Beliefs about illness, perceived stigma and service engagement in first onset of psychosis

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Overview

This thesis consists of three parts. Part One, a literature review, provides a thorough examination of current research that has explored predictors of patients' engagement with mental health care. Models of illness perceptions are examined and their potential application to furthering our understanding of the mechanisms underlying engagement in psychosis is considered. Part Two presents the empirical paper, which summarises an original piece of research exploring illness perceptions and perceived stigma in relation to engagement with early intervention in psychosis services. This study was conducted as part of a wider research programme and data collection was shared with another DClinPsych trainee - Tristan Morland. Part Three presents a critical appraisal of the study undertaken. It provides a brief background to the study, reflections on the process of conducting the research and a discussion of pertinent methodological considerations.

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Acknowledgments

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Part 1: Literature Review

Predictors of engagement with services for psychosis

Abstract

Common reluctance to engage with mental health care places individuals with

psychosis at greater risks for enduring disability and presents a major problem to

mental health services (Sainsbury Centre for Mental, 1998). Currently, mechanisms

underlying engagement are poorly understood. This paper considers some conceptual

and methodological challenges to studying engagement. This is followed by a

thorough review of current literature exploring factors pertinent to engagement,

including service related, individual and social factors. Social cognition models,

developed by health psychologist and utilised to explain engagement in physical

health are then considered, with a view to finding directions for future research that

will further our progress in understanding engagement in individuals with psychosis.

Introduction

The functional psychoses, and in particular schizophrenia, are frequently chronic and debilitating conditions that can limit individuals' potential to work, support themselves and have satisfying relationships. Recent years have brought significant developments in the clinical management of psychosis. The availability of atypical antipsychotic medication and psychosocial treatments, including family interventions, cognitive behaviour therapy for persistent psychotic symptoms and vocational rehabilitation, have significantly increased the potential for a better outcome, including higher quality of life and reduced health costs. However, many patients fail to engage with mental health services and benefit from the available treatment. Approximately 60% of patients discontinue their prescribed treatment within one year of experiencing their first episode of schizophrenia (Coldham, Addington & Addington, 2002; Novak-Grubic & Tavcar, 1999; Verdoux et al., 2000). Poor adherence to antipsychotic medication is associated with increased hospital admissions and poorer outcomes (Gray, Wykes, & Gournay, 2002). Patients who do not attend their outpatients' appointments after hospital discharge are twice as likely as those who keep their appointments to relapse and be re-hospitalised in the same year (Kruse, Rohland & Wu 2002; Nelson, Maruish & Axler, 2000). Clearly, increasing our understanding of what determines whether clients engage with the mental health interventions offered to them, or not, is needed. This would allow services to develop strategies enhancing engagement, so that patients can benefit from available treatments.

To date, numerous determinants of engagement have been explored in research, yet the results of the studies are inconsistent and our understanding of these determinants is still limited. The purpose of this review is, therefore, to consider

what might account for such a variation in the previous findings and to review current literature pertaining to engagement, with the aim of identifying important engagement determinants and directions for future research.

Selection of articles

Literature searches were performed using Medline and PsychLit electronic data bases up to December 2006 with a combination of keywords including: psychosis, schizophrenia, treatment engagement, help seeking, treatment motivation, adherence, non-adherence, mediation adherence, medication compliance. Additional articles were identified by cross-checking the references of obtained articles.

Complexities of studying engagement

There are considerable variations in methodology, design and the very conceptualisation of engagement employed across previous studies. All these factors complicate the process of studying engagement and limit the extent to which overall conclusions can be drawn from current research. These complexities will be summarised below as their understanding is pertinent to the critical examination of current findings and the development of more meaningful investigations.

Conceptual difficulties

Firstly, the very concept of engagement is often not clear. To date, no studies have defined the construct of engagement with services in a population diagnosed with psychosis (Tait, Birchwood & Trower, 2002). Different terminology has been used across studies including treatment compliance or adherence, help seeking and

treatment motivation. Moreover, some authors use these terms interchangeably (e.g. Mulder, Koopmans, & Hengeveld, 2005).

Secondly, to date, the majority of studies have used a very one-dimensional conceptualisation of engagement, concentrating on a single aspect, most commonly treatment compliance or treatment adherence. Both concepts have been broadly defined as "the extent to which a person's behaviour coincides with the medical advice given" (Sackett & Haynes, 1976, cited in Nosé, Barbui & Tansella, 2003). More recently, these terms have been criticised for their paternalistic connotation, as they imply that health professionals are correct in the advice they give to patients and that, by not following this advice, patients' behaviour is irrational (Day, 2003; Fawcett, 1995). However, it needs to be acknowledged that clients may have valid reasons for choosing not to accept treatment. For example, if the services offering mental health care are perceived as authoritarian, devaluing or culturally insensitive, patients' non-acceptance or discontinuation of their treatment appears to be a rational choice.

Moreover, it is not always beneficial for the clients to follow professional advice. This may be particularly evident in the area of the early intervention where risks of misidentifying psychosis are relatively high (Heinimaa & Larsen, 2002). In such cases engaging individuals with mental health treatment would pose risk to unnecessary medication exposure, monitoring and in consequence could negatively influence individuals' self-concept or even cause their avoidance of developmentally appropriate tasks and challenges.

More recently, the term "concordance" has been proposed as it implies that the client's views about the treatment should always be respected (Day, 2003). However, all the terms are still being used, and often substituted, across the literature.

Methodological complexities

This lack of a common definition of engagement and discrepancies in its conceptualisation has also resulted in a wide variation of methods used across studies. Aspects of engagement have, most commonly, been measured by assessing adherence to medication and appointment attendance (Corrigan, Liberman & Engel, 1990; Cruz, Cruz & McEldoon, 2001) but also willingness to follow physicians' advice (Burke & Ockene, 2001; Graybar, Antoniccio, Boutillier & Varble, 1989), participation in treatment sessions (Lysaker, Bell, Milstein, Bryson & Beam-Goulet, 1994; Kemp, Hayward, Applewhaite, Everitt, & David, 1996) and motivation in joining recommended treatment (Lysaker, Bell, Milstein, Bryson, & Beam-Goulet,1994).

Moreover, the methodology used to examine medication adherence only, still varies considerably across the studies. Using the system employed by Dolder, Lacro and Jeste (2003), measurement of medication adherence can be broadly categorized into three different types of assessments: (1) direct measures of biochemical levels of anti-psychotic medication in blood or urine; (2) indirect measures such as pill count, prescription refill or electronic screw cap devices; and (3) subjective measures consisting of patients' or clinicians' reports of medication adherence. All of these assessments either pose considerable ethical and cost related problems or have limited reliability and validity.

Design related complexities

Research into various aspects of engagement has also been complicated by differences in the designs employed by various studies. For example, whilst the majority of studies have used adherence to medication as a dependent variable, some

have used adherence to medication as an independent variable and missed appointments as a dependent variable (e.g. Kruse & Rohland, 2002).

Another aspect that complicates the measurement of adherence is related to the fact that treatment adherence is rarely an "all-or-nothing" phenomenon, and hence should be treated as a continuous variable. However, some studies have dichotomised patients into adherent and non-adherent, which further limits comparisons that can be made between their results.

Research on the predictors of engagement with services has been further hampered by an inherent selection bias, as individuals who consent to participate in research and complete the required assessments are likely to be more engaged than the general patient population. Conversely, patients who drop out of mental health services and are not accessible for research are less likely to be engaged. Hence, the research samples obtained are likely to be more engaged than the general population of clients that they are intended to represent, which limits the external validity of the studies.

Some researchers have attempted to overcome this selection bias by only using medical records and clinicians' reports to examine predictors of engagement. For example, Compton, Rudisch, Craw, Thompson and Owens (2006) measured determinants of missed first outpatient appointments in a community mental health setting of 234 consecutively discharged patients from two inpatient wards. The authors obtained data on their dependent variable, appointment attendance, from relevant outpatients' clinics, whereas independent variables were measured by reviewing patients' medical notes and by interviewing staff. However, such studies also have considerable limitations, as they cannot control for many confounding

factors, which depend on information that can only be obtained directly from the clients.

Recent attempts to conceptualise and measure engagement

More recently, it has been recognised that the concept of engagement is complex and reflects multiple dimensions that are conceptually related (Hall, Meaden, Smith & Jones, 2001; Tait et al., 2002; Tsang, Fung & Corrigan, 2006). Mental health care provision for clients, as advocated in clinical NICE guidelines (2002), usually involves multidisciplinary professionals, with medical input being only one aspect of care. As it can be observed in clinical practice, some patients may not be willing to take medication as prescribed; however, they may still be willing to engage in the psychosocial aspects of the mental health care offered to them. Therefore, medication adherence is only one component, not comprehensive enough to reflect the complex nature of engagement. To redress this balance, new dimensions have been suggested as important in the conceptualisation of engagement, such as patients' collaborative participation in the management of their illness (Tait et al., 2002), their openness about their personal and emotional problems, and the quality of the client-therapist interaction (Hall et al., 2001). Accordingly, new measures have been developed that aim to assess clients' engagement with mental health services more comprehensively (Hall et al., 2001; Tait et al., 2002; Tsang et al., 2006). These offer new opportunities for progress in research on engagement and its determinants. However, it needs to be acknowledged that these methods attempt to measure clients' engagement only from the perspective of professionals. Tait et al. (2002) have pointed out that engagement is always a two way process that reflects something about the client but also about the service. Therefore, developing measures that will assess clients'

perspective would also be needed to further enhance our understanding of the mechanisms underlying engagement.

What are the predictors of engagement?

Numerous factors have been examined as predictors of engagement. These can be broadly grouped into three areas: 1) factors related to the relationship between mental-health services and the patient; 2) patient-related individual factors; and 3) patient- related social factors.

1) Services - patient relationship factors

Coercive pathways to care

The Sainsbury Centre for Mental Health's influential 'Keys to Engagement' report (1998) indicates that the traumatic experience of being held under a section of the Mental Health Act 1983 and being subjected to aggressive treatment regimens such as involuntary depot medication, could lead to subsequent difficulties in engaging clients with mental health treatment. In an American survey conducted in the 1980s, known as the "Well Being Project", 47% of 500 members of the California Network of Mental Health Clients reported that they avoided contact with mental health care due to fear of being involuntarily committed (Campbell, 1997). This finding indicates that coercive practices in mental health care services may have a detrimental effect on help-seeking behaviour, deterring many individuals from engaging with mental health services even if they themselves have not been subjected to involuntary treatment. Similarly, Singh (2001) argued that coercive pathways to care, common particularly with black patients, could result in clients perceiving services as racist and authoritarian, which may be particularly destructive

for engagement. Because of such a perception of mental health services, patients are not likely to comply with medication and often decline voluntary admission, thereby increasing their risk of compulsory detention.

However, empirical investigations into the effects of involuntary treatment on subsequent engagement with mental health services have brought mixed results. Before looking at these results it is important to acknowledge that the formal legal status of patients' hospital admissions has been found less important than their personal experiences of the process of treatment entry (Monahan et al., 1995). Therefore, patients admitted involuntarily may not perceive a great deal of coercion. In contrast, some voluntary patients may feel that they have been manipulated by a process of coercive persuasion by, for example, not being given a clear option to refuse hospitalisation. Hence, exploring patients' individual experiences rather than actual formal status appears to be more important.

Some studies have found significant association between patients' perceived coercion and their future disengagement from medical treatment. For example, Weiden et al. (1991) followed 72 patients, 85% of whom had been diagnosed with schizophrenia, after an index hospitalization. 48% of these patients became non-compliant with medication over a year follow-up and perceived coercion was one of the significant predictors of their non-compliance.

Other studies, however, have failed to find any significant associations between individual experiences of being coerced into treatment and future engagement. Rain et al. (2003) examined the association of perceived coercion at the time of hospital admission with self-reported medication adherence and session attendance, after discharge to the community. The authors recruited their sample from three different acute psychiatric inpatient wards and interviewed them while in the hospital and up

to five times in the year following their discharge to the community, obtaining follow-up data for 825 patients. There were no significant differences in adherence between patients with high perceived coercion scores and those with low perceived coercion scores. This remained the case at all five follow-ups.

Other studies demonstrated that the effects of coercive pathways to care on subsequent treatment adherence were mediated by whether the client later perceived the treatment to have been beneficial in some ways (Swartz, Swanson & Hannon, 2001). The authors found that when mandated community treatment was sustained for at least six months, and led to perceived improvement in clients' mental health, both adherence with medication and willingness to engage in outpatient treatment were significantly improved. However, when involuntary treatment left patients feeling that they were being treated unfairly and not respected as a person, they were unlikely to seek help later on.

A more recent study by Swartz et al. (2003) examined the impact of the experiences of various types of perceived coercion on future voluntary help seeking. The authors employed a sample of 104 individuals with schizophrenia spectrum disorder. Only 36% of participants reported fear of coerced treatment as a barrier to seeking help for mental health problems. The authors concluded that coercive treatment experiences could be a deterrent to voluntary help seeking in the case of some patients; however, alternative explanations were possible. Those who have experienced coercion may have been more severely ill and mistrustful and therefore more reluctant or fearful to seek treatment before their hospitalization.

Overall, the literature indicates that negative involuntary inpatient treatment may be a traumatic experience for some patients and, in some cases, may impose barriers to help seeking. However, in the case of other clients, the benefits of

involuntary treatment may outweigh their negative consequences. Therefore, there is insufficient evidence to conclude that involuntary treatment deters most patients from seeking treatment in the future, especially if they do subjectively perceive some subsequent improvement in their mental health from compulsory treatment.

Type of antipsychotic medication offered to patients

Pharmaceutical companies claim that adherence can be improved with atypical antipsychotic medication. This is because the atypical medication has fewer extrapyramidal side effects than typical antipsychotics (e.g. Day, 2003). There is some empirical evidence supporting this assumption. For example, Yen et al. (2005) found that patients who received second-generation antipsychotics had higher medication adherence at follow-up interviews than those who received traditional antipsychotics. Similarly, McEvoy et al. (2006) conducted a randomised controlled trial (RCT) with 251 patients experiencing first episode psychosis. The participants were randomly assigned to two years of double-blind treatment with either olanzapine (an atypical antipsychotic medication) or haloperidol (a typical antipsychotic medication). After adjusting for baseline insight, haloperidol-treated patients were significantly more likely than olanzapine-treated patients to discontinue the study before 2 years, indicating the positive effect of atypical antipsychotics on patients' engagement with treatment. However, other findings have indicated that the type of psychotic medication may not have much influence on adherence. For example, Menzin, Boulanger, Friedman, Mackell and Lloyd (2003) compared 93 patients who received conventional antipsychotics with 205 patients receiving atypical antipsychotics and found that non-adherence rates were similar in both groups. Therefore the medication type appears to have limited validity in predicting

clients' engagement with services, and the mooted advantage of atypical medication over the typical antipsychotic in relation to treatment adherence remains to be clarified.

Relationships with clinicians

Some researchers have argued that the quality of the doctor-patient relationship may be an important predictor of medication adherence in psychiatry; however this is often underestimated in clinical practice (Bebbington, 1995; Mitchell, 2006). A large body of evidence indicating that patients' willingness to take medication is far more likely in the context of a perceived good therapeutic doctor-patient relationship, including perceived helpfulness and trust in the clinician, comes from the area of physical illness (Hanson, 1986; Ley, 1982; Piette, Heisler, Krein & Kerr, 2005). The importance of the collaborative relationship between patient and therapist referred to as the therapeutic alliance has also been widely acknowledged in psychotherapy for people with less severe mental health problems (Horvath & Luborsky, 1993).

A recent qualitative study highlighted that the quality of the clinician- patient relationship may be particularly relevant for the engagement of patients with mental health problems. McCabe, Heath, Burns and Priebe (2002) examined 32 routine consultations between psychiatrists and patients with schizophrenia or schizoaffective disorder. They observed that, in response to patients' active attempts to talk about the content of their psychotic symptoms, during consultations, doctors responded with reluctance and displayed discomfort in engaging with this topic. For example, in response to patients' direct questions about their psychotic symptoms, doctors tended to hesitate and to respond with questions rather than with answers. Moreover, when informal carers were present during consultations, the doctors

tended to smile or even laugh, indicating that they were reluctant to engage with the patients' concerns about their psychotic symptoms. Such behaviours resulted in noticeable interactional tension. The authors concluded that, in practice, engagement with services means engagement with the clinicians who provide treatment in a service. Therefore, as advocated by the authors, to increase clients' engagement with services, professionals need to be more responsive to patients' needs and concerns about their illness. This may lead to a more satisfactory outcome of the consultation, which in turn may improve engagement of such patients in the health service.

Moreover, some quantitative examinations have demonstrated the importance of the relationship with clinicians in predicting treatment adherence of patients with psychosis (Corriss et al., 1999; Frank & Gunderson, 1990; Weiden et al., 1991).

