considered to be a particularly good choice of methodology for researchers who are new to qualitative analysis and for drawing broad themes across a large dataset (Braun & Clarke, 2006). However, TA has limited interpretative power beyond the descriptive accounts in the data.

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Grounded Theory

Grounded Theory (GT), was developed by Glaser and Strauss in the 1960s and is a methodology for inductively generating theory (Patton, 1990). Key features of the GT approach include data driven or inductive analysis, collection and analysis of data simultaneously to allow continual development of the topic guide, theoretical sampling and the generation of theory from data (Strauss & Corbin, 1998) In particular the generation of theory from the data distinguishes GT from other qualitative approaches (Charmaz, 2000). Following the development of GT, Glaser & Strauss diverged on their opinions about the aims and principles of GT (Evans,

2013). Four different GT theory models have been identified in the literature and these are: Classic Grounded Theory, Strauss and Corbin approach, Constructivist GT and Feminist GT (Fernandez, 2012). A full review of these approaches can be found in Evans (2013). A limitation to GT is the pre-requisite for theoretical sampling in particular in samples where the participants represent a limited or homogenous group.

Discourse Analysis

Discourse Analysis (DA) is concerned with language and in general DA analysis involves reviewing sections of discourse to develop an understanding that moves from the basic sematic meanings of the words to a deeper meanings behind how and why language is used (Hodges, Kuper & Reeves, 2008). However, there are a number of approaches to DA which differ in the type of research question asked and the methods used to analyses data.

In a review of DA, Hodges et al. (2008) report that there are three approaches to DA: Formal Linguistic Discourse (FLD), Critical Discourse Analysis (CDA) and Empirical Discourse Analysis (EDA). The primary source of data for each approach is samples of written or oral texts. However, EDA also requires the addition of information on how the text is used in social settings and CDA requires both of these plus data regarding the institutions which produce the text (Hodges, Kuper & Reeves). EDA is concerned with broader themes in relation to how language is used with both micro analysis of language and a macro-analysis of how language is used in social settings. The aim of CDA is to move beyond the text to develop an

understanding of how language makes certain roles and institutions possible within society.

Interpretative Phenomenological Analysis

As outlined above a number of qualitative approaches exist, however in order to explore subjective experience and make sense of the meanings people with psychosis ascribe to their experiences of stigma, it is argued that a phenomenological approach is required (Smith, 2004). Interpretative Phenomenological Analysis (IPA) is particularly relevant for the research here, both for practical and theoretical reasons. Firstly, research aim one had a specific focus on subjective experience and the aims of the study presented in chapter three was to contribute understanding of stigma from the perspective of those who have experience of psychosis. The phenomenological approach of IPA seeks the perspectives and experiences of the individual and their world (Smith, 2004). Secondly, IPA was selected as it can be distinguished from other qualitative approaches in that it acknowledges the interpretative nature of subjective research. The IPA approach recognises that in order to understand the meanings that a person ascribes to their experiences interpretations are required on the part of the analyst; in this sense IPA research is considered to have a double hermeneutic (Smith, Flowers, & Larkin, 2009). Thirdly, as the focus of this study was subjective experience and not the development of explanatory theories, IPA was considered to be more appropriate than grounded theory, which has a primary purpose of developing explanatory theories (Glaser & Strauss, 1967). The approach adopted for data collection and analysis used in Study 1 was guided by Smith et al. (2009) and will be outlined below.

2.3.2 Sampling and ethical considerations

The sampling technique adopted was purposeful and as the research question was not related to the development of theory, theoretical sampling was not considered to be necessary (Coyne, 1997). Smith, et al. (2009) suggests that sampling in IPA research has to be purposeful rather than random because the nature of IPA research is to target certain participants who can offer their own perspective on a given topic. In the case of Study 1 the experience of interest was stigma.

A homogenous sample, in respect to participants all having experience of psychosis and having accessed mental health services for or because of these experiences was recruited for Study 1. In order to ensure a homogenous sample in relation to all participants having experience of psychosis, the inclusion criteria was all participants were required to have either an ICD-10 diagnosis on the schizophrenia spectrum or have met entry criteria for an Early Intervention in Psychosis service (EIS) on the Positive and Negative Syndrome Scale (PANSS). Although the sample was not homogenous on other variables such as age, education or employment, it is argued that the sample was homogenous in relation to the key aspects of the research aims i.e. experience of stigma and psychosis.

Participants were recruited to the study by the author making links with, and presenting the study to NHS services including community mental health teams and early intervention in psychosis services. Referrals were made by key workers within these services such as care coordinators or psychologists. Ethical guidelines from the National Research Ethic Committee (NREC) were followed; NREC and governance approval was sought and granted (NREC number = 10/H1014/48). Full informed consent was sought from all participants (see appendix 1 for the participant information sheet and appendix 2 for the consent form). Anonymity of the

participants was protected by assigning all participants a pseudonym and all personally identifiable data was removed from the transcripts.

The sample size was guided by Smith et al. (2009) and sampling was continued until no new themes emerged and saturation was reached (Smith, et al., 2009)

2.3.3 Qualitative interviews and analysis

Data was collected for this study via interviews with participants and in order to facilitate the interview a topic guide was developed. The topic guide (Appendix 3) was developed through a review of the existing stigma literature in particular qualitative studies. Four key areas for discussion were identified which included, (1) background to mental health experiences, (2) experiences of stigma, (3) internalised stigma including their own thoughts and feelings about themselves because of stigma and how this influences behaviour and (4) summary section to enquire which experiences had the greatest impact and an opportunity to say anything else about stigma which had not been discussed. The topic guide was used as a loose agenda for the interview. In order to conduct the interviews in line with guidance from Smith et al (2009) the participants were encouraged to talk freely about their experiences of stigma and this was reinforced by the author allowing the interview to be led by the participants, responding to the topics related to stigma that they raised. This method allowed the data obtained to driven by the participant experiences of stigma and not pre-contemplated interests of the researcher (Smith, et al., 2009). During the development of the topic guide the author sought consultation from the Psychosis Research Unit (PRU) Service User Reference Group (SURG), who met with the author to provide feedback on the suitability of the questions and the language adopted in the topic guide. Consultation with the SURG resulted in a reduction in the

number of questions on the topic guide and reinforced the guidance from Smith et al. (2009) that the interviews should be led by the participant.

Each interview was transcribed verbatim with all personally identifiable data being removed. All data analysis was carried out in line with approaches described by Smith et al (2009). Firstly, each transcript was read as a single case and a line by line analysis was carried out highlighting initial codes, these were drawn from the data and were aspects of the interview which the author considered important or meaningful. This was guided by paying particular attending to descriptive comments about stigma, linguistic comments (such as metaphors), the specific use of language in relation to stigma and conceptual comments about how the participant made sense of stigma. The transcript was read several times until emergent themes were identified from the initial codes, this was done by drawing connections between codes and attempting at all points to ground the emerging themes in the data to ensure that the process was inductive. As noted, each transcript was treated as a single case for which initial codes and emerging themes were developed, however as analysis progressed from the first transcript through to the ninth, whenever an existing theme was identified in a new transcript this was noted as recurrent. Once each interview had been analysed, the final step was looking across all nine interviews to develop super-ordinate themes which were considered to be representative of the themes across the nine cases.

2.3.4 Credibility

Examples of good practice in qualitative research include situating the sample by describing demographic characteristics, providing evidence of themes through sufficient examples from the data and providing credibility checks throughout

analysis from another researcher who is both an expert in the field and experienced in supervising qualitative research (Elliot, et al., 1999). In order to ensure the credibility of qualitative research, it is recommended that the researchers clearly state their theoretical orientations to the research (Elliot, et al., 1999).

In regards to Study 1, several steps were taken by the author to ensure credibility. Firstly, sensitivity was demonstrated when developing the topic guide and in the application of the guide. As noted above service users were consulted and it was developed in line with service user priorities, thereby being led by people with experience of psychosis and not only by the author. A number of the service user researchers have experience in carrying out qualitative research and the consultation provided was very valuable in shaping the authors approach to Study 1. The topic guide was used flexibly to ensure the interviews were driven by the participant's understanding of their experiences. Secondly, the author sought supervision from two service user researchers, following the first tape both of whom have conducted a number of qualitative studies. This allowed the author to obtain feedback on questioning style and technique and refine their approach for further interviews. Thirdly, as analysis took place supervision was sought throughout from the author's PhD supervisor who is a Professor of Clinical Psychology, expert in the field of psychosis and who has supervised a number of IPA studies. This allowed for continual credibility and validity checks on the themes as they emerged and when the super-ordinate themes were developed finalised. Fourth, an audit trail of the analysis of each transcript and the development of themes across cases was kept along with field notes and memos on the authors thoughts about the analysis. Finally, in the write up of this study, the author clearly stated their theoretical orientations as recommended by Elliot et al (1999). Given the limited word count of academic

journals, limited space was available to describe these processes within Study 1. Therefore, further attention will be paid here to the issues of reflexivity, the audit trail and credibility checks.

2.3.4.1 Reflexivity and Preconceptions

In a paper outlining the challenges and standards of qualitative research Malterud (2001) refers to reflexivity as the 'knower's mirror', in that reflexivity is concerned with the researchers awareness of the effect they may have on their qualitative research (Malterud, 2001). Reflexivity is a process which makes transparent to the reader how the researcher may have influenced the research (Malterud, 2001). Reflexivity should include identifying what preconceptions the researcher enters into the research with, their motives, background, perspectives, and preliminary hypotheses presented (Malterud, 2001).

Preconceptions brought to the project by the researcher and pre-study beliefs,

The desire to research stigma and therefore, the starting point for this thesis was an inherent concern about the impact of negative beliefs and perceptions of mental health problems on the wellbeing of people with lived experience of mental health problems. Although the focus of this thesis is psychosis this concern is in relation to all mental health problems. It is my personal opinion that the negative treatment of others because of stigma is a moral challenge to our society. Therefore, the most basic preconception I held was the belief that stigma is negative. My preconceptions about stigma and psychosis prior to the design and implementation of Study 1 may have been influenced by a review of the literature on stigma, which was undertaken as part of my PhD studies. This involved an in-depth review of stigma models, perspectives for reducing public stigma, the effects of stigma on wellbeing and also

the role of internalised stereotypes on depression and social anxiety. Finally, personal experience of mental health stigma has contributed to the personal perspective that public and internalised stigma is potentially damaging to wellbeing, self-concept and recovery.

As noted above a pre-study belief, based on previous quantitative research is that stigma is a threat to self-identity (Major & O'Brien, 2005) and that stigma can act as a second 'illness' (Schulze & Angermeyer, 2003). The second aim of this thesis was to explore associations between internalised stigma and emotional dysfunction in people at risk of developing psychosis and people with lived experience of psychosis not taking antipsychotic medication. Therefore, a number of empirical studies exploring these associations in other psychosis groups had been reviewed and there was a clear indication from the literature reviewed that internalised stigma was associated with depression, social anxiety, demoralisation, loss of empowerment and lowered self-esteem. Furthermore, pre-study beliefs about the effects of stigma on well-being may have been influenced by a review of the research evaluating associations between internalised stigma, which indicated that internalised stigma can result in a number of negative outcomes such as lowered self-esteem.

2.3.4.2 Validity checks and audit trail

An audit trail of initial codes and themes was achieved through the use of qualitative analysis software QSR NVivo9. All transcripts were imported to and stored in QSR NVivo9. During the initial phase of the analysis when a line by line analysis of the transcripts was taking place to develop initial codes, 'free nodes' were created in QSR NVivo9 for each code. Through this process, each node was then connected to

the corresponding section of transcript creating a clear audit trail between the initial codes and the data. Data can easily be identified and retrieved by selecting a node. Following the initial line by line analysis of each transcript, nodes were then reviewed to identify connections between nodes, which represented emerging themes. Free nodes which were considered related were organised into tree nodes. As with free nodes all tree nodes are linked to the relevant sections in the transcripts allowing easy access to the data that corresponds to the themes, thus creating a clear audit trail.

Once emerging themes were identified within each transcript these were discussed with the author's clinical supervisor who is a Professor of Clinical Psychology and who has supervised a number of IPA studies. The purpose of supervision was to review section of the transcripts associated with the emerging themes as a validity check on interpretations applied by the author. Additionally the memo function of QSR NVivo9 was used to record and review the authors thought processes and observations when analysing the data.

For practical reason the next stage of the analysis which involved reviewing the emerging connections between each of the cases and developing super-ordinate themes, apaper and pen method was used to organise the sections of transcripts. This involved physically copying and printing all of the relevant sections of transcripts from the nine cases and through discussion with the supervisor this was then organised into master and super-ordinate themes. The author was primarily responsible for interpretation of the data and organisation into master and super-ordinate themes. However, at three points in the analysis these were reviewed with the supervisor until agreement was reached that the structure of themes was based in the data. At each stage the organisation of the transcripts into master and super-

ordinate themes were recorded in supervision notes and the paper and pen version of the structure was stored in a secure NHS office.

2.3.5 Strengths and limitations

The strengths of qualitative research in attending to the subjective and contributing to the field of psychology have been debated (Nicholson, 1995). Whilst descriptions of how it feels to experience a particular event or situation are central to clinical work, a predominately positivist approach to research in social psychology, psychology and other related health fields has left little room to attend to the subjective when carrying out research. It has been reasoned by some that adopting a purely positivist approach to research which centres on hypothesis testing may result in less clinically relevant findings for the person who experiences the mental health difficulty, as the aims are researcher driven (Nicholson, 1995). It has been argued there is strength in investigating the subjective, including setting directions for future research and ensuring that research is led by those it is intended to help (Nicholson, 1995). In psychosis research, Geekie and Read (2009) provide a review of subjective research in psychosis and suggest this is a relatively neglected area and they propose this is a key area for better understanding issues in psychosis (Geekie & Read, 2009). Furthermore, in relation to stigma and psychosis there is only one other study, to the author's knowledge, that has attempted to understand the subjective experience of stigma using IPA (Knight et al., 2003). From this research, Knight et al. (2003) concluded that IPA is an effective tool in understanding stigma. Therefore, the author of this thesis argues that there is a sufficient research gap to continue the

initial work carried out by Knight et al (2003) in another sample of people with experience of psychosis.

There are limitations to qualitative research notably the small sample size and purposive sampling which limits generalisability of the findings to other populations. IPA acknowledges the double hermeneutic and steps can be taken to improve the credibility of themes developed in qualitative research, however it should be acknowledged that the interpretations made by the researcher can be biased and this is a limitation.

2.4 Quantitative methodology across the continuum of psychosis

The purpose of this section is to provide the reader with a detailed account of the methods used in Studies 2-4 which span two groups on the psychosis continuum.

2.4.1 Cross sectional design

Cross sectional design involves drawing one or more samples of data from a population at any one time (Shaughnessy, Zechmeister & Zechmesiter., 2000). This may involve the use of questionnaires or interviews at a given time. Through the application of statistical testing, in particular correlational tests, inferences can be made about the relationship between any variables. A correlation will assess the degree to which two variables co-vary with each other and the direction of the relationship; for example, positive (as one increase so does the other) or negative (as one increases the other decreases). Correlational analyses will also indicate the magnitude to which two variables co-vary, with 1 being a perfect relationship and 0 being no relationship at all (Field., 2009). One of the key limitations to this type of design is that it does not allow inferences to be made about the cause of the

relationship and it does not account for other factors or variables which have not been measured and which may influence the relationship (Field., 2009; Ployhart & Vandenberg., 2010; Shaughnessy et al., 2000). Therefore, this type of design is often used to explore for interesting relationships between variables in order to justify further investigation using a longitudinal design. In relation to studies 2 and 3, a cross-sectional design was used to explore for correlational relationships between internalised stereotypes of psychosis and several other variables including depression, social anxiety and symptoms along the psychosis continuum (as measure by the Comprehensive Assessment of At Risk Mental States in Study 2 and the Positive and Negative Syndrome Scale in Study 3). This data was gathered at baseline assessment (time 1). In relation to Study 4, cross-sectional comparisons were made between people who are considered to be at risk of psychosis and those with established psychosis on stigma variables measured by the Personal Beliefs about experiences questionnaire (PBEQ).

2.4.2 Longitudinal methods

The purpose of a longitudinal design is to sample the same participants at different time points, as opposed to cross-sectional designs which sample the same participants at one point in time. One of the main strengths of longitudinal design is it allows an assessment of change in participants scores over time and variables measured at one time can be used to predict scores at another time (Field., 2009; Shaughnessy et al., 2000). This is of particular benefit as often variables cannot be manipulated for ethical reasons (Field., 2009). It is recognised that longitudinal research is often limited by the commitment required by participants to engage in assessments over a long period of time and, therefore, attrition can be problematic. In

the context of this thesis, a longitudinal design was adopted for Study 2 in which variables were measured at baseline (time 1) and 6 month follow-up (time 2). Longitudinal design was also used in Study 3, variables were measured at baseline (time 1) and 3 month follow-up (time 2). Data was used at these time points to test whether the predictor variables significantly contributed to the variance in the outcome variables over time. Baseline level of the outcome variable was controlled for in both Studies 2 and 3. Predictor variables were selected on the basis of the research question, significant relationships identified in the cross-sectional correlational analyses carried out with baseline data and the existing stigma literature (Birchwood., 1993; Birchwood et al., 2005; Rooke & Birchwood., 1998; Birchwood et al., 2006; Karatzias et al., 2007).

2.4.3 Key Measures used in studies 2, 3 and 4

Across studies 2, 3 and 4 there are common measures used.A summary of these measures is provided below.

Personal Beliefs about Experiences Questionnaire

The PBEQ is measure of internalised stereotypes of psychosis which was used across Studies 2, 3 and 4. An outline of this measure and justification for the use of this questionnaire as the measure of stigma selected for these studies will be provided as the author recognises that there is number of stigma measures available as outlined in Chapter One.

The PBEQ is a revised version of the Personal Beliefs about Illness Questionnaire (PBIQ) which was developed to measure the extent to which people with psychosis endorse stereotyped appraisals of psychosis. The original version of the PBIQ had 5 subscales including perceived control over illness; internalisation

and acceptance of stigma; acceptance of lowered social position or containment; anticipated loss of expectations; and self as illness. The PBIQ has been shown to be a reliable measure (Birchwood, et al., 1993). On the basis that the PBIQ was developed as a specific measure of socio-cultural stereotypes of psychosis and consideration that other stigma measures available have been not developed specifically for use in psychosis populations, the PBIQ was considered to have good face validity and the most appropriate measure for use in the at risk of psychosis and the un-medicated psychosis population recruited to Studies 2-4. Furthermore, the research questions in Studies 2-4 were concerned with associations between internalised stereotypes and emotional dysfunction in people at risk of psychosis and those with established psychosis not taking anti-psychotic medication. A series of studies in the literature have explored the relationships between internalised stereotypes and emotion using the PBIQ therefore, adopting this measure for the studies 2-4 allowed for direct comparisons to be made with previous relevant research (Birchwood, Iqbal, et al., 2000; Birchwood, et al., 2005; Birchwood, et al., 1993; Birchwood et al., 2006; Karatzias et al., 2007).

In order to use the PBIQ in an at risk of psychosis population the measure was revised in two ways. Firstly the word illness was removed as this was considered to be a potentially stigmatising term in particular for young people at risk of psychosis who may not identify with the concept of 'illness'. Secondly, three items were removed from the PBIQ to produce the PBEQ, these items were: (1) my illness is too brittle or delicate for me to work or keep a job, (2) I will always need to be cared for by professional staff, and (3) If I am going to relapse, there is nothing I can do about it. With the at risk it was considered that these items were not valid for

this group. The revised version of the PBIQ, namely the PBEQ was considered the most appropriate measure for studies 2, 3 and 4.

The PBEQ, as a revised version of the PBIQ had not been validated in either at risk of psychosis or psychosis sample and therefore it is acknowledged that this is a potential limitation to this measure. In order to address this limitation principle component analysis and reliability testing of the PBEQ was carried out with both samples (see appendix 4 for a copy of the PBEQ).

The Beck Depression Inventory for Primary Care

The Beck Depression Inventory for Primary Care (BDI; Winter, Steer, Jones-Hicks, & Beck, 1999) is a 7 item questionne which was developed to screen for depression and was amended from the Beck Depression Inventory. The BDI-PC is used as a secrrening tool for self-reported depression in young people who are help seeking and was it was therefore particularly applicable for the EDIE 2 population (Winter, et al., 1999). The BDI-PC reflects diagnositc criteria for Major Depressive Disorder (MDD) and measures sadness, loss of pleasure, pessimis, past failuer, self dislike, self criticalness and suicidal thought, behavours or wishes (Winter, et al., 1999). Each of the 7 items are measured on a 4 point rating scale from 0-4. As a brief measure the BDI-PC is desirable for use in research to minimis particpant burden. The BDI-PC has been shown to have high internal consistency. See appendix 5 for a copy of the BDI-PC.

Social Interaction Anxiety Scale

The Social Interaction Anxiety Scale (SIAS; Mattick & Clarke., 1998) is composed of 20 items which related to a number of anxieties people may encounter in social

situations and participants are asked to rate the degree to which they feel each of the 20 statements are true for them from 0 (not at all) to 4 (extremely).

The SIAS has been shown to be a reliable and valid measure, with initial testing demonstrating high levels of internal consistency and test-retest reliability (Mattick and Clark., 1998). Subsequently, the SIAS has received extensive validation (Peters, 2000). Other measures of social anxiety are available, for example the Social Phobia Scale (Peters, 2000) and the Social Phobia and Anxiety Scale (SPAI), however as previous research in the area has used the SIAS to measure social anxiety, the SIAS was adopted for Studies 2-3 to provide a comparison of the results to the literature (see appendix 6 for a copy of the SIAS).

The Positive and Negative Syndrome Scale

The Positive and Negative Syndrome Scale (PANSS) was developed by Kay, Fizbein & Opler (1987) to address the limitations of the measures which at the time were utilised for assessing schizophrenia; in particular, the retest reliability and construct validity of the Assessment of Positive Symptoms (SAPS) and Assessment of Negative Symptoms (SANS) (Kay, Opler, Lindenmayer., 1988). It was also argued that these measures confused some of the positive and negative constructs and did not assess general psychopathology (Kay et al., 1988).

The PANSS was developed as a semi structured interview to assess 7 positive, 7 negative and 16 general symptoms of schizophrenia. Each of the 30 items is rated based on a description specific to that item and a rating from 1 – 7 is allocated for each item, with the ranges running from 1 as absent to 7 as extreme. The PANSS demonstrates good internal reliability for the positive subscale ($\alpha = .73$), negative subscale ($\alpha = .83$) and the general subscale ($\alpha = .79$) (Kay et al., 1987). The

PANSS also demonstrates good test-retest reliability for the positive subscale ($r = .80$), negative subscale ($r = .68$) and general subscale ($r = .60$) (Kay et al., 1987). Construct validity for the three subscales with a range of measures of psychopathology has been demonstrated (Kay et al., 1987).

The Comprehensive Assessment of At Risk Mental States

The Comprehensive Assessment of At Risk Mental States (CAARMS) was developed by Yung et al. (2005) to identify young people who are at ultra-high risk of developing psychosis. Ratings are made on a range of subscales that target different areas of psychopathology and functioning. The subscales on the CAARMS are as follows, (1) Unusual Thought Content such as concerns about thoughts being read, (2) Non-Bizarre ideas such as persecutory or suspicious ideas, (3) perceptual changes covering visual, auditory, olfactory, gustatory, tactile and somatic, (4) Disorganised Speech, (5) Aggression and Dangerous behaviours and (6) Suicidality and Self Harm. Each of these 6 scales is provided with a severity rating from 1-6, a frequency and duration rating from1-6 and a distress rating from 0-100 (with 100 being the most distressed). Intake criteria for meeting threshold on the CAARMS is via one of three routes, (1) state plus trait factors first degree family member with a psychotic disorder OR Schizotypal Personality Disorder plus a drop in functioning, (2) the attenuated symptoms route, or (3) the Brief Limited Intermitted Psychotic Symptoms (BLIPS).

The purpose of this measure in Studies 2 and 4 was firstly to identify young people at risk of psychosis and secondly to explore for possible relationships between internalised stereotypes of psychosis and symptoms on the CAARMS.

The CAARMS has been extensively validated and has demonstrated good to excellent reliability and validity (Yung et al., 2005).

2.4.4 Recruitment and sampling strategy across studies 2, 3 and 4

2.4.4.1 Recruitment strategy

Participants for Study 2 were recruited to the Early Detection and Intervention Evaluation Trial 2 (EDIE 2), which was a 36 month randomised controlled trial (RCT) of Cognitive Therapy plus Treatment as Usual (TAU) vs. TAU alone. EDIE 2 was funded by the Medical Research Council (Grant reference = G0500264) and participants were recruited from five sites in the UK namely, Cambridgeshire, Manchester, Glasgow, Birmingham and Norfolk. EDIE 2 was a registered trial with the ISRCTN (ISRCTN number = ISRCTN56283883). The participants were recruited from a range of statutory and non-statutory services. NHS services included Primary Care Mental Health Teams and General Practitioners and non-statutory agencies included young people's mental health charities, housing services and drug services. Recruitment involved making links with these services, presenting and promoting the trial and liaising with these services to obtain referrals (for a full review of the referral pathways into the EDIE 2 trial see Morrison, Stewart, French, Bentall et al, 2011). The author was an assistant research psychologist employed on the EDIE 2 trial for the full duration of the trial and was directly involved with recruitment for Study 2 and Study 4. The author was responsible for approximately 15% of the baseline assessments and was responsible for completing the measures at follow-up for approximately 15% of the participants.

Participants for Study 3 and the psychosis sample in Study 4 were recruited as part of the Assessment of Cognitive Therapy Instead of Psychosis (ACTION). ACTION was a randomised controlled trial of Cognitive Therapy plus TAU vs. TAU

alone for people with experience of psychosis who have chosen not to take antipsychotic medication. The ACTION trial was funded through the National Institute for Health Research (NIHR) via the Research for Patient Benefit (RfPB) programme (Grant number = PB-PG-1208-18053) and was registered with ISRCTN (number = ISRCTN29607432). Participants for the ACTION trial were recruited from two sites in the UK, the Northeast and the Northwest. The Northeast site covered two NHS trusts and the Northwest covered six NHS Trusts. The participants were recruited from mental health services within these trusts via liaison with services to present and promote the trial and clinicians from these services made referrals for participants. The author was the trial manager for ACTION for the duration of the trial whilst registered for this PhD. Therefore, the author played a central role in the development of the recruitment strategy and provided on-going trial management support through weekly supervision with research assistants. This included problem solved recruitment difficulties, modifying the recruitment strategy in response to recruitment rates, supporting the delivery of the research assessments by ensuring participants met inclusion criteria and providing weekly supervision to research assistants regarding deliver and rater reliability of the measures. The author was also directly involved in liaison with clinical services and recruitment through presenting to staff in NHS services, raising the profile of the study within participating NHS trusts.

2.4.4.2 Sampling strategy

The participants recruited for Studies 2-4 were required to meet very specific criteria for either at risk of psychosis or psychosis. Furthermore, due to ethical and governance reasons it is not possible to obtain lists of people who meet these criteria from services and randomly screen for participants. Participants who provided

informed consent and met the inclusion criteria were recruited and therefore the sampling strategy for both of these studies was a convenience sample. It is recognised that the nature of these samples are self-selecting, which is a limitation and which may introduce bias. These limitations are reflected in the discussion at the end Chapters 3 – 5.

2.4.5 Statistical procedures

In order to allow for statistical analyses to take place the PBEQ was validated for use with the group meeting criteria for ARMS and for use with the psychosis sample. In both cases the sample size was considered adequate for principle component analysis (Field, 2009) and procedures in SPSS were used to ensure sampling adequacy and sphericity was tested. Factor extraction was determined by visual inspection of the Scree plot as well as eigenvalues; where the sample size was adequate the Scree plot was used to determine the number of factors to extract this method was used, where the sample was lower in the psychosis group eigenvalues over one were retained (Kaiser, 1974). Oblique (direct oblim) rotation was selected on the assumption that the factors, as all related to some version of cultural stereotypes of psychosis are likely to be related (Field, 2009).

Where there were less than 25% of items missing from a measure, then pro-rating was used to calculate missing items. Where data for total or subscale totals were missing this data was treated as missing by SPSS in the statistical analyses. Prior to statistical tests being carried out, data was checked to ensure it met parametric assumptions. Distribution of data was analysed using visual inspection of the normal plot and values of skewness and kurtosis. Where data did not meet parametric assumptions non parametric tests were used. The main statistical procedures employed to address research aims 2-4 were cross-sectional correlational

analyses between internalised stereotypes and other psychological variables at baseline. Multiple regression analyses was used to determine the amount of variance internalised stereotypes contributed to depression and social anxiety over time with internalised stereotypes, depression and social anxiety scores at baseline as predictor variables and depression and social anxiety scores at follow up as outcome variables. Hierarchical (blockwise entry) regressions were used based on the assumption that the baseline level of emotional dysfunction would be the best predictor of emotional dysfunction over time; baseline depression or social anxiety was always entered on the first step followed by internalised stereotypes. Collinearity diagnostics were reviewed in each analysis. *t*-Tests and Analysis of Covariance (ANCOVA) were used to test difference in means across groups, either two or three groups respectively.

Power calculations

Analyses carried out for Studies 2, 3 and 4 were secondary analyses from the EDIE 2 and ACTION trial and the sample size for these studies was determined by the power calculations which were performed for the main analyses of these trials. The sample size for the analyses carried out in Studies 2, 3 and 4 were therefore restricted by the main trial power calculation and recruitment. There are notable limitations associated with post hoc power calculations and it is argued that they are not an indicator of prospective power (Zumbot & Hubley., 1998). Therefore, post hoc power calculations were not carried out; however the confidence intervals have been reported for each of the analyses.

2.4.6 Ethical considerations

National Research Ethics Committee and local NHS Research Governance Approval

NHS National Research Ethics Committee approval was given for both EDIE 2 (05/MRE05/61) and for the ACTION Trial (09/H1014/53). In order to access NHS participants in local services Research Governance approval was given.

Informed consent and capacity to consent

Participants were clearly informed of what taking part in the research would involve and were provided with a participant information sheet about the research study. The participant was given time to read the information sheet; they were encouraged to ask questions and discuss any concerns they might have about taking part in the study. Full informed consent was taken from each participant (see appendix 7 for ACTION Trial PIS; appendix 8 for ACTION Trial consent form; appendix 9 for the EDIE 2 PIS; appendix 10 for the EDIE 2 consent form).

Managing participant distress

It was recognised that participants may be concerned about whether or not to take part in the research studies. This was managed by making all participants aware that they are under no obligation to participate and that their decision about taking part did not affect their standard treatment or care. The participants were also informed that if they did choose to participate in the research studies were free to withdraw at any time without having to provide an explanation and that the decision to withdraw did not affect their standard treatment or care.

. Both the EDIE 2 and ACTION trial involved a number of assessments for the participants and there was a potential risk that participants could find the number of

measures distressing and/or tiring. Where clients experienced distress in relation to answering questions/talking about their experience distressed was managed by discussing any issues which had been raised, reminding participants that completing the measures is voluntary, applying clinical skills of empathy and where necessary signposting the participant to appropriate support services.

All participants in EDIE 2 and ACTION were provided with crisis cards detailing help line support numbers and information on how to contact their GP/ key worker or care coordinator. At the end of each assessment participants were asked if they were OK and any issues were managed as outline above. Furthermore, to reduce burden the participant was asked if they would like a break half way through or to split the assessment. To reduce any inconvenience to the participant, all of the assessments were completed at a non-stigmatising and convenient location for the participant.

2.5 Methodology used to explore the effectiveness of psychosocial interventions for psychosis stigma in young people

2.5.1 Randomised controlled trial (RCT)

Randomised Controlled Trials (RCT) are often referred to as the 'gold standard' in determining treatment effectiveness (Byar, et al., 1976) and have been referred to as the most rigorous methodology to determine a cause and effect relationship between an independent and dependent variable (Sibbald & Roland, 1998). The methodology of a RCT contains several key features: random allocation of participants to intervention groups, independent assessor or blind assessment of outcome, identical treatment of all experimental conditions and an intention to treat analysis.

Randomised controlled trials of stigma interventions with young people are rare and often when carried out the methodology used is cluster RCT due to the environment in which the study is being carried out i.e. schools, colleges or universities. In such institutions it is often difficult to assign students to an intervention at the individual level therefore allocation at the group or class level is usually adopted to manage this practical difficulty. However, there are significant limitations to using cluster RCT as they require more complex statistical procedures due to the violation of assumed independence of the data (Field, 2009; Murphy, Esterman, & Pilotto, 2006). In order to address this limitation Study 5 adopted a RCT design with randomisation at the individual level. Participants were randomised to one of two experimental conditions or the control condition. As noted, randomisation was done at the individual level; it was not stratified or carried out in permuted blocks.