Service related practical factors

Some research has highlighted the fact that practical service-related factors may influence patients' engagement with services. For example, Compton, Rudisch, Craw, Thompson and Owens (2006) found that a longer waiting period from hospital discharge to the follow-up appointment was a significant predictor of non-adherence, as measured by failure to keep the first appointment after psychiatric hospitalization. This is consistent with previous studies, which found that inadequate discharge planning resulted in subsequent lower rates of adherence to treatment (Caton, Goldstein, Serrano & Bender, 1984; McEvoy et al., 1989; Nelson, Maruish & Axler, 2000).

Overall, current literature suggests that service-related factors are important in predicting patients' engagement with mental health services. Of these, the most consistently supported by empirical evidence appear to be the quality of the

clinician-patient relationship and adequate discharge planning, including the time proximity between the client's discharge from hospital and their first appointment in a community setting.

2) Patient related factors

Sociodemographics

Numerous socio-demographic factors have been examined in relation to some aspects of engagement. Black or minority ethnic origin has been linked with reluctance to engage in mental health services (e.g. Bhui et al., 2003) and repeatedly found as a predictor of non-adherence (Coldham et al., 2002; Kampman & Lehtinen, 1999; Verdoux et al., 2000).

However, other demographics have shown to be less consistent in predicting adherence to treatment. In a recent comprehensive review of 103 studies looking at the predictors of treatment adherence, being young, male, unemployed and having low social functioning emerged as predictors of both non-adherence to medication and non-attendance to outpatient appointments (Nosé, Barbui & Tansella, 2003). However, other socio-demographic characteristics such as education level or living alone were not consistently associated with adherence. The authors of the review paper pointed out that many of the studies included in the review had some methodological and design limitations, with the majority failing to declare explicitly how adherence was measured. They also noted that when these demographics were entered into a regression analysis they explained a relatively small percentage of the total variance, indicating their limited predictive role in determining adherence. In another review of 39 studies that applied more stringent methodological criteria, age and gender were not found to be consistent predictors of non-adherence to

medication in schizophrenia (Lacro, Dunn, Dolder, Leckband & Jeste, 2002). More recent studies have also brought inconsistent results as to age and gender, with some reporting their significant association with treatment adherence (e.g. Mulder et al., 2005) and others failing to find a significant relationship (e.g. Yen, 2005; Tait, Birchwood & Trower, 2003). It is noteworthy that when demographics are found to predict medication adherence, they are able to explain only a small amount of variation in medication adherence. Therefore, the importance of socio-demographic factors in predicting various aspects of patients' engagement with mental health services appears to be limited.

Clinical factors

A number of clinical factors have been examined in relation to some aspects of engagement, predominantly adherence to treatment. First contact patients have consistently been found to be less adherent compared with patients who have had longer contact with services. Moreover, a history of non-adherence has repeatedly been found to be predictive of future non-adherence (Nosé et al., 2003; Lacro et al., 2002). In addition, longitudinal studies have found that medication adherence at the index interview could predict subsequent medication adherence, suggesting considerable stability over time (Buchanan, 1992; Scott & Pope, 2002; Yen et al., 2005). Another factor that has been found to have a negative effect on treatment adherence in patients with psychosis has been substance misuse (Coldham et al., 2002; Kampman & Lehtinen ,1999; Mulder et al., 2005; Nosé et al., 2003; Verdoux et al., 2000). Other factors that have been extensively studied in relation to treatment adherence include psychotic symptomatology and insight. However, these studies

have brought inconsistent or even contrary results and will be discussed in the following section.

Symptomatology

A large number of studies have examined the relationship between psychopathology and treatment adherence. More severe psychopathology was found in patients who discontinued treatment shortly after a first psychotic episode (Verdoux et al., 2000; Coldham et al., 2002), suggesting that higher severity of symptoms experienced by patients may predict their disengagement from mental health care. However, the above mentioned review, conducted by Nosé et al. (2003), found mixed results on the relationship of psychopathology to treatment adherence. A more recent study by Yen et al. (2005) showed no association between psychotic features and medication adherence in schizophrenic patients, considered to be in remission or to have minimal psychopathology, at both index and one-year follow-up. Similarly, Tait et al. (2003) found no relationship between service engagement and the level of psychotic symptoms. Other findings suggest that only certain positive symptoms of psychosis may explain patients' non-adherence to treatment. For instance, Bartkó, Herczeg and Zàdor (1988) observed that patients who did not comply with medication displayed grandiose delusions more often than compliant patients. Similarly, Mulder et al. (2005) found that only grandiosity and high suspiciousness, but not other symptoms, were associated with less motivation for treatment. Therefore, as suggested by the authors, only the patients who experience their relationships with the outside world as problematic may not see suggested treatment as adequate and hence be reluctant to engage with mental health services.

Depression

There is some empirical evidence suggesting that emotional status, particularly depression, affects patients' ability and/or willingness to adhere to recommended treatment, in a non-psychiatric population (Carney, Freedland, Eisen, Rich & Jaffe, 1995; DiMatteo, Lepper & Croghan, 2000). DiMatteo et al. (2000) synthesised 12 studies looking at the relationship between depression and non-compliance with treatment. Meta-analysis of these studies showed that depressed patients were three times more likely than non-depressed patients to be non-compliant with prescribed treatment. The authors suggested that depression might impair cognition, energy levels and motivation, resulting in difficulties in treatment adherence. Moreover, common in depression lack of hope that individual's actions will be worthwhile may also have a detrimental effect on adherence.

Since depression is often observed in patients with psychosis, particularly after the remission of positive symptoms, it seems plausible to predict that it also can have a negative impact on their engagement with services. However, there is a lack of empirical investigations in this area. One exception is a recent study by Watson et al. (2006) that examined the relationship between depression measured by the Beck Depression Inventory –II (BDI –II, Beck et al., 1996) and self reported medication adherence, in a sample of 100 patients diagnosed with a non-affective psychosis, within three months of relapse. The results showed that participants with higher levels of depression were less likely to adhere to their medication regimen; however, this relationship lacked statistical significance. Therefore, the role of depression in predicting engagement with treatment in individuals with psychosis awaits further empirical clarification.

Insight

It has been estimated that between 50% and 80% of patients with psychosis do not believe they have a disorder (Amador & Gorman, 1998). It is reasonable to expect that, if an individual does not recognise that he or she is ill, they will be unlikely to engage with offered treatment. This logical assumption has been widely explored in the empirical literature; however, the results of these investigations are not clear and sometimes even contradictory. The inconsistent findings may be caused by a wide variation in the conceptualisation of insight found across the studies. The concept of insight is complex and multidimensional and thus poses methodological challenges, some similar to those related to studying engagement. The literature on problems inherent in the concept of insight in psychosis is extensive. Its comprehensive discussion would extend the purpose of this review, hence only a short summary will be offered here for a brief consideration of the current conceptual understanding of insight and related methodological complexities, particularly in relation to studying aspects of engagement. This, in turn, will be followed by a summary of current findings. The interested reader might refer further to the available literature (e.g. Markova, 2005).

Early studies conceptualised insight as one's awareness (or its lack) of having a mental illness. They often relied on subjective clinical observations and many researchers measured insight by asking a single question: "do you have a mental disorder?" Later this arbitrary categorisation evolved to a single dimension and more recently, insight has been recognised as a multidimensional concept (Amador & Kronengold, 1998). David (1990) proposed that insight comprises three overlapping dimensions: (1) the recognition that one has a mental illness; (2) compliance with treatment; and (3) the ability to label the psychotic symptoms as being a consequence

of mental illness. Recently, the majority of tools measuring insight have utilised these three dimensions (e.g. Birchwood et al., 1994; David, 1990). However, the inclusion of the dimension 'compliance with treatment' into a definition of insight poses methodological difficulties for studying the relationship between insight and treatment compliance, as they consider overlapping processes. This limits the extent to which meaningful conclusions can be drawn from these studies. Nevertheless, as argued by some researchers, exploring the relationship between insight and treatment adherence (or compliance) can still be valid, because beliefs about compliance are not necessarily the same as actual treatment compliance (David, 1990; Kemp & David, 1995a).

Research exploring insight in relation to treatment engagement has focused predominantly on its relationship with medication adherence and, as mentioned above, has yielded inconsistent results. Many studies have found that medication adherence was significantly correlated with acknowledgment of illness (Bartkó et al., 1988; Kemp & David, 1995b; Smith, Barzman & Pristach,1997; Weiden et al., 1991) and/ or perceived benefits from medication (Lin et al., 1979; McEvoy et al., 1993). However, others have failed to confirm the relationship between insight and medication compliance (Barnes, McPhillips, Hillier, Puri & Joyce, 1997; Buchanan, 1992; McEvoy et al., 1989).

More recent studies have found only partial or no association between medication adherence and insight. Garavan et al. (1989) measured insight in individuals who were regularly compliant with medication and those who where irregularly compliant and found that the level of insight was similar in both groups. The authors concluded that the degree to which clinically stable outpatients with schizophrenia comply with medication is independent of insight. They suggested that

insight might be an important predictor of whether, or not, outpatients decide to take medication but it has no influence on the degree to which individuals adhere to medication. Yen et al. (2005) explored the associations between the three dimensions of insight and medication adherence at index interview and at one-year follow-up in outpatients diagnosed with schizophrenia and bipolar disorder, considered to be in remission or to have minimal psychopathology. The authors found that, in the case of patients with schizophrenia, only one aspect, insight into treatment, correlated positively with medication adherence at index interview. However, there was no correlation between any aspects of insight and medication adherence, at the one-year follow-up interview.

Trauer and Sacks (2000) explored the relationship between insight and medication adherence in severely mentally ill clients treated in the community. They found no relationship between self-asserted insight and self-asserted medication adherence. However, insight correlated with the level of medication adherence judged by clinicians. This interesting finding highlights the previously considered methodological complexities of studying medication adherence and the difficulties in making comparisons across studies that use different methodologies. A recent study by Tait et al. (2003), which employed a comprehensive measure of engagement, found no relationship between insight and any of the aspects of clients' engagement with mental health care.

To conclude, despite many studies finding a positive correlation between insight and medication adherence, a considerable number have failed to do so. Moreover, the correlation found in many studies appears to be weak (e.g., Lin et al., 1979) or only moderate (David, 1998). In addition, many patients will go along with treatment despite having very little insight. Furthermore, in the realm of physical

illness, many patients, despite not having impaired insight, fail to engage in their treatment. Therefore, insight seems to have a limited predictive validity for treatment engagement.

Psychological factors predicting engagement

Whilst the clarification of socio-demographic and clinical predictors is very important as it allows us to identify the risk factors, it does not tell us which of the clients from the risk group will engage with mental health services and what can be done to improve this engagement. However, there is some emerging evidence that certain psychological factors might be important determinants of clients' engagement. More encouragingly, these are potentially amenable to intervention and change.

Recovery style

It has been observed that individuals who have experienced an episode of psychosis differ in the meaning and beliefs that they attach to their experience. These different responses have been referred to as patients' individual psychological adjustment or recovery style. Recovery style has been conceptualised as a continuum with a sealing over style at one end and an integrating style at the other (McGlashan, Levy & Carpenter, 1975). A sealing over recovery style refers to a pattern of denial and repudiation where the individual attempts to encapsulate their psychotic experiences. In contrast, an integrating recovery style refers to a pattern of seeking to understand one's experiences and integrate them into one's life through curiosity, openness and assimilation. An integrating recovery style has been found to be associated with better long-term outcomes in schizophrenia (e.g. Thompson, McGorry & Harrigan,

2003). Tait et al. (2003) proposed that better outcomes could possibly be mediated by whether, or not, clients engage with mental health services. The authors examined the relationship of recovery style to engagement in 50 individuals with a diagnosis of schizophrenia. Those participants who showed sealing-over recovery styles displayed more difficulties in all aspects of service engagement. They had more difficulties in arranging and keeping appointments, in developing a collaborative relationship with their case managers, in seeking help in a crisis, and in adhering to prescribed treatments. Furthermore, this relationship was independent of their level of insight. Since a recovery style is fluid and changeable over time (Tait et al, 2003), psychological interventions, aimed at modifying recovery style, could improve patients' engagement with their treatment. However, this remains to be verified by further interventions studies.

Tait, Birchwood and Trower (2004), in a subsequent study, examined the mechanisms underlying style of recovery. Consistent with a previous finding (Drayton, Birchwood, & Trower, 1998), individuals who were 'sealing over' had a history of attachment difficulty with caregivers and reported more anxiety about interpersonal rejection and lower levels of closeness and dependence in relationships. These characteristics, in turn, predicted lower service engagement. The authors concluded that low engagement with psychiatric services might reflect individuals' attachment difficulties. Therefore, therapeutic work with clients, drawing on attachment theory, could help in the process of engagement.

Illness perceptions

Treatment engagement in physical health

Another approach to studying the meanings and beliefs people attach to their experiences of psychosis and their potential relevance for patients' engagement with mental health services, has originated from health psychology. In the area of physical illness, non-adherence to medication has also been a major concern, with estimations of approximately 30 % to 40% of patients not taking their prescribed medication (Meichenbaum & Turk, 1987). Moreover many individuals, against medical advice, lead lifestyles that endanger their physical health. Health psychologists have developed social cognition models to explain such behaviours (e.g. Connor & Norman, 1995). These theories appear potentially very useful in enhancing our understanding of the mechanisms underlying engagement in the mental health setting. Therefore, they will be discussed in more detail below, with a focus of their applicability to studying engagement in psychosis and with the aim of identifying directions for future investigations.

Central to social cognition models is a concept of illness perception or illness representation. These models assert that, just as people develop representations of the external world to explain and predict events, they form similar cognitive representations of the symptoms they experience or the diagnosis they are given. These, in turn, guide their behaviour directed at managing illness, including adherence or non-adherence to treatment.

The Self-Regulatory Model

The most influential of social cognition models is the Self-Regulatory Model (SRM; Leventhal, Nerenz & Steele,1984). The SRM asserts that individuals structure their

beliefs about illness along five dimensions. These are the perceived *identity* of the illness (the experienced signs and symptoms and the label given to these), the perceived *causes* of the illness, the likely *timeline* (a sense how long the illness will last), the perceived *consequences* (biological, social and behavioural) and the potential for *cure or controllability*. According to these beliefs, individuals will construct their own representation of the illness that will shape their attempts at coping. This coping is then appraised and the cognitive representations modified accordingly. In contrast with other social cognition models, the SRM also emphasises the emotional representations of the illness. Thus both the cognitive and emotional illness representations are embedded in a self regulatory feedback cycle consisting of three phases: (1) interpretation, where the person forms a representation of both of the illness and also of their emotional response to the illness; (2) coping, where the person selects actions to deal with both the illness itself and also the emotion; and (3) appraisal, where the person evaluates the effectiveness of the coping.

The SRM has provided a useful conceptual framework for understanding non-adherence behaviours in the area of physical health. Patients' decisions to follow treatment recommendations are influenced by their representations of the illness and their subsequent views on whether the proposed treatment is appropriate. Moreover, patients regulate their response to the illness threat in an attempt to achieve "common sense" coherence. Non-adherence could be a "common sense" response from the patient who perceives a lack of coherence between his or her own ideas about the illness, experience of symptoms and their doctor's instructions (Leventhal & Cameron, 1987).

Based upon the SRM, the Illness Perception Questionnaire (IPQ, Weinman, Petrie, Moss-Morris & Horne, 1996) has been developed to assess its key beliefs (time, identity, cause, control and consequences). Subsequently the IPQ has been revised and additional subscales were added including 'emotional response', 'coherence' and 'timeline cyclical' (IPQ-R, Moss-Morris et al., 2001). Both measures have been widely applied to a range of physical illnesses and have been found to account for a significant amount of variance in illness-related behaviours, including treatment adherence (e.g. Jessop & Rutter, 2003; Petrie et al., 1996).

Horne and Weinman (1999, 2002) proposed that the ability of the SRM to explain treatment adherence could be enhanced by extending its scope to focus on specific treatment and medication beliefs in addition to illness beliefs. The authors investigated the relationship between beliefs about the necessity of taking prescribed medication and concerns about taking it, and adherence among 324 patients with a wide range of chronic conditions (Horne & Weinman, 1999). The authors found that although the majority of participants believed that their prescribed medication was necessary for maintaining health, approximately a third had strong concerns about the potential adverse effects of taking it and these patients reported lower adherence. The medication beliefs held by patients were a stronger predictor of reported adherence than clinical and socio-demographic factors, which provides further empirical evidence that demographics have only limited value in predicting adherence to treatment. The authors postulate that patients are active decision-makers and are more willing to take medication as instructed if they believe that its necessity outweighs their concerns about taking it. This has important clinical implications, suggesting that eliciting and changing patients' beliefs about their medication could be particularly important for improving medication adherence.

Application of social cognition models to mental health

The application of social cognition models has only recently become a focus of study in relation to mental health. Before proceeding to review the studies that used the social cognition theory to examine aspects of engagement, it is important to acknowledge that historically there has been a lot of scepticism about the application of this theory in relation to people with severe mental health problems, perhaps because of an implicit assumption about a breakdown in thought or rationality in psychosis. A comprehensive discussion of the larger issue of whether social cognition theory, and specifically health belief models, can be applied to mental health, would be beyond the scope of this review. Therefore, only key relevant issues and findings supporting the potential usefulness of studying cognitive representations in psychosis will be highlighted.

Underpinning illness perception models is the assumption that people, when faced with illness, strive for some coherence in their understanding of it. However, people with psychosis may experience severe conceptual disorganization, sometimes referred to as thought disorder, where their beliefs may be inconsistent or even contradictory and confused. Secondly, illness perception models generally assume that people can clearly differentiate their illness from their identity. In contrast, people with psychosis are frequently not able to make such a distinction (see also Kinderman et al., 2006). These differences might be taken to suggest that studying cognitive representations of patients with psychosis may not be valid.

However, recent developments in psychological models of psychosis have provided both direct and indirect empirical evidence against these presumptions. Firstly, there is some empirical evidence in support of the continuity model of psychosis asserting that psychosis may be an atypical concatenation of interacting

cognitive and emotional processes, which themselves lie within the normal range (see Johns & van Os, 2001). In addition, it can be observed that people without a diagnosis of mental health problems may hold beliefs that are contradictory in their nature such as some scientific and religious beliefs. Furthermore, growing evidence points to the role of cognitive appraisals in the maintenance of the positive symptoms of psychosis (e.g. Garety et al., 2001) and in post-psychotic depression (Iqbal, Birchwood, Chadwick & Trower, 2000).

Moreover, some preliminary studies that compared the beliefs of people from three groups including psychosis, somatic illness and healthy controls, found that individuals from both illness groups held similar beliefs, which were distinct from those held by healthy participants (e.g. Haley, Drake, Bentall & Lewis, 2003). This indicates that people with psychosis, similarly to those with physical illnesses, will construct cognitive representations of their experience, which warrants further investigation.

The most extensive work in evaluating the applicability of the specifically self-regulatory model to psychosis has been recently done by Lobban and co-workers (see review Lobban, Barrowclough & Jones, 2003). The authors conducted a qualitative study exploring the validity of the SRM framework, in which 22 people with a diagnosis of schizophrenia were interviewed about their understanding of this illness (Lobban & Barrowclough, 2005). The analysis showed that people with psychosis tended to construct illness representations in relation to their mental illness and these were broadly similar to those found in physical illness. However, this study also highlighted that certain modifications were likely to be needed in order to apply the SRM framework to a population with schizophrenia. These included, for example, the necessity of replacing the term 'illness' by 'mental health problems'

and 'symptom' by 'experience' (see Lobban, Barrowclough & Jones, 2005). Accordingly, the authors adapted the IPQ-R for people diagnosed with schizophrenia and developed the Illness Perception Questionnaire for Schizophrenia (IPQS). They subsequently validated this new measure on a sample of 124 participants. The IPQS was shown to be a reliable and valid measure of cognitive representations of mental health problems (Lobban et al., 2005).

Subsequently, the authors tested the SRM framework to predict health outcomes in 124 people with schizophrenia (reported in Lobban, Barrowclough & Jones, 2004). The authors demonstrated that the amount of the variance accounted for by beliefs, although relatively small, was comparable to those reported in physical health. They concluded that cognitive representations in mental health appear to be at least as important as they are in physical health and that therefore the SRM provides a useful framework for investigations into the function of beliefs about mental health illness and how these can be modified to change the outcome.

To conclude, the above findings suggest that beliefs about illness are a legitimate construct in people with psychosis. In particular, the SRM framework, used extensively in physical illness, appears to be potentially useful for people with mental health problems and warrants further exploration. To that effect some studies have started to examine this model in relation to psychosis. These investigations will be reviewed in the following section, preceded by other studies that examined illness perceptions in relation to various aspects of engagement in psychosis.

Beliefs in psychosis and engagement

To date only a limited number of studies have explicitly examined the impact of patients' beliefs about their mental health problems on engagement and the majority of these looked at only one of its aspects - medication adherence.

Beliefs about medication

A few studies have employed social cognition models to investigate medication adherence in psychosis and found that perceived benefits of medication were a significant predictor of adherence to medication (Adams & Scott, 2000; Budd, Hughes & Smith, 1996). Similarly, Day, Bentall and Warner (1996) investigated patients' experiences of neuroleptic medication and found that it reflected a complex interrelationship between the perceived costs and benefits of taking it. These findings are consistent with research in physical illness and suggest that exploring and addressing patients' beliefs about antipsychotic medication might be important for improving medication adherence in people with psychosis.

Locus of control

Haley et al. (2003) examined the health beliefs of patients with a first episode of psychosis and their relationship to attitudes towards pharmacological treatment in the context of the duration of untreated psychosis. They looked specifically at one aspect of health beliefs, namely locus of control. The authors found that an external locus of control predicted positive attitudes to medication treatment. However, patients with an internal locus of control had significantly shorter duration of untreated psychosis, which implies that they sought help sooner. The authors suggested that individuals with an internal locus of control sought appropriate help sooner because they

believed that their state of health was the result of their own actions. Interestingly, there was no significant relationship between the locus of control and outpatient appointment attendance or contact with community psychiatric nurses. Therefore, these findings reiterate the complex nature of engagement, demonstrating that medication adherence and help seeking behaviours are distinct aspects of engagement. However, the limitation of this study was that it did not control for other factors that might decrease the duration of untreated psychosis, such as having social support, and therefore this interpretation remains somewhat speculative.

Studies that employed the SRM framework

Clifford (1998, unpublished; cited in Lobban et al., 2003) used the SRM framework, and employed the unmodified IPQ to examine non-adherence to medication in 38 psychiatric patients. She found a positive association between non-adherence to medication and the following key beliefs: a perception of fewer and less severe symptoms, perceived shorter duration of illness, perceived external attributions of causes and perceived more severe negative consequences of having schizophrenia.

Watson et al. (2006) assessed 100 patients diagnosed with psychosis with a version of the original IPQ modified for use in psychosis (Jolley & Garety, 2004) to examine the relationship between illness perceptions, emotional responses and attitudes to medication. The authors found that perceived negative consequences and higher levels of depression were negatively related to self-reported medication adherence. However, the perceptions of negative consequences were not able to significantly predict medication adherence when insight was added to the regression analysis.

The importance of the beliefs that people with psychosis hold about their illness and treatment comes also from studies on interventions aimed at improving adherence. Recent reviews of studies on interventions to enhance compliance with antipsychotic medication consistently found that educational interventions were the least successful at improving antipsychotic adherence (Dolder, Lacro, Leckband & Jeste 2003; Gray, Wykes & Gournay, 2002). In contrast, cognitive behavioural approaches, where intervention was tailored to an individual's beliefs, have been found to be more effective in increasing adherence rates. For instance, Kemp et al. (1996) used a combination of motivational interviewing and cognitive-behavioural based therapy, which improved patients' attitudes to treatment and adherence, further supporting the importance of patients' beliefs in engagement.

To summarise, all these preliminary studies suggest that illness perception models may be potentially useful in enhancing our understanding of patients' engagement with mental health services. However, only a few studies specifically tested the relationship between illness perceptions and engagement and these have only looked at one aspect of engagement, medication adherence. It is reasonable to expect that patients' beliefs may be potentially useful in predicting other aspects of their engagement with mental health services; however, this relationship has not yet been empirically examined.

3) Social factors

Research has indicated that, in addition to patients' individual characteristics, social and cultural factors may also play an important role in relation to individuals' engagement with mental health services. Two particularly important external factors are social support and stigma perceived by clients.

Social support

Studies that examined demographic predictors of engagement have repeatedly reported a positive association between a supportive family environment and adherence to treatment (Coldham et al., 2002; Compton et al. 2006; Kampman & Lehtinen, 1999). This indicates that social networks may play an important role in determining clients' engagement with mental health services. The SRM framework could enhance our understanding on how 'significant others' may affect clients' engagement with their mental health care. The model stresses the importance of social and cultural influences in the formation of patients' beliefs about their illness (Leventhal et al, 1984). Recent research demonstrated that the models of illness formed by relatives may play an important role in shaping patients' representations of their mental health problems (see Lobban et al., 2003). Future studies in this area could further enhance our understanding of how 'significant others' may influence clients' engagement with services.

Stigma

Perceived stigma is the belief that most people will devalue and discriminate against people who have mental health illness or use mental health services (Link et al, 1989). Researchers have distinguished between public stigma, which refers to the attitudes and behaviours of the public to a certain group, and self-stigma, which refers to peoples' awareness of the stigma attached to their own group. The latter appears to have the most detrimental effect on individuals, leading to diminished self-esteem and self-efficacy (Corrigan, 2004).

Recent qualitative studies have demonstrated that stigma around mental health services seems to be an important factor likely to hinder individuals' help seeking

behaviours and engagement with mental health services. Dinos et al. (2004) examined the views of 46 patients attending community and day mental health services. Narrative analysis revealed that stigma was a pervasive concern for a substantial proportion of the clients and some reported not asking for help, or refusing help, because of a fear of further stigmatisation.

Billings, Johnson and Pistrang (2006), in their qualitative study explored the experiences of individuals with first onset of psychosis. They found that many participants were conscious of stigma seen in relation to being involved with mental health services rather than having the psychotic experience per se. Corrigan and Watson (2002) pointed out that many individuals with psychosis are able to conceal their mental health problems. However, as participating in mental health services may result in other individuals becoming aware of their mental health problems and subsequently labelling them in a stigmatising way, it is logical to conclude that service users may not access this care in order to avoid this label and the resulting discrimination.

Surprisingly, very few quantitative studies have examined the relationship between perceived stigma and patients' engagement with mental health services. One exception is the study conducted by Sirey and co-researchers (2001) who investigated the effects of perceived stigma on service engagement in major depression. They found that high perceived stigma at the start of treatment was associated with a lack of adherence to antidepressants and with disengagement from psychiatric follow-up.

Tsang et al. (2006) have recently examined the correlation of their newly developed scale of treatment adherence to perceived discrimination by the public. They found that participants who had low attendance displayed a high level of

awareness of people with mental health problems being discriminated against by the public.

To summarise, current findings indicate that a significant cost of engaging in mental health treatment is the stigma associated with it. Many individuals may choose not to pursue mental health treatment because they do not want to be labelled as a mental health patient and to suffer the associated prejudice and discrimination that this entails. However, the evidence for the negative impact of stigma on engagement comes mostly from qualitative studies; hence, more quantitative research examining this relationship is clearly needed.

Summary and conclusions

Current literature on engagement in psychosis has focused predominantly on medical models conceptualising engagement as adherence to treatment and, in a research context, measuring it as adherence to medication. These studies have predominantly focused on exploring socio-demographic and clinical factors, particularly insight. However, their results are inconsistent and often contradictory. This may partially reflect the conceptual and methodological complexities faced by studies on medication adherence in general, as well as the specific methodological and design limitations of these studies. Nevertheless, research that employed more stringent methodologies implies that clinical and socio-demographics have only a limited value in predicting medication adherence.

More recently, other aspects of mental health care provision have been recognised as important for influencing patients' engagement with services and subsequent health outcomes. Patients may well be willing to engage in one aspect of this care but not in others. For example, a client may be willing to engage in

psychology, occupational therapy, and other psycho-social interventions, but may not be willing to take, or even be prescribed, anti-psychotic medication. It is therefore imperative to broaden the concept of engagement in a research context, beyond solely medication adherence. However, to date, only a very limited number of studies have explored predictors of engagement, using this broader understanding.

Following the recent development of psychological models of psychosis, researchers have turned to explore patients' individual experiences of mental illness and the beliefs they may have in relation to various aspects of engagement. For example, the recovery styles patients adopt after an initial psychotic episode have been found to predict their future engagement with mental health care. However, literature related to recovery style still refers to individuals' overall attitudes towards their experience of psychosis rather than to the more specific beliefs that might be important in predicting engagement.

The illness perception paradigm offers a possible solution to this dilemma. Recently, these models have begun to be explored in relation to psychosis and preliminary studies have indicated that illness perceptions may also provide a useful framework for explaining the health related behaviours of patients with schizophrenia, including their engagement in treatment. The identification of key beliefs in relation to engagement would have extremely important implications, as it would allow professionals to devise psychological models of predictors of engagement and subsequently develop appropriate psychological interventions enhancing patients' engagement with the mental health care offered to them. This, in turn, could improve outcomes for individuals with psychosis and reduce health costs to society. However, research using this framework in relation to psychosis is only in its infancy and so far has still attempted to explore patients' illness perceptions only

in relation to one aspect of engagement, medication adherence. Therefore, more studies are needed to verify the usefulness of this approach for studying engagement in people with psychosis.

The social context of patients' beliefs also appears to be particularly important in influencing their willingness to engage with health services. Recent qualitative studies have suggested that the stigma perceived by clients may be particularly important in determining how willing they may be to engage with mental health services. However, this relationship has not yet been confirmed by quantitative investigations.

Since both the cognitive appraisals made by people with psychosis as well as perceived stigma are potentially amenable to psychological intervention, further research enhancing our understanding of the relationship of these components of illness representations with engagement with mental health services is clearly warranted.

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Part 2: Empirical Paper

Beliefs about illness, perceived stigma and service engagement in first onset of psychosis

Abstract

In order for early intervention in psychosis services to successfully provide care for their clients, there needs to be a greater understanding of the determinants of the processes by which service users do, or do not, engage in the care offered. Social cognition models, developed by health psychologists, have indicated that illness perceptions are important in predicting engagement in care by people with physical health problems. Recently, the Illness Perception Questionnaire has been adapted for people with schizophrenia and offers a potential empirical resource for further understanding processes of engagement in the mental health arena. This study sought to explore the potential role of illness perceptions and perceived stigma in relation to engagement with services by clients with the first onset of psychosis. Fifty eight individuals with a diagnosis of first episode psychosis were assessed on illness perceptions, stigma and service engagement measures. Illness perceptions accounted for a significant amount of the variance in engagement. They appeared to explain engagement better than demographic and clinical factors. Different patterns of predictors emerged as important when the aspects of engagement were considered separately. Perceived stigma was not associated with engagement. The findings are discussed and clinical and research implications are considered.

Introduction

The last few decades have seen considerable changes in the outlook on the course and outcomes of psychosis. Today, psychosis is seen as a potentially manageable, or even reversible, condition. In particular, the first years are believed to constitute a biological and psychosocial critical period, having a major influence on the further course of the illness (Birchwood, Todd & Jackson, 1998). Firstly, most neurological deterioration occurs in the early stages of illness. Secondly, the emergence of psychosis, usually in adolescence or early adulthood, is at a time when young people are becoming more independent, are forming social relationships and making important educational or occupational choices, so it can cause significant disruptions to these developmentally important tasks. This can unfortunately lead to irreversible losses of individual opportunities, autonomy and social confidence.

Although first episodes are usually highly responsive to treatment (Lieberman et al, 1993), the risk of relapse is also very high and discontinuation of medication increases this risk up to five times (Robinson et al., 1999). Every relapse brings more, potentially irreversible, biological and psychological damage. However, there is considerable and growing evidence that intensive medical and psychosocial treatment, sustained for the first few years of illness, can significantly reduce the risks of further relapses and their damaging consequences (Petersen et al., 2005). Therefore, engaging clients in early treatment of psychosis is crucial and has become one of the priorities of the Department of Mental Health (1999). Accordingly, over the last few years, a considerable number of specialist early intervention services have been set up nationally that aim to offer comprehensive care for the first critical years.

However, the potentially advantageous effects of early intervention services can only be achieved when individuals engage with their treatment. Yet individuals with mental health problems are often reluctant to engage with mental health services and this is particularly evident for the fist episode group, with up to 60% discontinuing their contact with mental health services within the first year (Coldham, Addington & Addington, 2002; Novak-Grubic & Tavcar, 1999; Verdoux et al., 2000). Therefore, specialist early intervention services face the considerable challenge of trying to overcome this barrier in order to deliver appropriate interventions. As concluded by the 'Keys to Engagement' report (Sainsbury Centre for Mental Health, 1998), our current understanding of the mechanisms underlying engagement is limited and more research is needed to clarify them.

One particularly pertinent factor that has limited progress in research into this area is perhaps a poorly defined concept of engagement and the related lack of a formal measure of engagement. Until very recently, in parallel with dominant medical perspectives on psychosis, studies have considered engagement with mental health services as synonymous with medication adherence or appointment attendance. Only the last few years have seen an increasing recognition that other important aspects are also likely to be relevant, such as patients' help seeking behaviours and their collaborative participation in the management of their illness. Accordingly, new measures of engagement have been designed to assess engagement in this more comprehensive way (Hall, Meaden, Smith & Jones, 2001; Tait, Birchwood & Trower, 2002) and hence may be able to facilitate further research progress.