2.5.2 Measures of public stigma

As discussed in Chapter One, there are a number of measures available for evaluating public stigma (Link, et al., 2004). In order to inform which measures were suitable for Study 5 the author reviewed previous stigma intervention studies (Campbell, et al., 2010; Chan, et al., 2009; Pinfold,et al., 2005; Pinfold, et al., 2003; Schulze, et al., 2003) to select measures based on the relevance to the research question, the validity, the reliability and the feasibility of use with young people i.e. appropriate language. Supervision was sought from Professor Anthony P Morrison.

Four subscales from the Corrigan's Attribution Questionnaires (CAQ) were selected as previous research has demonstrated reliability for these four subscales as an overall measure of discrimination (Campbell, et al., 2010). The attribution questionnaire was completed in combination with a vignette regarding a man named

Harry who suffers from schizophrenia. There are four versions of this vignette which vary in the degree to which they indicate dangerousness and controllability of schizophrenia; a limitation to using these vignettes is that they are hypothetical pieces of information, which may not represent real world examples of mental health problems. Use of overtly positive or negative vignettes may act as confounding variable in intervention research, therefore for the purpose of the study presented in chapter seven the neutral vignette was selected to minimise possible confounds (see Appendix 11).

A measure of stereotypes and a measure of intended social distance from people with psychosis, which were developed specifically for use with young people (Schulze et al., 2003), were used in Study 5. Both of these measures were adopted from a study of interventions for stigma in young people (Schulze, et al., 2003) and therefore were considered to have good face validity for the sample recruited in Study 5. Whilst measures of social distance show good reliability (Schulze et al, 2003), the author recognises that a limitation to their use is social desirability bias, and therefore an under reporting of actual intentions (Link et al, 2004).

The three questionnaires used in Study 5 were self-report and did not require an assessor to complete them, thereby limiting potential bias from an independent rater. To minimise social desirability effects all questionnaires were anonymous and each participant complete the study on an individual personal computer (see Appendix 12).

2.5.3 Power calculation and Statistical analyses

An a-priori power calculation was carried out using GPower3 (Faul, Erdfelder, Lang, & Buchner, 2007). With an expected medium effect size of .30 based on previous research (Campbell et al., 2010), the power calculation indicated that a total sample

size of 111, using a F-test with a significance level of 0.05, would provide 80% power to detect an effect size of .30.

Where there were less than 25% of items missing from a measure, pro-rating was used to calculate missing items. Where data for total or subscale totals were missing this data was treated as missing by SPSS in the statistical analyses. Prior to statistical tests being carried out, data was checked to ensure it met parametric assumptions. Distribution of data was analysed using visual inspection of the normal plot and values of skewness and kurtosis. Where data did not meet parametric assumptions non parametric tests were used i.e. in the case of the outcome variable discrimination. Differences between the three groups on the outcome variables were analyses at end of treatment (time 2) and at 3 month follow up (time 3) using analysis of variance (ANOVA).Mixed models was used to evaluate whether the change in the outcome variables over time was significantly difference between the three groups.

2.5.4 Ethics

Ethical approval was received from the University of Manchester. The author attended the college a week before the Study commenced to inform the students about the study, provide them with an information sheet and encourage them to ask questions about the study (see appendix 13). Participants were able to consent for themselves as they were all over the age of 16. However, the students were given an information sheet for parents, to provide parents with an opportunity to find out more about the study. The students all had a full week to consider their participation and informed consent was provided by all who participated (see Appendix 14). The author was on hand after each session to answer any questions or concerns which

participants had about their involvement in the study or any topics which were

raised.

Chapter 3 Study 1 - It's just a very taboo and secretive kind of thing really': making sense of what it is like to live with stigma and discrimination from the accounts of nine people with experience of psychosis

'It's just a very taboo and secretive king of thing really': Making sense of what it is like to live with stigma and discrimination from the accounts of nine people with experience of psychosis.

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3.1 Abstract

Stigma is a common and pervasive problem for many people with psychosis. Much of the research examining internalised stigma has utilised quantitative methodology; however, it has been argued that to conceptualise experiences of psychosis research should also attend to subjective experience. This study explores accounts of stigma from nine people with psychosis through semi-structured interviews that were analysed using Interpretative Phenomenological Analysis (IPA). Three super ordinate themes of judgement, disclosure and psychological distress were identified. Analysis of the data found that stigma was experienced directly and indirectly through social judgements. In particular, it was considered that negative messages and the absence of positive images of psychosis in the media perpetuated social judgements. Difficulties were reported in relation to disclosure, including avoidance from others following disclosure and coping strategies to conceal experiences of psychosis. Ultimately, judgement and issues of disclosure had a negative impact on psychological wellbeing, either contributing to or resulting in psychological distress, including increased paranoia, anxiety and lowered self-esteem. Potential exits from the negative effects of stigma, including peer support were identified in the data. Implications for future research and clinical practice, including interventions to reduce internalised stigma, are suggested.

3.2 Introduction

Erving Goffman defined stigma as the association of a 'sign' or 'mark' with negative attributions, resulting in a stigmatised individual becoming discredited from society (Goffman, 1963). Stigma, both experienced and internalised is considered to be comprised of cognitive, emotional and behavioural components, and public stigma has recently has been conceptualised in terms of problems of knowledge, attitudes and behaviours (Thornicroft, 2007).

The incidence of anticipated, experienced and internalised stigma is high for people who have experience of psychosis (Brohan, et al 2010; Thornicroft, et al 2009). Stigma can discourage people from seeking help early thereby delaying access to treatment (Link, Struening, Rahav, Phelan, & Nuttbrock, 1997; Thornicroft, et al., 2009), acts as a mechanism for social exclusion, hampering recovery (Link, Struening, Neese-Todd, Asmussen, & Phelan, 2001; Link, et al., 1997; Ritsher & Phelan, 2004), reduces employment and education opportunities (Link, et al., 1997; Thornicroft, et al., 2009) and results in poorer physical healthcare and higher mortality rates (Thornicroft, et al., 2007). Much of this research has adopted quantitative methodology. However, it has been argued that the study of human experience should utilise not only quantitative but also qualitative approaches in order to fully understand the range of human experience (Lieberman, 1989; Nicolson, 1995).

Qualitative research in psychosis is relatively neglected, which may limit conceptualisations of psychosis (Geekie & Read, 2009). In relation to stigma and psychosis there are a small number of first person accounts and qualitative studies looking at how stigma is experienced by the individual with psychosis and also their

families (Dinos, et al., 2004; Gallo, 1994; González-Torres, et al., 2007; Knight, et al., 2003; Schulze & Angermeyer, 2003). Interpretative Phenomenological Analysis (IPA) is an approach to qualitative research analysis that has been utilised by one previous study exploring the experience of stigma relating to psychosis (Knight, et al., 2003). This methodology is concerned with the individual's account of an event whilst recognising that accessing this understanding is only possible through interpretation of the data through analysis (Smith, 1996). Using IPA, Knight et al. (2003) identified three super ordinate themes of judgement, comparison and personal understanding of psychosis. The authors concluded that stigma was complex, experienced on intra and interpersonal levels, spanned perceptions of the self across time and that IPA was an effective tool to understand issues in psychosis (Knight, et al., 2003).

We aim to further contribute to, and expand understanding of stigma and discrimination experienced by people with psychosis from the perspective of the expert through the use of IPA, and to inform directions for future research and intervention.

3.3 Method

3.3.1 Participants

Participants for this study were recruited via mental health services across Greater Manchester in the United Kingdom. The inclusion criteria were that participants should be aged between 16 and 65, either have an ICD-10 Schizophrenia Spectrum diagnosis or meet entry criteria for Early Intervention in Psychosis Services.

Four men and five women participated in this study and the mean age was 23 years old (range 19 - 54). Diagnoses were Schizophrenia (N = 6), Schizoaffective Disorder (N= 1) and Psychosis not otherwise specified (N = 2). The ethnicity of the sample was white British (N = 8) and Asian (N = 1). Four of the participants were in education, training or employment.

The sample was homogenous in having experienced psychosis i.e. all had to have received a diagnosis of or be in a service for psychosis although homogeneity was not achieved in respect to age. The sample size was selected on the basis of guidance from Smith et al. (2009) and recruitment continued until saturation of themes had been achieved.

3.3.2 Procedure

3.3.2.1 Data collection

Ethical approval was granted from the National Research Ethics Committee. Semi-structured interviews were conducted with each participant, lasting between 50 to 80 minutes. A topic guide was developed to provide a framework for the interviews, however to ensure that the interview was grounded in the participants experiences

the topic guide was used as a guide only. Key areas on the topic guide were participant's experience of their own mental health problems, understanding of stigma and of discrimination, their personal lived experiences of stigma and discrimination and their own self-perception in relation to the stigma. These topics related to the participant's personal experience of stigma in relation to their own mental health difficulties. This could relate to experiences with others such as family, friends and mental health professionals as well as their own thoughts about themselves. The interviews were carried out and transcribed by the first author. All transcripts were anonymised using pseudonyms and any personally identifiable data was removed.

3.3.2.2 Data analysis

The transcripts were analysed by the first author and the second author provided credibility checks. Data analysis followed the procedures from Smith et al (2009); the first transcript was read and re-read to allow the first author to engage with the text and develop initial codes which were reviewed and developed into emergent themes. This process was carried out with each transcript until each had a list of master and super-ordinate themes. Each transcript was read separately in turn however, there were some initial codes and emergent themes that were recurrent and in these instances these themes were listed as recurrent. Each transcript was reviewed when new super-ordinate themes emerged.

3.3.3 Credibility

In order to allow the reader an understanding of the author's interpretations of the data we state our research and clinical background. The author's research interests are the influence of internalised stigma on the development and maintenance of

additional psychological problems for people with psychosis, in particular research regarding depression and social anxiety. Working on several trials of cognitive therapy for psychosis, the cognitive model of psychosis has been influential in the author's research. However, in order to address any potential bias the interview topic guide was flexible, allowing interviews to be led by participants. The analysis was inductive and credibility checks were performed by the second author. An audit trail of decisions at each stage of analysis was kept.

3.4 Results

The super ordinate, master and subthemes are discussed below and presented Table 1.

Table 1: Study 1 Thematic Structure

Super-ordinate theme	3.4.1. Judgement	3.4.2. Disclosure	3.4.3. Psychological distress and possible exits
Master themes Sub themes	**3.4.1.1 Stereotypes** Fear Unpredictability Figure to mock	**3.4.2.1 Avoidance from others**	**3.4.3.1 Psychological distress related to disclosure** **3.4.3.2 Psychological distress related to judgement**
	3.4.1.2 Media as a primary source of judgement Images of violence Absence of positive images	**3.4.2.2 Concealment** Fear of exposure Less stigmatising terms	**3.4.3.3. Possible exits from psychological distress:** Acceptance Peer support
	3.4.1.3 Lowered social status Comparison to those without mental health problems Comparison to other Discredited	**3.4.2.3 Isolation** Rejection from others Personal avoidance of others	
	3.4.1.4 Multiple Judgement		

3.4.1. Judgement

Judgement was a clear super ordinate theme, participants outlined concerns of judgement in respect to others perceptions about psychosis and this was reflected in discussions about both close social networks and wider public perceptions.

3.4.1.1 Stereotypes

Of particular concern was how perceptions are shaped through stereotypes. All participants expressed concern about the influence of stereotypes on stigma. Jack reported that:

"If you mention that you have had psychosis then they think you are some kind of axe murderer or serial killer or something like that rather than being...kind of someone that has run into difficulties in their life, that they have a stress based illness so to speak".

The above quote is illustrative of the stereotypes that those with psychosis are people to be feared. In addition to this other common stereotypes that were seen as problematic by the participants were unpredictability and as someone who is to be mocked. Caroline explains how people with psychosis may be judged to be a source of amusement:

"You see people who will say...walk about quite like normal people will walk around with T-Shirts that have 'I hear voices and they don't like you' and it's like...oh my god it is not funny".

3.4.1.2 The media as a primary source of judgement

Concerns about negative content in the media and the perpetuation of stereotypes through the media were evident throughout the interviews. The media was described as a tool through which images of violence are reinforced. Jenine summarises how the media perpetuates the stereotype of danger, and that it is a primary source of education about psychosis for the public:

"A lot of people are not educated about schizophrenia, so they read in the paper 'schizophrenic has killed somebody' and in their mind they are thinking schizophrenia is really bad".

Alongside the media as a source of negative perceptions there was concern that the media did not provide hope or positivity about psychosis that there was an absence of positive images. Peter describes the absence of information which indicates people with psychosis do normal everyday things such as having intimate relationships and taking care of their children:

"You read in the papers all the time 'oh this guy just got out of hospital and he went and killed 3 people or whatever, you know what I mean? You read about it all of the time. I mean you don't see people… a story in the paper saying, 'Peter had a mental health problem for 12 months and he is all better now and he is living happily ever after and met someone and is doing a lot more with his son and doing great, you don't see that in the Sun or the News of the World, it's all grim and bad news and it's all the bad side of mental health".

3.4.1.3 Lowered social status

A theme of lowered social status was identified which related to the sense that those with psychosis were judged to be a lesser member of society. This occurred through direct experiences of stigma and discrimination and through the internalisation of

negative social attitudes. Comparisons of status were made to those without mental health problems (1.3.1); Lisa describes feeling second class in comparison to those without psychosis:

"I don't know, they [people with psychosis] are not seen as equals and having the same rights as normal people [...] as much as I have been educated about it because I have educated myself and I have gone to [name of charity], so I know a lot about psychosis I know as much as I can…so I try and educated my mum and dad and stuff like that...but I still feel like a second class citizen. I don't feel accepted".

Comparison of status was also made in relation to people with other mental health problems with concerns from participants that psychosis is seen as one of the 'lowest class' of mental health problems. John explained that:

"Most of my friends were suffering from depression or manic depression at first and I felt like they thought they were better than me because they were a depressive and I was a schizophrenic and that they weren't as bad as me".

In addition to reporting concerns about loss of social status and as a result of this, participants described a sense that they were discredited (1.3.3) by other people including family members, health professionals, work colleagues and friends. Amber explains:

"I was frustrated because I was like 'believe me I am not stupid. I know I may have acted in a stupid way but that wasn't my fault and I know that I haven't done it [taken illicit substances] and they...it was annoying because they kept saying it to me...but in the end they believed me...I think".

Here in this quote, Amber describes not being listened to or believed by health professionals, but experiences of being discredited were also described as people with psychosis being treated as children and infantilised.

3.4.1.4 Multiple Judgements

Whilst judgement was reported in relation to psychosis participants also considered other personal attributes to be stigmatised. These were described sometimes to be a consequence of psychosis such as being unemployed, being on benefits and being single. However, additional diagnoses and religious beliefs were also considered to be judged negatively and these negative attitudes were enhanced once others were aware that the person also had experience of psychosis. Isaac described:

"There is a lot of phobia towards Islam…I suppose a person who is sane or able to use reason it might not affect them so much but I feel a lot more affected. I don't like to go somewhere that I find the surroundings very different".

3.4.2. Disclosure

Disclosure of diagnosis to other people was expressed as a concern both for those who had direct experience of disclosing their diagnosis and for other participants who anticipated negative consequences from disclosing. Problems relating to disclosure arose from external sources such as friends and family, but also from internalised stigma. Issues relating to disclosure maintained a sense that psychosis is a 'taboo' subject.

3.4.2.1 Avoidance from others

Participants reported avoidance from friends and family following a disclosure of diagnosis. Often, this was reported to be due to other people being unsure of how to

approach the subject or to talk about psychosis, and contact could become indirect through one key family member. Isaac explains:

"People don't like to associate with those who have got this illness, because err, it's not...it's not like if a person has a physical illness...you can approach them and ask them how they are, but they are very wary of people who have got mental illness".

3.4.2.2 Concealment

A theme of concealing diagnosis from other people including close family and friends to wider social networks, including employers, was identified. Peter reported that: '

"Another thing I did before, when I met [name of friend] before she came round here. I got all the letters together that I had got and shredded them, I had some tablets left and I flushed them down the toilet, like got rid of all of the boxes; I got rid of the evidence because I was scared of her knowing that I had got a problem until I got to know her a little bit and feel comfortable to tell her. I was scared of her initially finding our because as a stranger she would think he is a fruit cake".

Alongside the need to hide diagnosis from others, were worry and fear of exposure. Participants reported concern that they may be 'found out' to be a member of a stigmatised group. Lisa articulated the concern about being found out to have psychosis in relation to attending social events:

"I always feel like the odd one out and like they are going to find out that I am not normal. I go for so long but then I just think they are going to find me out"

When it was not possible to conceal mental health difficulties from others, participants described opting for what they considered to be less stigmatising terms

that were considered more socially acceptable. The use of terms would vary, but words such as 'schizophrenia' or 'psychosis' were rarely used. Peter explains this:

"Yeh, if it is people that don't know me I will use the word ill and if it is people like yourself, medical people I will use the word psychosis and with my family just that I have been ill [...] if you use the word psychosis with someone who doesn't know you they look at it as though you are a psychopath or something. You know what I mean, like there is something wrong with you. I feel like that word is taboo you know".

3.4.2.3 Isolation

A consequence of disclosure issues was isolation from wider social networks outside immediate family members. Isolation was reported to occur through rejection from others following a disclosure of a psychosis. Lisa described friend's responses to disclosure that she was in contact with a mental health charity:

"Someone else phoned me up or wrote to me and I told them I was involved with [name of mental health charity] and they just didn't write back. I had a lot of rejection from friends at university...most of them. I'm not in contact with any of them; they all rejected me in the end".

Additionally, isolation was also reported to occur as a result of the participant avoiding others because of concerns that disclosure may become a reality and anticipated rejection if that were to occur. In relation to seeking a romantic relationship Jenine described:

"I won't get a boyfriend the way I am now because I'm afraid in case he finds out. I could never tell"

3.4.3. Psychological distress and possible 'exits'

Participants indicated that stigma could influence psychological distress which was described as negative emotions and beliefs about the self. Psychological distress included anxiety, lowered mood, reduced self-esteem and psychosis related experiences such as hearing voices.

3.4.3.1 Psychological distress related to disclosure

Psychological distress arose in response to disclosure, which occurred when a disclosure was made to family members, friends and wider social networks. Lisa expressed feelings of paranoia in relation to others knowing her diagnosis after being asked to declare any disabilities:

"You cannot really be open about your true diagnosis because people are so judgemental about it in society, it's just...every time I went to the [name of public building] I felt like they were watching me. I just felt really paranoid"

3.4.3.2 Psychological distress related to judgement

Direct and indirect experiences of judgement also resulted in psychological distress. Stereotypes and attitudes towards psychosis were described to result in reduced self-esteem, shame and embarrassment. Jenine reported:

"I would say it has knocked my confidence. I just feel so ashamed of it and it's really upsetting because it's not something I have inflicted on myself and it would be really nice if everybody just accepted someone who has got my illness as the same as accepting someone who has got diabetes or cancer, do you know what I mean? The illness is hard to deal with anyway without having to deal with the stigma"

3.4.3.3 Possible exits from psychological distress

Some participants suggested possible strategies that provided an exit from the negative effects stigma could have on psychological distress. A small number of participants reported that disclosure did not always result in psychological distress and that in some instances where acceptance was expressed this was viewed as an exit from distress. Caroline described:

"It wasn't until 18 or 19 when I got a close circle of friends that I trusted… were I couldn't hide the fact that in the morning or night I had to go and take tablets...when they asked me why I said because I hear things that aren't there...it was quite a relief for me to able to sit there and tell people".

Two participants reported that peer support and meeting other people with psychosis could reduce the impact of social judgement on psychological distress, providing a source of empowerment and normalising information. Caroline describes how meeting others with psychosis reduced feelings of shame and hopelessness:

"I use to be ashamed. I use to be sitting up all night crying because I couldn't handle it. But now I'm on meds I'm seeing a lot more people who experience it too and I realise we might be a bit eccentric and a bit difference but we still breathe and eat, we cry when you hurt us, we laugh when you make us laugh, we are still normal but we just experience some unusual symptoms".

3.5 Discussion

Currently, there is a considerable amount of quantitative data on stigma and psychosis and notably less qualitative research; to our knowledge, only one other IPA study has examined the Qualitative experience of stigma among people with psychosis (Knight, et al., 2003). It has been argued that to fully understand the experiences of psychosis and to ensure the direction of future research is based in the priorities of those with psychosis, research is required that attends to Qualitative experience (Geekie & Read, 2009). This study contributes the currently low volume of qualitative research in the area of stigma and psychosis.

The super-ordinate themes of judgement, disclosure and psychological distress were often complex, comprising of wider social processes such as the reporting of psychosis in the media and individual psychological processes such as internalised stigma. Each super-ordinate theme was closely connected, and we hypothesise that stigma can lead to problematic cycles stemming from judgement, resulting in dilemmas regarding disclosure, social isolation and psychological distress. Possible relationships between themes are summarised in figure 2.

Figure 2: Study 1 graphical representation of themes
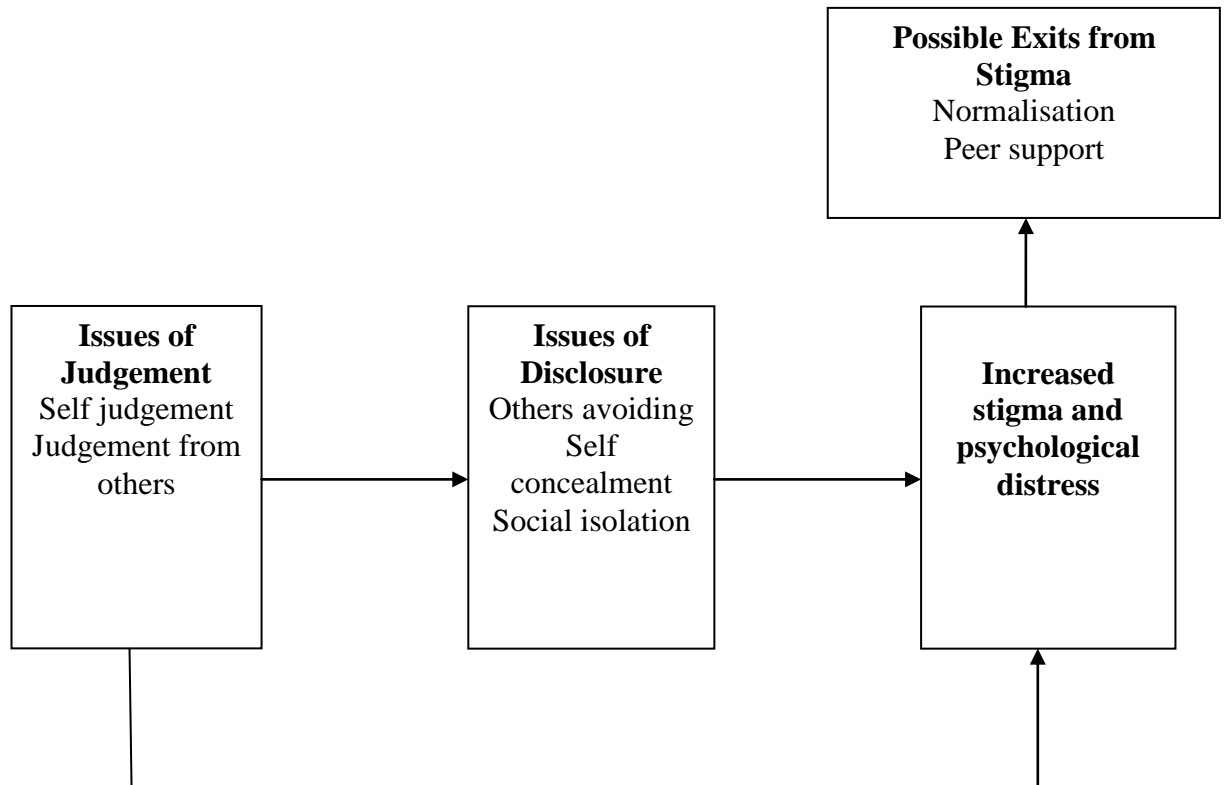
There are similarities between the themes described in this study and in other qualitative studies into stigma (Dinos, et al., 2004; González-Torres, et al., 2007; Knight, et al., 2003; Schulze & Angermeyer, 2003), which is suggestive that these are common problems faced by people with psychosis. There are parallels between the themes in this study and the wider stigma literature; in particular, it is clear that selective reporting of negative stories about people with psychosis impacts negatively on the public's attitudes (Angermeyer & Matschinger, 1996).

The aims and methodology of this study were comparable to Knight et al. (2003) and similarities were found between some of the themes, in particular issues relating to judgement. Whilst Knight et al. (2003) identified sub-themes associated

with disclosure, such as secrecy and avoidance; it was clear in our study that issues of disclosure dominated much of the concern about stigma and therefore was identified as a super ordinate theme. There is an indication in the wider stigma literature that concealable stigmas can result in difficulties associated with disclosure (Goffman, 1963; Bos, Kanner, Muris, Janssen, & Mayer, 2009; Chaudoir & Fisher, 2010; Ragins, 2008). However, there has been less focus in psychosis research on the role of disclosure on psychological wellbeing and functioning. The identification of positive exits or coping mechanisms for stigma, that are grounded in service user experience, is another finding that adds to existing literature and is an area which requires further research.

There are some limitations, which will be discussed before any clinical and research implications are suggested. It is recognised that as a qualitative study the sample size of nine people is not large enough to generalise findings, however it is a particular benefit that there are similarities between the findings of this study and the current literature in particular some similarities with the only other IPA study of psychosis stigma (Knight et al., 2003). Credibility checks were carried out with the second author; however, it is a limitation that participant validation was not sought.

Clinical and research implications

Most importantly, this study demonstrates that engaging service users with psychosis in meaningful conversation about their experiences produces rich and detailed information. We argue that discussions should regularly be held with services users regarding how stigma influences their lives in order to explore possible methods to combat the effects of stigma on wellbeing, and to inform the direction of future research and intervention.

The media was identified as a key source of stereotyping and negative attitudes. Clinicians may be well placed to work with the media to foster positive attitudes towards psychosis directly with the tabloids, but also via other media such as the internet. Research has demonstrated web-based education and normalising information about psychosis can reduce negative attitudes towards psychosis (French, et al., 2010).

To date a small number of studies have been conducted evaluating the feasibility and effectiveness of stigma interventions which have utilised cognitive behavioural techniques (Knight, Wykes, & Hayward, 2006; Lucksted Drapalski, Calmes, Forbes, DeForge, & Boyd., 2011; MacInnes & Lewis, 2008). Although there are some serious methodological limitations to these studies, including the absence of random allocation, or independent assessment, there is encouraging evidence for the application of such techniques to reduction of internalised stigma. Psycho-education and normalising information which dispels stereotypes and myths about mental health problems is considered to be an important aspect of psychosocial anti-stigma campaigns with the public (Pinfold, et al., 2003); this may be an effective strategy for reducing internalised stigma and for promoting acceptance from family members and friends considering the concern expressed about stereotypes by participants in this study. Techniques used in CBT such as evaluation of goals, problem solving and examining advantages and disadvantages have been shown to be helpful for people with other stigmatised attributes (Chaudoir & Fisher, 2010) and may address the difficulties associated with disclosure identified by the participants in this study. Future research should test the feasibility and clinical effectiveness of a Cognitive Therapy approach to internalised stigma, addressing the

current methodological limitations in existing stigma interventions for people with psychosis.

This study indicates that peer support and that acceptance from families and friends can reduce some of the concerns about judgement and disclosure. There is some evidence that peer support is effective in reducing stigma in people with other stigmatised conditions (Heijnders & van der Meij., 2006), and in relation to mental health, peer support has been associated with improved self-esteem (Verhaeghe, Bracke, & Bruynooghe, 2008). However, this is a relatively under-researched area and the possible benefits of peer support, and indeed what the active ingredients of peer support are for this group requires demonstration.

Chapter 4: Study 2 - Internalised stigma, emotional dysfunction and unusual experiences in young people at risk of psychosis

The following paper has been accepted at Early Intervention in Psychiatry.

Internalised stigma, emotional dysfunction and unusual experiences in young people at risk of psychosis

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4.1 Abstract

Aims: To investigate the relationship between internalised stigma, depression, social anxiety and unusual experiences in young people considered to be at risk of developing psychosis.

Method: 238 participants meeting criteria for an at risk mental state were recruited as part of a multisite randomised controlled trial of cognitive behavioural therapy for people meeting criteria for ARMS. The sample was assessed at baseline and six months using measures of at risk mental states, internalised stigma, depression and social anxiety.

Results: The Personal Beliefs about Experiences Questionnaire (PBEQ) was validated for use with an ARMS sample. Correlational analyses at baseline indicated significant relationships between internalised stigma and (1) depression, (2) social anxiety (3) distress associated with unusual psychological experiences and (4) suicidal thinking. Regression analysis indicate negative appraisals of unusual experiences contributed significantly to depression scores at 6 month follow up, when controlling for baseline depression and unusual psychological experiences.

Conclusions: These findings suggest that internalised stigma may contribute to the development and maintenance of depression in young people at risk of psychosis.

Keywords: at risk mental states; psychosis; internalised stigma; depression; social anxiety

4.2 Introduction

The development of criteria for identifying people who are at risk of developing psychosis has provided an opportunity to investigate preventative strategies (Phillips, Yung, & McGorry, 2000; Yung, et al., 2005). Yung and colleagues have operationally defined criteria for an at risk mental state (Secker, Armstrong, & Hill., 1999): attenuated or subclinical psychotic symptoms which have lasted for at least one week; transient psychotic symptoms lasting for a week or less which spontaneously resolve without either medical or psychological intervention; and either a first degree relative with psychosis or a diagnosis of schizotypal personality plus a reduction in functioning ('state plus trait').

Young people meeting criteria for ARMS often report other psychological difficulties, in particular depression (Verdoux, et al., 1999). In a recent randomised controlled trial of Cognitive Behavioural Therapy (CBT) for individuals at risk of developing psychosis, it was reported that 41% of the sample had a co-morbid diagnosis of major depressive disorder and 43% had a co-morbid diagnosis of anxiety (Addington, et al., 2011). Research has indicated a relationship between state at-risk symptoms and depression, showing associations between bizarre experiences, persecutory ideas and level of depression (Yung, et al., 2006). Yung and colleagues found that a high level of depression in young people who met criteria for ARMS was a significant predictor of psychosis (Yung, et al., 2007), indicating that depression may act as a risk factor for transition.

Psychosis is one of the most stigmatised mental health problems (Angermeyer, et al., 2004; Jorm & Wright, 2008). Recent research shows that people with psychosis are aware of the negative cultural stereotypes associated with

a diagnosis of psychosis; over 50% of the sample reported moderate to high levels of internalised stigma (Brohan, Elgie, Sartorius, & Thornicroft, 2010). Internalised stigma (or self-stigma) has been defined as "becoming aware of the label and identifying with the stereotypes" (Link, Yang, Phelan, & Collins, 2004) and also, "the internalisation of shame, blame, hopelessness, guilt and fear of discrimination associated with mental illness" (Corrigan & Watson, 2002). Research indicates that post-psychotic depression may develop in relation to self-stigmatising beliefs (Birchwood, et al., 2000; Birchwood, et al., 1993; Karatzias, et al., 2007). Similarly, the role of other stigma-related factors such as shame, marginalisation and entrapment has been associated with social anxiety in psychosis populations (Birchwood, et al., 2006; Gumley, et al., 2004; Karatzias, et al., 2007).

It has been argued that early detection and intervention (either pharmacological or psychological) is questionable in the ARMS group due to false positives (Warner, 2005). The potential stigma resulting from labelling people meeting ARMS criteria as at-risk could have potential negative consequences for their personal identity (Corcoran, et al., 2005; Yang, et al., 2010; Yung, et al., 2010). Although a decision has been made to not include a psychosis risk syndrome in the DSM-V, the proposal of this diagnose for young people meeting at risk criteria sparked an interesting debate about the potential consequences of labelling young people at risk with a formal psychiatric diagnosis (Corcoran et al., 2010; Ruhrmann, Schultze-Lutter & Losterkotter., 2010; Yung, et al., 2010). A number of articles expressed concern that this could result in a high number of young people being unnecessarily exposed to potentially harmful effects of stigma and discrimination (Corcoran, First, & Cornblatt, 2010; Yung, et al., 2010). Qualitative research has indicated that young people with ARMS may be concerned about stigma in relation

to their unusual psychological experiences, with all participants reporting a fear of negative reactions from other people because they had unusual psychological experiences (Byrne & Morrison, 2010), and the lack of systematic measurement of stigma and discrimination in young people help seeking for unusual psychological experiences has been identified as a limiting factor to understanding how young people at risk may be affected by stigma (Yang, et al., 2010).