To date, a broad range of service related factors and patient characteristics are believed to determine whether patients will, or will not, engage in their mental health

care. As indicated by the 'Keys to Engagement' report (Sainsbury Centre for Mental Health, 1998) patients may be unlikely to engage with services that are perceived as authoritarian, inflexible and culturally insensitive. In response, early intervention services have explicitly attempted to tackle the issues of disengagement. They have adopted a more flexible assertive outreach model, where staff have lower caseloads and therefore more time for their clients. Despite preliminary evaluations showing that services based on an assertive outreach model are able to retain more clients than generic community mental health teams (e.g. Marshall & Lockwood, 2001), lack of engagement is still problematic. This suggests that looking in more detail at particular client factors is vital.

Research exploring patient characteristics pertinent to engagement has concentrated, concurrently with the prevailing medical models of psychosis, on exploring various demographic and clinical factors. However, as concluded by recent review papers, the results of these studies are ambivalent and often contradictory (Lacro, Dunn, Dolder, Leckband & Jeste, 2002; Nosé, Barbui & Tansella, 2003). In addition, these review studies demonstrated that demographic and clinical factors, if significant, are able to explain only a relatively small variance in treatment adherence. Therefore they indicate that other factors may also be very relevant to engagement.

More recently, following the increased recognition of psychological and social factors in models of psychosis and a shift away from an exclusively medical perspective, researchers have made further progress in exploring psychological factors in relation to clients' engagement with mental health services. For example, clients' recovery style has been found to be an important predictor of engagement (e.g. Tait, Birchwood & Trower, 2003). These findings have important clinical

implications as they highlight the importance of psychological factors that are amenable to change. However, a concept of 'recovery style' refers to an overall attitude clients hold about their experiences and therefore does not specify which key beliefs of this attitude may be relevant to engagement. Hence, it provides somewhat limited guidance as to what therapeutic strategies could be used to facilitate engagement.

The field of health psychology offers a potential theoretical and empirical resource for further understanding engagement. Health psychologists have developed illness perception models to explain the health related behaviours of patients with physical illness, including their engagement in treatment. The most influential of these models has been the Self Regulatory Model (SRM; Leventhal, Nerenz & Steele, 1984). The SRM asserts that patients, when faced with a new health threat such as new symptoms or a diagnosis, will actively build cognitive models of this threat. These cognitive models will guide their coping strategies designed to reduce the emotional response to the threat. Therefore, the cognitive models will determine whether patients seek help and subsequently, whether they will engage, or not, in the treatment that has been offered to them. Patients with the same illness can have widely different illness perceptions and these will depend on the patients' knowledge, personal experience and social and cultural factors. Individuals structure their cognitions around five core components: identity, cause, control, timeline and consequences. These illness perceptions, operationalised in the Illness Perception Questionnaire (IPQ; Weinman, Petrie, Moss-Morris & Horne, 1996; IPQ – Revised, Moss-Morris et al., 2002), were found to predict patients' participation in cardiac rehabilitation (Petrie et al., 1996) and adherence to treatment in various physical conditions (e.g. Jessop & Rutter, 2003).

The application of illness perceptions to mental illness, and psychosis in particular, has only been considered in the last few years and, so far, only a few studies have examined illness perceptions in relation to one aspect of engagement, namely medication adherence. These preliminary studies found that positive attitudes to medication were significantly associated with an external locus of control (Haley et al., 2003), a perception of less severe and negative consequences of illness and perceived longer duration of illness (Clifford, 1998, cited in Lobban et al., 2003). The initial results of these studies suggest that illness perception models might provide a useful conceptual framework to explore which, if any, cognitions are related to patients' engagement with mental health services. Identification of key cognitions would allow the development of cognitive models of predictors of engagement and, based on these, the development of interventions enhancing engagement.

The SRM also stresses the importance of understanding health beliefs within the social and cultural contexts in which they occur (Leventhal et al., 1984). Recent qualitative studies have suggested that, in relation to patients' engagement with mental health services, a particularly important social factor might be stigma perceived by clients (Billings, Johnson & Pistrang, 2006; Dinos, Steven, Serfaty, Weich & King, 2004). Surprisingly, very few quantitative studies have examined the effect of stigma on patients' engagement with mental health services. Sirey at al. (2001) found that the perception of stigma at the start of treatment influenced subsequent treatment behaviours in patients with depression. More recently, Tsang, Fung and Corrigan (2006) found that individuals with low attendance rates displayed high level of awareness of people with mental health problems being discriminated against by the public. However, none of the quantitative studies has yet examined the

impact of perceived stigma on engagement with services, in people with the early onset of psychosis.

Aims

This study therefore aims to explore the relationship between illness perceptions, perceived stigma and engagement in individuals who have recently experienced a first episode of psychosis. Both illness perceptions and perceived stigma attempt to capture people's personal experiences and beliefs about their illness and have been found to affect individual's engagement in treatment in a range of physical conditions and depression. The preliminary studies have shown their value in predicting medication adherence in people with early psychosis. This suggests that they may be potentially useful in explaining individuals' engagement with services in this client group. Since both the cognitive appraisals of illness and perception of stigma are potentially changeable, a better understanding of how they relate to treatment engagement could open up an opportunity for designing interventions that can challenge these negative appraisals and in the longer term improve engagement and the outcomes of psychosis.

Hypotheses

1) Illness Perceptions will show one or more of the following associations with engagement with services

1.1) Perception of a longer illness timeline, more coherent understanding of mental health problems and higher perceived treatment control will show a positive association with engagement with services.

1.2) Low sense of personal control (helplessness and blame), perceived

worse consequences and higher negative emotional reaction will show a negative association with engagement with services.

2) Increased level of stigma will show a negative association with engagement.

Method

Design

The study adopted a quantitative, cross-sectional design.

Ethical Approval

The current study was conducted as part or a wider research programme that incorporated three linked-studies, for which data had been collected through a single series of interviews in order to avoid excessive demands on patients. These three studies titled "An evaluation of outcomes from two models of early intervention service provision and exploration of factors explaining these outcomes", were granted the ethical approval by the Camden & Islington Community Local Research Ethics Committee (Appendix A) and received R & D approval by the North Central London Research Consortium (Appendix B).

Settings

The study was conducted in an inner city Early Intervention Service (EIS) dedicated to providing specialist assessment and management of people aged 18 to 34, who have presented to mental health services with a first episode of psychosis. The service included a stand-alone, centrally based, EIS team and augmented CMHT

sectors, in which specialist EIS workers had dedicated space on their caseloads for the management of people eligible for the EIS.

Sample

The research participants were recruited from a continuous sample of referrals made to the EIS between March 2004 and March 2006. The inclusion criteria were: being accepted on the service's caseload and the capacity to consent to participation in the study, as deemed by the case-coordinators. The exclusion criterion was being too acutely unwell at the time of the data collection.

A total of 99 clients of the EIS were eligible to take part in the study. Of these, nine had moved out of the city or the country and hence lived too far away to be interviewed, two had opted out of all research at the referral time and three had disengaged from any contact with the service. A further nine did not respond to the letters and telephone calls made by their care coordinators during the time of data collection and four were considered too unwell to take part in the study, by their case coordinators, throughout the period of data collection. Of those who were asked to take part in the study, 15 refused and three agreed to participate but repetitively failed to attend the arranged appointments. A total of 54 clients from the stand alone EIS and a further seven clients from the augmented CMHTs consented and took part in the study. Of these, two participants demonstrated potential difficulties in comprehending some of the measures. Data for those rated as not fully understanding the interview were excluded, leaving 58 participants in the final sample.

Procedure

Shared data collection

The current study was conducted as part of a wider research programme and data was collected by a research team of two trainee clinical psychologists and one research assistant. This facilitated access to a large data set which could be analysed separately for three concurrent studies. All the researchers were trained in administering and scoring the clinical measures, and met frequently to ensure that the same data collection protocol was being followed. Six clinical interviews were initially conducted by the research team in pairs to check for inter-rater reliability on the scoring of the measures. As this was deemed sufficient, all subsequent interviews were conducted individually.

Recruitment of Participants

Initially, all potential participants were asked by their case coordinators whether they were willing to be contacted regarding this study and, if so, how this contact should be made (e.g. by a telephone call, email, a letter, or meeting in person at the end of one of their clinical appointments). Those who were willing to be contacted were then approached by one of the researchers, who gave them an information sheet about the study (see Appendix C) and offered to provide any further explanations. If a person was willing to participate, they were asked to sign the informed consent form (Appendix D) and the interview time was then arranged. Moreover, all clients who were not in contact with their care-coordinators were sent letters inviting them to take part, which were then followed by telephone calls.

Interviews

Participants were interviewed at a location convenient to them, subject to the consideration of safety, which was discussed by the researcher with the clinical team, prior to the interview. In the majority of cases, the interviews took place on the service's premises. However, some clients were interviewed at other locations such as their home, a cafe, or the hospital (in the case of those who were hospitalised at the time of data collection). The interviews were completed in one appointment lasting between 45 and 90 minutes. The participants were asked to complete the measures, with assistance from the interviewer where necessary. This was followed by a clinical interview to assess participants' severity of symptoms. Each participant was paid £15, in respect of the time given. With participants' consent, the information collected at the interviews was supplemented with the information routinely collected at the time of the referral to the EIS, such as age, self-declared ethnicity, date of referral and level of education. This was followed by asking the care coordinators to complete a client's engagement measure.

Measures

The full list of measures used in the interview is included in Appendix E. For the purposes of the current study, the participants were asked to complete the following measures:

The Illness Perception Questionnaire for Schizophrenia (IPQS)

This is a version of the Illness Perception Questionnaire – Revised (IPQ-R; Moss-Morris et al., 2002) recently adopted by Lobban, Barrowclough and Jones (2005) to measure cognitive representations of mental health problems held by people with a

diagnosis of schizophrenia. The IPQS was modified following qualitative interviews of 22 people with schizophrenia, in which they were asked an open ended question about their understanding of schizophrenia and more specific questions about each of the dimensions of the IPQ – R (for more detailed description see Lobban & Barrowclough, 2005). The results confirmed general construct validity of the IPQ-R for people with schizophrenia but also indicated that some modifications were needed. The general modifications included replacing the term 'illness' by 'mental health problem' and 'symptom' by 'experience' as well as adding an explicit instruction to orient people toward their current views. In addition, some of the IPQ-R statements were changed to reflect the nature of problems likely to be faced specifically by people with schizophrenia. For example, the statement: 'The symptoms of my illness change a great deal from day to day' was considered likely to reflect too short a timeframe for mental health problems and therefore was replaced with 'sometimes the symptoms of my illness are worse than other times'. In addition, some new items were included such as an item to assess the possible perception of positive effects of mental health problems on some individuals. A detailed description of specific modifications is provided in Lobban et al. (2005). The IPQS was subsequently validated on a sample of 124 people with a diagnosis of schizophrenia and all the subscales showed good construct validity, internal consistency and stability over time (Lobban et al., 2005).

The IPQS consists of subscales that measure beliefs about identity, cause, timeline acute/chronic, timeline episodic, consequences, personal control/cure, personal blame, treatment control/cure, illness coherence, and emotional representation of the illness experiences. The first two subscales were omitted from the current study. 'Cause' has been demonstrated as difficult to operationalise and

showed little relationship to other variables by Lobban et al. (2005). 'Identity' is a relatively lengthy subscale and it needed to be omitted due to time and resource constraints. The remaining subscales used in the current study consist of 47 statements about individuals' personal views of how they see their mental health problems. These are listed in Appendix F. Participants were asked to indicate how strongly they agreed or disagreed with each of these statements on a 5 point scale (1=strongly disagree, 2=disagree, 3=neither agree nor disagree, 4=agree, 5 = strongly agree). The scores for each of the following subscales were then derived by totalling the individual items scores:

a) Timeline acute/ chronic (6 items). A high score denotes a perception of a more chronic timeline.

a) Timeline cyclical (4 items). A high score denotes the perception of a more cyclical pattern of mental health illness.

b) Consequences (11 items). A high score indicates a perception of greater negative consequences resulting from having mental health problems.

c) Personal control (4 items). A high score indicates a perception of having greater personal control over mental health problems.

d) Personal control-blame (3 items). A high score indicates a higher degree of self-blame.

e) Treatment control/cure (5 items). A high score denotes the belief that treatment can be effective in alleviating mental health problems.

f) Illness coherence (5 items). A high score denotes a sense of having no coherent understanding of mental health problems.

g) Emotional representation (9 items). A high score denotes a strong negative emotional response as a result of mental health problems.

The Perceived Devaluation-Discrimination Scale

Perceived stigma was measured by the Perceived Devaluation-Discrimination Scale, developed by Link (1987, 1989). The scale has been shown to have good reliability and validity (Link, 1987). It includes 12 items that ask respondents' opinions about the extent to which 'most people' would devalue or discriminate against former patients with mental health problems. Therefore the scale focuses on perceptions of stigma rather than stigmatizing experiences. Each of the items is rated on a 5-point scale ranging from 1 to 5 (1 = strongly agree, 2 = agree, 3=neither agree nor disagree, 4 = disagree, 5 = strongly disagree). In six of the items, the scoring is reversed and the individual scores are then summed. A high score denotes a high perception of mental health stigma. The scale is included in Appendix G.

PANSS

Participants' current levels of symptomatology were assessed using the Positive and Negative Syndrome Scale Severity of psychosis (PANSS; Kay, Fiszbein & Opler, 1987). The PANSS is a widely used measure for assessing positive and negative symptoms, and general psychopathology. The measure showed good reliability and validity (Kay, Opler & Lindenmayer, 1988). It consists of 30 items each indicating current level of severity of a symptom ranging from 1 to 7 (1=absent, 7=extreme). The scores obtained on single items are added to obtain the results for 3 subscales: 1) positive symptoms (7 items), 2) negative symptoms (7 items), and 3) general psychopathology (16 items). Higher scores indicate higher levels of psychopathology.

Insight measure

Insight was measured using the PANSS G12 item where insight is defined as awareness of mental disorder, its social consequences and the need for treatment. Basis for rating is the client's thought content expressed during the interview. The scores range from 1 to 7 and higher scores indicate poorer insight.

Care Coordinators also completed the following measure:

Service Engagement Scale (SES)

This scale has been recently developed by Tait et al. (2002) to fulfil the need for a measure of engagement with community mental health services. The measure has been validated in a study in which 5 community psychiatric nurses completed the measure for 66 clients with a diagnosis of schizophrenia. The items have shown good validity and high test-retest reliability.

The SES consists of 14 items split into four scales:

(a) availability (3 items), which refers to the client being available for arranged appointments

(b) collaboration (3 items), which refers to the client actively participating in the management of their mental health problems

(c) help seeking (4 items), which refers to the client actively seeking help when needed

(d) treatment adherence (4 items), which refers to the client's attitude toward taking medication.

All the items are listed in Appendix H. Each item is rated on a 4-point scale, with 0 = not at all or rarely, 1 = sometimes, 2 = often, and 3 = most of the time. The subscales are calculated by adding up all the items. A global engagement score is derived by totalling all the subscales. Higher scores denote the client's greater level of difficulty engaging with services.

Analysis

Statistical analyses were performed using the Statistical Package for Social Science (SPSS) version 11.5. Descriptive statistics were used to examine the characteristics of the sample. All the measures were checked for reliability. The univariate associations between the illness perceptions on the IPQ-S were examined. The distributions of all continuous variables were checked for normality. The outcome variable, engagement, as measured by the Service Engagement Scale (SES) was significantly skewed and showed a floor effect as 14 participants (24 %) obtained a score of 0 indicating perfect engagement. Therefore engagement could not be considered as a continuous variable. Instead a median split based on the total SES scores was used to create a 'good engagement' group (scoring between 0 and 6) and a 'poor engagement' group (scoring between 8 and 41). None of the participants obtained a score 7. The two engagement groups were then compared on demographics and clinical measures with t-tests and chi-square tests, The first hypothesis, that illness perceptions would predict engagement, was tested with a logistic regression model where demographic and clinical predictors, significant at the univariate level, were entered into the first block and exploratory variables – illness perceptions were entered into the second block to hold the confounding variables constant. The second hypothesis, that level of perceived stigma would

predict engagement, was tested with correlation using the Pearson's Product-Moment correlation coefficient r.

Statistical power considerations

The current study was predominantly explorative as there is no known previous research upon which to base an accurate prediction of effect size. Based on projected recruitment (N=58), it was expected that it would be possible to enter up to five predictor variables into the final regression equation. It is acknowledged that this would only enable the detection of large effect sizes, however, it was anticipated that this would be sufficient for an exploratory study.

Results

Participant characteristics

The study sample comprised 58 clients. Thirty eight were male (66 %) and 20 were female (34%). Participants ranged in age from 19 to 36 years (M = 26, SD = 4.5). Twenty two (38%) participants were white British, 36 (62%) were from black and other ethnic minorities. Table 1 provides a breakdown of participants' ethnic background. Participants' length of education ranged from 5 to 24 years (M = 12.9, SD = 3.38). Twenty five (43%) lived alone, eight (14%) lived with their children, five (9%) with their partners, twelve (20%) with their parents and eight (14%) shared their accommodation with others (including sheltered accommodation). At the time of the interview all the participants had been with the Early Intervention Service between 11 and 35 months (M = 20.6, SD = 6.68). At the time of the interview 50

(86%) participants were living in the community and eight were hospitalised (two

under section).

Table 1. Participants' ethnic background

Ethnic background	n (total = 58)
White British	22
White Irish	1
White other	7
Mixed white/black African	1
Mixed other	1
Asian Bangladeshi	4
Asian other	1
Black or Black British Caribbean	4
Black or Black British African	8
Other Black groups (inc 'Black British')	6
Chinese	1
Other ethnic groups	2

Measures

Descriptive statistics

Descriptive statistics for all measures are shown in Table 2.

Table 2. Descriptives for all the measures

Measure	Range of scores	Mean	SD
IPQS -time line acute/chronic	7 – 28	16.17	5.06
IPQS- time line Cyclical	8 – 18	14.02	2.66
IPQS- consequences	16 – 48	34.34	6.73
IPQS- personal control	7 – 20	14.90	2.76
IPQS- treatment control	13 – 25	19.00	2.62
IPQS- coherence	5 – 21	12.24	3.38
IPQS- emotional Representation	12 – 43	28.15	6.51
Perceived Devaluation Discrimination Scale	25 – 57	38.55	7.55
PANSS-general psychopathology	16 – 44	25.81	6.39
PANSS –positive symptoms	7 – 30	12.10	5.51
PANSS-negative symptoms	7 – 21	11.17	4.09
PANSS – Insight	1 – 6	2.38	1.45
SES – total	0 – 41	10.24	10.94
SES-Availability	0 – 9	1.93	2.56
SES-Collaboration	0 – 9	2.60	2.58
SES-Help seeking	0 – 12	3.19	3. 58
SES-Treatment adherence	0 – 12	2.52	3.51

Measures' reliability

IPQS

All measures were tested for internal reliability using Cronbach's alpha split scales reliability test. The alphas were in the acceptable range for 'timeline acute/chronic' (α = .85), 'time line cyclical' (α = .72), 'consequences' (α = .74), 'personal control-helplessness' (α = .61), 'treatment control' (α = .74), 'coherence' (α = .69) and 'emotional representation' (α = .82). 'Personal control-blame' had low internal consistency (α = .48) and therefore was excluded from further analysis.

Service Engagement Scale (SES)

Cronbach's alphas were also calculated for the SES subscales. All subscales showed high internal consistency: 'availability' (α = .89), 'help seeking' (α = .92), 'collaboration' (α = .86), 'treatment adherence' (α = .92). The internal consistency for total scale was (α = .90)

The Perceived Discrimination-Devaluation Scale (PDDS) also showed good internal consistency (α = .84).

IPQ-S - associations among illness perceptions

The associations between illness perceptions were examined by univariate correlations and the results are presented in Table 3. Participants who viewed their condition as more chronic tended to perceive greater negative consequences, less personal control over their mental health problems and had higher emotional response. Greater perceived consequences were associated with less coherence. The perception of having greater personal control over mental health problems was

associated with the belief in treatment control but also with more coherent understanding of mental health problems.

The distribution of predictors

Although assumptions regarding the normality and linearity of the predictor variables' distributions are not required for logistic regression, multivariate normality and linearity of the predictors may enhance power (Field, 2005). Therefore, all independent variables were screened for normality.

The distribution for independent variables were non-significant for both skewness and kurtosis for the IPQS factors - 'time line acute/chronic', 'consequences', 'personal control-helplessness', 'personal control-blame', 'coherence' and 'emotional representation' as well as perceived stigma. IPQS – 'treatment control' was significantly negatively skewed (skewness = -1.047, z = 3.46, p < .05) and leptokurtotic (kurtosis = 2.098, z = 3.42, p < .05) and IPQS-'timeline cyclical' was significantly negatively skewed (skewness = -1.035, z = -3.24, p < .05). Three outliers were identified based on the distribution of these variables and were subsequently removed. Deletion of outliers improved the distribution of IPQS-'treatment control', which then approached normality. IPQS- 'time line cyclical' remained significantly skewed and therefore a square root transformation was applied.

Table 3. Inter-correlations between illness perceptions

Illness Perceptions	Timeline acute/chronic	Timeline cyclical	Consequences	Personal control	Treatment control	Coherence	Emotional representation
Timeline acute/chronic	_	.27*	.51**	- .30*	.01	.24	.43**
Timeline Cyclical		_	. 42**	.18	-.01	.13	.33*
Consequences			_	-.17	-.06	.28*	.63**
Personal control				_	.41**	-.35**	-.11
Treatment control					_	-.46**	-.05
Coherence						_	.40**
Emotional Representation							_

* Correlation is significant at the 0.05 level (2-tailed).
** Correlation is significant at the 0.01 level (2-tailed).

Engagement and demographic characteristics

T-test and chi-squared statistics were applied to compare the two engagement groups on socio-demographic factors. The results are summarised in Table 4. There were no significant differences with respect to age, gender, ethnicity (white British versus combined minorities) and education. The two groups differed significantly only on the length of time with the service, with those being longer in the service showing 'poor engagement'. Thus the length of time with the service variable was entered into further analysis.

Table 4. Demographics of the engagement groups

Confounding Variables	well engaged N=30 Mean (SD)	poorly engaged N=28 Mean (SD)	t-test (df)	Chi-squared (df = 1)
Age	26.63 (4.48)	25.68 (4.56)	0.80 (56)	
Education	13.32 (3.25)	12.37 (3.50)	1.04 (53)	
Time with service –months	18.86 (6.00)	22. 47(6.95)	-2.12 (56)*	
Gender				.837
Ethnicity				1.147

* p<.05

Engagement and clinical factors

The two engagement groups were also compared on negative and positive symptoms, general psychopathology and level of insight. There were no statistically significant differences between the two groups on any of the clinical characteristics (see Table 5).

Table 5. Clinical characteristics of the engagement groups

Confounding Variables	well engaged N=30 Mean (SD)	poorly engaged N=28 Mean (SD)	t-test df (56)	p
Positive sympt	11.83(6.09)	12.39(4.92)	-0.38	.70
Negative sympt	10.33(3.12)	12.07(4.81)	-1.64	.11
Insight	2.07(1.34)	2.71(1.51)	-1.73	.09

Engagement and illness perceptions

The first hypothesis, that illness perceptions would predict engagement, was tested by examining univariate associations followed by the regression analysis. The Pearson Product-Moment correlations were performed to assess the relationship between the illness perceptions and engagement. Only the 'time-line acute chronic' variable showed a statistically significant association with engagement ($r = .288$, $p = .028$). However, the decision was made to retain all the illness perception variables in the regression analysis to determine if they could jointly make significant contributions to the prediction of engagement.

The length of time with the service was entered into the first block to ensure that it was controlled for, and the illness perceptions were entered into the second block. The initial analysis (with all the illness perceptions entered into the second block) showed that three variables: 'timeline acute-chronic', 'consequences' and personal control – helplessness' contributed significantly to the model ability to predict engagement. The analysis was then run again with the exclusion of the illness perceptions that were statistically redundant in the previous stage. The regression model was significant and the length of time with the service alone was able to

account for 9.8 % of the variance in level of engagement ($R^2 = .098$, $\chi^2 = 4.41$ (1), p = .036). With the addition of the illness perceptions this increased significantly to 36.5 % ($R^2 = .365$, χ^2 (4) = 18.53, p = .001). Diagnostic statistics were examined to check for collinearity and variance inflation factors. All of them were satisfactory. Table 6 shows the individual contributions of each predictor. 'Time line-acute/chronic' made the largest independent contribution in predicting engagement followed by 'consequences' and 'control-helplessness'. Interestingly, the length of time with the service that emerged as a significant predictor in the earlier analysis, did not emerge as a significant predictor in the final step. This reflects a decline in the relative proportion of the variance explained by the length of time with the service when the illness perception variables are also present.

Table 6. Summary of logistic regression analysis for predictors of engagement

Variables	Standardised Coefficient (β)	S.E. of standardised Coefficient	Wald χ^2 (df = 1)	Sig.	Exp (β)
Months in the service	.059	.050	1.399	.237	1.06
Timeline Acute/chronic	-.311	.108	8.295	.004	.732
Consequences	.143	.059	5.837	.016	1.15
Personal control	-.289	.145	3.989	.046	.749

Specific components of engagement and illness perceptions

The predictors of the four subscales of engagement (SES – availability, SES-collaboration, SES- help seeking and SES- treatment adherence) were analysed separately to determine if they were different predictors of different components of

engagement. All the engagement variables due to significant departures from normality (similarly to engagement SES total score) were split into two groups at a median level (availability Md = 0, collaboration Md = 2, help seeking Md = 2, treatment adherence Md = 1). The analyses were run in the same manner as the analysis of the predictors of overall engagement. First, the two groups of each of the engagement components were compared on demographic and clinical factors. Subsequently, a series of stepwise logistic regressions were performed to explore whether, and to what extent, the illness perceptions would predict the engagement components. For each, the significant confounding demographic and clinical variables were entered into the first block and all the illness perceptions were entered into the second block. Then the analyses were repeated including only the significant predictors in the second block to examine their individual contributions to each of the engagement components and thereby produce the best possible model.

Availability

The two groups of 'availability' were compared on demographics and clinical factors. The groups differed only on the number of years of education with those with better education displaying higher levels of availability (t = 2.61, df = 53, p = .012). There were no other significant differences between the groups on other demographics or clinical characteristics.

The education level was entered into the first block to ensure that it was controlled for and the illness perceptions were entered into the second block. The education level alone was able to account for 14.8 % of the variance in level of engagement (R^2 = .148, χ^2 = 6.13, p = .013). However, when the illness perceptions were entered into the second block the overall model became non-significant.

Collaboration

The groups differed significantly on education level with the 'good collaboration' group having a higher level of education (t = 2.17, df = 53, p = 035). There were no significant differences with respect to age, gender, ethnicity and the time with the service.

The two groups of collaboration differed on negative PANSS symptomatology, with the 'poor collaboration' group showing higher levels of negative symptoms (t = - 2.90, df = 56, p = .035). The two groups also differed significantly on the level of insight, with the 'poor collaboration' group showing less insight (t = -2.84, df = 56, p = .006). There were no significant differences between the two groups on positive symptomatology or general psychopathology.

The significant confounding predictors: education level, negative symptomatology and insight were entered into the first block to ensure that they were controlled for, and the illness perceptions were entered into the second block. The initial regression analysis was significant and the confounding variables could account for 25. 2 % of the variance (R^2 = .252, χ^2 = 11.49 (1), p = .009). However, with the inclusion of illness perceptions, the model became non-significant and none of the illness perceptions showed independent contributions in predicting engagement. Moreover the confounding variables that were significant predictors in the earlier analysis did not emerge as significant when the illness perceptions were added.

Help seeking

The two 'help seeking' groups differed on the length of time with the service, with the 'poor help seeking' group being with the service longer (t = - 4.27, df = 56,

p < .001). There were no other differences on demographic or clinical factors between the two 'help seeking' groups.

The length of time with the service was entered to the first block and the illness perceptions were entered into the second block. Then the analysis was repeated including only the significant predictors in the second block. The regression model was significant and the length of time with the service alone was able to account for 31.2 % of the variance in level of engagement (R^2 = .312, χ^2 = 15.39 (1), p = < .001). With the addition of illness perceptions this increased to 42.3 % (R^2= . 423, χ^2 (4) = 22.04, p <.001-model). Table 7 shows the individual contributions of each predictor. The length of the time with the service made the largest contribution, followed by emotional reaction. Consequences, approached, but did not meet statistical significance (worse consequences – poor engagement).

Table 7. Summary of logistic regression analysis for predictors of help seeking

Variables	Standardised Coefficient (β)	S.E. of standardised coefficient	Wald χ^2 (df =1)	Sig.	Exp (β)
Months in the service	.149	.055	7.302	.007	1.161
Consequences	.145	.080	3.253	.071	1.156
Emot reaction	-.192	.084	5.177	.023	.825

Treatment adherence

The two groups of treatment adherence differed on the length of time with the service, with the 'poor treatment adherence' group being in the service longer (t = - 2.28, df = 56, p = .026). The two groups also differed significantly on insight, with the 'poor adherence' group showing less insight (t = - 3.30, df = 56, p = .002).

The length of time with the service and insight were therefore entered into the first block and the illness perceptions were entered into the second block. Then the analysis was repeated including only the significant predictors in the second block. Time with the service and insight could account for 27.6 % of the variance in treatment adherence. With the addition of the illness perceptions, this increased to 49.6 % (R^2 = .496, χ^2 = 13.48 (1), p = .004). Time line-acute/chronic, consequences and control-helplessness made independent contributions. Insight still showed an independent contribution. However, the time with the service, that had emerged as a significant predictor in the earlier analysis, did not emerge as significant in the second step of the analysis because its effect was explained more powerfully by the illness perceptions and insight. The effects are shown in Table 8.

Table 8. Summary of logistic regression analysis for predictors of treatment adherence

Variables	Standardised coefficient (β)	S.E. of standardised coefficient	Wald χ^2 (df =1)	Sig.	Exp (β)
Months in the service	.051	.054	.921	.337	1.053
Insight	.639	.266	5.775	.016	1.894
Timeline Acute/chronic	-.386	.135	8.184	.004	.680
Consequences	.149	.066	5.092	.024	1.161
Personal control	-.359	.171	4.419	.036	.698

Engagement and perceived stigma

To test the second hypothesis, that perceived stigma would predict engagement, the Pearson Product-Moment correlation was used. There was no significant correlation

between perceived stigma and engagement (r = - 0.30, p = .825). Nor were there any significant associations between stigma and any of the four components of engagement.

Other relationships of stigma

Stigma showed significant univariate associations with some illness perceptions sub-scales. There was a positive significant correlation between level of stigma and perceived consequences (r = .336, p = .01) and emotional reaction (r = .413 , p = .001).

Discussion

Illness perceptions and engagement

This study aimed to explore the relationship between illness perceptions, perceived stigma and engagement in individuals who have recently experienced a first episode of psychosis. The first hypothesis, that illness perceptions would predict engagement, was partly confirmed. A more chronic perception of mental health problems, less perceived consequences and more perceived personal control emerged as independent predictors of clients' engagement with the early intervention service for psychosis. In combination these illness perceptions accounted for the significant amount of variation in clients' engagement with mental health services. This is broadly consistent with the physical illness literature where illness perceptions were demonstrated to account for significant variation in clients' treatment adherence (Jessop & Rutter, 2003; Petrie et al., 1996) and further adds to a growing evidence (Lobban et al., 2004) that illness perceptions in psychosis may be as important as in physical illness.

The present findings offer important clinical implications. Physical health literature indicates that patients' illness perceptions can be easily accessed and modified by cognitive behavioural interventions (Petrie, Cameron, Ellis, Buick & Weinman, 2002). It is therefore possible that effective methods could also be developed to modify illness beliefs in psychosis, although this is, admittedly, a very different illness domain. The present findings offer the possibility that reducing clients' perception of more severe consequences and enhancing their control of treatment could improve their engagement with the services and therefore increase their chances for benefiting from treatment. However, a cross-sectional design of the present study cannot confirm causation. It is possible that clients' perception of less negative consequences of their mental health problems and higher control over them developed as a result of good engagement with the service. Therefore, future longitudinal studies would need to verify the relationship found.

Interestingly, the results indicate that patients' perception of the more chronic timeline of illness is associated with better engagement. This finding, broadly consistent with previous results (Clifford, 1998, unpublished, as cited in Lobban et al., 2003), does not offer straightforward implications for the clinical practice. In the context of the current view on psychosis as not necessarily a life-long condition (e.g. Marengo, 1994), the usefulness of changing clients' perception about the length of their illness to more chronic in order to increase their engagement appears questionable. It would perhaps be worth exploring in further qualitative studies how these illness perceptions may relate to engagement in patients with psychosis.

As asserted by the SRM framework, illness perceptions were associated with each other so clients who perceived their mental health problems as more chronic have also tended to see greater negative consequences and less personal control.

However, interestingly, different pattern of associations emerged in the regression analysis where perception of a more chronic course of illness, but less negative consequences and more personal control, appeared to predict engagement. While caution is needed with the interpretation of findings that emerged by post hoc analysis, it could be that only clients who see their illness as more chronic but perceive less consequences and more personal control over their mental health problems may be more likely to engage in treatment.