We aim to investigate the presence of internalised stigma in the ARMS population and to explore the potential impact of internalised stigma on depression, social anxiety and distress linked to unusual psychological experiences. We will first validate a revised version of the Personal Beliefs about Experiences Questionnaire (PBEQ), a measure of internalised stigma used with adult psychosis populations, in an ARMS population. It is hypothesised that: there will be a significant relationships between internalised stigma and depression, and between internalised stigma and social anxiety; there will be significant relationship between self -stigma and distress associated with unusual psychological experiences; there will be a significant relationship between internalised stigma and self-harm/ suicidal ideation; internalised stigma at inclusion will predict depression, social anxiety and suicidality severity at six month follow up, when controlling for baseline line depression, social anxiety and suicidality scores.

4.3 Methods

4.3.1 Sample

The participants consisted of 288 young people aged between 14 and 35 with no history of psychosis. All met criteria on the Comprehensive Assessment for At Risk Mental States (CAARMS) (Yung, et al., 2005). Data were collected from five

sites in the UK as part of the Early Detection and Intervention Evaluation for people at risk of psychosis 2 (EDIE 2) (Morrison, Stewart, French, Bentall, Birchwood, Byrne, et al., 2011; Morrison, French, Stewart, Birchwood, Fowler, Gumley., 2012).

4.3.2 Materials

Comprehensive Assessment for At Risk Mental States (CAARMS).

The CAARMS is a semi-structured interview designed to identify people who meet criteria for having an at risk mental state. The measure has 7 categories, however for the purpose of this study only the Positive Symptoms category, which comprises of four subscales, Unusual Thought Content (UTC), Non-Bizarre Ideas (NBI), Perceptual Abnormalities (PA) and Disorganised Speech (DS), each of which receives a global rating score (0-6), a frequency score (0-6) and a distress score (0-100). CAARMS symptom severity was operationalised as the summed scores of the global rating scale score and frequency score.

A measure of self-harm/ suicidal thoughts and behaviour was also incorporated into the CAARMS. The CAARMS has been shown to demonstrate good to excellent concurrent, discriminate and predictive validity and excellent inter-rater reliability (Yung, et al., 2005)

Personal beliefs about experiences questionnaire (PBEQ)

The PBEQ is a revised version of the Personal Beliefs about Illness Questionnaire (Birchwood, et al., 1993). It is a 13-item measure of cognitive appraisals of psychosis; each item is a statement of stereotypical social and scientific beliefs about psychosis which the respondent rates in relation to the degree to which he or she endorse the statements as true about themselves. Each item is rated on a four point scale (1-4): 'strongly disagree', 'disagree' 'agree' 'strongly agree. A

revised version of the original PBIQ was developed for the purpose of this study; three items were removed from the questionnaire as they were considered not to be related to the ARMS population, these items are as follows: "If I am going to relapse, there is nothing I can do about it", "I will always need to be cared for by professional staff", "People like me must be controlled by psychiatric services". In addition to removing these three items, the word "illness" from the original PBIQ has been substituted with the word "experiences". The original version of the PBIQ demonstrated good reliability (Cronbachs' alpha ranging from 0.51 to 0.71).

The Beck Depression Inventory for Primary Care (BDI-PC)

The BDI-PC (Winter, et al.,1999) is a shortened revised version of the Beck Depression Inventory (BDI) (Beck, Ward et al. 1961). The BDI-PC is comprised of 7 items that related to depressive symptoms, each rated on a four point scale (0-3). The BDI-PC is scored by adding the ratings for each item to produce a total score, with a range of 0-21. Testing of the measure has revealed high internal consistency (Cronbachs alpha = 0.88).

Social Interaction Anxiety Scale (Crocetti, Spiro, & Siassi)

The SIAS (Mattick & Clarke, 1998) is a 20-item questionnaire designed to measure levels of fear in social interaction situations,; each item is rated on a five-point Likert scale (0-5) as follows: "not at all", "slightly", "moderately", "very", and "extremely". The SIAS has received extensive validation (30).

4.3.3 Participants and procedures

The 288 participants in the ARMS group were referred to and recruited into EDIE 2. Of these, 238 completed the PBEQ at baseline and were included in the analysis. Ethical approval was granted from the Cambridgeshire 4 Research Ethics Committee REC reference number 05/MRE05/61. All participants provided full informed consent before completing any of the measures. Measures were administered at baseline assessment and at 6 month follow up, all except the CAARMS were completed as self-report.

4.3.4 Statistical analyses

The data were examined for normality using the analysis of Skewness and Kurtosis and visual inspection. The variables were normally distributed except for CAARMS UTC, PA and DS subscale distress scores, and therefore non-parametric equivalents were used. Data was analysed using SPSS for windows version 15.

4.4 Results

4.4.1 Validation of the PBEQ in the at risk population

In order to validate the PBEQ-R for the ARMS population, a principal component analysis (PCA) was conducted on the 13 items on the PBEQ-R with direct oblim rotation. The Kaiser-Meyer-Olkin measure verified the sampling adequacy for the analysis, KMO = .741, which is considered 'good' (Kaiser, 1974) and which is above the acceptable limit of .5 (Field, 2009). Bartlett's test of sphericity χ^2 (78) =

609.489, p < .001, indicated that correlations between each item were sufficiently large for PCA. An initial analysis was run to obtain eigenvalues for each component in the data. Four components had eigenvalues over Kaiser's criterion of 1 and in combination explained 57.2% of the variance. However, the Scree plot, indicated inflexions that would justify retaining components 1 and 2. Therefore, two components were retained based on the   Scree plot examination. Table 2 shows the factor loadings after rotation. The items that cluster on the same components suggest that component 1 represent negative appraisals of experiences (NAE) and component 2 represents the perceived social acceptance of experiences (Wisdom, Bruce, Auzeen Saedi, Weis, & Green). Reliability testing of these two components was carried out and Cronbach's alpha is reported in Table 2. As indicated in Table 1 the NAE subscale has a good reliability, Cronbachs α = .74; the SAE subscale has a lower reliability, Cronbach's α = .52.

Table 2: Study 2 Summary of exploratory factor analysis (N = 238)

	Rotated Factor Loadings	
Item	**Negative Appraisals of Experiences (NAE)**	**Social Acceptance of Experiences (SAE)**
1. My experiences frighten me.	**0.465**	-0.231
2. There must always have been something wrong with me as a person (to have caused these experiences).	**0.557**	-0.434
3. I am embarrassed to talk about my experiences.	0.159	**-0.652**
4. My experiences mean that I should be kept away from others.	0.438	**-0.500**
5. I find it difficult to cope with my current experiences.	**0.655**	-0.266
6. I am fundamentally normal; my experiences are like any other.	-0.372	**0.467**
7. I am capable of very little as a result of my experiences.	**0.737**	-0.061
8. My experiences are a judgement on me.	**0.442**	-0.435
9. I am powerless to influence or control my experiences.	**0.546**	-0.228
10. There is something about my personality that causes these experiences.	**0.603**	-0.138
11. It is hard for me to work or keep a job because of my experiences.	**0.633**	0.187
12. I can talk to most people about my experiences.	-0.076	**0.724**
13. There is something strange about me which is Responsible for these experiences.	**0.482**	-0.418
Eigenvalues	3.60	1.45
% of variance	27.69	11.17

A	0.74	0.52

4.4.2 Baseline characteristics of the sample and the PBEQ

In total 238 participants completed the PBEQ at baseline. Of these, 144 were male and 94 were female. The mean age of the sample was 26.70 and was predominately White British. The baseline characteristics of the sample are presented in table 3.

Table 3: Study 2 Baseline characteristics (N = 238)

Variable	Mean (SD/%)
Age	26.70 (4.26)
Male: female ratio	144:94
Number years in education	13.05 (2.33
Ethnicity	
White background	222 (93.3)
Black background	4 (1.7)
Asian background	2 (0.8)
Chinese	1 (0.4)
Other background	9 (4.2)
PBEQ; NAE subscale	23.96 (4.22)
PBEQ; SAE subscale	9.23 (2.01)
SIAS total	41.13 (16.62)
BDI-PC total	9.92 (4.42)
CAARMS severity summed	44.03 (18.27)

The mean and standard deviation for each of the 13 items on the PBEQ was calculated and the results are presented in table 4.

Table 4: Study 2 Baseline data for the PBEQ (N = 238)

	Mean (SD)	Range
1. My experiences frighten me	2.92 (.77)	3
2. There must always have been something wrong with me as a person (to have caused these experiences	2.60 (.82)	3
3. I am embarrassed to talk about my experiences	2.26 (.79)	3
4. My experiences may mean that I should be kept away from others	2.89 (.83)	3
5. I find it difficult to cope with my current experiences	2.94 (.77)	3
6. I am fundamentally normal, my experiences are like any other	2.02 (.72)	3
7. I am capable of very little as a result of my experiences	2.26 (.83)	3
8. My experiences are a judgement on me	2.52 (.80)	3
9. I am powerless to influence or control my experiences	2.61 (.81)	3
10. There is something about my personality that causes these experiences	2.80 (.77)	3
11. It is hard for me to work or keep a job because of my experiences	2.63 (.93)	3
12. I can talk to most people about my experiences	2.05 (.82)	3
13. There is something strange about me which is responsible for these experiences	2.61 (.78)	3

4.4.3 Correlational analyses

Pearson's correlation coefficients were performed between the baseline Negative Appraisals of Experiences (NAE) and Social Acceptance of Experiences (SAE) subscales measuring internalised stigma and (1) the baseline BDI and (2) the baseline SIAS (See Table 5). Significant positive correlations were found between NAE and depression (r = .538, p = <.0001) and with social anxiety (r = .472, p = < .0001). Significant negative correlations were found between SAE and social anxiety (r = -.393, p = < .0001) and depression (r = -.470, p = <.0001).

Pearson's correlations were performed between the baseline NAE subscale of the PBEQ and the four subscales on the Comprehensive Assessment of At Risk Mental States (CAARMS) at baseline. Tests revealed a significant correlation between the NAE subscale of the PBEQ-R and Non Bizarre Ideas (NBI) severity (r = .146, p = < .05). As indicated in Table 5 significant correlations were not found between NAE and the other subscales of the CAARMS. No significant correlations were found between SAE and any of the CAARMS subscales. Pearson's correlations were performed between baseline BDI and CAARMS severity scores, NBI distress and Disorganised Speech (DS) distress. Tests revealed a significant correlation between baseline BDI and baseline NBI distress (r = .268 p = <.0001). Tests also revealed significant a significant correlation baseline BDI and baseline suicidality severity (r = .273 p < .0001). Spearman's correlations were performed between baseline BDI and Unusual Though Content (UTC) and Perceptual Abnormalities (PA) distress. No significant correlations were found between baseline BDI and UTC distress and PA distress.

Spearman's correlations were performed between NAE and the CAARMS subscale distress scores. Tests revealed significant correlations with NBI ($r = .211$ $p = < .01$), PA ($r = .172$ $p = <.05$) and DS ($r = .146$ $p = < .05$), a significant correlation was not found between NAE and UTC (r = .066 p = .326). Spearman's correlations were also performed between SAE and the CAARMS distress scores, but none reached significance (see Table 5).

Significant Pearson's correlations were found between NAE and the CAARMS self-harm/ suicidal severity scale ($r = .211$ $p = <0.01$) and also between SAE and the CAARMS self-harm/ suicidal severity scale ($r = -.236$ $p < .01$).

Table 5: Study 2 Correlation Matrix for baseline variables

	NAE	SAE	BDI
BDI	.540**	-.474**	1.00
SIAS	.472**	-.393**	_
Unusual Thought Content Severity	-.007	.034	-.058
Non Bizarre Ideas Severity	.146*	-.124	.097
Perceptual Abnormalities Severity	.055	.003	-.041
Disorganised Speech Severity	.058	-.012	-.068
Suicidality Severity	.241**	-.236**	.273**
Unusual Thought Content Distress	.066	.028	.064
Non Bizarre Ideas Distress	.211**.	-.060	.268**
Perceptual abnormalities Distress	.172*	-.009	.0.95
Disorganised Speech Distress	.146*	-.081	.059

* Correlation is significant at the 0.05 level

** Correlation is significant at the 0.01 level

4.4.4 Regression analyses

In order to test the relationship between internalised stigma at inclusion and depression and social anxiety at 6 month follow up, hierarchical regression analyses was performed. In the first regression, depression scores on the BDI at 6 month follow up were entered as the dependent variable. The independent variables included in the analysis were baseline depression scores in step 1, NBI distress scores in step 2, suicidality severity score in step 3, negative evaluations about experiences (NAE) in step 4 and social acceptance of experiences in step 5, results of this multiple regression are presented in Table 6. As can be seen, Table 6 reveals that significant predictors of depression at follow up were baseline depression score ($\beta = .371$, Partial $r = .337$ $t = 4.242$ p = < .0001) and negative appraisals of experiences ($\beta = .191$, Partial $r = .180$ t = 2.163 p = < .05).

Table 6: Study 2 Regression Analyses

Predictor variable	B	SE B	B	*t*	*p*	95% CI B
Dependent variable BDI at 6 months						
BDI baseline	.393	.093	.371	4.24	.000***	.210 - .577
NBI Distress baseline	-.015	.011	-.100	-1.35	.179	-.036 - .007
Suicidal severity baseline	.166	.225	.054	0.73	.463	-.279 - .610
NAE baseline	.206	.095	.191	2.16	.032*	-.018 - .395
SAE baseline	.002	.004	.043	0.59	.553	-.006 - .011
Dependent variable SIAS at 6 months						
SIAS baseline	.218	.093	.205	2.347	.021	.034 - .402
NAE baseline	.161	.373	.043	.430	.668	-.578 - .899
SAE baseline	.251	.770	.032	.326	.745	.745 – 1.273
Dependent variable Suicidality severity at 6 months						
CAARMS Suicidality Severity baseline	.125	.068	.147	1.850	.066	-.008 - .259
NAE baseline	.041	.025	.128	1.607	.110	-.009 - .091
SAE baseline	-.001	.001	-.058	-.733	.465	-.004 - .002

In the second regression, scores on the SIAS at six months were entered as the dependent variable. The independent variables included in the analysis were baseline SIAS scores in step 1, negative evaluations of experiences in step 2, and perceived

social acceptance of experiences in step 3, results are presented in Table 6. As can be seen in Table 6, the only significant predictor of social anxiety at follow up was baseline social anxiety ($\beta = .218$, Partial $r = .205$ t = 2.347 p = < .05).

In the third regression, follow up scores on the suicidal severity scale from the CAARMS were entered as the dependent variable. The independent variables included in the analysis were baseline suicidal severity in step 1, negative evaluations of experiences in step 2, and perceived social acceptance of experiences in step 3, results are presented in Table 6. As can be seen in Table 6, there were no significant predictors of suicidal severity at follow up.

4.5 Discussion

Internalised stigma is associated with depression and social anxiety in an ARMS population, as well as being associated with distress and suicidal ideation. We also found that negative appraisals of unusual psychological experiences at baseline assessment contributed to depression at six month follow up when controlling for baseline depression, CAARMS symptoms severity and distress. Internalised stigma was not found to contribute social anxiety or suicidality severity at follow-up.

Results indicate that internalised stigma may contribute to additional psychological difficulties experienced by people meeting criteria for ARMS. Therefore, it is suggested that measuring stigma should be a key priority for researchers and clinicians working with this population. It has been argued that clarification regarding the possible effects of stigma and discrimination associated with being at risk of psychosis is required to fully understand the potential cost of being diagnosed with a Psychosis Risk Syndrome (Yang, et al., 2010) and our

findings suggest that there may be the potential for negative effects because of stigma if a formal psychosis risk syndrome was applied to this group.. However, distress associated with attenuated positive symptoms was associated with internalised stigma. This finding is broadly consistent with cognitive models of psychosis, which highlight negative appraisals as central to distress (Morrison, 2001). Therefore, this finding suggests that it is important to try and promote optimistic and non-pathological appraisals within the ARMS population. Given that internalised stigma is associated with both affective and psychotic symptoms, including subsequent depression, it is possible that stigma may indirectly contribute to transition to psychosis, since persistence of psychotic experiences is linked with increased levels of affective symptoms (van Rossum, Dominguez, Lieb, Wittchen, & van Os, 2009), and it has been suggested that depression and anxiety should be considered as necessary conditions for the onset of psychosis (Dominguez, Wichers, Lieb, Wittchen, & van Os, 2009). Therefore, we agree that caution should be exercised regarding the inclusion of a risk syndrome in DSM-V.

There are similarities between the findings of this study and previous research investigating internalised stigma in psychosis. Aspects of internalised stigma such as negative cognitive appraisals about experiences, perceived loss of social status, humiliation and entrapment are considered to underlie the development and maintenance of depression (Birchwood, et al., 2000) and social anxiety (Birchwood, et al., 2006) in psychosis. Recent research has identified perceptions of defeat and entrapment as a contributory factor to suicidal ideation in schizophrenia (Taylor, et al., 2010). Whilst significant relationships were found between internalised stereotypes and suicidality severity at baseline, this was not found to contribute to suicidality severity at follow–up; indeed, baseline suicidality did not

contribute significantly to the variance at follow-up. This is interesting and we hypothesis that this may be in part due to the benefits of enhanced monitoring offered on EDIE 2, which included regularly providing all participants with crisis cards containing details of how to access support in time of crisis and signposting to other agencies (benefits of enhanced monitoring were observed within the primary trial results (Morrison, et al., 2012).

There are several methodological limitations to our study. Validation of the PBEQ in the ARMS population indicates that it is suitable for use with this group and the reliability of the two subscales is comparable with the original subscales (Birchwood, et al., 1993). However, it should be noted that the reliability of the SAE subscale of the PBEQ could only be considered reasonable. As the PBEQ was the only measure of internalised stigma used in this study it was not possible to evaluate concurrent validity. It is acknowledged that multiple statistical analyses were conducted; however, due to the exploratory nature of this study, corrections for type 1 error were not made, and it could be argued that this limits the robustness of our findings. Although internalised stigma was a predictor of depression at follow-up, baseline depression accounted for the greatest variance in follow-up depression. This is likely to be due to the high correlation between depression scores at baseline and follow-up. Negative appraisals of experiences contributed a significant, but relatively small, amount to the variance in depression at follow-up. As discussed above, the personal beliefs about experiences questionnaire was a revised version of the personal beliefs about illness questionnaires; therefore, it is not possible to make direct comparisons with people with established psychosis. The research is also limited by the help-seeking and, therefore, self-selecting nature of the sample and it is acknowledged that this may have introduced bias. However, most other ARMS

studies incorporate help-seeking within the criteria, so our findings should be generalisable.

Research carried out in participants with psychotic diagnoses indicates relationships between stigma and psychological factors such as self-esteem, hopelessness, distress and difficulties in mentalising or thinking about one's own or others mental states (Lysaker, et al., 2007; Lysaker, et al., 2008). Therefore, future research should explore relationships between internalised stigma and such variables in people meeting criteria for ARMS. As noted, it could be hypothesised that the contribution of internalised stigma to depression in this group may act as a risk factor for transition to psychosis and future research should test whether stigma contributes to the evolution of positive symptoms. In order to understand the ontogeny of internalised stigma in psychosis, a longitudinal study following up people from ARMS to first episode and beyond would define how internalised stigma evolves throughout psychosis, the factors associated with internalised stigma over time and the consequences of stigma.

Clinical services that offer support to people at risk of psychosis should measure and monitor levels of internalised stigma. There is currently an insufficient evidence base for interventions in internalised stigma for both those with psychosis and those at risk of developing psychosis. However, Cognitive Behavioural Therapy (CBT), which has been shown to be an acceptable and effective treatment for those at risk of developing psychosis (Bechdolf, Wagner, Ruhrmann, Harrigan, Putzfeld, Pukrop, et al 2012; Morrison, et al., 2004; Morrison, et al., 2012), may be a suitable strategy for addressing internalised stigma as there is some evidence from small scale studies that CBT may be effective for this purpose in people with psychosis (Knight, Wykes, & Hayward, 2006; Lucksted, et al., 2011). In particular, recent

research indicates that promoting normalising, continuum based information about psychosis results in positive emotional reactions in the general public (Schomerus, Matschinger & Angermeyer., 2013) and it is likely that such normalising information about unusual psychological experiences promoted by the cognitive model may be helpful in preventing or reducing negative appraisals of unusual experiences and beliefs. Future research should test the impact of normalising continuum belief based information on internalised stigma in the at risk group. Analysis from the EDIE 2 trial indicated that stigma reduced over time for participants in CBT plus treatment as usual (TAU) and the TAU alone arm of the trial, with an observable benefit of CBT on negative appraisals of experiences in comparison to TAU (Morrison, Birchwood, Pyle, Flach, Stewart, et al., 2013); these results are a promising indication that CBT may be a feasible and effective intervention for internalised stigma in the at risk group

Chapter 5: Study 3 - Associations between internalised stereotypes of psychosis and emotional dysfunction in people with psychosis not taking antipsychotic medication

The following paper has been through peer review at Psychosis: Psychological, Social and Integrative Approaches, revisions have been requested and made.

Associations between internalised stereotypes of psychosis and emotional dysfunction in people with psychosis not taking antipsychotic medication

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5.1 Abstract

This study explores internalised stereotypes in people with psychosis who are not taking antipsychotic medication and tests for possible relationships between internalised stereotypes and emotional dysfunction. Sixty-six participants completed measures of internalised stereotypes and emotion at baseline. Cross section and longitudinal data was used to test for relationships between internalised stereotypes, emotional dysfunction and insight at baseline and three months. Difference in level of internalised stereotypes and clinical insight at baseline between those with psychological and other causal models of psychotic experiences was compared. Greater levels of internalised stereotypes of psychosis were associated with depression and social anxiety at baseline and internalised stereotypes contributed to the variance in depression over time. At baseline those with social anxiety had significantly greater levels of stigma. Participants who reported a psychological causal model for their psychotic experiences had significantly lower levels of stigma. Findings support a stigma model of emotional dysfunction in people with psychosis replicating previous findings in an anti-psychotic medication free group. Further research is required to demonstrate effective interventions for internalised stigma in those with psychosis to prevent further psychological difficulties.

Key words: Psychosis; Stigma; Anxiety; Depression

5.2 Introduction

Internalised stigma is thought to occur when negative labels associated with a stigmatised trait become assimilated into self-identity (Link, et al., 2004). A progressive mode of internalised stigma suggests internalisation occurs in two distinct stages; awareness and agreement with stereotypes followed by application of stereotypes to the self- resulting in psychological harm (Corrigan, et al.,2011) . Many people with psychosis report moderate to high levels of internalised stigma (Brohan, et al., 2010), which can reduce self-esteem (Camp, Finlay, & Lyons, 2002; Corrigan, et al., 2011; Livingston & Boyd, 2010; Lysaker, et al., 2007), reduce hope and empowerment (Livingston & Boyd, 2010; Vauth, et al., 2007) and increase feelings of demoralisation (Cavelti, et al., 2012).

Internalisation of stereotypes is associated with post psychotic depression and social anxiety in people with psychosis (Birchwood, et al., 2000; Birchwood, et al., 2005; Birchwood, et al., 2006; Karatzias, et al., 2007; Staring, Van der Gaag, Van den Berge, Duivenvoorden, & Mulder, 2009). Co-morbidity of emotional dysfunction in psychosis is relatively common, depression is associated with increased risk of suicidality (Drake & Cotton, 1986) and social anxiety is associated with life time rates of suicide attempts (Pallanti, Quercioli, & Hollander, 2004b). Therefore, a clear understanding of how stigma may contribute to the development or maintenance of depression and social anxiety in people with psychosis is required to inform interventions.

Social rank theory, has been used a paradigm to understand the development and the maintenance of emotional dysfunction in people with experience of psychosis (Birchwood, et al., 2005; Birchwood, et al., 2006; Iqbal, Birchwood, et al.,

2000; Rooke & Birchwood, 1998). It is argued that depression and social anxiety can occur in response to 'depressogenic' life events, leading to a loss of social status, shame, guilt, fear and embarrassment (Gilbert, 1992). Research has shown those with Post Psychotic Depression (PPD) report more negative appraisals of psychosis and lowered social status including loss, humiliation and entrapment than those who do not develop PPD (Iqbal, et al., 2000). There is also growing evidence to support a stigma processing model of social anxiety (Birchwood, et al., 2006; Karatzias, et al., 2007). This model hypothesises that awareness of stereotypes about psychosis before onset of a episode places an individual at risk of feeling they are of lower social rank and judged by others resulting in a cycle of negative appraisals, self-focus, catastrophic shaming beliefs and safety behaviours such as avoidance (Birchwood, et al., 2006). Clinical insight has been associated with depression, loss of self-esteem and hopelessness in people with psychosis (Mohamed, Rosenheck, McEvoy, Swartz, Stroup & Lieberman., 2009). Moreover, Staring et al. (2009) found that associations between insight and depression, quality of life and self-esteem were greater when participant also reported high levels of stigma.

A criticism of the research to date is that most has been cross sectional and a recent meta-analysis found only a minority of longitudinal studies evaluating the impact of stigma on outcomes (Livingston & Boyd, 2010). Furthermore, research investigating the relationship between internalised stigma and emotional dysfunction in those with experiences of psychosis has been with samples of people who experience psychosis and are taking antipsychotic medication. It is argued that some adverse effects of antipsychotic medication such as tremor and drooling may be associated with increased stigma (Hamer & Haddad, 2007) and adverse effects of antipsychotics include akinetic depression in 10-15% of cases and antipsychotic

induced dysphoria in 25% of patients (Mulholland & Cooper, 2000). Antipsychotic medication may act as potential confounding variable in stigma and emotional dysfunction research. To date, we know of no previous studies that have investigated possible relationships between internalised stereotypes and emotional dysfunction in people with psychosis who are not taking antipsychotic medication. This study presents a novel opportunity to explore previously demonstrated relationships between internalised stereotypes of psychosis and emotional dysfunction in a group of people who are not taking antipsychotic medication using cross sectional and longitudinal data. In order to do so a measure of social and scientific stereotypes of psychosis will be validated for use in this population. It is hypothesised that internalised stereotypes will not be significantly related to psychotic symptoms, but will be significantly related to depression, social anxiety and clinical insight at baseline. We also hypothesise that baseline level of internalised stereotypes will contribute to depression and social anxiety at 3 months. An exploratory analysis will be carried out to investigate for possible differences in internalised stereotypes and clinical insight between those with and without psychosocial causal explanations of psychosis.

5.3 Method

5.3.1 Participants

Of the 74 participants recruited to the a randomised controlled trial of cognitive therapy for people with psychosis not taking antipsychotic medication (ACTION Trial), 66 completed a measure of internalised stereotypes at baseline and were included in the analysis. Participants were recruited from mental health services in the UK and were referred to the trial by their clinician, full details regarding referral

pathways and CONSORT statement for the ACTION trial are reported by Morrison, Wardle, Hutton, Davies, Dunn, Brabban et al (2013). Inclusion criteria for the trial was participant are aged 16-65, have an ICD-10 diagnosis on the schizophrenia spectrum or meet entry criteria for early intervention in psychosis and have either been offered antipsychotic medication and refused or have discontinued antipsychotic medication for at least 6 months before entry into the trial. In addition, participants were required to score a minimum of 4 on delusions or hallucinations or a minimum of 5 on grandiosity, persecution or conceptual disorganisation on the Positive and Negative Syndrome Scale (PANSS) which was assessed at baseline. Participants were offered 9 months of CBT and a total of 30 of the 66 included in this study were allocated to the CBT arm of the trial.

5.3.2 Materials

Personal beliefs about experiences questionnaire (PBEQ)

The PBEQ is a revised version of the Personal Beliefs about Illness Questionnaire (PBIQ) (Birchwood, et al., 1993). The measure has 13 items that represent cognitive appraisals of psychosis that are based stereotypical social beliefs about psychosis. Items are rated on a four point scale (1-4): 'strongly disagree', 'disagree' 'agree' 'strongly agree. This revised version does not contain 3 items from the original PBIQ and the word 'illness' was substituted with the word "experience". The original version of the PBIQ demonstrated good reliability with Cronbachs' alpha ranging from 0.51 to 0.71 (Birchwood, et al., 1993). Factor analysis of the PBEQ indicated four components to the measure which represented concepts of self as abnormal, shame, loss of expectations and dangerousness. Reliability testing indicated good reliability for the self as abnormal, shame and loss of expectations

subscales 650 -.749. However reliability for the dangerousness subscale was lower at .145.

The Beck Depression Inventory for Primary Care (BDI-PC)

The BDI-PC (Winter, et al., 1999) is a shortened revised version of the Beck Depression Inventory (BDI) (Beck, et al., 1961). The BDI-PC is comprised of 7 items that related to depressive symptoms, each rated on a four point scale (0-3). The BDI-PC is scored by adding the ratings for each item to produce a total score, with a range of 0-21. Testing of the measure has revealed high internal consistency (Cronbachs alpha = 0.88).

Social Interaction Anxiety Scale (SIAS)

The SIAS (Mattick & Clarke, 1998) is a 20-item questionnaire designed to measure levels of fear in social interaction situations, each item is rated on a five-point Likert scale (0-5). The SIAS has received extensive validation and a cut-off score of 36 have been found to indicate social phobia (Peters, 2000).

Positive and Negative Syndrome Scale

The Positive and Negative Syndrome Scale (PANSS) is a valid and reliable measure of symptoms of psychosis (Kay, et al., 1987). It is a semi-structured interview assessing positive, negative and general symptoms of psychosis. There are 30 items (7 positive symptoms, 7 negative symptoms and 16 general psychopathology items). Each item has is rated on a 7 point scale, from 1 = absent to 7 = extreme. Insight was measured by PANSS general scale item 12, higher scores indicate less insight.

Reasons for not taking antipsychotic medication

Information was collected at baseline regarding the participant's reasons for not taking antipsychotic medication which are detailed in table 3. These categories were collapsed into two groups for analysis purposes which were either a psychological explanatory model or other reasons which included efficacy of antipsychotics, tolerance of antipsychotics and other health reasons.

5.2.3 Procedure

Recruitment of participants

Participants were referred via mental health services in the UK. After informed consent was taken, the measures were carried out at baseline and at 3 month follow up. NHS Research Ethical approval was granted (reference number 09/H1014/53).

Data analysis

The data were examined for normality using the analysis of Skewness and Kurtosis and visual inspection. The variables were normally distributed apart from negative PANSS total. Parametric tests were used for normally distributed data and non-parametric tests were used for data that violated parametric assumptions. Data was analysed using SPSS for windows version 16.

A principal component analysis (PCA) with direct oblimin rotation was conducted on the 13 items on the PBEQ to validate the revised version of the measure in this population.

Pearson's correlation coefficients were performed between baseline PANSS positive total and (1) BDI total score, and (2) SIAS total score. Spearman's correlation coefficients were performed between baseline PANSS negative total and (1) BDI total score and (2) SIAS total score. Pearson's correlation coefficients were

performed between the baseline subscales for the PBEQ and (1) baseline BDI and (2) baseline SIAS. Pearson's correlations coefficients were performed between insight and the 3 subscales of the PBEQ.

In order to test the relationship between internalised stereotypes and depression at 3 month follow up, hierarchical regression analysis was performed with BDI at 3 month follow as the dependent variable (DV) and the independent variables (IV) were self as abnormal in step 1, expectations in step 2 and shame in step 3. In order to test the relationship between internalised stigma and social anxiety at 3 month follow up, hierarchical regression analysis was performed. Social anxiety scores on the SIAS at 3 month follow up were entered as the DV and the IV's were self as abnormal in step 1, expectations in step 2 and shame in step 3.

Differences on internalised stigma between those with a psychological causal explanation of psychosis and those without were explored using *t*-test as was differences in insight between the two groups. The accepted level of statistical significance on all tests performed was .05.

5.4 Results

5.4.1 Validation of PBEQ

The Kaiser-Meyer-Olkin measure verified the sampling adequacy for the analysis, KMO = .749, which is considered 'good' (Kaiser, 1974) and which is above the acceptable limit of .5 (Field, 2009). Bartlett's test of sphericity χ^2 (78) =2.79.9, p < .0001, indicated that correlations between each items were sufficiently large for PCA. An initial analysis was run to obtain eigenvalues for each component in the data. Four components had eigenvalues over Kaiser's criterion of 1 and in combination explained 64.4% of the variance. The Scree plot, indicated inflexions

that would justify retaining components 1, however with a sample size of 80 the Scree plot cannot be considered the most reliable indication of number of factors and therefore all factors with an eigenvalue of 1 or more were retained (Field, 2009). Table 7 shows the factor loadings after rotation. The items that cluster on the same components suggest that component 1 relates to self as abnormal, component 2 represents expectations; component 3 represents shame and component 4 dangerousness. Reliability testing of these three components was carried out and Cronbachs alpha are reported in Table 7. As indicated the first three scales self as abnormal, expectations and shame had good reliability .650 -.749. However, the fourth scale dangerousness was low at .145 and was, therefore, not included in the main analyses.

Table 7: Study 3 summary of the exploratory factor analysis (N = 66)

Item	Expectation	Self as abnormal	Shame	Danger
1. My experiences frighten me.	.305	-.284	-.348	**-.849**
2. There must always have been something wrong with me as a person (to have caused these experiences).	.213	**-.788**	-.287	-.170
3. I am embarrassed to talk about my experiences.	.367	-.373	**-.787**	-.038
4. My experiences mean that I should be kept away from others.	.288	-.475	-.501	**.514**
5. I find it difficult to cope with my current experiences.	**.621**	-.366	**-.655**	-.389
6. I am fundamentally normal; my experiences are like any other.	.073	**.538**	.198	-.123
7. I am capable of very little as a result of my experiences.	**.713**	-.174	-.373	-.252
8. My experiences are a judgement on me.	.488	**-.535**	-.302	-.105
9. I am powerless to influence or control my experiences.	**.586**	-.281	-.436	-.365
10. There is something about my personality that causes these experiences.	.468	**-.716**	-.103	.080
11. It is hard for me to work or keep a job because of my experiences.	**.840**	-.178	-.046	.031
12. I can talk to most people about my experiences.	-.056	.170	**.843**	.153
13. There is something strange about me which is responsible for these experiences.	.235	**-.888**	-.294	-.045
Eigenvalues	**4.5**	**1.6**	**1.2**	**1.1**
% of variance	**34.44**	**12.15**	**9.51**	**8.3**
Cronbachs α	**.736**	**.749**	**.650**	**.145**

5.4.2 Baseline characteristics

The ethnicity of the sample was predominantly White British (84.8%) and the gender ratio of the sample was relatively equal with 36 males and 30 females. The age of the sample was relatively young with a mean age of 31.36. The ratio of antipsychotic naive to discontinued 34:34 respectively. The diagnosis of the participants was established using a standardised checklist (ICD-10) and all diagnoses were confirmed by a Consultant Psychiatrist by applying the ICD-10 checklist to vignettes based on the PANSS assessments for all cases. Diagnoses were as follows: schizophrenia n= 60 (90.9%), Schizoaffective n = 2 (3.0%), Persistent Delusional Disorder n = 3 (4.6%) and Psychosis Not Otherwise Specified n = 1 (1.5%). The baseline characteristics of the sample and descriptive statistics for each measure are presented in Table 8.

Table 8: Study 3 Baseline characteristics of the sample (N = 66)

	Mean (SD or %) or N
Age	31.36 (12.40)
Male: female ratio	36:30
Diagnosis	
Schizophrenia	60 (90.9)
Schizoaffective disorder	2 (3.0)
Persistent Delusional disorder	3 (4.6)
Psychosis Not Otherwise Specified	1 (1.5)
Antipsychotic naïve: discontinued ratio	32:34
Ethnicity	
White background	56 (84.8)
Black background	1 (1.5)
Asian background	4 (6)
Mixed background	3 (4.5)
Other	2 (3)
PANSS Total	68.75 (12.76)
Baseline PANSS Positive	20.83 (4.88)
Baseline PANSS Negative	14.68 (4.60)
Baseline PANSS General	36.34 (7.68)

Baseline BDI-PC	9.89 (4.56)
Baseline SIAS	41.66 (17.62)
PBEQ: Self as abnormal	13.56 (3.33)
PBEQ: expectations	10.95 (2.63)
PBEQ: Shame	5.88 (1.42)

In total 31.8% of the participants in the trial reported that they had decided not to take antipsychotic medication because of disagreement with the medical model of psychosis and/ or a preference for psychological causal models and treatment. 31.8% suggested that their reasons for not taking antipsychotics were due to side effects of the medication. A summary of the reasons for not taking antipsychotic medication can be found in Table 9.

Table 9: **Study 3 Reasons for not taking anti-psychotic medication**

Reasons for not taking anti-psychotic medication	N (%)
Side effects	21 (31.8)
Unable to take due to health reasons	1 (1.5)
Psychological causal model for psychosis (disagrees with medical model/ preference for psychological treatments and disagrees with diagnosis	21 (31.8)
Pregnant	2 (3)
Symptoms are treatment resistant	3 (4.5)
Other	16 (24.2)
Data unable to be captured	2 (3)

5.4.3 Correlational analysis

Significant correlations were not found between PANSS positive total and depression ($r = 1.04$, $p = >.05$) or social anxiety ($r = .028$, $p = >.05$). Significant correlations were not found between PANSS negative total score and depression ($r = .035$, $p = >.05$) or social anxiety ($r = .216$, $p = >.05$).

Significant positive correlations were found between self as abnormal and depression ($r = .375$, $p = <.001$) and social anxiety ($r = .514$, $p = < .001$). Significant positive correlations were found between expectations and depression ($r = .599$, $p = <.0001$) and social anxiety ($r = .418$, $p = < .001$). Significant positive correlations were found between shame and depression ($r = .338$, $p = <.0001$) and social anxiety ($r = .408$, $p = < .0001$). Significant negative correlations were found between insight and self as abnormal ($r = -.334$, $p < .01$) and shame ($r = -.297$, $p = <.05$).

5.4.4 Regression analyses

The results of the hierarchical regressions can be found in table 10. For the first regression with 3 month depression scores entered as the dependent variable (DV) results indicated that the significant predictor of depression over time was expectations ($\beta = .634$, Partial r = .595 t = 4.125, p = < .0001). When controlling for baseline level of depression the increase in R^2 when expectations was entered was .014 which was not significant (p = > .05). For the second regression with 3 month SIAS scores were entered as the DV, results indicated when shame scores were entered the R^2 was .114 which was borderline significant (p = .054).

Table 10: Study 3 Regression Analyses

Predictor variable	B	SE B	β	*T*	*p*	95% CI for B
DV = Depression at 3 months						
Baseline Self as abnormal	.057	.225	.039	.253	.802	-.403 - .517
Baseline Expectations	1.125	.305	.746	4.095	.000	.627 – 1.874
Baseline Shame	-.599	.529	-.192	-1.132	.267	-1.679 - .482
DV = Depression at 3 months (controlling for baseline depression)						
Baseline BDI	.691	.158	.609	4.358	.000	.366 – 1.015
Baseline Self as abnormal	-.098	.182	-.067	-.542	.592	-.470 - .273
Baseline Expectations	.444	.304	.265	1.457	.156	- .179 – 1.066
Baseline Shame	-.425	.420	-.136	-1.013	.320	- 1.285 - .434
DV = SIAS at 3 months						
Baseline Self as abnormal	-2.68	1.010	-.050	-.265	.793	-2.336 – 1.800
Baseline Expectations	.729	1.381	.114	.528	.602	-2.100 -3.558
Baseline Shame	4.717	2.345	.407	2.012	.054	-.086 – 9.521

5.4.5. t – Tests

t-Tests indicated that at baseline those with a psychological explanatory framework for their experiences scored significantly lower on beliefs about self as abnormal ($t = -2.34$ $p = < .05$) and shame ($t = -2.14$ $p = < .05$) than participants with other causal models. *t*- Test revealed those with a psychological explanatory framework scored significantly higher on PANSS G12 ($t = 4.81$, $p = <0001$).

5.5 Discussion

Significant relationships were identified between internalised stereotypes of psychosis and emotional dysfunction at baseline, with lowered expectations contributing to the variance in depression over time. However, lowered expectations did not contribute to the variance in depression at follow-up when controlling for baseline depression. Internalised stereotypes did not contribute to social anxiety over time. Prior research has demonstrated that perceived loss of social status is more frequently reported by those who experience post psychotic depression (Iqbal, et al., 2000). Findings from this study suggest that perceptions of being incapable, powerless and unable to find work because of psychotic experiences contribute to depression. The results of this study offer a signal that lowered expectations may contribute to depression in this group, which offers some support to the social rank theory of depression in people with psychosis. That is, conceptualising psychotic experiences/ diagnosis in a manner which results in loss of personal expectations may therefore be viewed as a depressogenic life event. Moreover, the findings of this study are supportive of previous research which has demonstrated significant

relationships between internalised stereotypes of psychosis, depression and social anxiety (Birchwood, et al., 2000; Birchwood, et al., 2005; Birchwood, et al., 1993; Birchwood, et al., 2006, 2007; Iqbal, et al., 2000). Previous research has primarily focused on first episode samples and or people with psychosis taking antipsychotic medication. The findings of this study suggest that a social rank approach to depression and social anxiety is replicable in other populations of people with psychosis including those who are antipsychotic medication free.

Analysis indicated that high level of clinical insight was associated with high levels of shame and agreement with the concept of self as abnormal, replicating previous research with this sample (Lysaker,et al., 2007; Staring et al., 2009). Participants with a psychological causal mode of psychosis reported less shame and perceptions of themselves as abnormal and scored as having less insight on the PANSS. Research with the public has found that psychological causal models of mental health problems are associated with less stigmatising beliefs about psychosis than biogenetic causal explanations (Read, 2007; Read, Haslam, Sayce, & Davies, 2006; Read & Law, 1999) and findings here indicate this may also be the case for those who experience psychosis.

We recognise there are limitations to this research which will be discussed before implications for clinical and future research are proposed. The sample size for the multiple regression was relatively low and findings could be due to limited power to detect and effect in relation to social anxiety (Field, 2009). In addition, the duration of follow up was relatively short at 3 months and the long term effects of internalised stereotypes cannot be inferred. We recognise that the PBEQ has not been tested for concurrent validity with other, more established measures of stigma. The PBEQ was selected based on face validity for measuring agreement with social

and scientific stereotypes about psychosis, and because of its use in related literature exploring the relationship between appraisals of psychosis and emotion (Birchwood, et al., 2005; Birchwood, et al., 1993; Birchwood, et al., 2007; Karatzias, et al., 2007). The original version of the measure was developed by Birchwood et al (1993) to "capture the degree to which subjects felt that the social and scientific beliefs about mental illness were accepted by them as a statement about themselves" (Birchwood, Jackson, Brunet, Holden, Barton.,2012 pp. 389) and Birchwood et al (2012) note that "the concepts underlying the original PBIQ were based in Stigma Theory (Estroff., 1989) and how pejorative cultural stereotypes of schizophrenia were accepted and internalised by the individual and how they had come to define the self" (Birchwood et al., 2012 pp 2). The definition of a stereotype is a negative belief, which is considered to be true about a group and applied to the whole group (Biernat & Dovidio, 2003). The three subscales utilised for the analysis in this paper, are self as abnormal, loss of expectations and shame. In particular concepts of abnormality, difference, being judged, shame and embarrassment are central aspects of stigma of psychosis and reported as concerns of stigma by people with psychosis (Knight,et al., 2003; Dinos,et al., 2004; González-Torres,et al., 2007). Therefore, it is also argued that the PBEQ is an appropriate measure of stereotypes of stigma. There are limitations to the measurement of casual explanations of psychosis as this was inferred from the self-reported reasons why participants were not taking antipsychotics. We suggest that this exploratory analysis is interesting for future hypothesis generation but that the limitation to the current measurement should be acknowledged.

This study was concerned with internalised stigma and in particular stereotypes only, as previous research has demonstrated that experienced stigma can

mediated the relationship between internalised stigma and depression (Mickelson & Williams, 2008) and can impact on self-esteem and anxiety (Norman, et al.,2011), the absence of other stigma measures may be a limitation.

Clinical and research implications

The findings of this study demonstrate that internalisation of public stereotypes of psychosis, in particular perceptions that people with psychosis are less able than others and therefore have lowered expectations, influences psychological distress and contributes to depression. Considering the growing evidence that stigma can contribute to depression and social anxiety, there is a need to better understand and to develop psychological interventions to target the impact of stigma on wellbeing. Clearly, the findings here and previous research indicate that at minimum services working with people with psychosis should screen for internalised stigma as these individuals may be more likely to developed co morbid emotional dysfunction. Furthermore, the finding that increased clinical insight is associated with higher levels of shame and agreement with the concept of self as abnormal is in line with previous research (Lysaker, et al., 2007; Staring et al., 2009 suggests that clinicians should be vigilant to the potential for patients to experience greater levels of internalised stigma if changes in insight occur. This may be particularly important to consider when diagnoses are being made. There is preliminary evidence for cognitive behavioural therapy (CBT) as a therapeutic intervention for internalised stigma (Knight et al., , 2006; Lucksted, et al., 2011) and change strategies used in CBT such as thought challenging strategies and normalisation may prove particularly beneficial for beliefs about self as abnormal and lowered expectations. Loss of expectations and shame in relation to psychosis may respond to therapeutic

interventions aimed at targeting self-criticism and shame. Compassion-focused therapy, which targets shame and self-criticism and aims to promote self-compassion (Gilbert, 2009) has been shown to reduce depression, anxiety, shame and self-criticism in people considered to have 'enduring mental health problems' (Gilbert & Procter, 2006). However the evidence base for stigma interventions is limited and comes largely from uncontrolled trials and there is a need for larger controlled trials of therapeutic interventions for internalised stigma (Mittal, Sullivan, Lakshminarayana, Allee, & Corrigan, 2012).

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Chapter 6: Study 4 - Internalised stereotypes of psychosis across ultra-high risk and psychosis populations

The following paper is in review at Psychiatry Research.

Internalised stereotypes of psychosis across ultra-high risk and psychosis populations

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6.1 Abstract

Stigma is highly problematic for those with psychosis; however, there is little research into internalised stigma in young people at risk of developing psychosis or how stigma differs between these groups. We explored cross sectional differences in internalised stereotypes across three groups on the psychosis continuum: participants at high risk of psychosis (n=238), participants with a first episode of psychosis (n=39), and participants with chronic psychosis (n=27). All groups were not taking antipsychotic medication. The strength of relationship between internalised stigma and emotion was compared between groups. Analysis of covariance revealed no differences between the three groups on internalised stereotypes and there were no significant differences in the strength of relationships between the groups on internalised stereotypes and emotional dysfunction. In each group it was evident that internalised stigma was associated with anxiety and depression. Findings suggest that for these groups, there is not a corresponding increase in level of internalised stigma and its impact on emotional dysfunction from at risk of psychosis to established psychosis. Effective psychosocial interventions and education are required to educate young people about psychosis to reduce stereotype endorsement, promote help seeking and minimise the likelihood of development of internalised stigma should they experience psychosis.

Keywords

Stigma; Psychosis; At Risk Mental States; Depression; Social Anxiety

6.1 Introduction

There is an international emphasis on early detection and intervention for psychosis (Bertolote & McGorry, 2005). The development of valid and reliable measures have allowed identification of people who are at ultra-high risk of developing psychosis, often referred to as experiencing an at risk mental state (Bertolote & McGorry, 2005; Phillips et al., 2000; Yung et al., 2005). The Comprehensive Assessment of At Risk Mental States (CAARMS) is one of the most frequently used measures for identification of people at high risk of psychosis (Parker & Lewis, 2006). Criteria on the CAARMS is met either via one of two state factors or via a trait and state factor (Phillips, et al., 2000; Yung, et al., 2005). State factors pertain to mental state changes either in the form of attenuated psychotic symptoms or brief limited intermitted psychotic symptoms (BLIPS) which spontaneously resolve without intervention within 7 days or less. The trait and state route combines trait risk factors, including a diagnosis of schizotypal personality disorder or family history of psychosis with mental state changes in relation to deterioration in functioning. Initial testing of the criteria's predictive validity, as measured by the number of people to make a transition to psychosis, revealed that 41% of the young people identified made a transition to psychosis (Yung, et al., 2003); however, lower rates of transition have been reported more recently (Yung, et al., 2007).

Knowledge regarding experienced, anticipated or internalised stigma in people who meet criteria for ARMS is limited (Yang, et al., 2010). Research trials and clinical services for people meeting criteria for ARMS report paying attention to avoiding stigmatising mental health settings and adopting non stigmatising language;

some have reported that involvement in a clinical trial for people meeting criteria for ARMS or engaging with a clinical service for this group has had little impact on stigmatisation of participants or service users (Broome, et al., 2005; McGorry et al., 2002). However, objective or systematic methods for measuring stigma in studies of ARMS populations have not been employed or reported. Rather, researchers to date have relied on verbal reports from clinicians or participants regarding feeling of stigma from their involvement in research (McGorry, et al., 2002). Qualitative research has indicated that young people meeting criteria for ARMS express concerns about being stigmatised because of their experiences (Byrne & Morrison., 2010). Furthermore, it has been argued that the knowledge of being at risk of a highly stigmatised mental health problem may alter self-perception, may result in internalised stigma and lead to avoidance of what may be perceived by the individual as stressful life choices (Corcoran, et al., 2005). This is of particular concern considering the number of false positive cases who meet criteria for ARMS (Corcoran, et al., 2005; Corcoran, et al., 2010; Yang, et al., 2010). There is a clear need to further understand the stigma experiences of this group (Morrison, et al., 2004; Yang, et al., 2010) and concerns about potential stigma were raised in relation to the proposal of a 'Risk Syndrome for Psychosis' (RS) in the Diagnostic and Statistical Manual, Fifth Edition (DSM V).

Whilst we know less about the stigma faced or internalised by people who meet criteria for ARMS, it is clear that for people with psychosis, stigma and discrimination are problematic. Those with psychosis may experience stigma from the public (Gaebel et al., 2002), from health professionals (González-Torres et al., 2007), from employers (Thornicroft, 2007) and families (González-Torres, et al., 2007). People with psychosis are often stereotyped as dangerous and violent

(Angermeyer & Matschinger, 2003; Arboleda-Florez, 2005; Jorm & Wright, 2008). The social stereotypes of psychosis can become internalised though agreement with and application of the stereotypes to self-identity (Corrigan, et al., 2011) and just over 40% of people with psychosis report moderate to high levels of internalised stigma (Brohan, et al., 2010a). Internalised stigma is associated with a range of negative outcomes such as feelings of demoralisation (Cavelti, et al., 2012) and loss of empowerment (Vauth, et al., 2007). Aspects of internalised stigma such as feelings of loss, shame and humiliation have been associated with depression (Birchwood, et al., 2000; Birchwood, et al., 2005; Iqbal, et al., 2000; Karatzias, et al., 2007; Rooke & Birchwood, 1998) and social anxiety (Birchwood, et al., 2006; Karatzias, et al., 2007) in people with experience of psychosis. Co-morbid emotional dysfunction has been shown to occur frequently in people with experience of psychosis (Karatzias et al., 2007, Pallanti, Querciolo, & Hollander., 2004) and research also demonstrated this is common in populations of people meeting criteria for ARMS (Addington, et al., 2011; Broome, et al., 2005). Whilst it is clear that people with psychosis report internalised stigma it is unclear whether those who are considered at risk of developing psychosis present with similar profiles of internalised stigma. Psychosis has been shown to exist along a continuum (Johns & van Os, 2001; Peters, et al., 1999;Van Os, 2003; van Os et al., 2000) but how internalised stigma is experienced along this continuum remains an unanswered question. Understanding internalised stigma across the continuum of psychosis may also provide further insight into factors that contribute to the development of internalised stigma as people move from being at risk of developing psychosis to a first episode and beyond and, therefore, move towards labelling with a highly stigmatised mental health problem. Furthermore, some adverse effects of

antipsychotic medication such as tremor and drooling may be associated with increased stigma (Hamer & Haddad, 2007); adverse effects of antipsychotics can include akinetic depression in 10-15% of cases and antipsychotic induced dysphoria in 25% of patients (Mulholland & Cooper, 2000) and service users frequently reporting problems associated with depression and sedation (Fakhoury, et al., 2001). Therefore, antipsychotic medication may act as potential confounding variable in research on stigma and emotional dysfunction in people with psychosis.

This cross sectional study aims to explore possible differences in internalised stereotypes across the psychosis continuum; specifically, between those who are considered to be at risk of developing psychosis, those with a first episode and those with recurrent psychosis, all of whom have chosen not to take antipsychotic medication. The strength of relationship between internalised stereotypes and depression and between internalised stereotypes and social anxiety in the at risk group and in an established psychosis group will be compared. It is hypothesised that there is a significant difference between those meeting criteria for ARMS, those with first episode and those with chronic psychosis on levels of internalised stigma with higher levels of internalised stereotypes as the groups move from at risk through to recurrent psychosis. Secondly, it is hypothesised that the strength of relationship between internalised stereotypes and depression and between internalised stereotypes and social anxiety will be significantly stronger in people with established psychosis, in comparison to those meeting criteria for ARMS. A particular strength of this study is the absence of any confounding effects of antipsychotic medication on either stigma or emotional dysfunction, since the inclusion criteria for both participant groups included not receiving such medication.

6.2 Methods

6.2.1 Participants

In total 66 of 74 participants who were recruited into the ACTION trial, a randomised controlled trial of Cognitive Therapy for people with psychosis who are not taking antipsychotic medication, completed the Personal Beliefs about Experiences Questionnaire (PBEQ), of these 39 were from early intervention in psychosis services and therefore classified as first episode and 27 were from severe and enduring mental health services and therefore classified as experiencing recurrent psychosis. Participants were eligible for the ACTION trial if they were aged between 16-65, either met criteria for entry into Early Intervention in Psychosis Service or had an ICD-10 diagnosis on the schizophrenia spectrum and had either been offered anti-psychotic medication and refused or had discontinued medication for 6 month or more. On entry into the trial all participants were experiencing psychotic symptoms as measured by the Positive and Negative Syndrome Scale (Kay, et al., 1987) which was defined as a score of 4 or more on delusions or hallucinations and a score of 5 or more on suspiciousness, grandiosity or conceptual disorganisation. Ethical approval was granted from the North West 9 Research Ethics Committee - Greater Manchester West reference number 09/H1014/53.

In total, 238 of 288 participants recruited into the Early Detection and Intervention Evaluation Trial (EDIE 2), a randomised controlled trial of CBT for people at risk of psychosis, completed the PBEQ at baseline. Participants were eligible for EDIE 2 if they were aged between 14 and 35 years old and scored at meeting criteria for ARMS on the Comprehensive Assessment of At Risk Mental States (CAARMS). Ethical approval was granted from the Cambridgeshire 4 Research Ethics Committee, REC reference number05/MRE05/61.

Participants for both the EDIE 2 and the ACTION trial provided full informed consent before entry into the trial and all measures were completed at baseline assessment.

6.2.2 Measures

Personal beliefs about experiences questionnaire (PBEQ)

The PBEQ is a revised version of the Personal Beliefs about Illness Questionnaire (Birchwood, et al., 1993). The PBEQ was revised for use with people meeting criteria for ARMS as the original version of the questionnaire contained three items that did not related to ARMS experiences as the measure was developed for use with established psychosis. The thirteen items on the PBEQ represent cognitive appraisals of psychosis and each item is a statement of stereotypical beliefs about psychosis. Each item is rated on a four point scale (1-4): 'strongly disagree', 'disagree' 'agree' 'strongly agree. Factor analysis indicates that the PBEQ has three reliable subscales which measure shame, beliefs about self as abnormal and expectations. Reliability testing with the ACTION population demonstrated good reliability in psychosis sample with Cronbachs' alpha's ranging from .650 -.749. Reliability testing in the ARMS sample also indicated good reliability with Cronbachs 'alpha ranging from .601 – 683.

The Beck Depression Inventory for Primary Care (BDI-PC)

The BDI-PC (Winter, et al., 1999) is a shortened revised version of the Beck Depression Inventory which is comprised of 7 items that relate to depressive symptoms, each rated on a four point scale (0-3). The BDI-PC is scored by adding the ratings for each item to produce a total score, with a range of 0-21. Testing of the measure has revealed high internal consistency (Cronbachs alpha = 0.88).

Social Interaction Anxiety Scale (SIAS)

The SIAS (Mattick & Clarke, 1998) is a 20-item questionnaire designed to measure levels of fear in social interaction situations; each item is rated on a five-point Likert scale (0-5) as follows: "not at all", "slightly", "moderately", "very", and "extremely". The SIAS has received extensive validation (Peters, 2000).

6.3.3 Data analysis

Data was analysed using the Statistical Packages for the Social Sciences (SPSS) version 15. Normality of variables was testing using the analysis of Skewness and Kurtosis and visual inspection. The variables were normally distributed and parametric tests were used in the analysis. Analysis of Variance (ANOVA) was used to test for baseline differences between the groups on age and levels of education and χ^2 test for gender. Analysis of Covariance (ANCOVA) was used for baseline PBEQ comparison between the three groups: ARMS, first episode psychosis and chronic psychosis, whilst controlling for baseline age. Bivariate correlations were used for relationships between variables and the Fisher r to z transformation to test for difference in the strength of correlation co-efficient's for the relationship between internalised stigma and (1.) depression and (2) social anxiety for those meeting criteria for ARMS and those with psychosis. In order to carry out this analysis the psychosis group was collapsed in to one rather than two psychosis groups.

6.3 Results

6.3.1 Baseline characteristics

A total of 238 people meeting criteria for ARMS who completed the PBEQ were included in the analysis. There were 144 males to 94 females with a mean age of 20.70 years and at 93.28% the sample was predominately White British. A total of 66 people with established psychosis were included in the analysis. The first episode group were made up of 39 people with a mean age of 23.82 years old, the sample was predominately white British at 84.61; the recurrent psychosis group was made up of 27 people with a mean age of 42.26 years old and again where predominately White British at 85.15%. Baseline characteristics of the samples are presented in Table 14. Analysis of variance revealed that there was a significant difference between the three groups in respect to age (F (2,301) = 191.73 p < .0001) and there was no significant difference in years in full time education (F (2,284) = 705, p >.05). There was no significant gender differences between the groups (χ^2 = 5.50, p >.05)

Table 11: Study 4 Baseline characteristics of the sample (ARMS = 238; First episode psychosis = 39; Recurrent psychosis = 27)

	Age	Education	Gender (N)	
	Mean (SD)	Mean (SD)	Male	Female
ARMS	26.70 (4.26)	13.05 (2.33)	144	94
First episode psychosis	23.82 (5.74)	12.97 (2.35)	17	22
Recurrent psychosis	42.26 (11.30)	12.46 (2.90	19	8

6.3.2 Analysis of covariance (ANCOVA)

ANCOVA was carried out between the three groups (ARMS, first episode and chronic psychosis) on all subscales of the PBEQ. No significant differences were found between the three groups on Shame (F (2.299) = 2.37, p > .05), expectations (F (2.297) = 1.75, p > .05) or self as abnormal (F (2.293) = 1.67, p > .05). No significant difference was observed between the three groups on either depression (F (2.298) = 1.01, p > .05) or social anxiety (F (2.276) = 2.51, p > .05). Results of the ANCOVA can be found in Table 12.

Table 12: Study 4 Analysis of Covariance

	ARMS Mean (SD)	First Episode Psychosis Mean (SD)	Recurrent Psychosis Mean (SD)	*F*	*p*
Self as abnormal	13.56 (2.50)	14.13 (3.41)	12.73 (3.01)	1.67	.190
Expectations	10.42 (2.39)	10.97 (2.78)	11.00 (2.45)	1.75	.175
Shame	5.69 (1.36)	6.10 (1.25)	5.56 (1.60)	2.37	.095
Depression	9.92 (4.42)	10.74 (4.53)	8.67 (4.39)	1.01	.365

6.3.3 Comparison of correlation coefficients

In order to test for difference in the strength of correlation coefficients between the three subscales on the PBEQ and depression and the three subscales on the PBEQ and social anxiety, the two psychosis groups were collapsed into one established psychosis group for comparison with the ARMS sample using the Fisher r to z transformation (Howell, 2002), thus reducing the likelihood of type 1 error due to multiple tests. First, bivariate correlations were carried out between each of the subscales on the PBEQ and depression and (2) social anxiety for the group meeting criteria for ARMS and the established psychosis group. Significant positive correlations were observed between each of the PBEQ subscales and depression and (2) social anxiety for each of the groups, see Tables 13 and 14 for the correlation coefficients.

Table 13: Study 4 Correlation matrix for ARMS group baseline correlations

		BDI	SIAS
Expectations	*R*	.451**	.422**
	N	235	216
Self as abnormal	*R*	.471**	.398**
	N	231	213
Shame	*R*	.332**	.325**
	N	236	218

** Significant at .001 level

Table 14: Study 4 Correlation matrix for psychosis group baseline correlations

		BDI	SIAS
Expectations	*R*	.599**	.418**
	N	66	61
Self as abnormal	*R*	.375**	.514**
	N	65	61
Shame	*R*	.338**	.408**
	N	66	61

** Significant at .001 level

The correlation coefficients in each group for each of the 3 subscales on the PBEQ were compared using the Fisher *r* to *z* transformation (Howell, 2002) and the results are presented in Table 15. No significant differences were observed between the two groups on either the correlation coefficients for internalised stigma and depression or internalised stigma and social anxiety.

Table 15: Study 4 Fishers r-z transformations

	BDI		SIAS	
	z	*p*	*z*	*P*
Self as abnormal	0.81	.41	-0.99	.32
Expectations	-1.45	.15	0.03	.97
Shame	-0.05	.96	-0.65	.52

6.4 Discussion

The primary aim of this study was to explore possible differences in levels of internalised stigma and the strength of relationship between internalised stereotypes and emotional dysfunction between those at risk of developing psychosis, those with a first episode of psychosis and those with recurrent psychosis. Contrary to our hypothesis, results indicated that the level of internalised stereotypes is similar in those at risk of psychosis as those with a first episode and recurrent psychosis. Of particular interest, the mean of each group indicated particularly high levels of shame about their experiences. Whilst significant relationships between internalised stigma and emotional dysfunction were found in both groups, there was no difference between the groups in regards to the strength of this relationship. Our findings indicate that there does not appear to be a progression in internalised stigma and its impact on emotional dysfunction as people move along the continuum of psychosis.

Labelling theory suggests that it is once a person is labelled as a member of an out-group, negative associations or stereotypes are then applied to them as a member of that out-group (Link & Phelan, 1999; Link & Phelan, 2001). Interestingly, whilst the group meeting criteria for ARMS have not received a formal diagnosis or confirmation of having a potentially stigmatising condition such as psychosis, which is considered to be 'out-group', the stereotypes of psychosis have still been internalised to a comparable level to that reported by those with a 'labelled' and stigmatised mental health problem and whom have contact with secondary care mental health services. This is particularly surprising considering the EDIE-2 trial staff adopted a rigorous approach to minimising stigma through carrying out

assessments in non-stigmatising settings and avoiding stigmatising language, and the assessment of internalised stigma occurred at initial entry to the trial. The results of this study suggest not only an awareness of the societal stereotypes of psychosis in ARMS participants, but also that these can be assimilated into self-identity before any diagnosis or formal labelling occurs.

Research indicates that depression and social anxiety can occur in psychosis as a result of appraising psychosis as shameful, humiliating, and seeing self as illness and it has been argued that these appraisal arise once the individual is diagnosed as with psychosis and therefore becomes a member of a stigmatised group (Birchwood et al., 2000; Birchwood, et al., 2005; Iqbal, et al., 2000; Rooke & Birchwood, 1998). As use of antipsychotic medication in previous studies may have confounded the level of depression in these groups, findings from this study indicate that these associations between stigma and emotional dysfunction remain significant in the absence of antipsychotics, providing further evidence for the work carried out by Birchwood and colleagues (Birchwood, et al., 2000; 2005;, Iqbal, et al., 2000; Rooke & Birchwood., 1998). Furthermore, qualitative research has found that whilst there are benefits to diagnosis for some people it can also result in feelings of stigma and discrimination (Pitt, et al., 2009). However, the results of this study suggest that internalisation of stereotypes may not simply occur through receipt of an official psychiatric label or via processes such as meeting criteria for entry into a psychosis service or receiving a diagnosis of a schizophrenia spectrum disorder. Furthermore, there is a signal that the internalisation of stigma does not simply increase along the continuum of psychosis in concordance with increasing severity of psychotic experiences and that the progression of internalised stigma may be more complex.

It has been argued that to internalise stigma one must associate with being a member of that stigmatised group (Corrigan, et al., 2011), and a possible interpretation of our results is that the ACTION trial participants are unique in that they had made a decision about treatment choice that was against the norm for most people with experience of psychosis by choosing not to take anti-psychotic medication, thereby demonstrating a considerable degree of autonomy. It may be that this group does not fully identify with an identity associated with psychosis. Future research should recruit other psychosis groups such as those taking antipsychotic medication in order to fully explore internalised stigma across the continuum of psychosis and control for factors such as insight and causal explanatory frameworks of psychosis.