Engagement as a multidimensional phenomenon

When different aspects of engagement were considered separately, some different patterns of predictors emerged as significant for each of the different aspects. This confirms the arguments in the literature that engagement is not a unitary phenomenon and therefore needs to be examined as a multifaceted one in order to increase our understanding of clients' engagement with mental health services (Hall et al., 2001; Tait et al., 2002).

Only 'treatment adherence' showed the same pattern of predictors as the overall score of engagement. Perceived chronic course of mental health problems, perceived less negative consequences and greater personal control over mental health problems were able to account for significant variation in treatment adherence as rated by the mental health professionals, suggesting that the 'treatment adherence' component may have accounted for a large part of the observed variation in the overall engagement score.

These results are consistent with preliminary studies that examined the relationship between the illness perceptions and medication adherence of people with mental health problems. Perceived longer duration of illness and perception of less

negative consequences of illness were found to predict medication adherence in patients with psychosis (Clifford, 1998, unpublished; cited in Lobban et al., 2003). It is noteworthy that Clifford (1998) used the original version of the IPQ that did not differentiate 'acute/chronic' and 'cyclical' perceptions on a course of illness that has been accounted for in a revised version of the IPQ. The present study suggests that only more chronic, but not cyclical, perception of mental health problems may be associated with engagement and, in particular, treatment adherence. The relationship between perception of less severe negative consequences of mental health problems and better treatment medication adherence is also consistent with a trend found by Watson et al. (2005).

Different effects emerged for the 'help seeking' component of engagement. Emotional representation showed significant effects on help seeking behaviours, with clients who had a stronger emotional reaction tending to seek help more. However, illness perceptions were not able to predict the other two components of engagement: 'availability' or 'collaboration'. This lack of observed associations could be due to illness perceptions not having any effect on clients' availability or collaboration, or alternatively, result from the insufficient power of the present study. Therefore further studies would be needed to verify the currently observed lack of relationship between illness perceptions and availability and collaboration.

Clinical and demographic factors' role in predicting engagement

Neither insight nor symptomatology were related to the overall scores of clients' engagement in the present study. This is consistent with recent findings (Tait et al., 2003) and provides further evidence that clinical factors may be less important in

predicting clients' engagement with mental health services than psychological factors.

However, insight was related to medication adherence and collaboration aspects of engagement. This finding is consistent with some previous studies demonstrating the negative association of insight and medication adherence (e.g. Watson et al., 2006). This negative relationship between insight and clients' medication adherence and collaboration, but not other aspects of engagement, indicates that clients who lack insight may not want to take medication but may still be willing to engage with other aspects of their care. Alternatively, the current finding could reflect some limitations of the measure of insight that has been employed by this study. The insight score on the PANSS interview, as used in the current study, is determined by the clinician taking into account the clients' expressed willingness to adhere to medication, similar to the rating of the medication adherence aspect on the engagement measure. Therefore there is some overlap of both insight and medication adherence measures that may be reflected in the association found. This could explain why the current finding is inconsistent with several studies that have not demonstrated a relationship between insight and medication adherence (e.g. Tait et al., 2003). Therefore, the use of another insight measure would be necessary to draw firm conclusions about the current relationship between insight and medication adherence.

Negative symptomatology showed a significant negative association with collaboration but not with other aspects or the overall engagement score. The 'collaboration' score reflects the clients' active participation in treatment goals setting and managing their illness. It is possible that impaired energy levels and

motivation, related to negative stymptomatology, had a detrimental effect on clients' active collaboration in their treatment planning.

The majority of the demographic factors including age, gender, ethnicity and educational level, failed to show a relationship with the overall scores of engagement. Only the length of time with the service showed a significant association. Surprisingly, clients who were with the service longer were less engaged. This is inconsistent with previous studies that have repeatedly reported the opposite; clients being in the mental health services longer showing better treatment adherence (Mowbray, Cohen & Bybee, 1993; Nosé et al., 2003). The current finding could reflect developments at the local service level. The early intervention service had been established for just three years when data collection started. It is therefore possible that developments within the service enabled the clinical staff to engage clients referred to the service more recently better than those referred at the time when the service had just been established. However, importantly, the length of time with the service was no longer significant in the model when illness perceptions were included, suggesting that these illness perceptions were able to predict clients engagement better.

Interestingly, when the engagement components were considered separately, different demographic and clinical factors emerged as significant. The increased length of time with the service appeared to have a negative effect on clients 'help seeking' behaviours and 'medication adherence' but showed no association with 'collaboration' or 'availability'. One possible explanation for this is that further into treatment clients developed skills allowing them to resolve any problematic issues themselves, in contrast to those who were in the service for a shorter length of time and were less able or willing to cope themselves. The association between longer

time with the service and less adherence to medication could mean that individuals may perceive less need for medication as the time from their psychotic episode increases. A recent qualitative study demonstrated that with an increased sense of well-being achieved in the recovery process, some patients developed beliefs in their own ability to cope without medication. This and their desire to be as normal as possible resulted in their withdrawal from treatment in an attempt to try 'carrying on as before' (Priebe, Watts, Chase & Matanov, 2005). However, the present study employed a mixed sample comprised of clients who had experienced only one psychotic episode as well as those who had experienced numerous relapses, and therefore the time of relative 'well-being' was not controlled for. Therefore, further research that would examine the length of time from most recent relapse, rather than the length of time with the service, may be needed to verify this hypothesis.

Finally, the last factor that showed a significant relationship with some components of engagement was level of education. Clients who had more years of education tended to be more available and more collaborative but did not differ on other aspects of engagement. One possible interpretation of this finding could be that, perhaps, the higher level of social and intellectual skills possibly held by those with better education, would allow them more active participation and collaboration in goal planning and setting, on an intellectual level.

Stigma and engagement

The second hypothesis, that perception of stigma would predict engagement, was not confirmed by this study. Contrary to expectations, the level of perceived stigma amongst the current sample was not related to their engagement with the early intervention service.

There are a number of factors that could account for this lack of association between individuals' perceived stigma about mental health and their engagement with the early intervention service. Link et al. (1989) proposed that once an individual enters psychiatric treatment, their beliefs that most people would devalue and discriminate against patients with mental health problems, would be transformed into an expectation of rejection. However, it is possible that individuals' positive experiences with services may help them to disconfirm these expectations. The provision of a non-stigmatising and culturally sensitive service is one of the priorities of the early intervention service, as specified by the guidelines of the National Service Framework for Mental Health (Department of Health, 1999). It is therefore possible that the current finding reflects a success of the service in tackling stigma issues, in their mental health care delivery. However, as the participants in the study had already been in the service for at least a year, this possibility could not be confirmed. Therefore, a future longitudinal study that would measure clients' perceived stigma at the time of service entry as well as later into treatment would be needed to verify the possible success of the service in tackling issues of stigma.

Another related explanation is that perhaps contact with other service users had de-stigmatising effects on some clients. Billings et al. (2006) in their qualitative study found that most participants reported that their contact with mental health services had changed their views about other people with mental health problems. Some clients reported that they were surprised to discover that other people with mental health problems, that they came across, were, contrary to their expectations, "quite normal, ordinary people who needed health services in order to be ok".

Sirey et al., (2001) found that high perceived stigma at the start of treatment was associated with disengagement from psychiatric outpatient care in people with

major depression. However, while younger patients perceived higher levels of stigma in comparison with older patients, paradoxically only the older, but not the younger, group of patients discontinued their treatment. Sirey et al. (2001) suggested that clients with depression may engage in cost-benefit analysis in relation to participation with offered treatment and if the perceived benefits of engagement are greater than the costs, they may be willing to engage. It is possible that some young individuals with psychosis, represented in the current sample, despite perceived stigma, were still willing to engage with the early intervention service, as they perceived greater personal benefits from engagement, such as help with independent living, including housing or educational and vocational prospects.

Recent work by Corrigan and Watson (2002) highlights some other complexities that may be relevant to the relationship between clients' perceived stigma and their willingness to engage with mental health services. Corrigan and Watson (2002) demonstrated that not all individuals with mental health problems who perceive stigma will internalize it. People with mental health problems adopt three different types of reaction to stigma. The first group of people will internalize the stigmatizing ideas endorsed by the society, they live in, and will believe that they are less valued because of their mental illness. In contrast, the second group will oppose the negative evaluations resulting from stigma and will react with anger and, if empowered, may even actively fight against the stigmatising ideas. The third group of people will show relative indifference in relation to stigma. Currently, it is unclear why some clients will internalise stigma and others will not and more studies are needed to clarify this (Corrigan, 2004). It is plausible that only individuals who internalize stigma may be unwilling to engage with services. However, the measure used in the present study could only assess individuals' perceptions of the stigma in

the general public and therefore was not able to discriminate between those who internalized stigma and those who did not. Therefore, future studies that examine clients' levels of internalized stigma rather then their perception of stigma may be able to better capture the relationship between stigma and engagement with mental health services.

Stigma and illness perceptions

The SRM asserts that individuals' beliefs about their health problems need to be understood in the social and cultural context in which they occur (Leventhal et al, 1984). As the pervasiveness of stigma around mental health problems endorsed in our society is well established (Angermeyer & Dietrich, 2005), stigma may have a particular role in shaping patients' beliefs about their mental health problems. However, as acknowledged in the literature, the role of stigma in the development and expression of illness perceptions has not yet been addressed in research (e.g. Lobban et al., 2004). The use of both stigma and illness perceptions measures allowed the possibility of exploring how illness perceptions were related to perceived stigma in people with early psychosis. The higher levels of perceived consequences and stronger emotional reaction demonstrated a significant positive association with perceived stigma. This confirms the assertion that perception of stigma may play an important role in shaping patients' beliefs and suggests that, in particular, higher levels of perceived stigma may result in greater perceived consequences of their mental health problems and an increase in emotional reaction. This, again, may have important implications for clinical practice. Since perceived negative consequences have been demonstrated to result in greater depression in people with schizophrenia (Iqbal, Birchwood, Chadwick & Trower, 2000; Watson et al., 2006), it is therefore

possible that reducing individuals' levels of stigma and/or empowering them to effectively cope with it, may reduce the perceived high consequences of individuals' mental health problems and increase their emotional well being. Furthermore, since higher perceived consequences appear to predict worse engagement with services, it may be possible that stigma impacts on engagement indirectly, which also provides indicators for clinical practice. However, again, post hoc analysis and repetitive testing could mean that the association found reflected a 'type I' error. Therefore, further studies would be needed to verify the relationship between perceived stigma and illness perceptions.

Limitations

There are several further limitations in the current study which need to be considered with regard to the final conclusions. Firstly, the relatively small sample size available for analysis limited the statistical power of the study and hence increased the chances of committing 'type II error', which incorrectly accepts lack of associations when they actually exist. Therefore, the current lack of association between emotional representation and illness coherence would need to be verified by future studies employing larger samples.

Secondly, not all the illness perceptions were explored in this study. Some potentially important dimensions of beliefs of the Self-Regulatory Model, such as 'identity' and 'cause', were omitted due to limited time resources. It is plausible that these beliefs are able to predict clients' engagement and it would be useful to clarity this in further studies.

Thirdly, despite extensive efforts to recruit clients who were disengaged from the service, the majority of the sample comprised clients who were to some degree

engaged. Therefore, similar to previous research on engagement or treatment adherence, the present study bears an engagement bias that limits the extent of the external validity of the present findings.

Fourthly, the current study has some methodological limitations that may have influenced the observed effects. Engagement is not an 'all-or-nothing' phenomenon and preferably should be considered as a continuous variable. However, the distribution of scores on the engagement measure in the present study showed a significant departure from normality. Therefore, the clients in the current study needed to be dichotomised into 'well' and 'poorly' engaged groups. Such dichotomisation of their engagement is to some extent artificial. The lack of a testable model and relatively low statistical power meant recourse to stepwise regression rather than systematic model building and testing. Replication is of course highly desirable in this context.

It is also important to consider that the present study has only examined patients' engagement from the professionals' perspective. Such an approach has been rightly criticised in the literature, for an assumption that withdrawal from the services is the fault of the clients (Tait et al., 2002). However, it is possible that clients may have valid reasons for not wanting to engage with services. Therefore, exploring participants' views on their non-engagement would further enhance our understanding of the mechanisms underlying it.

Finally, another aspect that may be pertinent to the final interpretation of the current findings relates to the ethnical diversity of the sample it employed. Under-representation of individuals from ethnic minorities is a common problem limiting the external validity of many studies. However, the majority of the sample employed in the present study came from ethnic minority backgrounds. Although this could be

viewed as a success, in the context of common problems faced by research in recruiting diverse samples, this could also limit the generalizability of the current findings. Although ethnicity has not confounded any of the associations measured, it is possible that current findings could reflect some cultural differences in illness perceptions and perceived stigma.

Conclusions

This study, in line with Sainsbury Centre Mental Health (1998) recommendations, represents an important attempt at empirical investigation of engagement with mental health services to further enhance our understanding of its underlying mechanisms. The study was innovative in the way that illness perceptions have not been previously examined in relation to engagement. As predicted, some illness perceptions were able to account for a significant amount of the variation in clients' engagement with the early intervention service. Moreover, they were able to predict clients' engagement better than demographic or clinical factors. Bearing the above limitations in mind, it can be concluded that illness perceptions appear to be important predictors of clients' engagement with mental health services. Since beliefs about illness are amenable to change, the present findings provide some indications for future research and possible developments in CBT interventions for psychosis.

Perceived stigma was not associated with clients' level of engagement in the current study. However, perceived stigma had a higher association with perceived consequences, which suggests that stigma can indirectly influence clients' engagement with services. It is also plausible that perceived stigma may have a negative impact on only those clients who will internalize it. Therefore, the

examination of the extent to which clients will internalize stigma around mental health problems, rather than their levels of perception of stigma, may be more useful to capture and explain the association between stigma and engagement.

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Part 3: Critical Appraisal

Introduction

In this paper, I am going to provide a brief background to my research project, including my reasons for choosing the area of first episode psychosis. This will be followed by reflections on some dilemmas and challenges that arose in the process of carrying out this study, many of which are likely to be faced by psychologists carrying out research in clinical practice. Finally, I will discuss some of the methodological issues pertinent to my study and consider how they may have impacted on current findings. Where possible, I will make some suggestions as to how they could be addressed by future research in this area.

Choice of the area of study

The area of early psychosis has been particularly appealing to me in terms of an opportunity for making significant change in people's lives when intervening early on. Having previously worked as an assistant psychologist in inpatient-settings, where a predominantly medical model was applied, I often felt very helpless looking at some young people diagnosed with schizophrenia and the pessimistic prognosis This is why, some years later, I welcomed with great excitement the new developments in psychological models of psychosis and the promising findings on the efficacy of some psychological interventions. I also welcomed with optimism the concept of a 'critical period' (Birchwood, Todd & Jackson, 1998), as it suggests that a diagnosis of psychosis no longer inevitably means life-long disability. The growing evidence shows that when intensive interventions, both medical and psychosocial, are introduced early, the prospects of recovery for many people with psychosis are much improved. I therefore sought a possibility to carry out a research project in the

area of early psychosis alongside a clinical placement in an early intervention service.

In my research, it was very important to me to examine a question that would be relevant to clinical practice and would hopefully result in some useful pragmatic implications. This is why I welcomed the ideas of my field supervisor to explore issues relevant to engagement. Problems with engaging clients are encountered by many clinicians who work with people with psychosis in the community but, surprisingly, are still poorly understood. I have experienced the extent of this problem myself in my clinical practice. I began my placement in early intervention with a great deal of excitement about the prospects of delivering psychological interventions, but instead spent the initial months trying to engage clients and better understand their reluctance to engage with the service. This has strengthened my beliefs about the right choice of a research question.

Why illness perceptions?

As I discussed in the literature review, research on engagement in psychosis has predominantly explored patients' demographics and clinical factors. Learning about these is certainly important but does not answer the question, pertinent to everyday practice, about what a clinician can do to improve engagement. Since perceptions of illness are potentially amenable to change, exploring this concept seemed relevant and appealing. Although there is some controversy surrounding the validity of applying the concept of illness beliefs in psychosis, it is noteworthy that similar scepticism was present a few decades ago in relation to the very application of psychological theory to explain the symptoms of schizophrenia, yet this approach now has a good evidence-base. Similarly, as individuals' interpretation of internal

and external experiences influence the development and maintenance of their symptoms, it is also plausible that other beliefs such as perceived control over treatment or perceived personal consequences, will contribute to clients' behaviours including engagement in treatment. Similarly stigma, so widely endorsed in our society, appears particularly relevant to engagement. However, as I was surprised to discover, there is a lack of quantitative investigations that explore how perceived stigma may impact on people's engagement with their mental health services.