Young people report stereotypical beliefs about mental health problems (Jorm & Wright, 2008) and social structures such as the media have been shown to negatively influence the opinions of young people in relation to mental health problems (Dietrich, Bujantugs, Kenzine, Matschinger & Angermeyer., 2006). Concerns about stigma have been found to influence and delay help seeking choices for people with a first episode of psychosis (Lincoln & McGorry, 1995), and the findings from this study suggest that those at risk have moved from simple awareness and agreement with stereotypes to internalisation; therefore, application of these stereotypes to themselves in the absence of a label or other possible stigmatising experiences. This is particularly concerning considering the number of false positives cases in at risk populations. There was considerable debate about the inclusion of a risk syndrome in the DSM V (Corcoran, et al., 2010; Drake & Lewis, 2010; Yang, et al., 2010; Yung, et al., 2010) and the proposal has been recently recommended for further study. The findings of this study suggest that this is a group

of young people at risk of psychosis and clearly at risk of internalised stigma, demonstrating a need for a clear understanding of factors that influence the development of internalised stigma in ARMS populations.

This study has several methodological limitations. The primary focus of this study was internalised stigma, however experienced stigma also occurs frequently in psychosis populations (Thornicroft, et al., 2009) and can meditate the relationship between internalised stigma and emotional dysfunction in other stigmatised traits (Mickelson & Williams, 2008). Therefore, this study is limited by an absence of measures of experienced stigma and discrimination and the findings are not able to account for the possible impact of labelling on experienced stigma and psychological wellbeing. The PBIQ was developed for use in psychosis populations with items representing cultural stereotypes of psychosis (Birchwood, et al., 1993) and therefore may not fully represent stereotypes internalised by young people meeting criteria for ARMS sample used here. Additionally, previous analysis of the PBEQ in a sample of young people at risk of psychosis using principal component analysis (PCA) indicated a different component structure to the PBEQ than analysed here (Pyle, Stewart, French, Byrne, Patterson, Gumley, et al., 2013) potentially limiting the validity of the subscales tested here in the at risk of psychosis sample. However, reliability testing of the subscales in the at-risk of psychosis sample did indicate good reliability. It could also be argued that as a revised version of the PBIQ was used with items relating to psychosis populations only removed, the measure may also not fully capture the range of internalised stigma in the psychosis population.

The absence of a group of people with psychosis who are taking antipsychotic medication and the cross sectional nature of the study limits the conclusion that can be drawn regarding the progression of internalised stigma across

the continuum of psychosis. The number of participants in the two psychosis samples may have limited the power to detect an effect. Longitudinal research which follows from at risk of psychosis to a first episode of psychosis and beyond would provide a clearer indication of how internalised stigma may develop and evolve post-diagnosis and identify factors that may predict or contribute to internalized stigma and its possible influence on emotional dysfunction.

Service users with experience of psychosis highlight self-stigma as a major issue (Schulze & Angermeyer, 2003) that needs to be addressed and the findings from this research suggest that internalised stigma is problematic pre- and post-onset of psychosis, with both groups reporting lowered expectations, shame about their experiences and appraisals that they were abnormal and significant positive relationships between internalised stigma and emotional dysfunction being demonstrated.

We recommend that psycho-education about psychosis is routinely provided to young people; not only has this been shown to lower agreement with stereotypes (Schulze et al., 2003) but this may also reduce internalisation of stereotypes for young people who become at risk of psychosis and those who go on to experience a first episode. Also, given that stigma has been shown to be a barrier to help seeking (Lincoln & McGorry, 1995), such psycho-education may improve help seeking (Barney et al., 2006; Eisenberg, Downs, Golberstein, & Zivin., 2009; Golberstein, Eisenberg, & Gollust., 2009). Research has demonstrated that the type of psycho-education offered is key to how effective the intervention is in reducing stigma (Read, 2007; Read & Harre, 2001; Read et al, 2006; Read & Law 1999). Biogenetic perspectives which promote the 'mental illness as any other illness ideology' and encourage the public to label and diagnoses symptoms of mental health problems,

has been found to increase pessimism towards people with mental health problems and increase the belief that those with mental health problems are dangerous (Kvaale, Haslam & Gottdiener, 2013). However, approaches that are psychosocial and promote an ideology that psychosis is an understandable reaction to life events have been shown to reduce stigma (Campbell, et al., 2010; Mehta & Farina, 1997; Read & Law, 1999). However, literature reviews have concluded that the biogenetic approach to anti-stigma interventions has been shown to increase stereotypical beliefs about psychosis, in particular perceptions of dangerousness and unpredictability as well as fear and desire for distance (Read & Harré, 2001; Read et al., 2006). Therefore, a normalising, non-catastrophic approach to the education of the public about psychosis would seem indicated.

The World Health Organisation has endorsed the Early Psychosis Declaration (EPD); one of the primary objectives of the EPD is to challenge the stigma of psychosis to prevent young people being disadvantaged by their experiences (Bertolote & McGorry., 2005). In light of the findings from this and previous research (Brohan et al., 2010; Corcoran, et al., 2005; Corcoran, et al., 2010; Thornicroft, et al., 2009; Yang, et al., 2010), both early detection services and clinical services for psychosis should consider the influence of internalised stigma on the psychological distress their service users experience, at a minimum screening for internalised stigma to highlight those service users who may require the option of support with issues of stigma.

Effective interventions for internalised stigma reduction have yet to be demonstrated in any large, multisite trial. Small scale studies have shown some promise regarding the use of cognitive-behavioural therapy (CBT) and/or psycho-educational approaches to reducing internalised stigma, as well as improving self-

esteem, recovery and empowerment (Knight, et al., 2006, Lucksted, et al., 2011, MacInnes & Lewis, 2008). However, these have been small studies with methodological limitations, which include the absence of a randomisation process and the absence of independent assessment. Considering the level of shame reported here by both those at risk of developing psychosis and those with established psychosis, it could be argued that definitive research is required to evaluate such promising interventions for internalised stigma in people with psychosis. It may also be worth exploring the feasibility and effectiveness of therapies developed to target shame, such as compassion focussed therapy (Gilbert and Procter, 2006). For people at high risk of developing psychosis, recent research has shown that cognitive therapy can reduce internalised stigma, and that regular contact with normalising, non-medical services also reduces internalised stigma over time (Morrison et al., 2013). In combination with our findings of high levels of internalised stereotypes at baseline, this is a compelling rationale for the provision of relatively benign, psychosocial interventions to people with at risk mental states.

Chapter 7: Study 5 - Efficacy of internet based psychosocial interventions for psychosis stigma reduction

The following paper is in review at Stigma, Research and Action

Efficacy of internet based psychosocial interventions for psychosis stigma reduction

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7.1 Abstract

Objective: This study examined young people's attitudes towards people with psychosis. The effectiveness of film based service user contact, educational information and a time matched control on psychosis stigma reduction in young people was evaluated. **Methods:** Young people between the ages of 16-18 were recruited and randomly assigned film based service user contact, educational information about psychosis, or a time matched control group. Discrimination, stereotype endorsement and social distance was assessed at baseline, end of intervention and at 3 month follow up. **Results:** Baseline analysis suggested relatively low level stigma. Whilst there was a decreasing trend in discrimination and stigma in the experimental conditions between baseline and end of intervention, significant differences were not observed between the experimental conditions and the control condition at end of intervention or at 3 month follow up. **Conclusions, implications and limitations:** Stigma and discrimination may be reducing in young people in the UK. Findings suggest a trend towards reduction in stigma and discrimination, immediately post film based service user contact and educational information about psychosis however superiority over control was not demonstrated. It is suggested that internet based interventions to reduce stigma with young people should be refined to ensure maximum engagement with the stigma reduction task. Considerations for the delivery of these interventions are suggested. Limitations are discussed including the design of the psychosocial interventions delivered and a high attrition rate at 3 month follow up.

Keywords: mass media, psychosocial intervention, service user contact, education, young people

7.2 Introduction

Psychosis is one of the most stigmatised mental health problems and people with psychosis are often stereotyped as dangerous, violent and unpredictable (Angermeyer, et al., 2004; Gaebel, et al., 2002). Research indicates that the public express a desire to maintain social distance from people with psychosis (Gaebel, et al., 2002), resulting in reduced opportunities to access education, work and health care (Link & Phelan, 2006; Thornicroft, 2007). Stigma is associated the development of additional psychological difficulties such as depression and social anxiety (Birchwood, et al., 2005; Birchwood, et al., 2006).

The reduction of stigma is a priority for clinicians and policy makers alike. The World Health Organisation launched an initiation to reduce the stigma and discrimination of schizophrenia, with anti-stigma programmes spanning 20 countries (Sartorius, 2005). In the UK, stigma reduction has been listed as a key priority in the cross-government policy 'No Health Without Mental Health (DH, 2011). There has been an increase in anti-stigma strategies over the past decade (Read, et al., 2006). Anti-stigma programmes that have opted to reach the masses have often used protest, education or contact with people who have experience of mental health problems (Corrigan & Gelb, 2006). Programmes that adopt either an educational or a contact approach to stigma reduction have been shown to have a small to moderate effect on reducing stigma and discrimination (Campbell, et al., 2010; Chan, et al., 2009; French, et al., 2010b; Pinfold, et al., 2005; Schulze, et al., 2003). Biogenetic approaches have promoted the idea that 'mental illness like any other illnesses and have assumed this message will remove blame from the individual who is the target of stigma. However, research has demonstrated the contrary, suggesting biogenetic approaches increase negative attitudes towards people with psychosis (Dietrich, et

al., 2004; Read, 2007). As well as the biogenetic approach, educational interventions for stigma reduction have also adopted a psychosocial approach to explaining the causes for mental health problems, and research suggests that the public prefer these to biogenetic explanations (Angermeyer & Matschinger, 1994; Hugo, Boshoff, Traut, Zungu-Dirwayi, & Stein, 2003; Jorm, et al., 1997). Psychosocial approaches have demonstrated small to moderate effects in reducing negative attitudes and intended behaviours towards people with psychosis (Campbell, et al., 2010; Pinfold, et al., 2003). A recent study which adopted Delphi methodology to establishing a consensus between experts in the field of stigma in relation to best approaches to anti-stigma interventions found high consensus regarding the use of recovery and 'see the person' messages (Clement, et al., 2012). In the same study reasonable consensus regarding use of social inclusion and high prevalence of mental disorder was also found (Clement, et al., 2012).These messages are consistent with a psychosocial perspective of psychosis.

Service user contact is commonly used as an intervention for stigma and discrimination (Couture & Penn, 2003). The model used for this has approach has been to include people with lived experience in the anti-stigma program as facilitators and to deliver testimonies of their experience (Campbell, et al., 2010; Pinfold, Stuart, et al., 2005; Schulze, et al., 2003). The effectiveness of service user contact has been demonstrated by a meta-analysis of over 200 studies (Pettigrew & Troop, 2000). Furthermore, qualitative accounts of participants in anti-stigma programmes suggest service user testimonies are one of the most important aspects of stigma intervention (Campbell, et al., 2010; Pinfold, Thornicroft, et al., 2005). It could be argued that educational information and service user contact may have different effects on attitudes; education may have an immediate effect on blame and

responsibility and service user contact on pity, coercion and segregation (Corrigan & Watson, 2007). However, the majority of research investigating the effectiveness of education and contact has combined the two approaches together and the conclusions that can be drawn regarding which is the more effective are limited.

A limitation to facilitator led programmes is the number of people that the intervention can be delivered to at any one time. Therefore, mass media interventions are increasing in popularity with film and internet based information being widely accessible (Clement, et al., 2012; Penn, Chamberline, & Mueser, 2003). Research into mass media interventions has produced some promising results (Clement, et al., 2012; French, et al., 2010) and there is an indication from these studies that contact remains effective when delivered via proxy methods such as film and documentary (Penn, et al., 2003). Film based contact has been shown to improve attitudes towards people with schizophrenia (Penn, et al., 2003), improve the effectiveness of educational information (Chan, et al., 2009) and computer based programmes have been shown to reduce desire for social distance, improve attitudes and knowledge post intervention and at 6 month follow up (Finkelstein, Lapshin, & Wasserman, 2008). More specifically, in relation to psychosis, the use of internet based normalising information presented in an audio format was found to significantly improve negative appraisals of hallucinations and unusual beliefs (French, et al., 2010).

Young people are commonly targeted in anti-stigma programmes (Campbell, et al., 2010; Pinfold, et al., 2003; Schulze, et al., 2003); this is an important group because although young people have an awareness of stereotypes, they may not fully endorse them till later in adulthood (Flavell, Miller, & Miller., 2001). Targeting young people may provide 'early intervention' for stigma and discrimination and

with the established importance of early detection and intervention of psychosis (French & Morrison, 2004) anti stigma campaigns aimed at young people may serve a dual purpose of reducing stigma and increasing help seeking (Pinfold et al, 2005; Chan et al., 2009).

Currently, knowledge regarding the 'active' components of psychosocial interventions used with young people to reduce stigma is limited. There is an indication that contact and education may have a differing effects on attitudes and behaviours towards psychosis, however this research was carried out with older students and evaluated attributions about psychosis only (Corrigan et al, 2007). This study aims to compare the effectiveness of film based service user contact, educational information about mental health and psychosis with a time matched control on stigma reduction. It is firstly hypothesised that contact will be significantly more effective than both education and control in reducing stigma and discrimination. It is secondly hypothesised that contact and education will be significantly more effective in reducing stigma and discrimination than the control.

7.3 Method

7.3.1 Participants

The study was offered to 530 students across 20 tutor groups at a Sixth Form College in the North West of England. 152 students provided consent and took part in the study, see Figure 3 for information regarding the flow of participants through the study.

Figure 3: Study 5 Flow chart of trial profile

```
                    ┌─────────────────────────┐
                    │    AS Level students     │
                    │   invited to participate │
                    │        N = 530           │
                    └─────────────────────────┘
                                 │
                                 ▼
      ┌──────────────────────────────────────────────────────┐
      │                  Consent obtained                     │
      │                     N = 152                           │
      └──────────────────────────────────────────────────────┘
           │                    │                    │
           ▼                    ▼                    ▼
   ┌───────────────┐   ┌──────────────────┐  ┌───────────────┐
   │   Time 1      │   │     Time 1       │  │    Time 1     │
   │   Control     │   │ Service user     │  │   Education   │
   │   N = 46      │   │   contact        │  │   N = 56      │
   │               │   │   N = 50         │  │               │
   └───────────────┘   └──────────────────┘  └───────────────┘
           │                    │                    │
           ▼                    ▼                    ▼
   ┌───────────────┐   ┌──────────────────┐  ┌───────────────┐
   │   Time 2      │   │     Time 2       │  │    Time 2     │
   │   Control     │   │ Service user     │  │   Education   │
   │   N = 41      │   │   contact        │  │   N = 51      │
   │               │   │   N = 47         │  │               │
   └───────────────┘   └──────────────────┘  └───────────────┘
           │                    │                    │
           ▼                    ▼                    ▼
   ┌───────────────┐   ┌──────────────────┐  ┌───────────────┐
   │   Time 3      │   │     Time 3       │  │    Time 3     │
   │   Control     │   │ Service user     │  │   Education   │
   │   N = 10      │   │   contact        │  │   N = 19      │
   │               │   │   N = 15         │  │               │
   └───────────────┘   └──────────────────┘  └───────────────┘
```
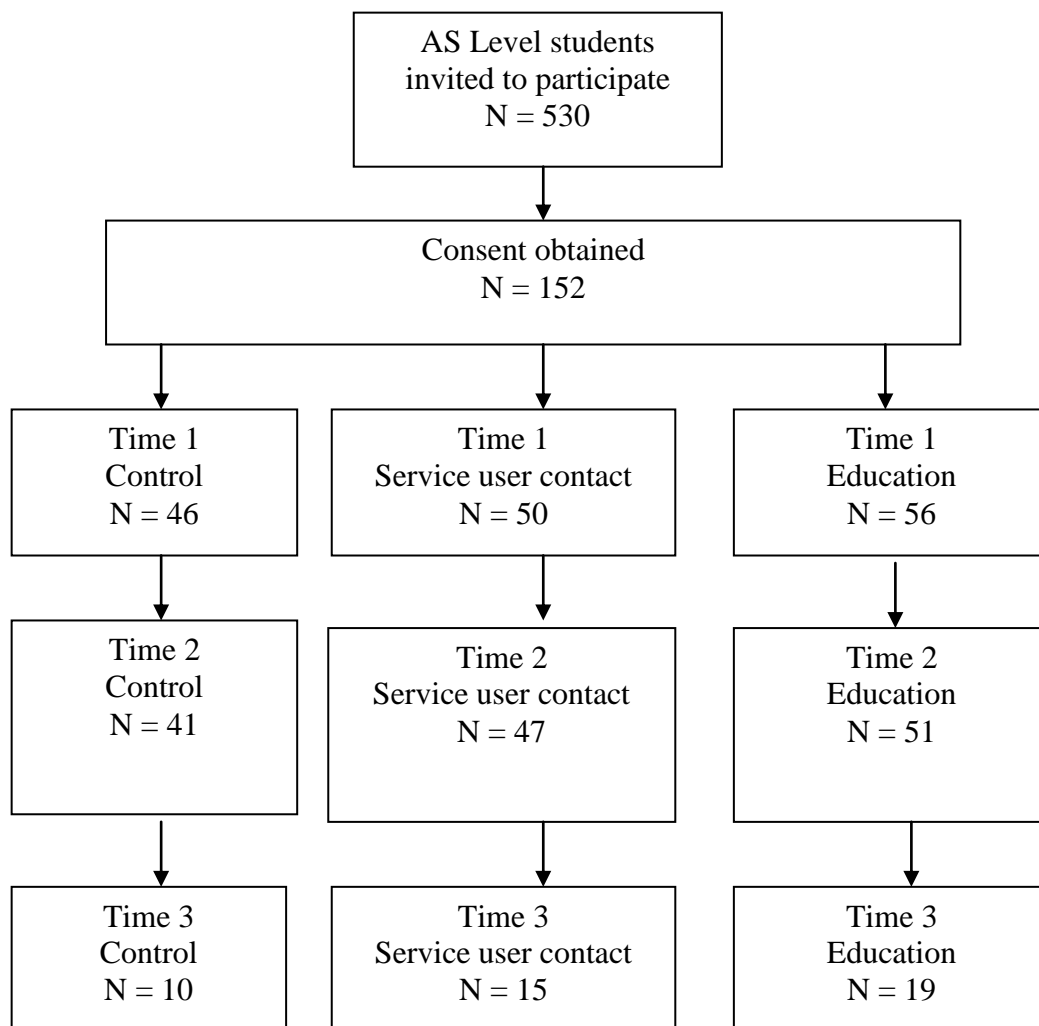
7.3.2 Design

A randomised controlled design was used and participants were randomised at the individual level via an online computer system. Randomisation was not stratified or in blocks but was true randomisation at the individual level. Participants were allocated to either film based contact group, which involved watching a 30 minute film about a teenager who had experienced psychosis, educational information group

which involved watching a 30 minute presentation about mental health and psychosis, or to the control condition which involved watching a 30 minute presentation about education and employment options post further education. Data was collected across three time points, baseline, immediately post intervention and at three month follow up. A purposive sampling strategy was adopted and all students who wished to consent to the study were included.

7.3.3 Materials

7.3.3.1 Corrigan's Attribution Questionnaire

The Corrigan Attribution Questionnaire (CAQ) (Corrigan, 2003) consists of 21 items each rated on a 9 point scale (1 = not at all, 9 = very much). Each question is answered in response to a vignette describing a man named Harry who has a diagnosis of schizophrenia. The initial version of the scale comprised of eight subscales, personal responsibility, pity, anger, fear, withholding help, avoidance, coercion and segregation. However as the help and avoidance subscales were highly correlated, and as the coercion and segregation were highly correlated these were combined to make a total of 6 subscales. All six subscales were found to demonstrate very good reliability (α=.70 – α=.96). For the purpose of the present study, the subscales fear, anger, coercion/segregation were selected to best reflect stigma and discrimination. In line with previous research these subscales were combined to form the outcome variable 'discrimination' which has been shown to have good internal consistency (α= .75 – α=.87 (Campbell, et al., 2010).

7.3.3.2 Stereotypes endorsement

Psychosis stereotype endorsement was measured using a scale designed for use with school children to evaluate the degree to which young people endorsed popular

stereotypes of people with psychosis (Schulze, et al., 2003). The measure is comprised of seven statements relating to stereotypes of psychosis which cover: ability to cope with stress, social background, treatability of psychosis, dangerousness, intelligence, unpredictability and creativity. In the original version of the questionnaire items were rated as either agree, disagree or unsure. The measured demonstrated good internal consistency (α= .71 −α= .73). For the purpose of this study the rating scale was altered to a 9 point Likert scale (1 = not at all, 9 = very much) in order to allow for greater response variation. Responses ranged from and students were asked to rate to the extent to which they agreed with the stereotypes. Two of the items (item 5 and item 7) were reversed scored. Reliability testing in this study revealed reasonable internal consistency (α = .56)

7.3.3.3 Social distance

Behavioural intentions towards people with psychosis were measured using a social distance scale developed for use with young people (Schulze, et al., 2003). The measured is comprised of 12 statements which relate to social contact with someone who has schizophrenia. Schulze et al (2003) developed the measure in conjunction with young people in order to ensure the items were age appropriate i.e. related to social activities young people would be involved with. In the original version of the questionnaire the items were all rated either agree, disagree or unsure. For the purpose of this study the rating scale was altered to a 9 point Likert scale (1 = not at all, 9 = very much) to allow for greater response variation. The measured demonstrated good internal consistency (α= .80 − α= .85) which was replicated in this study (α = .82).

7.3.3.4 Educational intervention

The educational presentation was based on a psychosocial paradigm of psychosis. In line with a recent consensus study, the emphasis of the presentation was on normalising, recovery focused information (Read, 2007) Normalising information was based primarily on Morrison, Renton, French & Bentall (2008), "Think you're crazy? Think again", which is a self-help cognitive therapy for book for psychosis (Morrison, et al., 2008). The presentation was divided into three sections, a general overview of mental health including normalising information, challenging two central myths about psychosis (dangerousness and recovery) and psychosis stigma.

7.3.3.5 Film based contact

The film based contact was one of four films developed by a service user as part of a series of films about psychosis that was recovery orientated. The film in general was from the perspective of the young person, but family members were also interviewed providing insight into their experience of psychosis as a family member. The service user was a similar age to the participants in this study and would likely be considered as a 'peer' or of equal status, one condition which has been shown to necessary for contact interventions (Corrigan, et al., 1999).

7.3.3.6 Control condition

The control condition was a 30 minute presentation about options for work and study following college.

7.3.4 Procedure

Approvals

Ethical approval was granted from the School of Psychological Sciences Ethics Committee (The University of Manchester). Student consent was sought for participation in the study and all students were provided with a parental information sheet. The students had one week to consider whether they wished to take part and were encourage discussing the study with their parents.

Data collection and analysis

Students provide a unique identifier in order to match their responses at each time point. The unique identifier was made up of the participant's mother's maiden name, date of birth and favourite colour. Data was collected at 3 time point's baseline (T1), immediately post intervention (T2) and 3 month follow up (T3). Data was gathered electronically at T1 and T2, due to restrictions with internet access T3 data was gather via pencil and paper method. The data was examined for normality using the analysis of Skewness and Kurtosis and visual inspection. Variables were normally distributed therefore parametric tests were used, except in the instance of the discrimination variable where non parametric tests where used. Data was analysed using SPSS version 15. Difference in outcome between the three groups at T2 and also at T3 was analysed using Analysis of Variance (ANOVA). Due to the attrition rate at T3 change in outcome between the groups over time was analysed using mixed models.

A priori power analysis indicated an overall sample size of 111 would be required to provide 80% chance of detecting an effect size of .30 between the three groups as significant at the 5% level.

7.4 Results

7.4.1 Descriptive data at baseline

The baseline characteristics of the sample are presented in table 16. Students were

between 16 and 19 years of age, the mean age of the sample was 16.79 (SD =.85)

Data relating to gender was available for 58 participants and was not captured for 93;

the male to female ratio for the 58 for whom gender data was available was 28:30.

Table 16: Study 5 Baseline Characteristics of the sample

	Mean (SD)	Range
Age	16.79 (.85)	16 – 19
Male: female	28:30	n/a
Discrimination	29.47 (10.59)	12 – 60
Social distance	35.80 (15.27)	12 – 79
Stereotypes	21.08 (6.47)	7 – 36

The means and standard deviations for each item on the discrimination, stereotype endorsement and social distance scale at are presented in tables 17 – 19. Overall, the mean score for each of the seven stereotypes, social distance and discrimination are generally low.

Table 17: Study 5 Mean (SD) for baseline Stereotypes Questionnaire

	Mean (SD)
Someone who has schizophrenia cannot cope with stress before exams	4.02 (1.96)
Mostly, someone who has had schizophrenia comes from a family with little money.	1.71 (1.31)
Someone who has schizophrenia cannot be helped by the doctors.	2.09 (1.59)
When meeting someone with schizophrenia, one should better watch out.	2.47 (1.53)
Someone who has had schizophrenia can be good at school*	3.35 (2.39)
Someone who has had schizophrenia blow his/ her top for the slightest reason.	3.34 (1.86)
Students who have schizophrenia are particularly good at art or music.	4.18 (1.58)

Table 18: Study 5 Mean (SD) for baseline Social Distance Questionnaire

	Mean (SD)
I would be afraid to talk to someone who has schizophrenia.	2.66 (1.92)
I would not be upset or disturbed to be in the same class as someone who had schizophrenia.	5.46 (3.08)
I could imagine making friends with someone who has had schizophrenia.	5.92 (2.55)
I would feel embarrassed or ashamed if my friends knew that someone in my family had schizophrenia.	2.14 (2.01)
If the person sitting next to me developed schizophrenia I would rather sit somewhere else.	2.40 (1.96)
If one of my friends developed schizophrenia, I would go and see him/ her at the hospital.	7.87 (2.12)
I would not invite someone who has schizophrenia to my birthday party.	2.35 (2.11)
I would not bring along someone who has had schizophrenia when I meet my friends.	2.63 (2.24)
When going on a class outing, someone who has had schizophrenia should rather stay at home.	2.37 (2.09)
I would never fall in love with someone who has had schizophrenia.	3.48 (2.60)
Someone who has had schizophrenia should not work in jobs that involve taking care of children or young people.	4.61 (2.65)

	Mean (SD)
Someone who has schizophrenia should not go to a regular school.	2.64 (2.60)

Table 19: Study 5 Baseline Mean (SD) for CAQ

	Mean (SD)
I would feel aggravated by Harry.	1.34 (1.04)
Harry would terrify me.	1.91 (1.42)
How angry would you feel at Harry?	1.50 (1.20)
If I were in charge of Harry's treatment I would require him to take medication.	7.07 (2.37)
I think Harry poses a risk to his neighbours unless he is hospitalised.	2.14 (1.65)
How irritated would you feel about Harry?	1.85 (1.46)
How much do you agree that Harry should be forced into treatment with his doctor even if he does not want to?	3.96 (2.65)
I think it would be best for Harry's community if he were put away in a psychiatric hospital.	1.76 (1.12)
How much do you think an asylum, where Harry can be kept away from his neighbours, is the best place for him?	1.79 (1.38)
How scared of Harry would you feel?	1.94 (1.33)
How frightened of Harry would you feel?	1.95 (1.34)
If I were in charge of Harry's treatment, I would force him to live in a group	2.08 (1.65)

home.

7.4.2 Discrimination variable

Figure 6 displays the means for the discrimination variable at each time point and suggests that whilst each condition has a decrease in discrimination scores between baseline and end of intervention and an increase in scores between end of intervention and 3 month follow-up there is little difference in these means. Kruskal Wallis tests at T2 did not reveal a significant difference between the three conditions on discrimination scores at end of intervention (H = .932, df = 2, p = .672) or at 3 month follow-up (H = .307, df = 2, p = .858). Mixed models indicated no significant difference between the change in film and education scores in comparison to the control over time; on average the film group is 2.2 points lower on discrimination but this is not significant (t = -.457 p =.648 CI -11.6 − 7.3) and on average the education group is 1.8 points lower than the control but this is not significant (t = -.388 p = .698 CI -10.8 − 7.3).

Figure 4: Study 5 Change in discrimination pre, post and at follow up for each condition
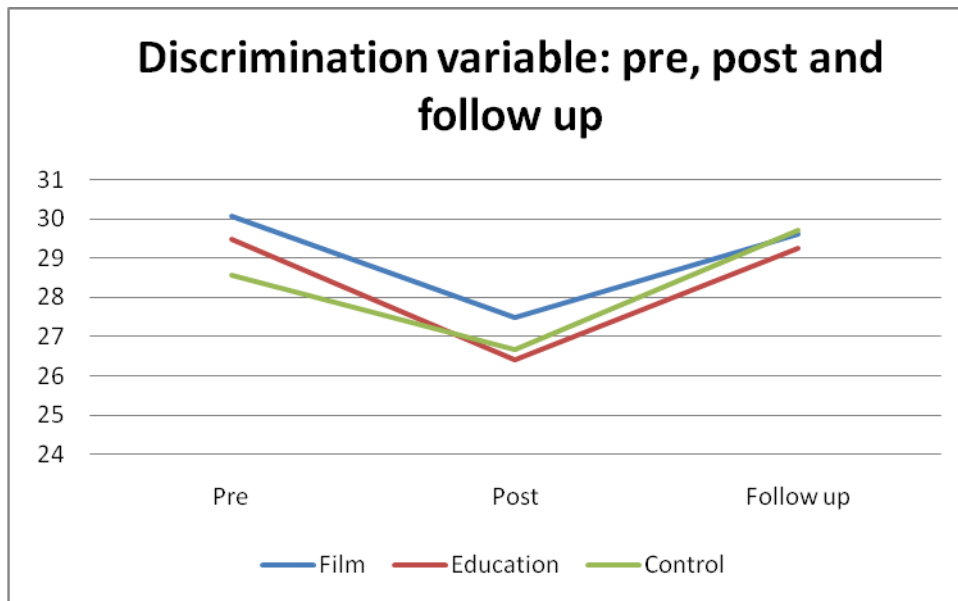
7.4.3 Social distance

Figure 7 displays the mean social distance score at each time point for each group. Whilst the gradient in the film group sees a decreasing trend and the education sees a decreasing trend between baseline and end of intervention, there is an increase between end of intervention and 3 month follow-up to higher than baseline. The gradient of the control group changes very little between each time point. Analysis of variance (ANOVA) at end of intervention did not reveal a significant difference between the three conditions on the social distance variable (F =.174, df = 2,130, p = .841). A significant difference was not observed between the conditions at T3 for the social distance variable (F = .129, df = 2, 38, p = .287). Mixed models indicated no significant differences between the film and education scores in comparison with the control over time, on average the film group is 0.7 points lower on social distance but this is not significant (t = -..115 p =.909 CI -13.8 − 12.3) and on average the education group is 1.3 points higher than the control but this is not significant (t = .208 p = .836 CI -11.6 − 14.3).

Figure 5: Study 5 Change in social distance pre post and follow up for each condition

Social distance: pre, post and follow up
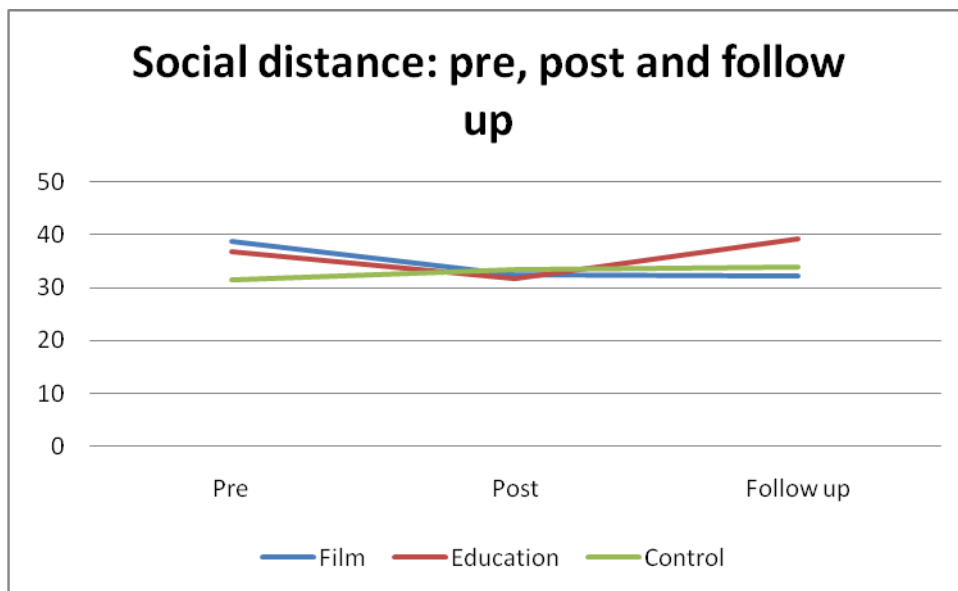
Figure 6: Study 5 Change in stereotype endorsement pre, post and follow up for each condition

Stereotype endorsement: pre, post and follow up
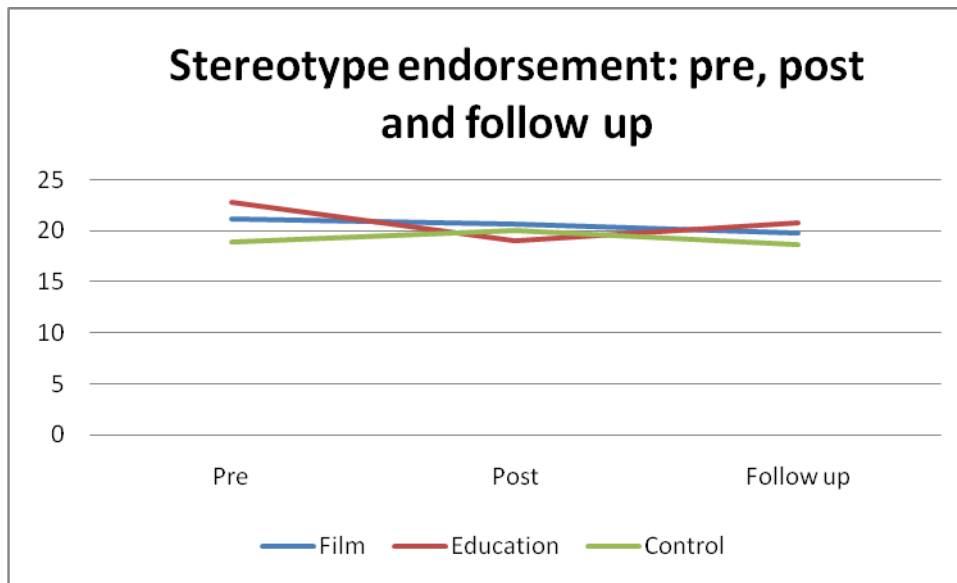
7.4.4 Stereotype endorsement

Figure 8 displays the mean stereotype endorsement score at each time point for each group. There is a small decreasing trend in the film group across all time points, with the education group seeing a decreasing between baseline and end of intervention that is not maintained at 3 month follow-up. For the control group there is an increasing trend between baseline and end of intervention that then decreases by 3 month follow-up. However, ANOVA revealed no significant difference between the three groups at end of intervention ($F = .534$, df = 2,137, $p = .587$) or T3 ($F = .223$, df = 2, 38, $p = .801$). Mixed models indicated no significant differences between the film and education scores in comparison with the control over time, on average the film group is 0.1 points higher on stereotype endorsement but this is not significant ($t = .027$ p =.979 CI -7.3 – 7.5) and on average the education group is 3.8 points higher than the control but this is not significant ($t = 1.0$ p = .302 CI -3.5 – 11.1).

Table 20: Study 5 Between groups test

Outcome	Baseline to post immediately intervention		Baseline to follow up	
	F/H*	*P*	*F/H**	*p*
Discrimination	.932	.627*	.307	.858*
Social distance	.174	841	.129	.287
Stereotypes	.534	.587	.223	.801

* Non parametric test Kruskal Wallis used

7.5 Discussion

Results from the baseline survey of students in this study were generally positive and encouraging considering the existing literature suggests negative public perceptions about psychosis (Byrne, 2001; Gaebel, et al., 2002; Jorm & Wright, 2008). However, students did demonstrate more negative beliefs towards the use of coercion and the need for enforced medical treatment. Results here are similar to another study with young people in the UK who also found positive attitudes in general towards psychosis (Roberts, Somers, Dawe, Passy, Mays, Carr, et al., 2007). The results of this survey may indicate that there has been some improvement in young people's attitudes towards people with psychosis. However, it is acknowledged that those who have positive attitudes may be more likely to participate in stigma research and the college were selected as it had policies in place for promoting an ethos of respecting diversity.

It was hypothesised that film based contact would be significantly more effective in reducing stigma and discrimination than either education or control, this hypothesis was not supported. Secondly, it was predicted that film based contact and education would be significantly more effective in reducing stigma and discrimination than control, this was not supported. Power calculation indicates the sample size was adequate at end of intervention to detect and effect however the sample size was not large enough to detect an effect at follow-up limiting any conclusions that can be drawn regarding the absence of any observed difference at follow-up. However, the absence of a significant difference between the two

experimental conditions and the control is surprising considering previous research has clearly indicated the effect of education, contact (in vivo or proxy) or a combination of both on reducing negative attitudes and behaviours towards people with psychosis (Campbell, et al., 2010; Chan, et al., 2009; Finkelstein, et al., 2008; French, et al., 2010; Penn, et al., 2003; Pinfold, Stuart, et al., 2005; Pinfold, Toulmin, et al., 2003; Roberts, et al., 2007; Schulze, et al., 2003). However, it should be noted that the number of studies which directly compare these two approaches to control using the internet is limited and those that have done so have been carried out with older college students (Corrigan, et al., 2007) or university students (Finkelstein, et al., 2008). It could be argued that the absence of an observed difference could be a consequence of the design and delivery of the interventions. Prior research studies have delivered interventions directly by a facilitator often using creative methods to engage the participants in the programme such as drama (Roberts, et al., 2007), games (Schulze, et al., 2003), artwork (Schulze, et al., 2003) and class discussion (Pinfold, Toumlin, et al., 2003; Schulze, et al., 2003). Those that have used video based interventions have been time limited with interventions lasting around ten minutes (Corrigan, et al., 2007). Participation in this study required students to concentrate on an isolated task, requiring their attention for 45-60 minutes (depending on the speed at which they completed the questionnaires). It could be argued that the results of this study are an indication that, for this age group, a more creative and engaging approach which required limited attention may be more effective in reducing stigma and discrimination in comparison with control. Finklestein et al (2008), suggest that in order for messages to be consolidated in isolated tasks, features which aid this process, such as multiple choice questions, should be incorporated (Finkelstein, et al., 2008) and it is recommended that future

research into computer based anti-stigma interventions should incorporate the use of such features. Whilst the use mass media interventions are desirable and allow for cost effective dissemination of anti-stigma materials (Penn, et al., 2003), it is questionable whether this method is as effective as face to face interventions. Pinfold et al. (2005) note that the facilitators who administered their programmes reported that the sharing information within a setting that allows for discussion was an important aspect (Pinfold, et al., 2005). Future research should aim to evaluate whether mass media interventions such as film or online information are as effective as face to face interventions. It should also be noted that other studies have included service user consultants in the design of the research, for example, 'Open the Doors Programme', suggests that one goal of any programme should be to have active involvement of service users and members of the target audience to ensure that the design of the research and the intervention is appropriate (Stewart, 2008). This study did not consult with service users or students in the development of the educational presentation or the selection of the film based service user testimony, which may have limited the effect of the messages of each and it is recommended that future research attend to this limitation.

There are limitations to this study and it is recommended that the results are considered with these limitations in mind. Firstly, the overall level of stigma in this group was low at the baseline survey leaving little room for improvement in stigma and discrimination scores, which draws into question the external validity of the study. The time frame in which the participants had to complete baseline, intervention and end of intervention was limited to 60 minutes as it had to fit into the college timetable, with each class lasting 60 minutes and depending on the reading ability of some of the students, accurate answering of the questionnaires may have

been affected by the need to complete before the end of the class. In addition, because of time restrictions the volume of data which could be collected was limited; information regarding subjects taken at college, reading level, command of English was not collected and possible effects of this could therefore not be accounted for. In addition the college expressed that they did not wish for their students to be asked about either their own or their families' mental health. Previous research has indicated that those with experience of mental health problems more likely to change negative opinions about people with mental health problems (Pinfold, et al., 2003), The absence of data regarding the possible extraneous variables means it is impossible to rule out any potential confounding factors. The effect of gender on the dependent variable was not evaluated due to missing data, considering the evidence to suggest that females are less likely to stigmatised this would be a potentially important co varying factor that may have confounded the results. Finally, the attrition rate at T3 was high and this may have limited the power of the study to detect and effect between the groups.

Limited conclusions can be drawn regarding the active ingredient in anti-stigma programmes. Results here do not demonstrate a significant difference between contact, education or control. However, there are notable limitations to this study as listed above and future research should be designed with these limitations in mind. It could be argued that in a mass media age anti stigma interventions delivered to an audience of young people should either harness engaging face to face deliveries or mass media interventions should ensure they are developed in a manner that capture and sustain attention in the task and the involvement of young people are service users would seem paramount to achieving this.

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Chapter 8: Integration and discussion of the five studies

8.1 Outline of the chapter

The purpose of this chapter is to summarise the main findings from each of the five studies and to explore common themes that have emerged from the research as a whole.

Firstly, to re-orientate the reader to the aims of this thesis, the methodologies employed and the main findings each will be summarised below. Secondly, the overarching themes that have emerged from the results of the five studies will be discussed. Thirdly, the strengths and limitations across the five studies will be discussed, followed by suggestions for clinical practice and future research implications. Finally, the overall contribution of this thesis to the psychosis stigma literature will be evaluated.

8.2 Summary of the main aims, how they were achieved and main results

The aim of this thesis was to explore the influence of psychosis stigma on psychological processes experienced by those with psychosis and those at risk of developing psychosis and to contribute to current understanding regarding best practice for stigma reduction in young people. In order to achieve this four broad aims were set each will be discussed in turn.

Aim One: To understand people with psychosis' subjective experiences of stigma and discrimination by placing the service user as the expert in stigma and with a focus on the impact of stigma on psychological wellbeing.

The first aim was addressed in Study 1 using qualitative methodology. Interpretative Phenomenological Analysis (IPA) techniques were used to analyse transcripts from interviews with nine people who have experience of psychosis. Three super-ordinate themes of judgement, disclosure and psychological distress were identified. Stereotyping was seen to be a central component to judgement, with participants reiterating some of the quantitative research on stigma which has identified common stereotypes of psychosis as danger and unpredictability. Furthermore, judgement was seen to be perpetuated and emphasised by the media who were considered to be a key institution responsible for disseminating messages that people with psychosis are violent and for a perceived lack of normalising or positive stories about people with psychosis. Ultimately, societal judgements were considered to result in lowering of social status with people who experience psychosis being low in the social hierarchy. Disclosure was a central concern for the participants in Study 1, and this was in respect to experiences of other people avoiding them following a disclosure, experiences of concealment because of fear of being exposed as 'psychotic' and social isolation which occurred as a result of others avoiding and concealment. The third super-ordinate theme centred on psychological distress, which arose for participants because of issues relating to judgement and disclosure, which they considered to impact on their mood, self-esteem, anxiety, paranoia and voices. Whist stigma was predominantly reported to be a negative experience, an interesting and

promising finding was the report that acceptance following disclosure and peer support can minimise some of the effects of stigma.

The diagrammatic representation of possible relationships between themes (Figure 4) suggests that for the participants in Study 1 there was a directional relationship between the three super-ordinate themes of stigma: judgment (on the left) generates issues of disclosure (middle) leading to stigma and distress (right), with separate pathways from both judgement and disclosure to stigma and distress.

The results of Study 1 were representative of some of the key findings from the only other IPA study of stigma in psychosis; in particular, the theme of judgement, negative attitudes and the impact of judgement on life was identified in both this and the study conducted by Knight et al. (2003). However, in Study 1 there was a clear emphasis that disclosure and the issues surrounding disclosure, such as lived experience of other people avoiding them, fears and worries about being found out and behaviours to conceal a diagnosis were a central problem of stigma. This finding may be a signal that there needs to be a clinical and research focus on supporting people with psychosis regarding issues of disclosure as in other stigmatised conditions (Chaudoir & Fisher, 2010; Ragins, 2008). At present extensive work into disclosure of mental health problems in the workplace is being carried out by researchers at the Institute of Psychiatry as part of the SAPPHIRE project (although this work is not specific to psychosis). The work carried out to date includes a systematic review of the literature on disclosure in employment over two decades from 1990 -2010. Findings from the review indicated four super-ordinate themes in the 48 papers selected for review, which included (1) expectations and experiences of discrimination, (2) other reasons for non-disclosure, (3) reasons for disclosure and (4) disclosure dimensions (Brohan, Henderson, Wheat, Malcolm,

Clement, Barley, et al., 2012). Expectations and experiences of disclosure in the work place included concerns that disclosure of a mental health problem would reduce opportunities to be hired, decrease credibility, result in rejection and stigma; other reasons for not disclosing included a desire to maintain privacy over intimate concerns and experiences (Brohan et al., 2012). The review also identified some positive experiences of attitudes towards disclosure from a service user perspective including being a role model, having had a positive experience of disclosure and being able to be honest (Brohan et al., 2012). A decision aid tool has been developed which covers the pros and cons of disclosure, personal needs, disclosure values, when and whom to tell and making a decision has been developed to use either independently or with a clinician; the primary aim of the tool is to reduce decision making conflict (Henderson, Brohan, Clement, Williams, Lassman, Schauman, et al., 2012). The decision aid tool is currently being piloted in an exploratory RCT (Henderson et al., 2012).

Aim Two: To investigate the relationship between internalised stereotypes of psychosis and emotional dysfunction in young people at high risk of developing psychosis and those with established psychosis not taking antipsychotic medication.

The second aim of this thesis was achieved using cross-sectional and longitudinal quantitative methods in Study 2 and in Study 3. Study 2 addressed the relationship between internalised stereotypes and emotional dysfunction in young people meeting criteria for an at risk mental state; Study 3 addressed this aim in a group of people with psychosis not taking antipsychotic medication. Both of these populations

represent some aspect of the psychosis continuum and to the authors knowledge Studies 2 and 3 are novel in that the research aims have not been addressed by prior research in these two groups.

In both studies, internalised stigma was assessed using a measure of internalised stereotypes of psychosis the Personal Beliefs about Experiences Questionnaire (PBEQ). In Study 2, variables measured included, depression, social anxiety, at risk symptom severity, distress associated with symptoms and suicidality. In Study 3, other variables measured included depression, social anxiety, symptoms and causal model for psychotic experiences.

The results of Study 2 and 3 indicate that for young people at risk of psychosis and those with psychosis not taking antipsychotic medication, there is a cross sectional positive relationship between internalised stereotypes of psychosis and levels of depression and social anxiety. Furthermore, longitudinal analyses indicated that baseline level of internalised stereotypes predicted level of depression at follow up, although for the psychosis population in Study 3 this did not remain significant when controlling for baseline level of depression. In the at risk of psychosis group, cross-sectional analyses also demonstrated significant relationships between internalised stereotypes and distress associated with symptoms reported on the Comprehensive Assessment of At Risk Mental States (CAARMS) and suicidality. Interestingly, in Study 3 those with a psychological causal model for their experiences of psychosis had lowered levels of internalised stereotypes in comparison with those with other causal models.

It is proposed that Study 2 contributes valuable information to the argument that a formal psychosis risk syndrome in DSM-V may be detrimental to this group of young people, and raises concern for the impact of societal stereotypes on young

people who are at risk of psychosis. Moreover, this highlights a need to improve access to normalising, psychosocial educational programmes about psychosis which promote psychosis as an understandable reaction to life events (Read et al., 2006). The importance of increasing access to normalising information about psychosis has been outlined in the Early Psychosis Declaration (Bertolote & McGorry., 2005), in order to minimise the potential that stereotypes are endorsed at an early age and applied to the self should psychotic experiences develop.

In line with the literature (Birchwood et al., 1993; Birchwood et al., 2005; Karatzias et al., 2007; Rooke & Birchwood., 1998), the findings from Study 3 indicate that internalising cultural stereotypes of psychosis may contribute to additional psychological difficulties, and in particular depression, for people with psychosis; a particular strength of Study 3 was the absence of antipsychotic medication, which may act as a possible confound. Furthermore, the results of Study 2 replicate the research carried out in relation to internalised stigma and emotional dysfunction in the at risk of psychosis population. The results of Study 2 and 3 are suggestive that exploring issues relating to stigma in clinical practice may be important to understanding client's emotional difficulties; opening a dialogue with clients about stigma may provide an opportunity to address any concerns they have about the stigma. These results also indicate that clinical practice should avoid the use of stigmatising terms and information about psychosis which may reinforce the cultural stereotypes of psychosis.

8.2.3 Aim Three: To explore possible difference in the level of internalised stereotypes and the strengths of relationship between internalised stereotypes and emotional dysfunction between those at risk of psychosis and those with psychosis.

The third aim was achieved by Study 4, a cross-sectional study in which statistical analyses were used to test for possible difference in the extent of internalised stigma in those at risk of developing psychosis and those with psychosis and secondly to test for a difference in the strength of correlation between internalised stereotypes and emotion between these two group. There was no difference between the two groups in regards to levels of shame, loss of expectations and perceptions of self-as-abnormal, and that similar relationships between internalised stereotypes and emotional dysfunction existed in both groups.

The finding that there was no difference between the at risk of psychosis group and the psychosis group is important.; The psychosis group have either a formal diagnosis on the ICD-10 Schizophrenia spectrum or were in Early Intervention for Psychosis services, whereas the at risk group, although meeting criteria for the EDIE 2 trial, were at no point provided with a formal diagnosis and were not exposed to potentially stigmatising language or secondary care mental health settings. Furthermore, the measures of internalised stereotypes were taken at baseline assessment; therefore, before prolonged exposure to EDIE 2. Labelling Theory (Link et al., 1989) posits that most people are exposed to stigma against mental illness from myriad sources across their whole life, but it is once a person is

labelled as having a certain mental health problem via formal label/ access to treatment settings that stigma can occur. The result of Study 4, therefore, raises the question of whether young people at risk of psychosis apply cultural stereotypes of psychosis to themselves in a way that is comparable to those with psychosis. Certainly, for the two groups studied here there is no observable difference, adding further weight to the importance of challenging stereotypes about mental health problems at a societal level in young people, to prevent such an early onset of internalised stigma.

8.2.4 Aim Four: To survey young people's attitudes and intended behaviours towards people with psychosis and to examine the effectiveness of internet based psychosocial interventions aimed at reducing stigma and discrimination of psychosis in young people.

The fourth aim was addressed by Study 5 which surveyed the attitudes of 152 young people between the ages of 16 and 19 years towards people with psychosis and testing the efficacy of internet based psychosocial interventions for stigma. In the randomised controlled trial three conditions were compared on measures of stigma: proxy service user contact, educational information and a time-matched control.

Baseline survey of attitudes found that the young people who participated in this study overall reported encouraging attitudes towards psychosis, except in the instance of coercion and medication where the mean scores indicated agreement with requiring people with schizophrenia to take medication. Results of the study also indicated no significant difference between the education, proxy contact and time matched control condition on discrimination, social distance or stereotype

agreement; therefore, a difference in efficacy between the experimental and control conditions was not observed. This is an interesting find considering previous literature which has demonstrated an effect of psychosocial education or contact on stigma reduction (Campbell, Shryane, Byrne, & Morrison, 2010; Chan, et al., 2009; Finkelstein, et al., 2008; French, et al., 2010; Penn, et al., 2003; Pinfold, Stuart, et al., 2005; Pinfold, Toulmin, et al., 2003; Roberts, et al., 2007; Schulze, et al., 2003). The main conclusion regarding this finding was that the design of such interventions may require young people to act as consultants regarding the development of anti-stigma interventions, and it is speculated that internet based interventions, which require self-directed study, should be developed to be brief and delivered in an engaging manner.

8.3 General discussion

8.3.1 The problem with stereotyped appraisals of psychosis

A common theme running through Studies 1-4 is the influence of stereotypes on distress for those with psychosis and at risk of psychosis. Both the qualitative and quantitative, cross-sectional and longitudinal findings reported herein have shown that cultural stereotypes of psychosis are related to depression and social anxiety. Moreover, internalised stereotypes were found to contribute to levels of depression over time. The findings for depression were more conclusive than for social anxiety, and whilst correlational analyses in these studies indicate a relationship between internalised stereotypes and social anxiety, this finding did not stand up to longitudinal analyses. The results across these studies are suggestive that stereotyped appraisals about psychosis are a central problem of stigma for those at risk of psychosis and those with psychosis not taking antipsychotic medication. The qualitative findings of Study 1 clearly implicate stereotypes as a problem of social judgements about psychosis, including the media images of psychosis as violent. Qualitative data indicated that stereotyping as a form of judgement can result in issues of disclosure and contribute to emotional distress including shame and lowered self-esteem.

As discussed in Chapter One, stereotypes are socially defined cognitive structures or beliefs, which are negative in content and applied to a group by members of society. Furthermore, it was discussed in Chapter One that stereotypes are influenced by social norms and by structures in our society such as the media. The progressive model of stigma (Corrigan et al., 2011) and modified labelling

theory (Link et al., 1989) both highlight that most people are exposed to the stereotypes of mental health problems from a young age through socialisation into our cultural beliefs and norms. Therefore, the qualitative and quantitative findings from this thesis that indicate stereotypes continue to be problematic for people with psychosis and for young people even before the onset of psychosis provide further impetus to the argument that stereotypes should be challenged. Comprehensive large information campaigns which educate the public about psychosis using a variety of media methods have been shown to change behaviours and beliefs about psychosis (Joa, Johannessen, Austad, Friis, McGlashan, Melle, et al., 2008). The TIPS early intervention programme demonstrated that educating people through the multiple methods using newspapers (national and local), brochures distributed to the public, commercials on TV, the radio and in cinemas, education for GP's and education providers and the use of the internet increased help seeking behaviours (Joa et al., 2008).

The findings that internalised stereotypes predict depression over time are in line with the wider literature on internalised stigma and negative outcomes, which has demonstrated the negative effects of internalised stigma on self-esteem, demoralisation, hope and empowerment (Camp, et al., 2002; Cavelti, et al., 2012; Corrigan, et al., 2011; Livingston & Boyd, 2010; Lysaker, Buck, Taylor, & Roe, 2008). More specifically, results of the studies 1-4 replicate previous research demonstrating the negative effects of internalised stereotypes on depression (Birchwood, Iqbal, et al., 2000; Birchwood, et al., 1993) in two groups which have not previously been studied. Previous research, which has also utilised the Personal Beliefs about Illness Questionnaire (PBIQ), has used social rank and theory as a paradigm to understand the development of post-psychotic depression (PDD).

Research has demonstrated that the perception of being lower social rank, having lost social roles and being subordinate to others is associated with depression in people with psychosis (Iqbal et al., 2000; Rooke & Birchwood., 1998). Shame is also a central concept of social rank theory and there are distinct overlaps between the concept of internalised stereotypes and the concept of shame, which can be defined as either thoughts and feelings that others judge you negatively or as unattractive (external shame), or self-directed thoughts and feelings that relate to being unattractive, flawed or bad (Gilbert & Proctor., 2006). In this definition of shame, it is posited shame is related to negative appraisals about the self, which are based on the belief that one considered flawed in the minds of others or the self. Gilbert and Miles (2000) have argued that 'social put down' can leave to a person experiencing or appraising themselves to be devalued can result in depressed mood (Gilbert & Miles., 2000). In relation to depression, previous research has demonstrated that social rank comparisons and shame are highly correlated with rumination and that shame contributes to depression in non-clinical samples (Cheung, Gilbert & Irons., 2004). The author argues, along with previous researchers (Birchwood et al., 2006; Iqbal et al., 2003; Rooke &d Birchwood., 1998) that there are important comparisons to be drawn between social rank theory, social put down and shame with the concepts of stigma and internalised stigma. This, as discussed below, may be important when considering interventions for people with psychosis who report internalised stigma.

8.3.2 Stigma processes across psychosis continuum: Effect of labels on internalised stereotypes

Modified labelling theory proposes that all people in society are aware of the stigma associated with mental health problems, and if a person becomes labelled with that mental health problem they are then at risk of engaging in a number of behaviours to manage the potential damage from this label (including secrecy and withdrawal), which may result in further mental health problems. Link et al (1989) argue that an official label is important because it associates the person with the stigma and they have proposed that formal labels come through diagnosis, contact with treatments/ treatment centres for mental health problems such as medication (Link et al., 1989). In support of modified labelling theory, the qualitative findings from Study 1 clearly indicated that people with psychosis who feel judged and stereotyped by their label can engage in a number of strategies to manage the threat of others finding out about this stigmatising label. Strategies included secrecy about diagnosis and withdrawal. Furthermore, the results of Study 3 suggest that for those with a diagnosed psychosis, internalised stigma can contribute to the development and the maintenance of other psychological difficulties which is in line with the what Link et al (1989) consider to be the end result of labelling for some people. However, the results of Study 2 and Study 4 indicate that for the at risk of psychosis group, whom the author perceived to be an non-diagnosed group, internalised stereotypes contributed to depression and a difference was not observed between this and the psychosis sample in regards to the level of internalised stereotypes. Based on modified labelling theory the author hypothesised that those 'further along' the

psychosis continuum with regard to symptoms but also access to secondary care mental health services and receipt of a formal diagnosis would internalised stereotypes to a greater degree. However, as noted, the results of Study 4 did not support this hypothesis. Whilst it could be argued that this group may have felt labelled through inclusion in the EDIE 2 trial, the hallmarks of labelling, as outlined by Link et al (1989), did not apply to this group; they received no diagnosis from the research trial as being 'at risk of psychosis', stigmatising language such as 'psychosis' was avoided as was mental health jargon, this young group did not have sustained contact with potentially stigmatising secondary care mental health services and were seen by trial staff in non-stigmatising settings such as their home or at a college or university. Furthermore, it could be hypothesised that if participants had felt labelled by inclusion in the trial; however, the measure of internalised stereotypes was taken on first assessment with the research team and, therefore, at a point of limited contact. If, however, participant's internalisation of stereotypes at baseline assessment had been influenced by acceptance into the trial, this raises even more concerns over the application of formal psychiatric diagnoses to this group and provides evidence for the concerns raised by a number of researchers and academics in response to the inclusion of the risk syndrome in the DSM and therefore the formal labelling of young people as at risk of psychosis (Morrison, et al., 2010; Yang et al., 2010).

Overall, the finding that young people meeting criteria for at risk of psychosis are influenced by the effects of labelling prior to an official psychiatric diagnosis and that this can contribute to depression, raises concern about how stigma is currently influencing young people and draws into question whether social structures such as educational institutions and health care services are providing

effective and sufficient intervention to minimise stereotypes of psychosis in young people, or indeed whether mental health education is being offered to children early enough.

8.3.3 Demonstrated need for effective stigma intervention strategies

A clear commonality between each of the studies presented in this thesis is that each demonstrates a need for effective stigma interventions for young people in the public, as well as young people at risk of psychosis and people with established psychosis. The findings from the studies highlight particularly important areas for intervention in relation to psychosis stigma, as will be discussed.

The subjective accounts of stigma from participants in Study 1 suggest that interventions which support people with issues of disclosure including shame, isolation and anxiety, are required. There is a signal from the data that peer support and acceptance may be a method to reduce the negative effects of judgement and disclosure. As will be discussed below in section 8.5 and 8.6, the author argues stigma intervention research could accumulate an in-depth understanding of appropriate interventions if led from a service user perspective. This could be achieved through further qualitative research or consensus studies of service user priorities regarding interventions for internalised stigma.

Until recently, stigma researchers have focussed their attention on interventions for public stigma, and clearly if public stigma was eradicated, so too would internalised stigma. However, it is highly unlikely that public stigma can be reduced to such a degree, in a speed efficient enough to reduce the problem of internalised stigma for those who currently experience psychosis and for the next generation of people who experience psychosis. Hence, the author argues that

research resources investigating interventions should be placed in the clinical arena as well as the public. A recent critical review of the literature on internalised stigma highlights that there is a low number of intervention studies (Mittal, et al., 2012). In this review, a total of 14 studies that detailed an intervention for internalised stigma were identified across mixed diagnoses, but predominately psychosis and depression, with approaches to intervention focussing on coping skills and empowerment. Mittal et al (2012) also emphasised a need to identify groups of people with mental health problems who may be at high risk of internalising stigma (Mittal, et al., 2012). The influence of stereotypes on wellbeing identified in this thesis indicates that stereotypes are an appropriate target for any intervention. As discussed in Chapter 1, stereotypes are faulty, negative appraisals held about a certain group (Link & Phelan, 2001). As stereotyping is a cognitive process, Hayward and Bright (1997) propose that cognitive approaches are likely to be a key intervention strategy for reducing internalised stigma (Hayward & Bright, 1997). Further implications for clinical interventions for internalised stigma are discussed in section 8.5 of this chapter.

Of concern, is the finding which indicates that internalisation processes may begin very early on in a young person's progression into mental health problems and the mental health system. Therefore, understanding best ways to communicate with young people about psychosis in order to educate the next generation about psychosis is key intervention that can address public stigma and minimise the risk of internalised stigma in those who are at risk of being a target of stigma. Providing normalising messages, which are in direct contrast to myths and stereotypes, to young people who may be experiencing unusual experiences could counteract some of the effects of stereotypes. Furthermore, the findings in Study 5 demonstrate the importance of research which aims to better understand the active components of

public stigma interventions and best practice regarding the mode used to deliver interventions. There is indication in the literature, from a study conducted by Clement et al (2012) that mass media interventions such as DVDs can be effective in reducing stigma in adults training to work in the health care profession (Clement, et al., 2012). The results of Study 5 indicated no difference between education, proxy contact and control; however, the author suggested that young people should be consulted in depth regarding the most appropriate method to deliver psychosocial interventions for stigma.

8.4 Critical analysis of methodology and data analysis

Whilst the methodological limitations of each study have been discussed within their respective chapters, the author recognises that there are some key methodological limitations that are common across the studies. These will be discussed in order to allow the reader to make suitable conclusions about the thesis and the proposed implications for theory, practice and future research.

8.4.1 Sampling

In respect to the samples included in the thesis, there is a clear limitation to the absence of a (1) larger sample and more general sample of people with psychosis i.e. people with psychosis taking antipsychotic medication and (2) samples of people with psychotic like experiences who are not help seeking. Inclusion of these samples would be particularly beneficial for Study 4 when comparing internalised stigma across the psychosis continuum. In relation to the psychosis sample recruited, it could be argued that there is uniqueness to this group as they had chosen not to take antipsychotic medication for 6 months at least. Although research indicates that

between 30-40% of people with psychosis discontinue antipsychotic medication (Lieberman, Stroup, McEvoy, Swartz, Rosenheck & Perkins et al., 2005), this treatment remains the treatment of choice in the NICE Guidelines for the management of schizophrenia (NICE., 2009) and research with people who are not taking antipsychotic medication is unique. It could be assumed from labelling theory (Link et al., 1989) that psychosis groups who take antipsychotic medication may report greater levels of internalised stigma through regular contact with services. The additional of a sample of people taking antipsychotic would allow findings to be generalised and be more representative of the psychosis continuum.

Ultimately, to better understand the development of internalised stigma across the continuum of psychosis the most effective sample would be one which had been followed longitudinally from at risk status to a first episode and beyond as this would provide the most accurate understanding of how internalised stigma develops in people with psychosis.

The samples recruited to each of the five studies were self-selecting which may have introduced bias (Heckman, 1979). It could be argued that this was a particular problem with Study 5 which may have attracted participants who had an interest in psychology or mental health; this may account for the particularly low levels of stereotypes, discrimination and desire for social distance in the sample of young people who volunteered to take part in the research. The author did not measure variables such as the participant's personal experience of mental health problems on request of the college; neither was a question pertaining to choice of courses undertaken. This information may have indicated whether there was a bias in the sample.

There is an under-representation of Black and Ethnic Minority groups across the studies. The majority of participants across the studies were of White British origin, which is a serious limitation considering the incidence rates of psychosis in BME groups (Bhugra, et al., 1997). Thornicroft (2009) has highlighted a generic limitation to mental health stigma research to date has been a lack of focus on multiple stigmas including ethnicity. In relation to the studies presented in the thesis they are not able to account for stigma in these ethnic groups but there was a signal from Study 1 that multiple stigmas may exist and be problematic for those experiencing them.

8.4.2 Measures

As discussed in Chapter 2 the personal beliefs about experiences questionnaire (PBEQ), which was used in studies 2-4 was selected based on its face validity for measuring psychosis stereotypes and that it was used in previous research exploring the relationship between appraisals of psychosis and emotion (Birchwood, et al., 2005; Birchwood, et al., 1993; Birchwood, et al., 2007; Karatzias, et al., 2007). Other valid and reliable measures of internalised stigma are available but they have been developed from information from mixed cohorts of mental health problems rather than being developed specifically for use with people with psychosis (Brohan, Slade, et al., 2010; Corrigan, et al., 2006; Dinos, et al., 2004; King, et al., 2007).