Research in clinical psychology – a scientist-practitioner model

Adopting a scientist-practitioner model in clinical psychology is something that I particularly value and has influenced my decision to pursue my career in clinical psychology. This model of work entails not only everyday clinical practice that is informed by evidence and applying scientific principles in this practice but also contributing to the evidence base through conducting research. The opportunity for my personal contribution to evidence-based practice seemed very worthwhile and potentially very rewarding. However, as I have learnt by carrying out this research, it also engenders many dilemmas and challenges that a clinical psychologist needs to resolve. In the following part of this paper, I will reflect on some of the challenges I encountered when carrying out the present study, as they may be relevant to all who conduct research in clinical settings. Whilst some of them raise questions to which there are no clear-cut answers, others could be resolved by careful consideration and planning before undertaking research activity.

Involvement of staff in the recruitment and data collection

As is often the case when conducting research with a vulnerable population, contacting participants directly was considered too intrusive. Research participants were therefore approached initially via their care co-ordinators. This meant that it was necessary to engage the whole clinical team in the research process. In order to facilitate this, my colleague and I attended the team meeting prior to data collection to introduce ourselves and present our study rationales, hoping that this would secure the co-operation of care co-ordinators' to play an active role in recruitment. However, whilst many members of the team were very helpful, some presented a significant challenge to the recruitment process. For example, some care co-ordinators initially agreed that they would ask their clients about participation in the study and would let me know the outcome but then, I often found myself waiting in vain for their response. I quickly realised that I needed to be far more proactive and specific. I tried to establish when exactly the care co-ordinators were going to see their clients and to arrange specific times when and how I could contact them to find out the outcome. I also found it helpful to check the booking diary to see when the clients were being seen by their care co-ordinators and I tried to be there at these times to prompt the worker. Moreover, I learnt that at times staff hesitated to ask their clients as they were faced with some dilemmas, as to whether their clients were well enough to take part. Some staff also expressed concerns about their clients getting paid for taking part in the research study and the possibility that they would spend this money on drugs or alcohol. All these issues presented a considerable obstacle to the recruitment process. It was therefore important for me to build a good working relationship with the staff, so that they felt comfortable addressing their

concerns with me and I could assist them with making the best decision as to whether, and when, to recruit a client.

My research also involved the care coordinator of each participant completing a brief engagement questionnaire about their client. Again, at the planning stage, I had not anticipated many difficulties with obtaining this measure from the clinical staff as it was estimated that it would take only about five minutes to complete. However, again, whilst obtaining this measure from the majority of the staff was unproblematic, in some cases this proved extremely difficult. Moreover, surprisingly, some staff despite being very helpful with the recruitment process seemed far less willing to complete this brief scale. Some needed several phone-calls, emails, and my repeated visits to the service to actually complete it. Towards the end of my data collection one of the members of the staff commented that she was not keen on this questionnaire, as she felt as if she was being examined on her performance. I realized that the reluctance of some staff to complete this measure may not have resulted from lack of time or enthusiasm but from worrying that their performance in engaging clients would be judged. On reflection, I should have been more transparent about the purpose of this questionnaire and made it more explicit to all the team at the very beginning that their performance would not be examined.

It is worth commenting on the fact that the team I was conducting my research in, was also set up as part of larger randomised control trial, comparing stand alone and augmented CMHT models of early intervention service provision. Early intervention services are also required by the department of health to complete a lengthy battery of clinical outcome measures every six months. Therefore, the team was already engaged in many research activities, in addition to demanding day-to-day clinical work with a challenging client group. This highlighted for me the

competing priorities that clinical staff have to deal with in their everyday practice and the challenges that researchers coming into a team must face in order to work with gatekeepers to clients and data.

In conclusion, this has been an important lesson for me in conducting future research in terms of preparing for the challenge of collecting data from clinicians and investing considerable time in engaging members of staff in the research. I expect that in many NHS settings where staff are very busy with clinical activities they will not share the same motivation and enthusiasm with a researcher. Therefore, it may be crucial to involve staff in research planning and to spend sufficient time with them exploring possible implications for clinical practice, as this might increase their enthusiasm for research and their willingness to help.

Ethical dilemmas

Carrying out research with patients diagnosed with psychosis, as with any vulnerable population, poses many unresolved ethical dilemmas (for a review see e.g. Dunn, Candilis & Roberts, 2006). Although many of these issues concern studies posing risks to patients, such as medical or psychological intervention studies, some were also relevant to the present study despite risk being perceived as relatively low. One important issue pertinent to this study is related to the ability of psychotic patients to provide informed consent. I attempted to include as broad a population as possible in order to access the range of engagement and thereby increase the external validity of the study. However, despite the participants being judged as able to give informed consent to the interview by their care co-ordinators, some were clearly experiencing symptoms of psychosis and some were still in-patients at the time of the interview. This raised some ethical dilemmas regarding the extent to which these clients were

able to provide meaningful informed consent in the face of experiencing current symptoms? For some, their symptoms may have led them to perceive pressure to participate in the project, which to some extent is equal to a degree of coercion into research. Such issues present a dilemma as to whether to recruit symptomatic clients and risk imposing coercion or to exclude such clients but, in so doing, reduce the scientific validity of the research and consequently limit our opportunities for further understanding of psychosis?

Another ethical dilemma, I encountered in this study, was related to the financial incentives used to recruit research participants. As demonstrated by a series of semi-structured interviews conducted by Roberts, Warner and Brody (2000), many people with schizophrenia express altruistic attitudes pertaining to research, including seeking to help science, to help others with the illness and to help foster hope. However, it is reasonable to expect that many individuals, similarly to the 'normal population', would lack such altruistic motivation. It is therefore possible, that for some clients, the money paid for participation may have been a major, if not the exclusive, motivation for taking part. This, in turn, questions participants' efforts and willingness to give honest accounts, which is a problem, encountered in research with all human participants, and questions the validity of such studies. Moreover, as mentioned above, some of the care co-ordinators worried that their clients with substance misuse problems would spend the money earned in research on drugs or alcohol. Knowing that a patient has a drug dependency and is likely to use money earned in research to abuse drugs has, understandably, raised concerns with clinicians, who may feel uncomfortable in exposing their clients to such a situation. However, how ethical is it for clinicians to make an ultimate decision on their clients' behalf? There is also another valid concern, namely, how ethical would it be

not to pay participants for their efforts and time given? There is also an unresolved dilemma, particularly pertinent to this study, as to how to encourage participants who are not well engaged in the services to take part in such studies? How many participants would be willing, on purely altruistic grounds, to help services that they have not generally been interested in? How should we, therefore, ensure the validity of research if making a decision to include only a group of clients with highly altruistic attitudes? Whilst it is beyond the remit of this review to attempt to solve this dilemma, this has highlighted for me the importance of making these decisions transparent to the reader in order that consumers of the research can appraise how valid the findings of the study are, given the procedures undertaken.

Researcher versus clinician boundaries

The research interview in the current study entailed participants completing self report questionnaires for the most part, but it also included a clinical interview in order for the researcher to complete the Positive and Negative Symptom Scale (PANSS). Whilst many recruited clients were well recovered and reported enjoying taking part in the research study, a significant minority were clearly unwell and still symptomatic. Moreover, a few clients reported some distress they were experiencing in their lives at that time. At these times, I found it difficult not to act as a clinician and not to explore the difficulties they were experiencing further, with the aim of providing help. However, instead, I needed to restrict my role to that of a researcher. I have always tried to debrief clients and to remind them of my researcher's role. In some cases I tried to encourage clients to discuss with their clinicians certain issues they had disclosed to me.

A few clients commented that some interview questions 'made them think about certain issues'. While for some this was a positive experience, a couple of clients appeared to be distressed. In these situations I felt that the ethical obligation of my researcher's role required me to check if they felt able to carry on and to remind them about their rights to withdraw from the research at any point. This conflicted with my temptations to carry on, being aware of the time and energy I had already put into recruitment and the pressure, to attain a sufficient sample size for my study to obtain some meaningful results.

I also found it difficult to restrict myself to a researcher role when being asked by some clinicians to provide feedback on their clients' mental state. Whilst at times I felt tempted to discuss my own clinical observations and reflections with them, I needed to ensure that my feedback was general and fully respected participants' confidentiality.

Whilst I was only working in this Early Intervention Service in a research capacity, I anticipate that the issue of maintaining boundaries between clinical and research roles may be even greater when conducting research in a psychologist's own clinical work setting, both in relation to clients and professional colleagues. This is an interesting area of debate, perhaps beyond the remit of this review, if psychologists are to work as scientist practitioners, actively involved in the production of research in the services in which they are working clinically.

Other dilemmas

At the time of data collection, I was faced with some unexpected situations in which, on reflection, my clinical judgement, again, may have been compromised to some extent by the pressure to collect data from as many participants as possible. For

example, I had one participant who turned up for the appointment with his partner who also had been diagnosed with psychosis and who was clearly very symptomatic. The participant insisted that he wanted his partner to be present during the interview. While the partner kept laughing and interrupting, I was faced with the dilemma of whether to carry on with the research interview or not?

On another occasion, a participant attended her appointment with her young child. In response to my suggestion to re-arrange the interview time, the client decided that she wanted to take part on that day. I started the interview with both of them and felt comfortable when asking this client to fill out the questionnaires herself. However, when it came to the clinical interview, I realised that it was inappropriate to discuss personal issues related to participant's mental health in front of her young daughter. This was despite my clients' reassurance that she felt happy to do so. It was important for me to model to the client the inappropriateness of a child witnessing the 'adult-related content' of the discussion. In this particular situation it was possible to make a quick arrangement and leave the child in the waiting area under care of the receptionist and the client's care coordinator, who happened to be available at that time and knew the child. However, on reflection, I am aware that I should have rearranged this appointment at the beginning despite facing the risks of losing this client's participation in the research.

On reflection, recruiting participants can involve lots of time and energy on the researcher's behalf. This, together with a pressure to collect as much data as possible, may at times conflict with clinical priorities. Whilst it is tempting to prioritise data collection, especially in situations where there are no clear cut answers on how the researcher should behave, a researcher should always try to examine their motivation and choose more ethically appropriate option.

Team work

Although this research represents a substantial piece of my own work, it would have not have been possible without the involvement of many people. The most important role has been that of my supervisors. My clinical supervisor helped me with formulating research questions and with access to the clinical population of study; my academic supervisor helped me with some statistical dilemmas and provided helpful feedback on writing up. I realised how important supervision is, particularly for the inexperienced researcher, when my supervisor unexpectedly left for maternity leave. In this case, I was fortunate to have substantial support from an enthusiastic, relatively newly qualified, yet impressively knowledgeable and experienced clinical psychologist working in the service, who stepped into the supervisor's role. This reiterated for me the importance of receiving adequate, frequent guidance and supervision, on what could otherwise be a rather isolated endeavour.

In the current study, I have also shared data collection with a fellow trainee and with a research assistant. Sharing data collection enabled us to recruit a larger number of participants in a relatively short period of time. Moreover, by forming a small research team we were able to share our reflections on best recruitment strategies and were a source of mutual support while coping with recruitment challenges. We were able to provide our clients with very flexible times for the interviews. When there were concerns about the safety of a female researcher going to a participant's home, my male colleague was able to take over. On the other hand, as my colleague was on a clinical placement in the research setting, there were times when he felt that interviewing some clients would interfere with his clinical work and I was able to help with resolving such issues.

The benefits of sharing research work with a team are invaluable, and I would preferably seek a teamwork approach in conducting research in my future practice. The source of mutual support, encouragement and space for dealing with research dilemmas may be particularly relevant to a researcher- practitioner carrying out research in the NHS, where demands on clinical work make the research less of a priority. However, there also are some important drawbacks of sharing data collection. In this case, we needed to compromise on the number of measures each of us could include in the research interviews. This may be overcome if the researchers share the same data sets but then concentrate on different aspects. Secondly, our shared data collection may inevitably have introduced some bias. Despite frequent meetings to clarify our approach to interviewing, consistency of test administration and interpretation could not be guaranteed. However, similar data collection bias is inevitable across different research projects and researchers are faced with such bias when comparing their results.

Methodological complexities

In the final part of this paper, I will reflect on some of the methodological complexities pertinent to this area of study that may have influenced the current findings. While some of these reflections are specific to this study, others may be more generalisable and may reflect issues that will need to be addressed by future studies in this area.

Illness Perception Questionnaire for Schizophrenia (IPQ-S)

The self-regulatory model asserts that beliefs about an illness show a logical interrelationship and association between the identity, causes, consequences, and

timeline dimensions. However, due to time constraints, the dimensions of 'identity' and 'cause' were not tested in the current study. Research on physical illness has highlighted that both perceived 'identity' and 'cause' have proved to be important in the prediction of treatment adherence in physical illness (e.g. Petrie & Weinman, 2006) and therefore may be also relevant to engagement in psychosis. Whilst the IPQ-S 'causal' scales have been demonstrated by Lobban et al., 2005 as difficult to operationalize and showed low internal reliability in the authors' subsequent study (Lobban et al., 2004), suggesting that the IPQ may have limited utility to adequately capture this dimension in people with schizophrenia, the 'identity' scale showed good properties and appears to be very relevant. It would be interesting to explore how this dimension can further enhance the current findings of this study.

I would also like to comment on some practical challenges that arose when administering this questionnaire to some participants. Many participants commented that they found the questions of the IPQ –S interesting and in some cases they 'made them think about their mental health problems, which had been a positive experience. However, others appeared to find concentrating on the questions very difficult. This method appeared to have posed more cognitive demands on some participants, particularly in concentration and attention, than other administered questionnaires. Participants requested questions to be repeated or clarified more frequently with this measure than with other measures employed by the present study. Moreover, some participants commented that they found some questions confusing and that they were puzzled by feelings of being asked about 'the same things' repetitively. This was particularly evident in patients who were symptomatic, or those for whom English was not their first language. These difficulties may have been particularly pertinent for the current research sample where inclusion criteria have been very broad.

Perhaps the above described difficulties would not be observed if all the participants were proficient in English, had at least average cognitive function, and were not highly symptomatic, at the time of the interview. However, these observations question the degree to which this questionnaire can be applicable to the whole population of patients with schizophrenia and, further, whether simplifying it would capture the complexity of the area it attempts to measure.

Stigma measure

While planning the current study, I came across only one published study that has examined the impact of stigma on engagement with treatment in people with mental health problems (Sirey et al, et al. 2001) Therefore, I used the Perceived Devaluation Discrimination Scale (Link, 1987) employed by this study. However, as Links' measure assesses the level of awareness of stigma in society, its design is not able to examine the personal impact the perceived stigma would have on an individual. As highlighted by Corrigan and Watson (2002), not all individuals with mental health problems will internalize stigma endorsed in our society, even if they are highly aware of it. Therefore measuring personal reaction to stigma appears to be more relevant to enhancing our understanding of how it may impact on engagement. The scale developed recently by King et al., 2007, published subsequently to my research planning, appears to open up opportunities to further enhance our understanding on how stigma may impact on behaviours in people with psychosis, including their engagement with mental health services.

Engagement measure

Research on engagement has been limited by the poorly defined concept of engagement and, until very recently, a lack of standardized measures. This gap has now been filled by the development of new measures (Hall et al., 2001; Tait et al., 2002). These scales aim to measure not only medication adherence but also other important aspects of engagement. The Service Engagement Scale (SES; Tait et al., 2002) has been shown to have good psychometric properties. Its development, as hoped by the authors, certainly opens up opportunities for progress in research on engagement and provides a useful clinical tool. However, as the SES may provide a good and brief instrument for monitoring clients' engagement in clinical practice, it appears to have some limitations for research. Firstly, although aiming to capture engagement in a comprehensive manner, the scale appears to lack some dimensions that may also be important to the concept of engagement, as proposed by Hall et al. (2001), such as the interaction between client and therapist, communication openness, and the client's perceived usefulness of treatment. Secondly, the dimensions the SES measures are being assessed using only three or four questions and hence may not reflect the complexity of these dimensions well enough. The SES presents issues that need to be taken into consideration in future studies, for example, how to rate patients' medication adherence if they are currently adherent only because hospitalized at the time of the interview. Moreover, as noted above, transparency about the SES is required, as some clinicians may feel they are being evaluated on their clinical skills or efforts in engaging clients. It would be important to clarify these issues in any future studies employing this measure.

Another issue that arose in relation to this measure relates to the distribution of the scores this measure yielded in the current investigation. It is important, in

research, that the measure used to asses the studied concept is able to provide good normal distribution. This has been what I had hoped for in this study because, as discussed in other papers of this thesis, engagement is clearly not an 'all-or-nothing' phenomenon and therefore should be considered as a continuous variable. However, the distribution of engagement on the SES significantly departed from normality as some clients achieved 'perfect' engagement scores at one end of the scale. Therefore, in order for statistical analyses to proceed, results on this scale needed to be dichotomised into two groups. The particular distribution of clients' engagement obtained in this study may reflect some of the characteristics of the setting where the study was carried out. Active engagement is a primary aim of early intervention services, therefore obtaining a high number of clients who were 'perfectly engaged' with the service may reflect the success of the service's efforts in engaging their clients, rather than a limitation of the measure. However, interestingly, the study by Tait et al., (2004) that has been conducted in similar settings, resulted in a somewhat different distribution of engagement scores, with only two participants being rated as perfectly engaged. Further studies would be needed to validate this measure.