There are some limitations to the use of this measure which the author will outline. The PBEQ is a revised version of the Personal Beliefs about Illness Questionnaire (PBIQ; Birchwood et al., 1993): revisions included removing the word illness and replacing it with experience and removing 3 items that were unlikely to fit with experiences of young people meeting criteria for at risk of psychosis. As the factor structure of the PBIQ had not been determined by statistical

methods i.e. exploratory factor analysis and as the PBEQ had not been validated for use in at risk populations validation of this measure was required. Therefore, principle component analysis (PCA) was carried out with the EDIE 2 and ACTION sample. In the EDIE 2 sample the reliability of the second factor (perceived social acceptance of experiences; SAE) was questionable. The reliability of this subscale could be improved by the addition of new items which relate to social acceptance. This could be achieved through a review of the literature or via qualitative research. In relation to the existing literature, there is currently little research evaluating stigma or internalised stigma in young people at risk of psychosis. However, qualitative research carried out by Byrne & Morrison (2010) has indicated that young people at risk of psychosis report concerns that others perceived them to be unusual or strange because of their experiences. However, the aim of the research carried out by Byrne & Morrison was to explore the perceptions of interpersonal relations and communication in young people at risk of psychosis and whilst stigma was generated as a theme within young people's perceptions the data available from this study to generate items is limited. Alternatively, new items could be generated via new qualitative research carried out with young people at risk of psychosis. Thematic analysis of data obtained from focus groups with people at risk of psychosis could provide rich and detailed accounts of perceived social acceptance, which could then be used for item generation.

Prior to the research carried out in Studies 2-4, the PBEQ had not been subjected to psychometric testing. Moreover, the PBIQ from which the PBEQ was derived was also not subject to psychometric evaluation via standardised statistical procedures i.e. Principal Component Analysis (PCA) or Factor Analysis (FA). Therefore, one aim of Studies 2 and 3 was to psychometrically evaluate the measure

in order to locate underlying dimensions of the items on the PBEQ and to test the reliability of these dimensions prior to use in Studies 2, 3 and 4. There are a number of statistical procedures which can be used to identify the underlying dimensions of a set of variables; the two most commonly used procedures are either PCA or FA (Field, 2009).

PCA allows the data set to be reduced to linear components within the dataset and to identify the extent to which a variable within the dataset contributes to the component (Field, 2009). There are a number of benefits to PCA which have been summarised by Field 2009, who notes, "principle component analysis is a psychometrically sound procedure" and "it is conceptually less complex that factor analysis" (Field, 2009 pp. 638). However, a limitation to PCA is that latent variables are not identified via this method; therefore assumptions cannot be made about the underlying factors of the components. A further limitation of PCA is the conclusions that can be drawn are limited to the sample collected. Generalisation to other samples can only be assumed if further analysis with a different sample reproduces the factor structure (Field, 2009). It is recognised this may be a limiting factor to using PCA and in the case of Studies 2 and 3 it was found that the factor structure of the PBEQ was different to the EDIE 2 sample when tested in the ACTION sample. In order to compare internalised stereotypes between these two groups in Study 4 the factor structure from the PCA with the psychosis sample was tested for reliability in the ARMS sample and as reliability was demonstrated this factor solution was used for comparison in the study in chapter six. However, it could be argued that the two factor structures identified in the study presented in Study 2 were more valid for the ARMS population. Furthermore, the author recognises that the full version of the PBIQ may have been more applicable to the sample in Study 3 and may have

allowed for a more through exploration of internalised stereotypes and the relationship to emotional dysfunction than the shortened and revised reversion of this measure. A new version of the PBIQ is now available which has additional items and has been shown to be reliable, valid and sensitive to change (Birchwood, et al., 2012).

As with the majority of the measures used throughout this thesis, the PBEQ is a self-report measure. Criticism of self-report measures include under or over reporting of experiences (Aiken, 2002) however the PBEQ may present with an additional problem relating to the possible ambiguity with the word 'experience' which could have been misinterpreted to mean any experience. Although the PBEQ was carefully administered informing participants the items related to the experiences disclosed in the CAARMS of PANSS assessment, ambiguity could have influenced answers. The focus of studies 2, 3 and 4 was stereotyped appraisals of psychosis, however, the author recognises that this may neglect behavioural and emotional aspects to internalised stigma and that these studies cannot account for the effects of experienced and perceived stigma which, Study 1 and previous research has highlighted is problematic for people with psychosis (Brohan, Slade, et al., 2010). A narrative literature review carried out to identify service user's priorities and preferences for outcomes in psychosis indicated that improved social and functional ability and satisfaction was a priority for people with lived experience of psychosis (Byrne, Davies & Morrison, 2010). It could be argued, therefore, that broader concepts of functioning such as quality of life and well-being might be more suitable dependent variables, from a service user perspective, for the regression analyses carried out in Studies 2 and 3.

The author recognises that the absence of construct validity of the PBEQ with other established measures of internalised stigma is a limitation and that it could be argued that the PBEQ measures other constructs which are likely to be related to internalised stigma such as self-efficacy. However, it is important to note that the measure was developed by Birchwood et al (2013) to "capture the degree to which subjects felt that the social and scientific beliefs about mental illness were accepted by them as a statement about themselves" (Birchwood et al., 2013 pp. 389). More recently, Birchwood et al (2012) note that "the concepts underlying the original PBIQ were based in Stigma Theory (Estroff., 1989) and how pejorative cultural stereotypes of schizophrenia were accepted and internalised by the individual and how they had come to define the self" (Birchwood et al., 2012 pp 2). The definition of a stereotype is that it is a negative belief which is considered to be true about a group and applied to the whole group (Biernat & Dovidio, 2003). It is proposed by the author that the concepts on the PBEQ, as suggested by Birchwood et al (1993; 2012), represent scientific beliefs (including medical perspectives of schizophrenia) and social beliefs about psychosis which are negative including concepts that people with psychosis are abnormal, have something wrong with their personality, should be kept away from other people and an inability to have meaningful roles like work. Therefore, whilst it is acknowledged that the absence of concurrent validity is an issue, it is also argued that the PBEQ is an appropriate measure of stigmatising stereotypes of psychosis.

The focus of this thesis has been on the experience of stigma, psychological consequences and methods to reduce public stigma; however issues such as resilience to stigma, coping and empowerment are not addresses. Shih (2004) has argued that whilst there is a strong rationale for focussing on the negative effects of

stigma, there is a gap in our understanding of factors that assist people with mental health problems in overcoming stigma, such as empowerment. A focus on resilience, empowerment and positive aspects to psychosis could better inform best practice regarding internalised stigma reduction (Shih, 2004).

8.4.5 Statistical limitations

There are two main statistical limitations to the quantitative studies across this thesis; these are multiple hypothesis testing and the absence of Bonferroni corrections and missing data.

It is recognised that in studies 2 to 4 a number of statistical analyses were carried out; multiple hypotheses were tested and it could be argued that the number of analyses conducted may have increased the chance of Type 1 error. One statistical option that can be utilised to limit the chance of Type 1 error is to apply Bonferroni correction; this was not done in the cases of Studies 2-4 because of the exploratory nature of the research. However, should the reader wish to, this can be easily applied by multiplying the alpha value by the number of tests conducted.

It is acknowledged that there was a proportion of missing data from each of the studies. Techniques were not utilised to impute data and SPSS operates by deleting missing cases from the analysis; therefore, it could be argued that the deletion of missing data could have biased the sample (however, in the primary trial analyses for the studies concerned, there were no differences in baseline data that discriminated between complete and missing cases). It is also acknowledged that missing data can limit statistical power, increasing the chance of Type 2 error. Missing data can be particularly problematic in longitudinal trials such as EDIE 2

and ACTION; a major ethical consideration of any research is that it is voluntary and that participants should not experience undue distress or burden because of participation. The burden of multiple assessments and measures in longitudinal trials can result in missing data.

As discussed in Chapter 2, the sample sizes Studies 2, 3 and 4 were pre-determined by the power calculation for the main trial intention to treat analysis. This can raise questions regarding the power to detect and effect and the risk of Type 2 error. However, it is widely accepted that a sample of 10 participants is required per predictor in a regression (reference from Graeme MacLennan) and therefore it could be argued that the samples were large enough to detect an effect.

8.5 Implications for clinical practice

Group cognitive behavioural (CBT) approaches to internalised stigma for people lived experience of psychosis have been examined in combination with self-acceptance strategies (MacInnes & Lewis, 2008), empowerment (Lucksted, et al., 2011), problem solving and self-esteem strategies (Knight, et al., 2006; Lucksted, et al., 2011). One of the key aspects of these internalised stigma reduction strategies has been examining and challenging stereotypes and stereotyped appraisals of self (Knight, et al., 2006; Lucksted, et al., 2011; MacInnes & Lewis, 2008; Mittal, et al., 2012). However, the current evidence base for internalised stigma reduction strategies is limited by methodological problems with the existing research including low numbers in the samples, and absence of random allocation of participants, blinding and independent assessment. Furthermore, findings from Study 1 are suggestive that any intervention should consider how problems of disclosure can be

supported therapeutically. Stigma disclosure models (Chaudoir & Fisher., 2010), which have been developed in relation to other stigmas such as homosexuality, may prove applicable to the area of psychosis. In particular, cognitive behavioural approaches which offer strategies such as problem solving, considering advantages and disadvantages and role play practice may prove effective in supporting people with psychosis in making decisions about disclosure and concealment (Chaudoir & Fisher., 2010). Research regarding interventions for problems around disclosure for people with mental health problems is currently limited. However, researchers at the Institute of Psychiatry from the SAPPHIRE research programme are currently testing the feasibility and effectiveness of decision tools for disclosure in the work place (Henderson, et al., 2012).

Current research regarding clinical interventions for internalised stigma indicates that normalising information, which is designed to counteract public and internalised stereotypes, may prove a valuable tool in challenging stereotyped appraisals in people across the continuum of psychosis (Knight, et al., 2006; Lucksted, et al., 2011; MacInnes & Lewis, 2008). Whilst stereotypes typically represent misguided information, normalising information typically represents evidence based information. Trials of CBT for psychosis in populations of people with psychosis and those meeting criteria for ARMS indicate that normalising information is an effective component of CBT (French & Morrison, 2004; Kingdon & Hansen, 2004; Turkington, Kingdon, Turner, & Group, 2002). A user-led qualitative study, which investigated service user perceptions of CBT for psychosis indicated that the participants found normalising to be a valued process, and one that is central process in improving personal understanding of experiences (Kilbride, Byrne, Price, Wood, Barratt, Welford, et al., 2013). Furthermore, a recent Delphi

study evaluating expert opinions of key components of CBT for psychosis highlighted normalisation as a key component of CBT which aids stigma reduction (Morrison & Barratt, 2010). Therefore, it is suggested that services working with those at risk of psychosis and those with psychosis utilise normalising information that challenges common stereotypes of psychosis. This may be achieved effectively and economically through self-help or resource books for psychosis that have been developed by leading clinicians in the field which contain normalising information that are easily accessible; self-help or resource books for service users which contain normalising information such as 'Think You Are Crazy: Think Again' (Morrison, Renton, French, & Bentall, 2008) or web-based information such as podcasts (French, et al., 2010) or websites such as www.aminormal.com. It is clear that normalising resources exist and that if services actively promote and increase access to such materials this may have an immediate impact on any internalised stereotyped appraisals they hold regarding psychosis on contact with the service. A normalising approach is consistent with the message from general public interventions that normalising, psychosocial approaches are preferred to biogenetic ones, which makes sense given people with psychosis are part of the public also, and internalise these messages. The cross-government document 'No Health Without Mental Health' proposes steps that the government intend to take to ensure that people have a good start in life. These include, making stigma and discrimination reduction a key priority for all public and health care services. The author argues that NHS investment in working with children in schools to educate them with normalising psychosocial messages about mental health and psychosis would prove beneficial in promoting positive, normalising messages that would transcend into the next generation. This may be particularly important as at a young age when beliefs about

self and others are emerging. Research has been carried out at the Sussex Psychosis Research Interest Group (SPRIG) which has investigated the effectiveness of a story book intervention for 7-8 years old's in improving mental health schema and reducing stigma and results of the study indicated that the intervention had a strong effect on improving knowledge about mental health and positive attitudes towards people who experience mental health problems (Carroll, Jamieson, Ferassi, Brown, Greenwood., 2013).

In summary, there is a need for services working with people who experience psychosis to provide messages that are consistent with a normalising and therefore psychosocial approach. Considering the findings from a systematic review (Read et al, 2006), which demonstrated that overall biological messages about psychosis are associated with negative beliefs, it would seem appropriate to minimise the biogenetic messages.

The UK government recently launched 'Talking Therapies: A Four Year Plan of Action', which is linked to 'No Health Without Metal Health' (DH, 2011). This document sets out plans to improve access to psychological therapies (IAPT) for serious mental illness (SMI) including psychosis. Currently a pilot site in the UK has been identified for IAPT SMI. If IAPT for psychosis is rolled out nationally, this will vastly increase the access to CBT for those with psychosis. Therefore, a demonstration of the effectiveness of low intensity CT based interventions for internalised stigma such as normalising may inform the approach taken by IAPT for SMI; a programme such as IAPT SMI may be a potential route to increase access to anti-stigma interventions for those with psychosis.

The findings presented in each theme and previous research regarding the negative effects of stigma on people with psychosis (Birchwood, et al., 2005; Karatzias, et al., 2007; Karidi, et al., 2010; Link, Struening, Neese-Todd, Asmussen, & Phelan, 2001; Livingston & Boyd, 2010; Lysaker, et al., 2008; Staring, et al., 2009) suggest that people with established psychosis and those who are at risk of psychosis are likely to present to clinicians and services with concerns about stigma that may be contributing to their psychological distress. Morrison (2001) reports that many people with psychosis present with appraisals that they are 'they are going mad' or 'will be locked up'. Whist stigma can threaten wellbeing and risk the prolongation of psychological difficulties, if an individual is able to perceive access resources to help them cope with potential threats from stigma the end product of stigma does not have to be a threatened identity and distress (Major and O'Brien, 2005). Therefore, the author emphasises the importance of clinicians becoming aware of the problems of stigma and opening up dialogue with participants regarding stigma. This could be through the use of psychometrics or as part of initial assessments. Using psychometric measures of stigma may open dialogue between clinician and client about stigma, their subjective experiences or concerns about stigma and this would allow services to highlight those who are most susceptible to the effects of stigma and those who may stigma considered in a formulation of their psychological distress. Becoming aware of issues relating to stigma may include clinicians challenging some of their own stigmatising beliefs about psychosis, as research indicates that clinicians are not exempt from stigmatising (Gonzalez-Torres, Oraa, Aristegui, Fernandez-Rivas, & Guimon, 2007; Mukherjee, et al., 2002; Pinfold, Byrne, et al., 2005). Mass media resources such as DVD based service user contact has been shown to be effective in reducing stigma in nurses (Clement, et al.,

2012), such DVD's are produced by the mental health charity Rethink and may provide an economically viable strategy that can reach large numbers of clinicians at any one time (Clement, et al., 2012). Such an economically viable strategy would have minimal impact on resources in terms of staffing. Services working with people who experience may also be well placed to open up and embrace discussions with service users about concerns regarding disclosure. As discussed disclosure is difficult for many people with concealable stigmas and decisions regarding disclosure are complex and benefit from support (Chaudoir & Fisher., 2011; Corrigan & Matthews., 2003), clinicians working in the field may therefore be well placed to support people with disclosure decisions.

In addition to input from social and clinical services support from peer networks may prove an effective intervention in reducing internalised stigma in people with psychosis. There is an indication of this from the accounts in Study 1 and from the literature that peer support is effective in improving social outcomes such as increasing social networks (Davidson, Chinman, Kloos, Weingarten, Stayner, & Tebes., 1999) but also promoting empowerment (Corrigan, Larson & Rusch., 2009; Van Tosh & del Vecchio., 2000). Corrigan et al (2009) suggest that peer-support offers a network of social contacts in which there is no hierarchy and all members are equal, therefore no member of the group is of lower social status; empowerment is at the heart of service user operated groups (Corrigan et al., 2009).

In the UK organisations such as the Hearing Voices Network provide a place for people who hear voices and experience visions to talk about their experience freely with other people who have similar experiences and their approach is inclusive and de-stigmatising, with their website advertising 'whoever you are and whatever you are experiencing, you are welcome here' (http://www.hearing-voices.org/).

However, research is required to better understand who is attracted to peer -support and self-help and larger scale studies are required to demonstrate effectiveness (Davidson et al., 1999).

8.6 Proposals for future research

Whilst proposals for future research have been suggested in Studies 1-5, there are some key overarching suggestions for future research that can be made.

This thesis clearly outlines the rationale for investigating effective stigma intervention strategies for those at risk of psychosis and those with established psychosis. As discussed above, there is some preliminary evidence for the feasibility and effectiveness of stigma interventions, which have largely been on CBT techniques and empowerment (Knight, et al., 2006; Lucksted, et al., 2011; MacInnes & Lewis, 2008). However, there are serious methodological flaws with each of these studies, and further research is required to address these flaws by implementing randomisation, blinding procedures and increased number of participants and to provide a demonstration of evidence based interventions for internalised stigma.

Although a CBT approach is encouraged in this thesis, future research should also explore the application of other therapeutic models to internalised stigma. This thesis highlights that people who meet criteria for an at risk mental state and those with psychosis report shame in relation to their experiences. Approaches to shame include the social rank theory which proposes that shame, depression and social anxiety are influenced by perceptions of and changes in social rank; notably loss of rank or social attractiveness (Gilbert, 2000). The extensive work carried out by Birchwood and colleagues (Birchwood, et al., 2005; Birchwood, Mason, MacMillan, & Healy, 1993; Birchwood, et al., 2006; Rooke & Birchwood, 1998) has bridged a theoretical gap between the stigma literature and social rank literature, demonstrating

key aspects of rank based appraisals are evident in people with psychosis who experience depression and social anxiety (Birchwood, Iqbal, & Upthegrove, 2005; Birchwood, et al., 2006; Rooke & Birchwood, 1998). Compassion Focused Therapy (CFT) has been developed specifically for people with high levels of shame and has been shown demonstrated feasibility and some effectiveness in reducing shame (Gilbert & Procter, 2006). A compassion focussed approach lends itself to exploring the effects of stigmatising environments on feelings of shame and concerns about others perceptions and personal perceptions of the self in relation to having experienced psychosis. In relation to psychosis, CFT has demonstrated some feasibility in psychosis groups through a case series report of CFT for people who hear malevolent voices (Mayhew & Gilbert, 2008). Gumley, Braehler, Laithwaite, MacBeth & Gilbert (2010) have reasoned that the focus of CFT on affect regulation may sooth threat experiences and promote recovery in people with experience of psychosis. Therefore, future research regarding stigma interventions should consider application of the CFT model to internalised stigma initially through case series to develop the model and then through an open trial of CFT for internalised stigma.

Research demonstrates that around 50% of people with psychosis internalise stigma (Brohan et al, 2010). However, there is currently lack of research investigating why some people with psychosis internalise stigma, when others do not or they internalise it to a lesser degree. Understanding which psychological factors increase the propensity to internalise stigma is likely to be important for the development of internalised stigma interventions. The following section will draw on the current literature to develop hypotheses for how psychological processes may relate to internalised stigma.

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Psychological flexibility is defined as the having the capacity to embrace ones private experiences in the presence, and engage or disengage in patterns of behaviour (Hayes, Strosahl & Wilson, 2012). There is an indication from the wider stigma literature that psychological in-flexibility may contribute to public stigma towards people with mental health problems and that it may contribute to internalised stigma in people who experience difficulties with body weight (Masuda, Hill, Morgan, Cohen, 2012). Levin, Luoma, Lillis, Hayes & Vilardaga (2013) have argued that there is a signal from studies which evaluate the efficacy of the Acceptance and Commitment Therapy (ACT) on stigma reduction that psychological flexibility is related to stigma, given ACT targets psychological flexibility (Lillis & Hayes, 2007). However, it should be noted that these findings are from small scale intervention studies and results are limited by this. Until recently, stigma research evaluating psychological flexibility has been limited by the availability of appropriate psychometric measures. However, recent research by Levin et al (2013) has resulted in the development of Acceptance and Action Questionnaire – Stigma (AAQ-S) which has been shown to be a valid and reliable measure of psychological flexibility in relation to stigma (Levin et al., 2013). Future research should address whether psychological flexibility contributes to levels of internalised stigma in people with experience of psychosis.

Self-criticism and self-attacking is a psychological process which is understood to be critical self-comments, dialogues and feelings about the self (Gilbert, 2010). This may take the form of beliefs that one is inadequate or inferior (Gilbert, 2010). Alongside this a person may experience emotions of anger and contempt for oneself (Gilbert, 2010). Gilbert suggests that self-criticism, self-attacking and shame typically arise from early experience with hostile and/ or abuse

relationships, such as abuse, bullying and neglect (Gilbert, 2009). Furthermore, self-criticism is through to act as a safety strategy, in particular when it has developed because of abuse and trauma (Gilbert, 2009; 2010). For example, if a child is under threat of abuse from a parent, in order to avoid the abuse they may avoid 'stirring-up' the parent through self-monitoring and self-blame, which may then be triggered in threat situations as an adult as a strategy to reduce threat (Gilbert, 2010). Self-criticism has been associated with a number of mental health problems including depression and anxiety (Gilbert & Miles, 2000; Gilbert, 2010). In relation to psychosis, research has indicated that self-attacking (a form of self-criticism) is higher in people who experience paranoid delusions than people with depression or healthy controls (Hutton, Kelly, Lowens, Taylor & Ta, 2013). It is argued that there are parallels between self-criticism and the shame, blame and hopelessness (Corrigan & Watson, 2002) of internalised stigma. Leading on from this, Gilbert (2009; 2010), suggests that those who are self-critical may have developed this safety strategy as a response to trauma or abuse. Given the well-established research which demonstrates high prevalence of childhood abuse and trauma in people with psychosis (Read, Hammersley, & Rudegeair, 2007), childhood trauma may also contribute to the internalisation of stigma.

Recent research conducted by Park, Bennett, Couture & Blanchard (2013) indicates that internalised stigma is associated with dysfunctional attitudes namely, defeatist performance beliefs and beliefs about the likelihood of success. Park et al. (2013) argue that dysfunctional beliefs about performance and success may result in maladaptive behaviours such as social isolation and withdrawal, which have been demonstrated to be an outcome of internalised stigma. However, the findings from

Park et al. (2013) are limited by generalisability as the sample comprised primarily of older male participants (Park et al, 2013).

Given the above research there is an indication that psychological variables such as psychological flexibility, dysfunctional attitudes and self-criticism may play a role in contributing to internalised stigma. Future research should aim to explore causal relationships between these (and other psychological variables) and internalised stigma. Structural equation modelling (SEM), which is a technique used to test causal relations using a combination of statistical data (Pearl, 2000) would lend itself to testing how multiple psychological factors contribute to IS, which in turn would advance interventions for internalised stigma. Alongside existing therapeutic approaches, stigma intervention strategies should widen the focus from clinician/ academic lead exploration of stigma to user led research and intervention. Study 1 highlights the richness of information that can be drawn from exploring subjective experience and from listening to the experts (service users) experience for example, the theme of psychological distress and possible exits highlighted that some service users may have very useful stigma exit strategies tried and tested and based on lived experienced; strategies that clinicians and other service users could learn from. A focus in the research on service users' priorities about stigma and experiences of coping is essential in ensuring that interventions developed, tested and delivered are grounded in the experiences of those who are the target of stigma. This could be initially explored through a qualitative approach, such as grounded theory, to develop a model of stigma exits or coping that is based on lived experience. Results of this study could service to inform a model of resilience, coping and empowerment from stigma related to psychosis, which could feed into therapeutic interventions for stigma. Alternatively, Delphi methodology could be

used to draw consensus from service users about effective coping strategies, best methods for empowerment and examine the valued outcomes related to stigma and discrimination that service users want, and could, therefore, inform appropriate targets and goals for interventions.

Studies 1-4 suggest that stereotypes of psychosis are internalised early into a person's experiences of psychotic like phenomena. However, what the research in this thesis is unable to answer is just how early stereotypes are internalised and whether specific factors contribute to internalisation; for example, as social networks, socio economic status, time use or education. Further research is required to better understand how, when and why internalised stigma develops in those meeting criteria for ARMS population. Two studies are proposed, the first an exploration of stigma in the 'at risk of psychosis' population using qualitative methodology. As this is an under researched area and the literature is sparse, a grounded theory approach may be most effective, from which a model of stigma in the ARMS population can be developed with results from this study informing the development of a specific measure for stigma in for use in the ARMS population. Secondly, a study exploring predictors of internalised stigma in the ARMS population would provide vital information for understanding young people who are more likely to internalise stigma.

Research has demonstrated that people with lived experience of psychosis are aware of public stigma, which in turn can lead to internalised stigma (Angermeyer, Matschinger, & Schomerus, 2013; Corrigan et al, 2011; Thornicroft et al, 2009). Given the negative effects of stigma on wellbeing, which have been identified by the studies in this thesis and by previous research (Dinos et al, 2004; Livingston & Boyd, 2010; Lysaker et al, 2008), a key area for future research is the primary

prevention of stigma in young people. In particular, it is argued that very early prevention of stigma in children, before stereotypes, prejudice and discrimination become entrenched will be important in minimising negative public perceptions of mental health problems in the future. To date much of the research evaluating anti-stigma interventions with young people has targeted adolescents and there is limited research evaluating feasibility and effectiveness of interventions for children. Research suggests that stereotype formation may occur in children as young as four years of age (Bigler & Liben., 2007), although it is thought that these are not fully endorsed until later in adolescence (Flavell, et al., 2001). Therefore, future research should aim to work with children as young as four years old.

Whilst the research into early intervention in stigma is currently limited, the literature on how children form stereotypes may offer important insights for developing best approaches to preventing stigma in children. Adults and in particular adults who children consider to be in a position of power are a key factor in influencing the formation of stereotypes and prejudice towards another group (Bigler, Brown, & Markell, 2001; Bigler & Lieben, 2007). In an experimental study evaluating the effects of implicit links about status on in-group and out-group prejudice, Bigler et al (2001) found children who were classed as high group status (as opposed to low group) developed prejudicial biases towards other groups when authority figures in their school environment made use of socially distinct categories within the classroom. However, children in both the high and low status groups did not develop biases when the authority figures did not make use of the groups in the classroom (Bigler et al, 2001). Moreover, Bigler & Lieben (2007) suggest that stereotypes and biases develop when attributes applied to a group are considered to be salient, made salient via cultural processes and delivered by authority figures in

the child's environment. The research conducted by Bigler et al. (2001) & Bigler & Lieben (2007) suggest that stigma interventions for children require the support of adult authority figures in the child's environment. Therefore, it is likely that early intervention programs will need to motivate and work with adults in order to effect change in stereotype formation in children. Future research should aim to explore how the perceptions of other authority figures, aside from teachers, can influence the development of stereotypes in children. Parents are likely to be an important group to target given they are a consistent authority figure in a child's environment. Qualitative methods such as Discourse Analysis which evaluate how language is used and the meaning behind language (Hodges et al, 2008) may be an appropriate methodology to explore parent-child verbal interactions about mental health.

Recent unpublished research by the Sussex Psychosis Interest Group (SPRiG) has investigated mental health schemas of children aged between seven and eleven years of age. Findings have suggested that children actively search for meaning about, and certainty in relation to other people (Johnstone, John, & Greenwood, 2013). Crowters & Greenwood (2013) found that children who had greater baseline knowledge of mental health problems had more positive schemas towards children presented in vignettes as having a mental health problems (Crowters & Greenwood, 2013). Following on from this, researchers at SPRiG have carried an investigation of the effects of a story book contact intervention on stigma in children aged between seven and eleven years of age. Children were allocated to either receive the story book intervention with mental health information about the characters or without mental health information about the characters. It was found that all the children engaged with the intervention, but those who received the intervention in combination with mental health information reported more positive

attitudes and intended behaviours towards people with mental health problems (Carroll et al, 2013). Although unpublished at present the findings from the research carried out ay SPRiG are promising and suggest that early intervention based on psychosocial education and story book based contact can be effective in promoting positive schema about mental health problems. However, the number of children recruited was low (N=42) and future research is required to test the generalisability of this approach. The authors do not state what type of mental health information was offered and given the evidence that biogenetic perspectives as associated with increased stigma (Kvvale et al, 2013) future research should adopt a psychosocial perspective to early interventions. Furthermore, as adult authority figures are important factors in determining stereotype formation in children (Bigler et al, 2001; Bigler & Lieben, 2007) future research should include parents and care givers to test whether inclusion of parents in early intervention programmes could have longer term positive benefits for children's mental health schemas.

Finally, a key area for future research is a longitudinal study of stigma using repeated measures over time of both internalised and experienced stigma to follow people as their experiences progress along the continuum of psychosis; following people from at risk to first episode and beyond. This would provide a comprehensive evaluation of how stigma develops along the continuum of psychosis and what factors may influence stigma.

8.9 Conclusions

A common theme that runs throughout this thesis is that internalised stigma influences psychological wellbeing, in particular depressive mood. Prior research suggests that stigma is associated a range of negative effects on psychological wellbeing; however, the research presented here is novel, furthering the existing

literature base by exploring these relationships in new samples. This is further evidence that stigma deserves its place as one of the six national priorities of the 'No Health without Mental Health' manifesto (DH., 2011).

Stigma intervention research and development should learn more about the subjective experiences of those who have themselves faced stigma, overcome its negative effects or indeed have rebuffed it with a particular focus on factors which increase resilience to stigma and empowerment.

Most importantly, any stigma research, whether it is with service users or the public, needs to evolve continually by ensuring that its subjects are at the heart of the research.

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Appendices

Appendix 1: Study 1 Participant Information Sheet

Participant Information Sheet

Title of project: An Exploration of Subjective Accounts of Stigma and Discrimination from People with Psychosis: A Qualitative Study

We would like to invite you to take part in a research study. Before you decide you need to understand why the research is being done and what it would involve for you. Please take time to read the following information carefully. Talk to others about the study if you wish.

What is this research about?
Research has indicated that sometimes people with psychosis may experience, or may anticipate that they will experience, negative attitudes and/ or behaviours from others. In relation to this, our aim is to find out the perspective of people who have experience of psychosis. This information will allow us to understanding these types of experiences and how they may impact on the lives of people who experience psychosis. It may also inform future methods to reduce negative attitudes and behaviours towards people with psychosis. 'Psychosis' is a term used to describe a range of different experiences including hearing distressing voices or having very distressing beliefs about being harmed by others.

Why have I been chosen?
We are inviting people to take part in the research who have experience of psychosis and are in contact with a mental health team. In total we aim to recruit 8-12 participants.

What will it involve for me?
If you decide to take part, you will be asked to talk to the researcher about how other people have responded to you since experiencing psychosis. Things you will be asked may include describing your thoughts on how you believe other people perceive psychosis, situations in which people may have behaved differently towards you since you have experienced psychosis, the impact of any changes in attitudes and behaviours towards you by others and how you think negative attitudes and behaviours about psychosis can best be changed. However, we don't have to talk about anything you don't feel comfortable talking about.

This will be audio taped so that the researcher can look for any common themes. The recordings will be stored securely on a computer and destroyed at the end of the study. The researcher's clinical and academic supervisor Professor Morrison may listen to some of the recordings in order to aid analysis.

Expenses and payments
You will receive a payment of £10 for the interview session.

What are the alternatives for treatment?
You can access treatment in the usual way, via your care team, regardless of whether you take part in this research trial or not.

What are the advantages and disadvantages of taking part?
It is hoped that by learning about your experiences we will understand the ways in which others attitudes and behaviours towards psychosis can impact on the lives of people who have psychosis. It is also hoped that learning about your experiences will help develop new ways to reduce negative attitudes and behaviours towards psychosis.
It is hoped that taking part in this study will allow participants the opportunity to talk about their personal experiences in a non judgemental, empathic environment.

It is possible that talking about your personal experiences may cause you some distress. The person interviewing you will be sensitive to this and has previous experience of interviewing people with similar difficulties. You will have the opportunity to discuss any concerns at the end of interview and you are free to withdraw from the project at any point without it effecting any treatment you are receiving.

Do I have to take part?
It is up to you to decide. We will describe the study and go through this information sheet, which we will then give to you. If you decide you would like to take part we will then ask you to sign a consent form to show you have agreed to take part. You are free to withdraw at any time, without giving a reason. This would not affect the standard of care you receive.

Can I withdraw from the study if I change my mind?
If you decide to take part you are still free to withdraw at any point, without giving a reason. A decision to withdraw at any time, or a decision not to take part, will not affect the standard care you receive.