To conclude, both concepts of 'illness perception' and 'engagement' are relatively new in the area of psychosis. Newly developed tools to measure these important concepts open up opportunities for helping us to understand why people may want, or may not, to engage with mental health services. However, future studies are needed to verify the extent of their potential usefulness in furthering our understanding of engagement.

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Appendices

Appendix A

Ethical Approval

06/Q0511/40

NHS

Camden & Islington Community Local Research Ethics Committee

Room 3/14
Third Floor, West Wing
St Pancras Hospital
4 St Pancras Way
London
NW1 0PE

Telephone: 020 7530 3799
Facsimile: 020 7530 3931
Email: katherine.ouseley@camdenpct.nhs.uk

25 July 2006

Mr Stephen Pilling
Consultant Clinical Psychologist and Director of CORE
University College London
CORE
1-19 Torrington Place
London
WC1E 7HB

Dear Mr Pilling

Full title of study: An evaluation of outcomes from two models of early intervention service provision and exploration of factors explaining these outcomes

REC reference number:)

Thank you for your e-mail of 07 July 2006, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information was considered at the meeting of the Sub-Committee of the REC held on 18 July 2006. A list of the members who were present at the meeting is attached.

Confirmation of ethical opinion

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

Ethical review of research sites

The Committee has designated this study as exempt from site-specific assessment (SSA). There is no requirement for other Local Research Ethics Committees to be informed or for site-specific assessment to be carried out at each site.

Conditions of approval

The favourable opinion is given provided that you comply with the conditions set out in the attached document. You are advised to study the conditions carefully.

Approved documents

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

Document	Version	Date
Participant Information Sheet: With changes illustrated	2	20 June 2006
Participant Information Sheet: Original document	1	04 May 2006
Participant Information Sheet: Revised document	2	20 June 2006

Research governance approval

You should arrange for the R&D department at all relevant NHS care organisations to be notified that the research will be taking place, and provide a copy of the REC application, the protocol and this letter.

All researchers and research collaborators who will be participating in the research must obtain final research governance approval before commencing any research procedures. Where a substantive contract is not held with the care organisation, it may be necessary for an honorary contract to be issued before approval for the research can be given.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

Please quote this number on all correspondence

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

Yours sincerely

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Ms Stephanie Ellis
Chair

Email: katherine.ouseley@camdenpct.nhs.uk

Enclosures: *List of names and professions of members who were present at the meeting and those who submitted written comments*

Standard approval conditions

Copy to: *Professor Peter Fonagy*
Clinical Health Psychology,
University College London
1-19 Torrington Place
London
WC1E 7HB

Key Collaborator: Miss Rhianne Doherty, Assistant Psychologist

R&D Department for NHS care organisation at lead site

Appendix B

NHS

**North Central London
Research Consortium**

Research Operations Unit
3rd Floor West Wing
St Pancras Hospital
4 St Pancras Way
London NW1 0PE

General Enquiries: 020 7445 8506
Office Fax: 020 7530 3235

August 30th 2006

Mr Stephen Pilling
Director of CORE and Consultant Clinical Psychologist
CORE
Sub Department of Clinical Health Psychology
University College London
1-19 Torrington Place
London WC1E 7HB

Dear Mr Pilling,

LREC Ref: 06/Q0511/40
Title: An evaluation of outcomes from two models of early intervention service provision and exploration of factors explaining these outcomes

I am pleased to confirm that the above study has received R&D approval, and you may now start your research in the Camden and Islington Mental Health and Social Care Trust. May I take this opportunity to remind you that during the course of your research you will be expected to ensure the following:

- **Patient contact:** only trained or supervised researchers who hold the appropriate Trust/NHS contract (honorary or full) with each Trust are allowed contact with that Trust's patients. If any researcher on the study does not hold a contract please contact the R&D office as soon as possible.
- **Informed consent:** original signed consent forms must be kept on file. A copy of the consent form must also be placed in the patient's notes. Research projects are subject to random audit by a member of the R&D office who will ask to see all original signed consent forms.
- **Data protection:** measures must be taken to ensure that patient data is kept confidential in accordance with the Data Protection Act 1998.
- **Health & safety:** all local health & safety regulations where the research is being conducted must be adhered to.
- **Adverse events:** adverse events or suspected misconduct should be reported to the R&D office and the Ethics Committee.
- **Project update:** you will be sent a project update form at regular intervals. Please complete the form and return it to the R&D office.
- **Publications:** it is essential that you inform the R&D office about any publications which result from your research.
- **Ethics:** R&D approval is based on the conditions set out in the favourable opinion letter from the Ethics Committee. If during the lifetime of your research project, you wish to make a revision or amendment to your original submission, please contact both the Ethics Committee and R&D Office as soon as possible.

Please ensure that all members of the research team are aware of their responsibilities as researchers. For more details on these responsibilities, please check the R&D handbook or NoCLoR website:
http://www.noclor.nhs.uk

We would like to wish you every success with your project.

Yours sincerely,

Angela Williams
Research Governance Manager

Appendix C

CLIENT INFORMATION SHEET

The Early Intervention Service: Finding out about client's views and experiences since being in contact with the service

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.

- Part 1 tells you the purpose of this study and what will happen to you if you take part
- Part 2 gives you more detailed information about the conduct of the study

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.

PART 1
What is the purpose of the study?

We would like to find out more about our clients' beliefs and experiences since being in contact with the Early Intervention Service. We are interested in looking at people's symptoms, their views about their illness, how they think others view their illness, how they feel about their life in general and the recovery they have made, and their satisfaction with mental health services. The information we obtain will be used in several ways.

Why have I been asked to take part?

You have been asked to take part because you are in contact with the Early Intervention Service We are inviting people to take part in the study if they have been in contact with our service for between 1 and 3 years.

Do I have to take part?

It is up to you to decide whether or not you would like to take part. If you decide to take part you will be given this information sheet and asked to sign a consent form. If you do decide to take part you are still free to withdraw at any time and without giving a reason. A decision to withdraw at any time, or a decision not to take part, will not affect the standard of care you receive now or in the future.

What will happen to me if I take part?

You will be invited to meet with a researcher who will ask you some questions that will take approx 1 hour – 1hr 30 mins. Areas covered will include questions about your symptoms and your views about your mental health problems and about how others view them. We will also ask you about your social circumstances and ask you how content you are with your life in general and how far you feel you have recovered from your mental health problems. Finally, we would like to know how satisfied you are with the mental health services you have received.

The researchers would also like to have access to information that clinical staff regularly record about you to monitor your progress and to monitor how well the service as a whole is performing.

You may stop the interview at any time and the interview would be arranged at a time and place that is convenient for you.

What are the possible benefits of taking part?
The information gained from the study may be used to inform development of our service, hopefully improving the services offered to patients in the future.
Participants will also be given £15 for their completion of the interview as a small token of our gratitude.

What are the possible disadvantages of taking part?
Many people feel it is helpful to talk about their experiences, however some people may find discussing some aspects of their personal experience distressing. If you find any topic upsetting and you wish to stop the interview at any point you are free to do so.

What if there is a problem?
If you have a concern about any aspect of this study, you should ask to speak to the researchers who will do their best to answer your questions, their contact details are below. You can also talk to your Care Coordinator about the study.
If you remain unhappy and wish to complain formally, you can do this through the NHS Complaints Procedure or you can contact the Independent Complaints Advocacy Service on 0845 120 3784.

Will my taking part in this study be kept confidential?
All information that is collected about you during the course of the research will be kept strictly confidential. Any information that is kept about you will have your name and address removed so that you cannot be recognised from it. When we report on the research, it will not be in any way possible to identify you from the report.
Clinical staff responsible for your care will not be told anything about the answers you give, nor will we pass the information on to any other agency. The only situation in which the researcher would pass any information on to clinical staff is if they have reason to be concerned about your or someone else's immediate safety following the interview (for example, if you tell them you are about to harm yourself).

Contact details
xxxxxxxxxxxxxxxxx
xxxxxxxxxxxxxxxxx
xxxxxxxxxxxxxxxxx

PART 2
What happens to the results of the study?
The information collected will be anonymised and written up in a report. The report will not contain any personal information from which you could be identified. The results are also likely to be published in a journal read by people planning and researching mental health services. Some of the analyses of the data will be used by two doctoral clinical psychology students to write the theses that will help help them qualify as clinical psychologists.

Who is organising and supporting the research?
The research is being organised by staff working in the Departments of Clinical Health Psychology and Mental Health Sciences, at University College London and in Camden and Islington Mental Health and Social Care Trust. Camden and Islington Mental Health and Social Care Trust support the project.

Who has reviewed this study?
The study has been reviewed by Camden and Islington Community Local Research Ethics Committee.

Thank you for reading this

Appendix D

Camden and Islington **NHS**

Mental Health and Social Care Trust

CONSENT FORM FOR CLIENT

Interviews at 1 year looking at client's experiences and thoughts since being with the Early

Intervention Service.

a. I confirm that I have read and understand the information sheet for the above study and have had the opportunity to ask questions.

b. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving a reason, without my medical care or legal rights being affected.

c. I understand that the interview records and data will be stored confidentially.

d. I understand that if there are concerns about self harm or harming another the researcher may be in contact with the clinical team to ensure that support is available to me.

e. I give permission for relevant professionals in the mental health services to be contacted and for my medical notes to be looked at for some routinely collected social and clinical data.

f. I agree to take part in the above study.

_____   _____   _____
Name of client   Signature   Date

_____   _____   _____
Name of person taking   Signature   Date
consent (if different from
researcher)

_____   _____   _____
Researcher   Signature   Date

Appendix E

Camden and Islington Early Intervention Service
CLIENT INTERVIEWS

To Be Completed:

No.	Interview Measure	Tick when completed
1	Manchester Short Assessment of Quality Of Life (MANSA)	
2	Mental Health Recovery Measure	
3	The Illness Perception Questionnaire	
4	Client Satisfaction Questionnaire	
5	Perceived Devaluation Discrimination Scale	
6	Positive and Negative Symptom Scale (PANSS)	
7	Education and Employment	

Date Completed _____

Researcher _____

EIS Number _____

Gender_____

Age_____

Ethnic Origin _____

Appendix F

IPQ-S (Lobban, Barrowclough & Jones, 2005)

We are interested in your own personal views of how you NOW see your mental health problems. We understand that your views are likely to have changed considerably over time, but please indicate how you NOW view things.

Please indicate how much you agree or disagree with the following statements about your mental health problems by ticking the appropriate box.

	VIEWS ABOUT YOUR MENTAL HEALTH PROBLEMS	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree
IP1	My mental health problems will last a short time					
IP2	My mental health problem is a serious condition					
IP3	There are some things which I can do to control my symptoms					
IP4	There is little treatment available that can improve my mental health problems					
IP5	I get depressed when I think about my mental health problems					
IP6	I feel very puzzled by my mental health problems					
IP7	My mental health problem is likely to be permanent rather than temporary					
IP8	My mental health problem does not have much effect on my life					
IP9	To some extent what I do can determine whether my mental health problems get better or worse					
IP10	When I think about my mental health problems I get upset					
IP11	My treatment will be effective in managing my mental health problems					
IP12	I don't have any understanding of my mental health problems at all					
IP13	My mental health problems will last for a long time					
IP14	My mental health problems have financial consequences					
IP15	My mental health problems make it more difficult for me to do day to day things					
IP16	Nothing I do will affect my mental health problems at all					
IP17	My mental health problems make me feel angry					

	VIEWS ABOUT YOUR MENTAL HEALTH PROBLEMS	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree
IP18	The negative effects of my mental health problems can be prevented (avoided) by my treatment					
IP19	I feel that I don't know anything about my mental health problems					
IP20	My mental health problems will pass quickly					
IP21	Sometimes I have more symptoms than other times					
IP22	My mental health problems cause difficulties for those who are close to me					
IP23	My actions will have no effect on the outcome of my mental health problems					
IP24	My mental health problems do not worry me					
IP25	My mental health problems make no sense to me at all					
IP26	I expect to have this mental health problem for the rest of my life					
IP27	I don't get on as well with my family since my mental health problems					
IP28	If I tried harder I could control my symptoms					
IP29	Having this mental health problem makes me feel anxious					
IP30	My treatment can control my mental health problems					
IP31	I have a clear picture or understanding of my mental health problems					
IP32	I have times when I am well and times when I am not so well					
IP33	My mental health problems have messed up my social life					
IP34	I could do more to help myself					
IP35	My mental health problems mean that I am valued less by other people					
IP36	My mental health problems make me feel afraid					
IP37	There is no treatment that can help with my condition					
IP38	Sometimes the symptoms of my mental health problems are worse than other times					
IP39	My mental health problems make working very difficult					

	VIEWS ABOUT YOUR MENTAL HEALTH PROBLEMS	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree
IP40	If I was a stronger person I would get better					
IP41	My mental health problems make me feel worthless					
IP42	Some of my symptoms will be there all the time but others will come and go					
IP43	I have lost important relationships as a result of my mental health problems					
IP44	I get very frustrated by my mental health problems.					
IP45	My mental health problems have had some positive effects on my life					
IP46	My mental health problems will improve in time					
IP47	I feel a sense of loss due to my mental health problems					

Appendix G

The Perceived Devaluation-Discrimination Scale (*Link, 1987*)

We are interested in your views on how individuals with mental health problems are perceived.

Please read each statement carefully and indicate how much you agree or disagree with each item by circling the appropriate number.

		Agree Strongly	Agree	Neither agree nor disagree	Disagree	Disagree Strongly
A	Most people would willingly accept a former mental health patient as a close friend.	1	2	3	4	5
B	Most people believe that a person who has been in a mental health hospital is just as intelligent as the average person.	1	2	3	4	5
C	Most people believe that a former mental health patient is just as trustworthy as the average citizen.	1	2	3	4	5
D	Most people would accept a fully recovered former mental health patient as a teacher of their young children in a public school.	1	2	3	4	5
E	Most people feel that entering a mental health hospital is a sign of personal failure	1	2	3	4	5
F	Most people would not hire a former mental health patient to take care of their children, even if he or she had been well for some time.	1	2	3	4	5
G .	Most people think less of a person who has been in a mental health hospital.	1	2	3	4	5
H	Most employers will hire a former mental health patient if he or she is qualified for the job.	1	2	3	4	5
I	Most employers will pass over the application of a former mental health patient in favour of another applicant.	1	2	3	4	5
J	Most people in the community would treat a former mental health patient just as they would treat anyone.	1	2	3	4	5
K	Most young women would be reluctant to date a man who has been hospitalised for a serious mental disorder.	1	2	3	4	5
L	Once they know a person was in a mental health hospital, most people will take his opinion less seriously.	1	2	3	4	5

Appendix H

Service Engagement Scale (Tait Birchwood & Trower, 2002)					
AVAILABILITY					
1	The client seems to make it difficult to arrange appointments	0 Not at all or rarely	1 Sometimes	2 Often	3 Most of the time
2	When a visit is arranged, the client is available	3 Not at all or rarely	2 Sometimes	1 Often	0 Most of the time
3	The client seems to avoid making appointments	0 Not at all or rarely	1 Sometimes	2 Often	3 Most of the time
COLLABORATION					
4	If you offer advice, does the client usually resist it?	0 Not at all or rarely	1 Sometimes	2 Often	3 Most of the time
5	The client takes an active part in the setting of goals or treatment plans	3 Not at all or rarely	2 Sometimes	1 Often	0 Most of the time
6	The client actively participates in managing his/her illness	3 Not at all or rarely	2 Sometimes	1 Often	0 Most of the time
HELP SEEKING					
7	The client seeks help when assistance is needed	3 Not at all or rarely	2 Sometimes	1 Often	0 Most of the time
8	The client finds it difficult to ask for help	0 Not at all or rarely	1 Sometimes	2 Often	3 Most of the time
9	The client seeks help to prevent a crisis	3 Not at all or rarely	2 Sometimes	1 Often	0 Most of the time
10	The client does not actively seek help	0 Not at all or rarely	1 Sometimes	2 Often	3 Most of the time
TREATMENT ADHERENCE					
11	The client agrees to take prescribed medication	3 Not at all or rarely	2 Sometimes	1 Often	0 Most of the time
12	The client is clear about what medications he/she is taking and why	3 Not at all or rarely	2 Sometimes	1 Often	0 Most of the time
13	The client refuses to co-operate with treatment	0 Not at all or rarely	1 Sometimes	2 Often	3 Most of the time
14	The client has difficulty in adhering to the prescribed medication	0 Not at all or rarely	1 Sometimes	2 Often	3 Most of the time