Will my taking part in this study be kept confidential?
All data recorded in this study will be completely confidential. All information about your identity will be stored separately from data gathered during the study, and will only be matched with your consent. All participants will be assigned an identification number which will be used to match responses. All data will be stored securely either on paper, or password protected databases. Personal data will not be kept any longer than 12 months, and will be destroyed by this time. Completely anonymous copies of people's responses may be retained for up to 20 years after the study.

If there are any particular concerns about you that are raised through your participation in this study, we may ask for your consent to refer these concerns to either your NHS management team, where applicable, or another suitable professional. Due to our duty of care to you, in extreme cases it may be necessary to breach the confidentiality of this study and inform your management team or a

suitable professional of your responses. This would include cases where the specific intent to hurt yourself or others has been made clear.

What will happen to the results of the research study?
It is intended for the results of the study to be published in an academic journal. If you are interested in receiving a copy of any publications from this study, please tell the researcher at the interview.

Who is organising and funding the research?
The research is sponsored by The University of Manchester.

Who has reviewed the study?
All research in the NHS is looked at by independent group of people, called a Research Ethics Committee to protect your safety, rights, wellbeing and dignity.

What if there is a problem?
Complaints
If you have concerns about any aspect of this study, you should ask to speak to the researcher who will do their best to answer any questions. If you are unable to resolve your concern or you wish to make a complaint regarding the study, please contact a University Research Practice and Governance Co-ordinator on 0161 275 7583 or 0161 275 8093 or by email to research-governance@manchester.ac.uk . You can also seek independent advice from The Patient Advice and Liaison Service (PALS) on 0161 945 7973.

Harm
In the event that something does go wrong and you are harmed during the research and this is due to someone's negligence then you may have grounds for a legal action for compensation against The University of Manchester but you may have to pay your legal costs. The normal National Health Service complaints mechanisms will still be available to you. The University of Manchester Indemnity insurance offers no-fault compensations.

Further information and contact details
If you require any further information you can contact:

Melissa Wardle
Research Assistant
Email: Melissa.wardle@gmw.nhs.uk
Tel: 0161 772 4350 / 07767760767

Prof. Antony Morrison
Professor of Clinical Psychology
Email: tony.morrison@manchester.ac.uk
Tel: 0161 275 2554

Appendix 2: Study 1 Consent Form

CONSENT FORM

Client Identification Number for this study:

Title of Project: An exploration of subjective accounts of stigma and discrimination from people with psychosis.

Chief Investigator: Ms Melissa Wardle

Name of Researcher:

 Please initial box

I confirm that I understand the nature of the study proposed, having read and understood the information sheet provided. I have had opportunity to ask questions, and I am satisfied with the answers I received.

☐

I understand that my participation is voluntary, and that I am free to withdraw from the study at any time. Should I wish to withdraw, I understand that I can do so without giving reason, and without my medical care or legal rights being affected.

☐

I agree that you may audio record the interview and I understand that I may have a copy of any tapes made.

☐

I agree that the project supervisor Professor Morrison may hear the tape to aid data analysis.

☐

I understand that data collected during the study may be looked at by individuals from the University of Manchester, from regulatory authorities or from the NHS Trust, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records

☐

I agree that if I decide to withdraw from the study then the researchers can continue to use the data and information I have already given them unless I ask for this to be destroyed.

☐

I agree to take part in the study.

Subject Name   Date   Signature

………………………   … / … / ……   …………………….

Researcher   Date   Signature

………………………   … / … / ……   …………………….

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Appendix 3: Study 1 Topic Guide

Background

- Could you give me a brief history of the reasons why you became involved with (insert name of mental health service)*?*
- What words or terms do you use to refer to these experiences that you have described
- What does the phrase 'stigma of mental health problems' mean to you?

Prompts/ additional areas to explore; Can you give me some example of that please? If the person is unsure about the term stigma use other language such as prejudice/ negative attitudes/discrimination/ negative behaviours.

Experienced stigma

- What attitudes do you think people have about the types of mental health difficulties you have described?

Explore who has these attitudes/ family/ friends/ professionals/ general public/ institutions such as the media

- How do you think people behave towards people who experienced the types of mental health difficulties you have described?

Explore who has these attitudes/ family/ friends/ professionals/ general public/ institutions such as the media

- Were you aware of these attitudes and behaviours before you began to experience these difficulties?

How did this affect you? Explore whether it changed behaviour such as help seeking or thoughts towards self

- Have people you know expressed these attitudes to you?

If yes, how has this impacted on you?

- Have you experienced any stigma in relation to anything else?

Prompts: Race, gender, sexuality, other health problems

Internalised stigma

- What were your attitudes about people who experience mental health problems before you experienced the difficulties you have described?
- What are your attitudes now?
- Have your opinions of yourself changed since your experienced a mental health problem?

Do you think differently about yourself?
Do you feel differently about yourself?
Has diagnosis or mental health label affected you in anyway?
If yes, how has think impacted upon you?
Do you do things differently because of these thoughts/ feelings about yourself?

Summary

- Of the experiences you have mentioned which have had the greatest impact upon you.
- Do you feel there are issues relating to stigma and discrimination which we have not talked about?

Appendix 4: Personal Beliefs about Experiences Questionnaire

PERSONAL BELIEFS QUESTIONNAIRE - REVISED

NAME _____ **DATE** _____ **SESSION** _____

INFORMATION: Please take a few minutes to complete the questions below by circling your answer. If you need any help, you can ask the person who is conducting your session. Thank you for your time.

1) **My experiences frighten me…**

1	2	3	4
Strongly disagree	Disagree	Agree	Strongly Agree

2) **There must always have been something wrong with me as a person (to have caused these experiences)…**

1	2	3	4
Strongly disagree	Disagree	Agree	Strongly Agree

3) **I am embarrassed to talk about my experiences…**

1	2	3	4
Strongly disagree	Disagree	Agree	Strongly Agree

4) **My experiences may mean that I should be kept away from others…**

1	2	3	4
Strongly disagree	Disagree	Agree	Strongly Agree

5) I find it difficult to cope with my current experiences…

1	2	3	4
Strongly disagree	Disagree	Agree	Strongly Agree

6) I am fundamentally normal, my experiences are like any other…

1	2	3	4
Strongly disagree	Disagree	Agree	Strongly Agree

7) I am capable of very little as a result of my experiences…

1	2	3	4
Strongly disagree	Disagree	Agree	Strongly Agree

8) My experiences are a judgement on me…

1	2	3	4
Strongly disagree	Disagree	Agree	Strongly Agree

9) I am powerless to influence or control my experiences…

1	2	3	4
Strongly disagree	Disagree	Agree	Strongly Agree

10) There is something about my personality that causes these experiences…

1	2	3	4
Strongly disagree	Disagree	Agree	Strongly Agree

11) It is hard for me to work or keep a job because of my experiences…

1	2	3	4
Strongly disagree	Disagree	Agree	Strongly Agree

12) I can talk to most people about my experiences…

1	2	3	4
Strongly disagree	Disagree	Agree	Strongly Agree

13) There is something strange about me which is responsible for these experiences…

1	2	3	4
Strongly disagree	Disagree	Agree	Strongly Agree

THE END
THANK YOU FOR YOUR TIME

Appendix 5: The Beck Depression Inventory for Primary Care – (BDI- PC)

BDI⁻7

This questionnaire consists of groups of statements. Please read each group of statements carefully, then pick out the **one statement** in each group which best describes the way you have been feeling during the **past 2 weeks, including today!** Circle the number beside the statement you picked.   If several statements in the group seem to apply equally well, circle the statement which has the largest number.

---

1   **0**   I do not feel sad.
      1   I feel sad much of the time.
      2   I am sad all the time.
      3   I am so sad or unhappy that I can't stand it.

2   **0**   I am not discouraged about my future.
      1   I feel more discouraged about my future than I used to be.
      2   I do not expect things to work out for me.
      3   I feel my future is hopeless and will only get worse.

3   **0**   I do not feel like a failure.
      1   I have failed more than I should have.
      2   As I look back, I see a lot of failures.
      3   I feel I am a total failure as a person.

4   **0**   I get as much pleasure as I ever did from the things I enjoy.
      1   I don't enjoy things as much as I used to.
      2   I get very little pleasure from the things I used to enjoy.
      3   I can't get any pleasure from the things I used to enjoy.

5   **0**   I feel the same about myself as ever.
      1   I have lost confidence in myself.
      2   I am disappointed in myself.
      3   I dislike myself.

6	**0**	I don't criticize or blame myself more than usual.
	1	I am more critical of myself than I used to be.
	2	I criticize myself for all of my faults.
	3	I blame myself for everything bad that happens.

7	**0**	I don't have any thoughts of killing myself.
	1	I have thoughts of killing myself, but I would not carry them out.
	2	I would like to kill myself.
	3	I would kill myself if I had the chance.

Appendix 6: Social Interaction Anxiety Scale

Case Number: _____
Assessment number: _____
Collected By: _____
Date: _____

For each question, please circle a number to indicate the degree to which you feel the statement is characteristic or true of you. The rating scale is as follows:

0 = Not at all characteristic or true of me
1 = Slightly characteristic or true of me
2 = Moderately characteristic or true of me
3 = Very characteristic or true of me
4 = Extremely characteristic or true of me

	Not at All	Slightly	Moderately	Very	Extremely
1. I get nervous if I have to speak to som in authority (teacher, boss).	0	1	2	3	4
2. I have difficulty making eye contact wit others.	0	1	2	3	4
3. I become tense if I have to talk about myself or my feelings.	0	1	2	3	4
4. I find it difficult mixing comfortably with people I work with.	0	1	2	3	4
5. I find it easy to make friends of my own	0	1	2	3	4
6. I tense up if I meet an acquaintance in street.	0	1	2	3	4
7. When mixing socially, I am uncomfortab	0	1	2	3	4
8. I feel tense if I am alone with just one person	0	1	2	3	4
9. I am at ease meeting people at parties	0	1	2	3	4
10. I have difficulty talking with other people	0	1	2	3	4
11. I find it easy to think of things to talk ab	0	1	2	3	4
12. I worry about expressing myself in case awkward.	0	1	2	3	4

13. I find it difficult to disagree with another point of view.	**0**	**1**	**2**	**3**	**4**
14. I have difficulty talking to attractive pers of the opposite sex.	**0**	**1**	**2**	**3**	**4**
15. I find myself worrying that I won't know what to say in social situations.	**0**	**1**	**2**	**3**	**4**
16. I am nervous mixing with people I don't know well.	**0**	**1**	**2**	**3**	**4**
17. I feel I'll say something embarrassing w talking.	**0**	**1**	**2**	**3**	**4**
18. When mixing in a group I find myself worrying I will be ignored.	**0**	**1**	**2**	**3**	**4**
19. I am tense mixing in a group.	**0**	**1**	**2**	**3**	**4**
20. I am unsure whether to greet someone know only slightly.	**0**	**1**	**2**	**3**	**4**

THANK YOU FOR YOUR HELP

Appendix 7: Study 3 Participant information sheet (ACTION Trial)

Randomised Controlled Trial of Cognitive Therapy for Psychosis for people not taking medication

INFORMATION FOR PARTICIPANTS

You are being invited to take part in a research study. This study has been reviewed by the Northwest 6 Research Ethics Committee – Greater Manchester South. It is important for you to understand why the research is being done and what it will involve. Please take time to read the information carefully, and discuss it with others if you wish. Feel free to ask us if there is anything that is not clear, or if you would like more information. You may wish to read the information sheet more than once, and should take time to decide whether or not you wish to take part.

What is the purpose of the study?

Some people with psychosis continue to experience their difficulties despite taking medication. We know from research that cognitive therapy can improve such difficulties in some cases. Further research is needed to identify if cognitive therapy is helpful for people who are not taking medication. This study will help to address this question.

Why have I been given this information?

We are looking for people who have been offered anti-psychotic medication and have decided that they would not like to take it or have chosen to come off their anti-psychotic medication for whatever reason (e.g. because of side effects), and have not taken medication for the last 6-months or longer. This is because we want to know

whether a psychological talking treatment (called 'cognitive therapy') on its own (i.e. without antipsychotic medication) is helpful to people who experience psychosis.

Volunteers should be experiencing psychosis (such as hearing distressing voices or holding unusual beliefs) and be experiencing persistent difficulties. If you fit these criteria, we would like to invite you to enter our study.

Do I have to take part?

No. As entry to the study is entirely voluntary, it is up to you to decide whether or not to take part. You should not feel under any pressure to make the decision. If you do decide to take part, you will be asked to sign a consent form. Even after signing you are still free to withdraw at any time and without giving a reason. This will not affect any care you may receive in the future. Additionally, if you decide to take part in the study and then later on also decide that you would like to take anti-psychotic medication then that will not be problematic. Furthermore, if you are in the group that receives cognitive therapy (see below for further details), therapy would not stop if you decide to take medication.

What will happen to me if I take part?

You will be invited and met by researchers at a convenient location for you to discuss the study in more detail. Here we will explain the exact nature of the research, explaining our reasons for conducting this study and answer any questions you may have. If you decide that you wish to continue, you will be met again by the researcher and asked to fill in 9 questionnaires and talk to someone for

approximately 2½ hours (this can be split over 2 or more sessions if you wish), in order to check that you are suitable for the study.

Following this, if you are found to be suitable, you will be asked to sign a consent form and we will arrange to see you once every 3 months (i.e. 7 times) for a period of 18 months, to monitor how things are for you. These sessions will also take up to 2½ hours. You may also be asked to take part in a psychological talking treatment (called 'cognitive therapy'). In addition, you will be asked if you would like to take part in an interview about your preferences and treatment choices, both at the beginning and end of the study – this interview will be conducted by a service user researcher (someone who has previously used mental health services because of psychotic experiences).

Will this study involve treatment?

Sometimes, because we do not know which way of treating patients is best, we need to make comparisons. Therefore, people will be put into groups and then compared. The groups are selected randomly – i.e. selected by chance. Patients in each group will have a different treatment and these are compared. Half of the people who agree to take part will be offered psychological treatment (cognitive therapy). This will give those people a chance to focus on whatever is of most concern to them at that moment. This treatment will consist of up to 26 sessions of cognitive therapy (usually about one hour each on a weekly basis). The sessions will take place at a convenient location for you such as your home or GP surgery. These appointments will all be within working hours.

Some sessions will be recorded so the quality and content of the therapy you receive can be assessed, to ensure all participants have a similar experience. These audiotapes/cds will be available for you to listen to if you wish (some people find this useful), and afterwards, any such tapes/cds will be kept in a locked cabinet and destroyed at the end of the study.

We hope that the treatment and monitoring will help you. However, this cannot be guaranteed. The information we get from this study may help us in the future treat people with psychosis better.

What are the advantages and disadvantages to taking part?

If you take part in the study, it is hoped that both the treatment and monitoring will be helpful to you. It is possible that they will improve any mental health difficulties that you are experiencing.

However, it is also possible that talking about some of these issues may be upsetting. You will have the opportunity to discuss any concerns you have with the researcher and you are free to withdraw from the study at any point.

What happens if I lose the capacity to consent to continue in the study?

For a variety of reasons people can sometimes lose the capacity to decide whether to continue to take part in a study. This could happen if you become unwell, for example. Although this is an unlikely event, we are obliged to take certain steps to ensure we respect your wishes if this happens.

We will ask you to appoint a Personal Consultee. This is a person who you trust and who knows you well enough to tell us whether you would wish to continue to participate (e.g., friend, family member, carer or someone with Lasting Power of Attorney). However this person cannot be professionally involved in your care.

If you cannot identify a Personal Consultee you can appoint a Nominated Consultee. A Nominated Consultee has the same role as a Personal Consultee although they can be professionally involved in your care (e.g., GP, solicitor). However Consultees must not be connected with the study in any way.

If you cannot appoint a Nominated Consultee we can help you with this. GMW NHS Trust has a Panel of Nominated Consultees who are trained in this role. Please ask the research assistant or your therapist for more information if you require this.

Consultees cannot consent on your behalf. However if you lose capacity they can advise us as to whether you would wish to continue to participate.

We will ask you to consent to us sharing enough information about the study (and your participation) with your Consultee in order to allow him or her to fulfil their role.

To avoid any uncertainty or confusion, we will also ask you to tell us in advance what your wishes are should you lose capacity. We will ask you whether (1) you would wish to continue to participate despite not having the capacity to consent to

this, (2) you would wish to withdraw from the study or (3) you would wish to withdraw from the study until you regained your capacity to consent to participate.

If you wished to continue to participate despite not having capacity to consent to this, then we would only continue if (1) you and your Consultee agree to this at the time, (2) your therapist and medical practitioner (GP or psychiatrist) agree that no harm will be caused by doing so and (3) you have clearly stated in advance that you would like to continue (and you have not withdrawn this statement).

For a variety of reasons (e.g., concerns about confidentiality) you may decide you would rather not have a consultee. Although this will not stop you being able to take part, please note that for legal reasons we would therefore have to withdraw you from the study if you lose capacity to consent to continue. Unfortunately we would have to do this despite your expressed wishes now or at the time and despite the possibility that being withdrawn could cause you harm.

Will taking part in the study cost me anything?

No. The study will only involve your time. In order to compensate you for this, and any expenses incurred, you will received a payment of £10 at 5 out of 7 assessments, which will be at the following:- the end of the initial assessment, and at the 3, 6, 9, and 18 month assessments.

Who will know I am participating in the study?

Other people involved in your care such as your Consultant Psychiatrist, Care Coordinator and GP will be informed.

Who will have access to information collected about me during this study?

Your records (written and audio-taped) from the study will be as confidential as your medical records. We will hold some personal information on file at the University. Your personal details will not be routinely available to the researchers because all forms will be completed using an anonymised personalised identification number and will be kept in a securely locked place. University staff who are not part of the investigation team will not have access to your details.

What will happen to the results of the research?

After the study is completed, we will analyse the results and submit them for publication in a scientific journal. Presentations may also be given at scientific conferences. You will not be identified in any publication or presentation. If you wish to know the outcome of our research, we will be happy to discuss them with you.

Who is organising the research?

The chief investigator is Professor Tony Morrison from the School of Psychological Sciences Department at the University of Manchester. This study has been approved by the Wrightington, Wigan and Leigh Research Ethics Committee.

Please keep this information sheet. Thank you for considering this proposal.

Appendix 8: Study 3 Consent form (ACTION Trial)

CONSENT FORM

Client Identification Number for this study:

Title of Project: Randomised Controlled Trial of Cognitive Therapy for

Psychosis for people not taking medication

Chief Investigator: **Professor Tony Morrison**

Name of Researcher:

Please initial box

1. I confirm that I understand the nature of the study proposed, having read and understood the information sheet provided. I have had the opportunity to ask questions, and am satisfied with the answers I received.

2. I understand that my participation is voluntary, and that I am free to withdraw from the study at any time. Should I wish to withdraw, I understand that I can do so without giving reason, and without my medical care or legal rights being affected.

3. I agree to take part in the study.

4. I agree that the researcher may inform my general practitioner and care coordinator of my involvement in the study.

5. I understand that relevant sections of my medical notes and data collected during the study may be looked at by individuals from the research team, regulatory authorities or from the NHS Trust, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records.

6. I agree that the researcher may audio tape sessions as required and understand that I may have a copy of any tapes made.

7. Capacity to consent to continue:

a. I wish to continue to participate should I lose the capacity to

consent to continue. I understand I can reverse this advance decision at any point.

I do not wish to continue to participate should I lose the capacity to consent to continue. I understand I can reverse this advance decision at any point, while I retain the capacity to do so. ☐

b. I agree that if I am withdrawn for this or any other reason then the researchers can continue to use the data and information I have already given them unless I ask for this to be destroyed. ☐

c. I wish to have a Personal / Nominated Consultee. ☐

I do not wish to have a Personal / Nominated Consultee. ☐

d. I consent to my Consultee offering advice on my behalf should I lose capacity to consent to continue to participate. ☐

I do not consent to my Consultee offering advice on my behalf should I lose capacity to consent to continue to participate. ☐

e. I agree that you may write to my Consultee providing details of this study and my involvement in it. ☐

I do not agree. ☐

f. Your Personal or Nominated Consultee's name, address and telephone number can be written below. This can be completed now or at a later stage:

Participant Name	Date	Signature
………………………	… / … / ……	……………………

Researcher	Date	Signature
………………………	… / … / ……	……………………

1 copy for patient; 1 copy for researcher; 1 copy for GP notes

Appendix 9: Study 2 Participant information sheet (EDIE 2Trial)

Early Detection and Intervention Evaluation 2

PARTICIPANT INFORMATION SHEET

You are being invited to take part in a research study. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

Thank you for reading this

THE STUDY

This study is designed to monitor people who may be at risk of developing a mental health problem and to evaluate a psychological treatment to see if it is helpful in preventing such difficulties. It is hoped that this will allow us to find out what factors are important in predicting who develops a mental health problem and whether or not a psychological treatment works to reduce these problems. This information will hopefully be useful in preventing some mental health problems in future.

WHAT DO I HAVE TO DO TO TAKE PART?

You have been referred to us by a member of health or social care or educational staff (for instance, your General Practitioner or a teacher). If you decide to take part it will involve filling in six questionnaires and talking to someone for about 1½

hours (this can be over two or more sessions if you wish). Following this, we will arrange to see you once a month for a period of up to 2 years (on a monthly basis for the first 6 months, and then every 3 months) to monitor how things are for you. These sessions will take about an hour. You may also be asked to take part in a psychological treatment (a talking therapy called 'cognitive therapy'). We will also collect some information about your use of health services over the duration of the study from your medical records. In order to compensate you for your time and any expenses incurred, you will receive a payment of £20 at the end of the initial assessments, and then at the one-year and two-year assessments. With permission from you, your GP will be informed that you are taking part in the study.

If the study is not appropriate for you (for example, because you turn out not to be at risk of developing mental health problems, or because your problems are already too severe), then we would like to use the information from your assessments to compare with people that are in the study, in order to help us to learn about how these problems might develop.

IS THERE ANY TREATMENT INVOLVED?

Sometimes, because we do not know which way of treating patients is best, we need to make comparisons. People will be put into groups and then compared. The groups are selected by a computer which has no information about the individual – i.e. by chance. Patients in each group then have a different treatment and these are compared. Half of the people who agree to take part will be offered a psychological treatment. This will include information about how to manage stress, sleeping difficulties and several other common problems that people experience, as well as a

chance to focus on whatever is of most concern to you at the moment. The treatment will consist of up to 25 sessions (about 50 minutes each, usually on a weekly basis).

People receiving the treatment will be asked if their sessions can be audiotaped (this is optional). These audiotapes will be available for you to listen to, if you wish (some people find this useful), and afterwards, any such tapes will be kept in a locked cabinet and destroyed at the end of the study.

We are also interested in looking at how the treatment might work, which would involve asking you to fill in an extra 6 questionnaires about the way that you think about yourself and other people and how you make sense of things that happen (at month 1 and again at month 6). Again, this aspect is optional.

We hope that both the treatment and the monitoring will help you. However, this cannot be guaranteed. The information we get from this study may help us to treat future patients better.

ARE THERE ANY RISKS OR BENEFITS TO TAKING PART?

If you take part in the study, it is hoped that both the treatment and the monitoring will be of help to you. It is possible that they will reduce any mental health problems that you are experiencing or prevent other problems from developing. However, it is possible that talking about some of these issues may be upsetting.

DO I HAVE TO TAKE PART?

No. Taking part is entirely up to you. If you do not wish to take part it will not affect any treatment that you currently receive. Also, if you do decide to take part, you are able to change your mind and withdraw from the study at any time without it affecting your care either now or in the future.

WILL MY INFORMATION BE KEPT CONFIDENTIAL

All information that is collected about you during the course of the research will be kept strictly confidential. Any information about you, which leaves the hospital/surgery, will have your name and address removed so that you cannot be recognised from it.

WHAT WILL HAPPEN TO THE RESULTS OF THIS STUDY

The results will be published in a medical journal and through other routes to ensure that the general public are also aware of the findings. You will not be identified in any report/publication arising from this study.

WHAT IF I WANT ANY FURTHER INFORMATION

If you want any further information or have any questions, please ask the researcher or telephone Hannah Taylor or Melissa Wardle on 0161 275 2554

WHAT IF I WANT TO MAKE A COMPLAINT?

If you want to complain about any aspect of this study, please contact Professor Tony Morrison, School of Psychological Sciences, University of Manchester, Manchester M13 9PL or telephone 0161 275 2554

Appendix 10: Attribution questionnaire vignette

Please read the story below and then answer all of the questions which follow:

Harry is a 30 year old single man with schizophrenia. Although he sometimes hears voices and becomes upset, Harry has never been violent. Like most people with schizophrenia, Harry is no more dangerous than the average person. He lives in an apartment and works as a clerk in a large law firm. His symptoms are usually well managed with the appropriate medication.

1. I would feel aggravated by Harry.

Please circle the appropriate response below:

1 = not at all	2	3	4	5	6	7	8	9 = very much

2. How angry would you feel at Harry?

Please circle the appropriate response below:

1 = not at all	2	3	4	5	6	7	8	9 = very much

3. *I* think Harry poses a risk to his neighbours unless he is hospitalized.

Please circle the appropriate response below:

1 = not at all	2	3	4	5	6	7	8	9 = very much

4. If I were an employer, I would interview Harry for a job.

Please circle the appropriate response below:

1 = not likely	2	3	4	5	6	7	8	9 = very likely

5. I would feel pity for Harry.

Please circle the appropriate response below:

1 = none at all	2	3	4	5	6	7	8	9 = very much

6. I would think that it were Harry's own fault that he is in the present condition.

Please circle the appropriate response below:

1 = no, not at all	2	3	4	5	6	7	8	9 = yes, absolutely so

7. How controllable, do you think, is the cause of Harry's present condition?
Please circle the appropriate response below:

1 = not at all under personal control	2	3	4	5	6	7	8	9 = completely under personal control

8. How irritated would you feel by Harry?

Please circle the appropriate response below:

1 = not at all	2	3	4	5	6	7	8	9 = very much

9. How dangerous would you feel Harry is?

Please circle the appropriate response below:

1 = not at all	2	3	4	5	6	7	8	9 = very much

10. I think it would be best for Harry's community if he were put away in a psychiatric hospital.

Please circle the appropriate response below:

1 = not at all	2	3	4	5	6	7	8	9 = very much

11. I would share a car or pool with Harry each day.

Please circle the appropriate response below:

1 = not likely	2	3	4	5	6	7	8	9 = very likely

12. How much do you think an asylum, where Harry can be kept away from his neighbours, is best?

Please circle the appropriate response below:

1 = not at all	2	3	4	5	6	7	8	9 = very much

13. I would feel threatened by Harry?

Please circle the appropriate response below:

1 = No, not at all	2	3	4	5	6	7	8	9 = Yes, very much

14. How scared of Harry would you feel?

1 = not at all	2	3	4	5	6	7	8	9 = very much

15. How certain would you feel that you would help Harry?

Please circle the appropriate response below:

1 = not at all certain	2	3	4	5	6	7	8	9 = absolutely certain

16. How much sympathy would you feel for Harry?

Please circle the appropriate response below:

1 = none at all	2	3	4	5	6	7	8	9 = very much

17. How responsible, do you think, is Harry for his present condition?

Please circle the appropriate response below:

1 = not at all responsible	2	3	4	5	6	7	8	9 = very much responsible

18. How frightened of Harry would you feel?

Please circle the appropriate response below:

1 = not at all	2	3	4	5	6	7	8	9 = very much

19. If I were in charge of Harry's treatment, I would force him to live in a group home.

Please circle the appropriate response below:

1 = not at all	2	3	4	5	6	7	8	9 = very much

20. If I were a landlord, I probably would rent an apartment to Harry.

Please circle the appropriate response below:

1 = not likely	2	3	4	5	6	7	8	9 = very likely

21. How much concern would you feel for Harry?

Please circle the appropriate response below:

1 = none at all	2	3	4	5	6	7	8	9 = very much

Appendix 11: Public stigma questionnaires

Please read each of the following statements and then select the number which corresponds with how much you believe this. Please give a response to all statements. For the following statements please indicate how much you agree or disagree with the statement based on the following scale

	Agree	Disagree	Unsure
Some who has had schizophrenia can not cope with stress before exams	1	2	3
Mostly, someone who has had schizophrenia comes from a family with little money.	1	2	3
Someone who has had schizophrenia cannot be helped by the doctors.	1	2	3
When meeting someone with schizophrenia, one should better watch out	1	2	3
Someone who has had schizophrenia can be good at school.	1	2	3
Someone who has had schizophrenia blows his/ her top for the slightest reason.	1	2	3
Students who have had schizophrenia are particularly good at music or art.	1	2	3

	Agree	Disagree	Unsure
I would be afraid to talk to someone who has had schizophrenia *	1	2	3
I would not be upset or disturbed to be in the same class as someone who had had schizophrenia *	1	2	3
I could imagine making friends with someone who has had schizophrenia. *	1	2	3
I would feel embarrassed or ashamed if my friends knew that someone in my family had schizophrenia. *	1	2	3
If the person sitting next to me developed schizophrenia I would rather sit somewhere else.	1	2	3
If one of my friends developed schizophrenia, I would go and see him/her at the hospital	1	2	3
I would not invite someone who has had schizophrenia to my birthday party	1	2	3
I would not bring along someone who has had schizophrenia when I meet my friends	1	2	3
When going on a class outing, someone who has had schizophrenia should rather stay at home	1	2	3
I would never fall in love with someone who has had schizophrenia	1	2	3
Someone who has had schizophrenia should not work in jobs that involve taking care of children or young people	1	2	3
Someone who has had schizophrenia should not go to	1	2	3

regular school			

Appendix 12: Study 5 Participant information sheet

<div align="center">

School of Psychological Sciences

Participant Information Sheet

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Title of project: An evaluation of mass media mental health awareness programmes for young people in further education.

Introduction

People who experience mental health problems often say that one of the most upsetting aspects of their difficulties is that people may treat them differently afterwards; neighbours may no longer want to talk to them or employers may be reluctant to give them a job. The negative attitudes that society can hold make it harder for those with mental health problems to recover from their difficulties. This study aims to investigate the effectiveness of two mass media, mental health awareness programs, in reducing unhelpful attitudes and behaviours towards mental health problems.

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

You will be randomly allocated to 1 of 3 conditions. If you are allocated to the first condition of the study you will be asked to watch a presentation and listen to a podcast which will provide information about the frequency, nature and causes of mental health difficulties. If you are allocated to the second condition of the study you will be asked to watch a short documentary about a person who has experienced

a mental health problem. If you are allocated to the third condition you will be asked to watch a short program that is not about mental health problems. All participants will be asked to complete an initial questionnaire, a questionnaire at the end of the intervention and at three and six months later you will be asked to complete some questionnaires. Example questions include: If you were an employer, would you interview someone with mental health problems for a job? How responsible, do you think someone with mental health problems is for their present condition? Would you feel afraid talking to someone who had mental health problems?

Will my data be anonymous?

Your data will remain <u>strictly confidential</u> ; you will be given a study identification number and the questionnaires you complete will l only be identifiable by the identification number. Your name <u>will not</u> be used or published in any material related to the study. If, after you have participated, you wanted your data to be destroyed the researcher could arrange this.

Will my data be confidential?

All data recorded in this study will be completely confidential. All participants will be assigned an identification number which will be used to match responses. All data will be stored securely either on password protected databases. Completely anonymous copies of people's responses may be retained for up to 20 years after the study.

Do I have to take part?

You do not have to take part in the study. If you decide to take part and then later change your mind, either before they start the study, during it or afterwards, you can withdraw without giving your reasons, and, if you wish, your data will be destroyed. Your decision will not affect any aspect of your schooling.

Where can I obtain further information if I need it?

If you have any further questions you can contact Melissa Wardle by email on Melissa.wardle@postgrad.manchester.ac.uk or you can leave a message for her on: 07767760767. Alternatively, you can contact Melissa's supervisor, Professor Anthony P Morrison, by email on: Anthony.p.morrison@manchester.ac.uk.

This project has been approved by the

School of Psychological Sciences Research Ethics Committee

Appendix 13: Study 5 Consent form

School of Psychological Sciences

Consent form

Title of Project: A Randomised Controlled Trial of Psychosocial Mass Media Interventions to Reduce Stigma and Discrimination of Psychosis in Young People

1. Have you read the Participant Information Sheet?	**YES/NO** Initials:……
2. Have you received enough information about the study?	**YES/NO** Initials:……
3. Do you understand that you do not need to take part in the study and if you do enter you are free to withdraw:- * at any time * without having to give a reason for withdrawing * and without detriment to you?	**YES/NO** Initials:……
5. Do you agree to take part in this study?	**YES/NO** Initials:…….

Name of participant: …………..………..…… **Signed:** .... **Date:** ....

Name of researcher: ………...…………..… **Signed:** .... **Date:** ....

This project has been approved by the

School of Psychological Sciences Research Ethics Committee